THE LIVED EXPERIENCE OF FATHERS OF YOUNG ADULT CHILDREN WITH SCHIZOPHRENIA

by

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ABSTRACT

A qualitative phenomenological research method was used to explore and describe the lived experience of six fathers of young adult children with schizophrenia who volunteered to participate in this study. The following six themes emerged from the analysis of these fathers' stories through the seven steps of phenomenological analysis outlined by Colaizzi (1978): reflection on roles and responsibilities, a sense of devastation and vulnerability, a sense of sadness and loss, a sense of frustration with the mental health system, a sense of admiration for their child, and a sense of having gained personally.

The findings of the study indicated that reflection on their early roles and responsibilities as fathers before the onset of their child's illness helped the participants in this study make meaning of the roles and responsibilities they assumed as their child's illness progressed. The participants experienced a sense of devastation and vulnerability when their child received the diagnosis of schizophrenia, as they began to face the realities of living with a child with schizophrenia, and especially when dealing with crisis situations. They also experienced a sense of sadness and loss. Five kinds of losses were described: loss of who their child once was, loss of their child's potential to be productive, loss of dreams for their child's future, loss experienced in fathers' present lives, as well as loss of hopes and dreams for their own future. A sense of frustration was reported in response to various aspects of the mental health system. Two additional themes emerged from the analysis of the participants' stories that were not reported as themes in previous studies: a sense of admiration for their child and a sense of having gained personally. The study concludes with a discussion of implications for counselling practice, implications for mental health policy, as well as implications for future research.
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CHAPTER ONE: INTRODUCTION

My interest in schizophrenia and the family arises from personal experience. As the mother of an adult child with schizophrenia, I have personally experienced the difficult and at times traumatic journey of parenting through the help-seeking years prior to my son’s diagnosis, as well as the ongoing experience of parenting in the acute and chronic stages of his illness. I have witnessed the effects of my son’s illness on my own family. Through interaction with other parents and mental health professionals, both informally and in psycho-educational, family conference, and support/advocacy group settings, I have become convinced of the need for greater understanding of the parental experience, especially the experience of fathers.

The onset of schizophrenia in the family has been described as “a disaster in which all are victims of the event and its sequelae” (Terkelsen, 1987a, p. 128). Although schizophrenia is one of the most common of the major mental illnesses, the voices of parents of adult children with schizophrenia are rarely heard. The research that has focused on the experience of parenting an adult child with schizophrenia has been based primarily on the experience of mothers. Fathers have had few opportunities to voice their experiences (Howard, 1998; Pfeiffer, 2001). The majority of fathers who have participated in the very limited available research were often moved to the point of tears as they told their stories (Howard, 1998; Pfeiffer, 2001). One father described his experience of parenting an adult child with schizophrenia as “a life-crushing event” (Howard, 1998, p. 409). Similar descriptions by other fathers in the research literature make it clear that fathers of children diagnosed as schizophrenic may be profoundly affected by their experience. The lived
experiences of fathers who are parenting an adult child with schizophrenia are the focus of this study.

To provide a context for understanding the experience of fathering an adult child with schizophrenia, this chapter will begin with an overview of the current understanding of schizophrenia: the definition, incidence and course of the illness, as well as the difficulty in establishing a diagnosis and the resultant impact on the parenting experience. Finally, the research question will be posed and the purpose of the proposed study will be discussed.

**Definition of Schizophrenia**

Broadly understood, schizophrenia is a mental illness characterized by disordered thinking, usually involving hallucinations and delusions that frequently result in a marked decrease in the level of functioning (Birchwood & Jackson, 2001). Over the years since schizophrenia was first identified by Bleuler in 1911, the concept of schizophrenia has repeatedly been contested in the literature, and the definition of schizophrenia has undergone many revisions (Birchwood & Jackson, 2001). In 1967, Laing suggested that the experiences and behaviours labeled as schizophrenia were a reaction to an “unlivable social situation” (p. 79). He proposed that future society would look back and see that “what we call ‘schizophrenia’ was one of the forms in which, often through quite ordinary people, the light began to break through the cracks in our all-too-closed minds” (p. 90). A decade later, Szasz (1979) argued from a moral standpoint that schizophrenia was not a disease, but rather a term invented by psychiatrists to justify forms of social control. More recently, from the perspective of social constructionism, Boyle (2002) explicated reasons for the persisting controversy surrounding the concept of schizophrenia and called for discussion of possible
alternatives to the study of behaviour and experience outside of the framework of medical
diagnosis. She lamented

... the reluctance to consider fully the idea that psychotic behaviours and
experiences are relational, that they arise in social and interpersonal contexts, that
their form and content are given meaning by those contexts and that such behaviours
are officially transformed to 'pathology' only through a relationship of unequal
power (p. 316).

It has also been suggested that the term “schizophrenia” may represent a group of disorders,
which it is anticipated, will be differentiated through future research (Henn, 2001).

Another theoretical perspective on schizophrenia which has been gaining support in
the research literature is known as continuum theory. Proponents of continuum theory,
propose a continuum ranging from affective disorders to schizophrenia (Varma, 1997). This
theory is based on a number of studies that have established that familial factors that
predispose individuals to schizophrenia also predispose to other schizophrenia related
disorders such as schizoaffective disorder (Varma, 1997). In a review of the research
literature that has addressed the relationship between affective disorders and schizophrenia,
Taylor suggested that schizoaffective disorder may be a variation of schizophrenia (Taylor,
(DSM-IV-TR) in the discussion about family patterns in schizophrenia, also recognizes a
group of disorders known as the schizophrenia spectrum, which, although not currently well
defined, likely includes schizoaffective disorder (American Psychiatric Association, 2000).

Despite differences of opinion, three diagnostic classification systems are currently
accepted within the mental health professions: The Diagnostic and Statistical Manual of
Mental Disorders (DSM-IV) (American Psychiatric Association, 1994), ICD-10 (World Health Organization, 1992), and the Research Diagnostic Criteria (Spitzer, Endicott, & Robins, 1978). These classification systems differ mainly in terms of the length of time required to establish a diagnosis, but employ similar symptom criteria (Birchwood & Jackson, 2001). The DSM-IV criteria are most often used in North America to determine a diagnosis of schizophrenia. According to the DSM-IV, the diagnosis of schizophrenia requires the presence of two or more of the following five characteristic symptoms: (a) delusions, (b) hallucinations, (c) disorganized speech, (d) grossly disorganized or catatonic behaviour, and (e) negative symptoms, e.g. social withdrawal, poverty of speech. These characteristic symptoms must be significantly present over at least a one month period. In addition to these symptoms, an individual with schizophrenia will exhibit significant social or occupational dysfunction compared to his/her level of functioning prior to the onset of symptoms. Continuous signs of the illness must be present for at least six months. Other possible causes of symptoms, such as schizoaffective and mood disorders, pervasive developmental disorders, substance abuse, or other general medical conditions, must be ruled out before a diagnosis of schizophrenia can be confirmed.

The symptoms of schizophrenia are frequently categorized as positive or negative (Andreasen, Roy, & Flaum, 1995). Positive symptoms include hallucinations, delusions, bizarre behaviours, and marked disorders of thinking (Andreasen et al., 1995). These symptoms can be considered an addition to the normal repertoire of human experiences (Birchwood & Jackson, 2001). Negative symptoms include social withdrawal, impairment of attention, lack of energy, poverty of speech, or a blunting of drive or emotions (Andreasen et al., 1995), which reflect an absence of the normal abilities that are part of
negotiating the activities of daily living (Birchwood & Jackson, 2001). The majority of individuals with schizophrenia experience both positive and negative symptoms (Cutting, 1995).

**Incidence and Course of Schizophrenia**

Research to date suggests that schizophrenia presents universally across cultures (Jablensky, 1995; Birchwood & Jackson, 2001). The individual life-time risk of developing schizophrenia is one percent (Birchwood & Jackson, 2001). Research addressing the prevalence of the illness among males and females has produced mixed results. Buchanan and Carpenter (2000) state the risk of developing the illness is similar for males and females. Birchwood and Jackson (2001) state that although some earlier studies found schizophrenia to be equally prevalent among males and females, more methodologically advanced studies have found that the incidence of schizophrenia among males is higher than among females. It is, however, well established that males usually experience an earlier onset. Hambrecht, Maurer, Hafner, and Sartorius (1992) report an average onset of three to four years earlier for males than for females, while others report an earlier onset of as much as five to ten years (Lewine, 1980, cited in McKenna, 1994). In an analysis of the multinational WHO-Determinants of Outcome-Study (Sartorius et al., 1986), which included 1,292 cases of schizophrenia from 10 countries, Hambrecht et al. pointed out the large excess of males (50 percent of total male participants) with onset between age 15 years and the middle twenties, compared to females (37 percent of total female participants) within the same age range. A marked peak in the frequency distribution of age of onset for males occurred in the early twenties. For females the frequency distribution indicated two peaks: a moderate peak in the
twenties and a second less moderate peak after age 40. More than twice as many females (22 percent) experienced a late onset (after age 40) than males (10 percent).

Although there is a high degree of variability in the course and outcome of schizophrenia, females tend to have a more optimistic outcome (Birchwood & Jackson, 2001). Males tend to have more frequent and longer periods of hospitalization and are less likely to do well in community settings (Angermeyer, Goldstein, & Kuhn, 1989). There are mixed reports in the literature regarding the long term outcomes of schizophrenia. Birchwood and Jackson (2001), in their summary of five follow-up studies (duration of follow-up varied from 5 to 37 years), reported that approximately 20 to 25 percent of individuals with schizophrenia experience a single acute psychotic episode and subsequently recover almost completely, whereas approximately 30 percent experience a poor outcome with repeated acute psychotic episodes resulting in a progressive level of impaired function across the lifespan. They point out, however, that these findings must be considered cautiously, as the methods used to measure recovery varied across studies and most of the data originated from hospital admission records, which may not accurately reflect the population.

More optimistic results were reported by Harding, Brooks, Ashikaga, Strauss, and Brier (1987a; 1987b) in their longitudinal studies of 82 patients with chronic schizophrenia who were considered unlikely to achieve significant recovery. After a period of 32 years, Harding and associates discovered a remarkable improvement in 62 to 68 percent of the participants. Although it has been suggested that the improvement may have been due to biochemical changes in the brain that are part of the aging process (Breier, Schreiber, Dyer & Pickar, 1991), Harding et al.'s research does suggest a more optimistic outcome in terms
of late term recovery for many individuals with chronic schizophrenia than was previously assumed.

**Difficulty in Establishing a Diagnosis**

Although the onset of schizophrenia can be sudden and severe, the symptoms of schizophrenia may develop slowly over time, sometimes over years (Jablensky, 1995). Early signs of the illness often occur during adolescence or early adulthood, when the “child” is often still living with his/her parents. During adolescence, these symptoms can be difficult to distinguish from normal responses to the psychological and emotional adjustments that are part of adolescent development (Tuck, du Mont, Evans, & Sharpe, 1997). The negative symptoms of social withdrawal, decreased energy, flattened affect, and poverty of speech can easily be misconstrued as laziness, or an unwillingness to cooperate (Potrzebowska, 1993). It is well recognized that prolonged negative symptoms, especially when they persist over a number of years, result in a great emotional burden on the family and are associated with increased likelihood of a poor prognosis (Birchwood & Jackson, 2001). When negative symptoms insidiously develop in the early stages of the illness, the positive symptoms, which eventually become the more obvious indictors for intervention, can be initially difficult to recognize. In retrospect, many parents describe early signs of unusual behaviour as very confusing and recall their struggle “to frame events as normal” (Tuck et al., 1997, p.120). The words of one parent capture these sentiments: “I think I had an intuition about it but I thought, oh well, you know, he’s just different” (Tuck et al., 1997, p. 212).

The difficulty in establishing an early diagnosis becomes greater when schizophrenia is co-morbid with other disorders such as depression and substance abuse (Birchwood &
Jackson, 2001). Experimentation with drugs and alcohol in adolescence, increasingly prevalent over the past decades, adds further confusion to the understanding of behavioural changes. Crisis situations in the early stages of the illness result in enormous stress on families (Petrzebowska, 1993). Suicidal ideation is not uncommon. Ten to fifteen percent of individuals with schizophrenia end their lives by suicide (Birchwood & Jackson, 2001). Given that early intervention and treatment has been linked to a more positive outcome, a great responsibility for recognition of symptoms falls on parents and failure to do so can be a source of lingering guilt (Milliken, 2001).

**Purpose of the Study**

A great deal of research interest has focused on “schizophrenia and the family” over the past 50 to 60 years (Birchwood & Jackson, 2001). Early research was based on theories of etiology, mainly focused on mother-child interaction, whereas later work drew attention to relationships between family members (Atkinson & Coia, 1995). More recent research is based on a vulnerability-stress model of schizophrenia. This model, in addition to identifying possible biological influences on schizophrenia, has drawn attention to families living with mental illness through research addressing the concepts of “expressed emotion,” a descriptor of the emotional climate within family relationships, and “family burden,” the impact of the illness on the family. Over the past 15 years a slowly growing body of qualitative research has begun to explore the parental experience of caring for adult children with schizophrenia (Bulger, Wandersman, & Goldman, 1993; Chelsa, 1991; Clinger, 1999; Jones, 1997; Jungbauer & Angermeyer, 2002; Milliken, 2001; Pauch, 1996; Ryan, 1993; Thorpe, 1994; Tuck et al., 1997; Vatri-Boydell, 1996). The participants in these studies have overwhelmingly been mothers and little if any differentiation has been made between
the experience of mothers and fathers. By aggregating these experiences one may easily assume that the experiences of fathers are the same as mothers.

It is clear that many individuals with schizophrenia require years of care-giving. The high economic and social costs of care-giving to society have been acknowledged, but the economic, social, and emotional costs to the family have yet to be fully understood. As a result of the shift from institutionalized to community care, an increased burden of care has fallen on the family (Atkinson & Coia, 1995). A number of studies have suggested that when the burden of care falls on the family, the mother in the family typically assumes most of the care-giving responsibility (Ascher-Svanum, 1989; Guberman, 1988; Milliken, 2001; Pauch, 1996; Thurer, 1983; Vatri-Boydell, 1996). Studies of the mothering experience of caring for a child diagnosed with schizophrenia described the interminable nature of maternal care-giving (Thorpe, 1994). Mothers reported living with multiple losses in a context of shifting parental roles in response to the changing needs of their child at various stages of the illness (Milliken, 2001). Multiple contradictions in the mental health system added to the stress of coping with mental illness in the family, and mothers voiced a great need for support (Vatri-Boydell, 1996). Very little, however, has been written about the experience of fathers of a child with schizophrenia.

A thorough search of the research literature revealed only three qualitative studies, Howard (1998), Nystrom and Svensson (2004), and Pfeiffer (2001), that have specifically addressed the fathering experience. The participants in these studies shared many of the primary concerns voiced by mothers, but to different degrees. They also had additional concerns related to interpersonal relationships with their spouse, their schizophrenic child, and professionals within the mental health system. Although these studies have provided
valuable insight into the fathering experience, they are incomplete. Most of the participants were interviewed on average 15 to 20 years after their child had been diagnosed. Given the changes in family structures and parental roles, as well as changes within the mental health system over the past 20 years, the experience of fathering an adult child diagnosed within the past 10 years may be different. The voices of these fathers have largely been absent from the literature. The current study addresses this gap.

The current study addressed questions such as: What is it like to be a father of a child diagnosed with schizophrenia in late adolescence or early adulthood? How do fathers make sense of their experience? What impact has this experience had on their lives? Are there areas of the fathering experience that are as yet unrecognized? What can they tell us that would enhance the effectiveness of helpers as they seek to support, enable, and empower this population? The overarching research question guiding the study was: **What is the nature and the meaning of the lived experience of fathers whose young adult children have been diagnosed with schizophrenia?**

The purpose of the current study was to provide a greater understanding of the experience of fathering an adult child with schizophrenia by giving voice to fathers whose children have been diagnosed within the past 10 years. By giving voice to these fathers I hoped to honour and validate their experience. Van Manen (1992) suggested that phenomenological research increases thoughtfulness, discernment, and perceptiveness, which leads to effective action and interaction. The results of the current study could therefore enhance the ability of helpers to enable and empower fathers, contribute to a more complete understanding of families of the mentally ill, as well as stimulate interest in further research.
CHAPTER TWO: REVIEW OF THE LITERATURE

What is known about the experience of fathering an adult child with schizophrenia? As noted in chapter one, an extensive literature review has revealed only three studies that have specifically addressed the fathering experience, although a number of studies have focused on parenting an adult child with schizophrenia, drawing largely on the experiences of mothers. This literature review will focus mainly on the qualitative studies which have utilized inductive approaches to understanding the parenting and fathering experiences. However, in order to provide a background understanding of the research context in which these studies are embedded, the first section of this chapter, entitled The Research Context: Schizophrenia and the Family, will briefly summarize literature that has provided an understanding of “schizophrenia and the family” from primarily deductive approaches. A review of the qualitative research which addresses the parenting experience will follow, culminating with research that has specifically focused on fathering an adult child with schizophrenia. Areas that require greater understanding will be identified, and attention will be drawn to how this understanding could be valuable to professional helpers, parents, family members, and ultimately, society at large.

The Research Context: Schizophrenia and the Family

A great deal of research has been directed towards the study of schizophrenia and the family over the past sixty years. This review of the research context will begin with a brief summary of the early history of mental illness and the family, as well as early theories of etiology, which reflect assumptions about families that led to the period of institutionalization of the mental ill and the subsequent period of deinstitutionalization. A summary of the more recent research based on the vulnerability-stress model will follow.
Attention will be drawn to how this research has affected assumptions regarding parents of adult children with schizophrenia.

**Early History of Mental Illness and the Family**

Little is known about mental illness and the family prior to the 19th century. Literature from the colonial period of US history suggests that mental illness was often equated with demon possession and civil disobedience (Riesser & Schorske, 1994). Treatment for the mentally ill in the absence of mental health professionals often meant restraint or punishment (Riesser & Schorske, 1994). In the early 19th century, social stressors were thought to be the primary etiological factors in the development of mental illness. One of the primary responsibilities of the family was to protect its members from these stressors (Terkelson, 1990). The onset of mental illness was therefore considered a sign that the family had failed in its responsibility, and separating the mentally ill from “failure families” was encouraged. Asylums were established to provide the mentally ill with a safe haven from social stressors (Terkelson, 1990).

From the middle of the 19th to the middle of the 20th century, institutions for the mentally ill provided highly structured environments in which the relationship between the psychiatrist and his patient was considered key to recovery (Riesser & Schorske, 1994). However, in the 1950’s and 1960’s, treatment for the mentally ill began to shift from institutionalized care to community care (Terkelson, 1990). This shift coincided with the development of neuroleptic medications, which helped stabilize patient’s behaviours to the degree that made community living possible. Deinstitutionalization was spurred on by the growing recognition that institutional care had deleterious effects on the mentally ill, in direct contrast to the earlier belief that the mentally ill required shelter from social and
family stressors (Terkelson, 1990). As a result of deinstitutionalization, the burden of care for the mentally ill was shifted largely to families in the community. Local communities, however, were unprepared to meet the needs of the mentally ill and their families (Atkinson & Coia, 1995; Terkelson, 1990).

Early Theories of Etiology

Institutionalized care accompanied the rise of psychoanalytic theories. Early psychoanalytic theories focused on mothers as primary agents in the etiology of schizophrenia (Terkelson, 1990). One of the early psychiatrists, Hadju-Gimes (1940), characterized mothers of schizophrenic children as “cold, rigorous [and] sadistically aggressive” (p. 423). Another well-known psychiatrist, Fromm-Reichman (1948), coined the term “schizophrenogenic mother” (p. 265) and suggested that schizophrenia was the result of the “severe early warp and rejection [the schizophrenic patient] encountered in important people of his infancy and childhood, as a rule, mainly in a schizophrenogenic mother” (p. 265).

During the early period of deinstitutionalization, a number of additional theories implicated fathers as well as mothers in the etiology of schizophrenia. Lidz (1957) hypothesized that “ego weakness of schizophrenia may be related to the introjection of parental weaknesses” (p. 241). In his study of 16 middle-to-upper class families with schizophrenic members, Lidz observed marital difficulties which he called “marital schism” and “marital skew” (p. 241). Marital schism was characterized by a lack of emotional support between spouses and chronic “undercutting of the worth of one partner to the children by the other” (p. 243). Mothers of schizophrenic patients were characterized as “emotionally cold and distant” (p. 244), and fathers as “ineffectual” (p. 243). In marital
skew, serious psychopathology in the dominant partner was tolerated as normal by the other partner in order to achieve a degree of stability within the family. Lidz suggested that both marital schism and marital skew blocked normal growth and development in the child, which, in turn, contributed to the development of schizophrenia.

Bateson (1956) based his theory on communication analysis, and hypothesized that schizophrenia developed in a child who was caught in a “double bind,” “a situation in which no matter what a person does, he can’t win” (p. 251). Bateson stated, “we must expect a pathology to occur in the human organism when certain formal patterns of breaching occur in the communication between mother and child” (p.251). Although he drew attention to mother-child communication, Bateson cautioned not to “assume that the double bind is inflicted by the mother alone, but that it may be done either by mother alone, or by some combination of mother, father and/or siblings” (p. 253). He described a series of distorted communications, which he believed led to the development of abnormal defenses and eventually, schizophrenia in the child.

Using a family systems approach, Bowen (1961) conceptualized “the family as the unit of illness” (p. 40). By observing 18 families as part of an in-residence treatment program, Bowen described an “intense interdependent triad” (p. 48) between father, mother, and their schizophrenic child which he called an “undifferentiated ego mass” (p. 43). He stated that relationships within the triad differed from the emotional relationships that these parents had with their normal children. Bowen described the family with a schizophrenic member as “a functionally helpless organism, without a leader, and with a high level of overt anxiety” (p. 50). Similarly, another prominent theory proposed by Wynne and Singer (1963), suggested that family patterns of communication may be linked to the development
of thought disorders in offspring. He noted that families with schizophrenic offspring were characterized by over-focused and constrictive thinking, and described their emotional life as “deeply enmeshed” (p.197).

Atkinson and Coia (1995) pointed out that early theories tended to equate association with causality, and therefore ruled out other explanations for family responses, such as the possibility that family interactions could be directly influenced by schizophrenic behaviour, or other factors not yet considered. Whatever the case, early theories implying causality significantly contributed to the blame and guilt that has all too often characterized relationships between families of schizophrenic children and mental health professionals (Atkinson & Coia, 1995; Milliken, 2001; Terkelsen, 1987a). Although Milliken (2001) suggests that “when professionals blame mental illness on poor parenting, mothers take the majority of the blame” (p. 160), fathers also were implicated in their child’s difficulties, either in their interactions with their child or in their relationships with their spouse.

*The Vulnerability-Stress Model of Schizophrenia*

More current research on the etiology of schizophrenia is based on a vulnerability-stress model, which acknowledges biological, psychological, and social influences in the development of schizophrenia. According to this model, psychosocial stresses influence underlying vulnerability factors resulting in the emergence or exacerbation of psychotic symptoms (Zubin & Spring, 1977). From this perspective psychotic symptoms are triggered by a lower level of stress in individuals with a greater vulnerability to schizophrenia than in individuals with a lower level of vulnerability. Over the past 20 years, research based on the vulnerability-stress model has focused on the influences of biological factors, as well as the concepts of expressed emotion and family burden, each of which will be summarized below.
Biological Factors

There is strong evidence to indicate that the development of schizophrenia has a biological component. Studies of monozygotic and dizygotic twins, as well as studies of adopted children of schizophrenic parents, suggest that genetic factors may interact with environmental factors to increase the overall vulnerability to schizophrenia (Asherson, Mant, & McGuffin, 1995; Birchwood & Jackson, 2001). A number of studies have focused on the biochemical influence of neurotransmitters, especially dopamine, noradrenalin, and serotonin. It is known that major antipsychotic drugs block dopamine receptors, however, neurotransmitter systems are as yet not fully understood (Birchwood & Jackson, 2001). New brain imaging techniques have provided impetus for studies directed towards identifying structural abnormalities in the brain of schizophrenic patients. A number of abnormalities have been reported, including ventricular enlargement, limbic system pathology, thalamic pathology, changes in frontal and temporal areas, as well as structural asymmetry in some cortical regions (Falkai & Bogerts, 1995). Findings across studies, however, have been inconsistent. Birchwood and Jackson suggest that “none of these [biological] proposed mechanisms are sufficiently well understood and their status can best be understood as risk factors” (p. 60).

Expressed Emotion

The concept of expressed emotion was instrumental in shifting research attention away from family interaction as the primary etiological agent in the development of schizophrenia, towards “family attitudes and behavior as an exacerbating factor of a preexisting disorder” (Kanter, 1987, p. 374). Expressed emotion, which incorporates components of critical comments, hostility, and emotional over-involvement, is based on the
work of Brown, Monck, Carstairs, and Wing, (1962). Brown et al. in their one year study of 128 schizophrenic men and their families, found a positive correlation between expressed emotion in the family and the frequency of relapse in the schizophrenic member. Some subsequent studies (Brown, Birley, & Wing, 1972; Vaughn & Leff, 1976) which supported this finding have led to the assumption by many mental health professionals that families with high levels of expressed emotion are characterized by criticism, hostility, and an unhealthy degree of emotional over-involvement (Kanter, 1987). In his review of the research on expressed emotion, Kanter challenged this assumption, and stated that there are times when a high level of emotional involvement may be helpful. He suggested that the concept of expressed emotion may have further contributed to the sense of blame that families of schizophrenic children have all too commonly experienced in their interactions with mental health professionals.

King (2000) sought to bring further clarification to the understanding of expressed emotion by examining the direction of influence between symptom severity in 29 schizophrenic adults and the expressed emotion of their mothers. By using a cross-lagged panel analysis, she found that, contrary to previous opinion, expressed emotion in mothers appeared to be the effect of symptom severity rather that its cause. King’s study went one step further by suggesting that maternal emotional over-involvement may have a salutary effect on hostile uncooperativeness, as “higher ratings of [maternal] emotional over-involvement were associated with less severe hostile uncooperativeness [in the schizophrenic child] nine months later” (King, 2000, p. 74). King’s study pointed out that the relationship between expressed emotion and the course of schizophrenia is much more complex than has previously been assumed. Studies of expressed emotion, when taken
together, point to the need for more research addressing assumptions about parents of children with schizophrenia. Although most studies addressing expressed emotion have focused on the effect of the family environment on the symptoms in schizophrenia, these recent findings, which indicate that expressed emotion may be the effect of symptom severity, suggest that expressed emotion may be related to family burden, a concept which has been the subject of extensive research in mental illness.

Family Burden

Family burden is a concept used to describe the effects of mental illness on the family (Jungbauer & Angermeyer, 2002). Some clinicians and researchers, such as Atkinson and Coia (1995), have pointed out that the term “burden” carries negative connotations. They suggest that individuals with schizophrenia may resent being considered a burden and using the term to describe the impact of caring may elicit feelings of guilt in care-giving family members. The term “burden,” however, continues to be used extensively in the literature. One of the early studies of “burden” in relation to mental illness was Hoenig and Hamilton’s (1966) study: The schizophrenic patient in the community and his effect on the household. In their study of 62 mentally ill patients and their caregivers, Hoenig and Hamilton discovered that the term “burden” meant different things to different people, both inside and outside of the family. To provide further clarification, Hoenig and Hamilton introduced the terms “objective burden” and “subjective burden.” Objective burden referred to “adverse effects on the household” (p. 167), which included observable costs such as financial expenses, as well as abnormal behaviours that caused disruption of everyday life. Subjective burden referred to how family members felt about the effects of schizophrenia on the family and the extent to which these effects were considered a burden.
Since Hoenig and Hamilton's (1996) study, a number of objective burdens associated with caring for the mentally ill have been identified in the literature, including: financial problems, time commitment required to provide care and advocate for the mentally ill, the physical demands of care-giving, disruption of everyday routines in the household, restriction of social activities, impaired relationships outside of the family (Hatfield & Lefley, 1993), as well as lost time and wages, and the effects of fatigue and emotional strain on the ability to work (Pfeiffer, 2001). Subjective burdens reflect the emotional distress associated with the difficult and bizarre behaviours of the mentally ill family member, as well as distress from secondary sources such as complaints and reactions of siblings in the family, and reactions within the community (Hatfield & Lefley, 1993). Two recent studies, Jones (1997) and Jungbauer and Angermeyer (2002), compared the nature of subjective caregiver burden in various types of client-caregiver relationships. These studies will be reviewed in this section because they point out that individuals in various family roles experience subjective burdens somewhat differently, which has implications when seeking to understand the experience of fathers.

Jones (1997), in a longitudinal study (three waves of data over three years) conducted telephone interviews with 143 family care-givers (parents, spouses and children) using the Caregiver Burden Instrument developed by Tessler (1989). He found that the dominant subjective burden for parents was the weariness associated with long term commitment to providing care, an involuntary expectation these parents felt they had to meet. Parents also voiced an ever-present concern regarding the future when they would no longer be able to provide for their child's needs. In addition, parents experienced feelings of guilt associated with having been blamed for causing the illness. The dominant subjective
burdens for care-giving children, siblings, and spouses were somewhat different. Children caring for mentally ill parents experienced feelings of having been “robbed of a parent” (Jones, 1997, p. 85). Sibling care-givers emphasized ambivalent feelings and the stress of being in a “sandwich” position between the mentally ill sibling and other siblings, which resulted in “forced divided loyalties” (p. 85). In spousal subjective burden loss was identified as a central feature; loss of an earlier relationship, as well as loss of dreams for the future. Spousal care-givers also expressed an awareness of the voluntary nature of the care-giving relationship and experienced a great deal of ambivalence in their relationship with their schizophrenic partner.

Similar findings were reported by Jungbauer and Angermeyer (2002) in their comparative study of the subjective burden experienced by parent and spousal care-givers. Through in-depth narrative interviews, guided by a questionnaire with 52 spouses and 51 parents (42 mothers and 9 fathers), Jungbauer and Angermeyer found that both family roles and the symptomatic course of schizophrenia influenced the nature of subjective burden. Both spousal and parental care-givers differentiated between acute burden associated with acute symptoms and chronic burden experienced in more stable phases of the illness. Acute burden was characterized by shock, anxiety, and feelings of helplessness. Chronic burden, although less dramatic, had a more severe adverse effect on the quality and course of care-givers’ lives. In the chronic phase, the constant fear of another acute episode was always “hanging like a sword of Damocles over everyday life” (p. 115). In the day-to-day relationship, care-givers experienced a sense of “permanent ambivalence” (p. 115) as they struggled with the inability to determine whether or not problematic behaviours were due to illness. A significant cost in terms of care-giver’s mental health was associated with care-
giver burden. Exhaustion, burnout, and at times, severe bouts of depression were not uncommon. The subjective burden that was unique to parental care-givers in this study was related to the lack of definitive answers to questions about the causes of schizophrenia and the resultant ever-present “diffuse feelings of guilt” (p. 117). Parents tended to “vacillate between hope and anxiety” (p. 117) as they lived with an unending sense of responsibility in a climate of uncertainty.

As in previous studies, the majority of participants in studies of care-giver burden were female. Jones (1997) stated that 75 percent of the participants in his study were female and 50 percent were parents; the relative number of mothers and fathers was not provided. Similarly, in Jungbauer and Angermeyer’s (2002) study, parental responses of mothers and fathers were not distinguished from each other. Given that the nature of subjective burden was found to vary with respect to roles in the family (parent, child, sibling, and spouse), one wonders if, and how, the nature of the father’s subjective burden might be different than the nature of the mother’s subjective burden. The little that is known in the research literature about the subjective burden experienced by fathers will be reviewed in the final section of this review entitled The Experience of Fathering an Adult Child with Schizophrenia.

In summary, the early research that focused on schizophrenia and the family led to assumptions about mothers, fathers, and family environments that have significantly contributed to the difficulties experienced in the working alliances between parents and mental health professionals. More recently, research based on the vulnerability-stress model has increased the awareness of the interplay between biological, psychological, and social influences in the development and course of schizophrenia, as well as the impact of schizophrenia on the family. Recent studies addressing family burden have provided an
awareness that individuals in various family roles experience subjective burden somewhat differently, which suggests a need for a more in-depth understanding of the experience of fathering an adult child with schizophrenia. A more in-depth understanding of the parenting experience, as well as the fathering experience has been provided through the research that has utilized inductive qualitative approaches.

**Parenting an Adult Child with Schizophrenia: A Review of the Qualitative Research**

New and enriched understanding of the experience of parenting an adult child with schizophrenia has emerged through the qualitative research undertaken and reported in the past fifteen years. By giving “voice” to parents as they told their stories in their own language, these studies have contributed to a greater understanding of the parenting experience than was possible with previous methods. As noted in the reviews of research on family burden, with the exception of the three studies specifically addressing the fathering experience, participants in the qualitative studies have overwhelmingly been mothers. This section entitled *Parenting an Adult Child with Schizophrenia* will begin with a review of the qualitative research that has included both mothers and fathers as participants, followed by a brief summary of studies addressing the experience of mothers. Attention will then be focused on the three studies that have addressed the experience of fathering an adult child with schizophrenia.

**The Parenting Care-giving Experience: Studies Including Both Mothers and Fathers**

The research which has included both mothers and fathers has drawn attention to three aspects of the parental experience: forms of parental care-giving, the impact of the diagnosis on the parental experience, and the changing nature of parental roles over the course of the illness.
Forms of Parental Care-giving

One of the earliest qualitative studies to address the parental care-giving experience was Chesla’s (1991) study, “Parents’ caring practices with schizophrenic offspring.” Chesla conducted three semi-structured interviews with 21 parental care-givers over a three month period within the natural context of care-giving, the home. Her interview data was supplemented with 25 hours of direct observation of parental care in the home with half of the participant families. Using a hermeneutic phenomenological approach, Chesla identified four forms of parental caring-giving: engaged care, conflicted care, managed care, and distanced care.

Engaged care was described as caring with a high degree of involvement: emotionally, socially, physically, and practically. Despite the high degree to which their lives were disrupted by changes in the symptoms of the illness, parents using engaged care “exhibited a level of acceptance with the situation as it stood” (p. 455). Engaged parents were more interested in fostering their child’s self-esteem than improving his/her level of functioning. They sought access to the child’s world and worked to engage him/her in the real world. “Whenever I can, I ask his opinions on things. I like to have him come to me and have him try to help me. Otherwise I’m shutting him out. To me, it would be devastating to shut him out” (p. 456). Parents who used a conflicted care approach were constantly experiencing anger, resentment, and disappointment. They struggled to find a balance between their own personal concerns and the concerns of their schizophrenic child, with very limited success. These parents often considered their child’s behaviour manipulative rather than a ‘symptom’ of illness. As a result they were frequently distressed and dissatisfied.
In the third form of care-giving, managed care, parents actively informed themselves about the illness through reading the available literature, and viewed their caring as treatment. By objectively setting long term goals and treatment plans for interventions, they were often able to achieve remarkable results. One parent explained, "I began to try to figure out all the ways that I could maybe ... work with him with all those disabilities, which are rather enormous disabilities, and still do something that would be creative and that he wouldn't realize was therapy" (p. 460). However, managed care at times became an overwhelming burden for some participants. For example, one mother described herself as "a prisoner of the disease" (p. 461).

Distanced care was exhibited only by fathers and characterized by a dependence on the child's mother to provide the direct care the child required. Although these fathers expressed interest in their child, Chesla states they were not personally involved with their child. This suggests a possible difference in the care-giving experiences of mothers and fathers. The results of Chesla's study, however, must be considered cautiously, as demographic information regarding the participants is incomplete and confusing. It is not clear how many fathers participated in the study and whether the information about distanced care was provided by fathers themselves or by their partners, as the men are not quoted in the discussion. One also needs to consider that the care-giving roles in many families today may be quite different than they were for the participants in Chesla's study, given that the interviews were conducted in the mid 1980's, and the mean age of participants was 56 years.
Impact of the Diagnosis of Schizophrenia on Parental Care-giving

Using a phenomenological approach, Tuck et al. (1997) drew attention to the impact of the diagnosis of schizophrenia on parental care-giving. For the nine primary care-givers in Tuck et al.'s study (two fathers and seven mothers), the onset of the illness prior to the diagnosis was "the most puzzling thing in the world" (p.120). When parents sensed that something was wrong, they struggled "to frame events as normal" (p. 120). They desperately searched for help and became frustrated with the inability of mental health professionals to identify the problem. Receiving the diagnosis of schizophrenia was described as a transforming experience accompanied by shock, grief, and uncertainty. Parents expressed a need to understand the implication of schizophrenia on their own lives, as well as on their child's life. One care-giver expressed: "That was sorrow and worry, I'd say those were the first reactions [to the diagnosis]. And worry about how am I, what does this mean for his future and what does this mean for my future. The uncertainty of what to do or how it was going to happen" (p. 121). Tuck et al. summarized the effect of the diagnosis "as a destructive force that interrupts and radically transforms the normative family life trajectory" (p. 118).

Care-giving after the diagnosis was characterized by endless caring and learning to live with constantly changing levels of hope and despair. Care-givers often found themselves dealing with distressing, and at times, repellent behaviour, especially with regard to poor personal hygiene. Paranoid delusions contributed to escalations of conflict. In the midst of ongoing stress, care-givers struggled to make sense of their experience and to maintain a separate identity from that of their child, often resulting in a lack of self-confidence. In the words of one parent:
This whole thing takes away your self-confidence. I have always felt that I knew something about raising children. I raised good children. And in conversation with other people I had an opinion [about child raising] and I thought my opinion was worth something. I no longer do. And you can tell me, you can sit and tell me all day long, as many times as you want to, that this is not my fault. I know that this is not my fault. But the truth is, I feel like a failure at the most important, one of the most important things of my life. The confidence that I show now, a lot of it is superficial, it's bravado (p. 123).

Tuck et al. provide rich insight into the period before the diagnosis, which is not addressed in depth in other studies. However, they do not differentiate between the experiences of mothers and fathers which lead one to wonder whether the experience of fathers in the very confusing and traumatic period prior to the diagnosis is different than that of mothers.

*The Changing Roles of Parents Caring for an Adult Child with Schizophrenia*

By using a grounded theory approach involving interviews with 29 parent caregivers (relative numbers of mothers and fathers not provided) who were members of a support group, Milliken (2001) pointed out that care-giving over the course of an adult child's illness involved a process of "redefining parental identity" (p. 149). Redefining parental identity for the participants in her study involved the following five stages: a) "becoming marginalized," b) "the disenfranchised parent," c) "embracing the collective," d) "parental suffrage," and e) "evaluating my life" (p. 150). This process was not necessarily linear. Given the lengthy and unpredictable course of schizophrenia, any or all of these stages could be repeatedly negotiated.
The first stage, becoming marginalized, was described as a transition period during which parents redefined their identity from “parent of a normal adolescent or young adult” to “parent of a child needing help.” With the increase in bizarre and dangerous behaviour, the participants in her study became more actively involved in helping and protecting their child by seeking help from family doctors, mental health professionals, and the police. Instead of experiencing more freedom as their child moved into adulthood, these parents were “instinctively pulled back into a more involved care-giving role” (p. 152). Throughout the help-seeking process, they repeatedly encountered barriers from legal and mental health sources, as well as from their schizophrenic child and found their “heretofore taken-for-granted parental rights denied” (p. 152).

In the second stage, as a disenfranchised parent, care-giving revolved around “caring for a bizarre stranger who resembled their child” (p. 152). Although some parents felt they had a good relationship with mental health professionals, many (specific numbers not provided) felt misunderstood by professionals and friends. Some parents felt blamed for their child’s illness, or stigmatized by people in their social network who were uncomfortable with mental illness. Misunderstanding, blame, stigma, and the overwhelming demands of care-giving led to increasing isolation. During the third stage, embracing the collective, parents became involved with other parents in a support group. Milliken (2001) states that through the support group these parents “redefined their child” (p. 153): the process through which parents “come to symbolically redefine their child and the recipient of their parenting as the whole schizophrenic community” (p. 153). In the fourth stage, parental suffrage, parents became actively involved in volunteer work, advocating for better
services, as well as seeking to increase public awareness and acceptance of mental illness.

In the last and final stage, parents began to refocus on themselves and their own needs.

Milliken's study provides insight into the role-changing experience of a small sample of parents recruited through the British Columbia Schizophrenia Society and leads one to wonder: How role changes experienced by parents who are part of a support group differ from the role changes experienced by parents who are not part of a support group? How role changes affect a mother's or father's ability to parent? What effects role changes have on a mother's self-concept as a woman, or on a father's self-concept as a man? Are role changes experienced differently by mothers and fathers, and if so, how?

_The Experience of Mothering an Adult Child with Schizophrenia_

The following studies describe the experience of parenting an adult child with schizophrenia from the perspective of mothers. Taken together, they provide insight into five major themes: a) the contradictory nature of mothering an adult child with schizophrenia, b) mothering as a return to earlier patterns of mothering, c) mothering as "interminable," d) support needs, and e) the experience of grief and loss. Each of these themes will be briefly summarized below. Studies addressing the mothering experience are included in this literature review because they provide a springboard for questions about the experience of fathering: Are these aspects of mothering also a part of the fathering experience? If so, are they experienced differently, and if so, how?

_The Contradictory Nature of Maternal Care-giving_

Vatri-Boydell (1996) sought to provide an in-depth look at "the hidden realities of caring [for an adult child with schizophrenia]" (p.1). Guided by feminist theory, using in-depth open-ended interviews with 25 mothers in the Toronto area, Vatri-Boydell discovered
that mothers’ caring-giving experiences were fraught with the following contradictions. The mothers in her study were expected to care for their children and were told they had the skills to do so, but were blamed when anything went wrong. When their child was discharged from hospital after an acute psychotic episode, these mothers were given no choice but to take the child home. Later, when difficulties arose at home, they were told to “kick the child out.” They were informed that schizophrenia was a biological illness and later were led to believe they had caused the illness. Vatri-Boydell also stated that the mothers in her study compromised their own safety by choosing not to report incidents of violence, preferring to suffer in silence, rather than to incur the possibility of jail or life on the streets for their child. She suggested that, “what protects the mentally ill individual actually ends up hurting the mother providing the care” (p. 161).

Mothering as a Return to Earlier Patterns of Mothering

Through in-depth interviews, Pauch (1996) studied the care-giving responsibilities of seven middle class white mothers of adult children with schizophrenia who were members of a self-help group sponsored by the Manitoba Schizophrenia Society. The children represented by these mothers were living in subsidized housing provided by the Manitoba Schizophrenia Society. Using phenomenological methodology, Pauch found that care-giving for the mothers in her study meant returning to patterns of mothering they had used when the child was young. These mothers felt as if they were “picking up the pieces” (p. 121), doing for the child what he/she seemed unable to do for him/herself. Care-giving for these mothers also involved staying “in tune” with the child’s needs, providing information to service providers, and monitoring ongoing changes. In their efforts to help, support, and protect their child, they frequently found themselves in a double bind: the adult child
viewed monitoring as interference and service providers questioned the mother’s ability to be objective. Care-giving for the participants in Pauch’s study became an overwhelming experience with little time for anything else.

*The Interminable Nature of Mothering an Adult Child with Schizophrenia*

“Interminable mothering” emerged as an overarching theme in Thorpe’s (1994) ethnographic study of six mothers living with adult children with schizophrenia in the Toronto area. The mothers in her study were all members of a support group. Mothering for these women involved protecting, advocating, and balancing. Protecting required a high degree of vigilance because of the ever-present concern about suicide and the need to constantly monitor for compliance with medications. Mothers became advocates for their child within the family, the mental health system, the justice system, as well as the community at large. They felt the responsibility to continually reassess their child’s strengths and needs, in order to find appropriate programs and activities for their child. Balancing involved a struggle to maintain a sense of normalcy in the child’s and the mother’s life within the limitations imposed by the illness. Mothers lived with uncertainty, as well as lack of understanding and support. Unpredictable symptomotology and a sense of “normlessness” contributed to ongoing uncertainty. Making plans became difficult and thinking about the future was, at times, overwhelming. Uncertainty increased when mothers felt misunderstood by family members, helpers, and others in the community. Mothers in Thorpe’s study described feeling abandoned and isolated, in great need of support.

*The Need for Support*

The need for support, the struggle to find it, and the unmet expectations and disappointments along the journey to finding help, were recurrent themes in the literature
One of the identified barriers to procuring help was the refusal of professional helpers to hospitalize a child before the occurrence of a severe crisis.

Crisante's (2000) study, "Experiences with involuntary hospitalization: A qualitative study of mothers of adult children with schizophrenia" explored the difficulties mothers faced when caring for an adult child who is potentially dangerous to him/herself or others and doesn't recognize the need for, or accept, help. Using phenomenological methodology, Crisante conducted in-depth interviews with three mothers identified through the Calgary Chapter of the Schizophrenia Society of Alberta. Crisante's findings indicated that "experiences with involuntary hospitalization for mothers of adult children with schizophrenia have been very demeaning and result in them feeling baffled, victimized, anxious and unfairly judged" (p. 79). The results of Crisante's study, while echoing themes identified in the literature, must be considered cautiously, given the small size of her sample.

Lack of support in formal and informal helping systems have led many mothers of adult children with schizophrenia to search for support from others in similar circumstances (Pauch, 1996; Terkelsen, 1987b). Pauch (1996) stated that support groups can provide a forum in which to share experiences with others who can understand and also can serve as a means to become "armed with information and knowledge that comes from experience" (p.165). Consistent reports of need for support throughout the literature underscore the need for further study of the support needs of parents at all stages of their child's illness.

Grief and Loss

Grief and loss were central themes in the research on mothering children diagnosed with schizophrenia. Mothers in Thorpe's (1996) study voiced three-fold losses: loss of
what the child once was, loss of the child's potential, as well as loss of the mother's personal future. In Milliken's (2001) study, mothers expressed grief associated with the loss of the child they once knew, as well as the loss of hopes and dreams for their child's future. They were grieved as they observed the difficulties of their child's day-to-day existence. The course of grief fluctuated with the ups and downs of symptom severity and became "a roller coaster ride of emotions" (Milliken, 2001, p.160). Pauch (1996) reported that the mothers in her study also grieved the loss of supports that their child once had. A number of additional studies have identified grief and loss as an integral part of the experience of parenting an adult child with mental illness (Atkinson, 1994; Davis, 1998; Doka, 1989; McGregor, 1994; Miller, Dworkin, Ward, & Barone, 1990).

Osborne and Coyle (2002), however, questioned the universal prevalence of grief and loss in parental responses to schizophrenia. Through an in-depth case analysis of four parents (three mothers and one father), they found differences in the way these parents conceptualized grief. One parent in their study did not acknowledge loss. Osborne and Coyle suggested that concepts of loss may be influenced by the degree of parental acceptance of the illness, or by the degree of change between the child’s pre-morbid self and his/her present self. For the parents in their study who did acknowledge loss, the child’s continued presence made it difficult to deal with grief and come to any resolution. Osborne and Coyle’s findings need to be considered cautiously given the small sample size.

In summary, the findings of the studies that focus on the mothering experience elicit a number of questions regarding the experience of fathers: Is the experience of fathers characterized by multiple contradictions? Do fathers of children with schizophrenia return to patterns of interacting with their child that are similar to the ways they interacted with
their child when he/she was young? What are the support needs of fathers and how have they met those needs? How do fathers of a child with schizophrenia experience loss? How does the experience of grief and loss affect a father’s life?

**The Experience of Fathering an Adult Child with Schizophrenia**

As has already been noted, a thorough review of the literature revealed only three studies, Howard (1998), Nystrom and Svensson (2004), and Pfeiffer (2001), that have focused on the experience of fathering an adult child with schizophrenia.

The first researcher to specifically address the experience of fathering was Howard (1998). Howard used a qualitative naturalistic method with semi-structured interviews to describe the lived experiences of twelve fathers by exploring their involvement in caring for their adult children with schizophrenia. At the time of the interviews, most of these fathers were retired (mean age 67 years); only two were still employed fulltime. The mean age of the adult child with schizophrenia was 35 years. The fathers in Howard’s study had been caring for their schizophrenic child for an average of 15.67 years. Three themes emerged in her study: involvement in care, unresolved issues, and severity of the event.

The fathers in Howard’s study reported that although their wives were the primary care-givers of their schizophrenic child, as fathers, they were actively involved as care-giver helpers. Involvement for these fathers included: financial support; “direct monitoring of the child during times of crisis and following hospitalization; and assisting in decisions about medical treatment, education, work, and housing” (p. 406). Three fathers in Howard’s study assumed the role of primary caregiver when their spouses were unable to do so because of health concerns.
The theme of unresolved issues included concerns related to the quality of time spent with other children in the family who were well, 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, referred to the extremely stressful nature of care-giving itself. One father described his care-giving experience as “life crushing” (p. 409). These fathers stated that the early stages of the illness, before the diagnosis had been established, were the most stressful. Howard suggested that the significant time lag which frequently occurs between initial symptoms and the time of diagnosis, exacerbates stress. When asked to compare the severity of the experience of caring for an adult child with schizophrenia with other difficult life events, without exception, the fathers in Howard’s study stated that the experience of caring for an adult child with schizophrenia was the most difficult experience in their lives. Other difficult events to which the experience was compared included abuse as a child, serious illnesses, death of loved ones, and war experiences.

Clearly, these fathers were profoundly affected by their experience. Eleven of the twelve fathers were emotionally stirred to the point of tears during the interviews. Every one of these fathers expressed surprise at their own emotional reactions. Several fathers stated that it was the first time they had ever talked to anyone about their experience. The stigma of mental illness was identified as one of the barriers in communicating with others. One father stated, “My worst enemy in this struggle is stigma – stigma born of superstition and even the professionals who have chosen to help us as their vocation” (p. 407). Despite the severity of the experience, one father noted positive outcomes; “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). He
attributed these positive outcomes to his supportive family noting how: "... support from spouse and siblings are a must" (p. 409).

According to the literature, it is difficult to find fathers of children with schizophrenia who are willing to participate in research (Pfeiffer, 2001; Nystrom & Svensson, 2004). Howard states that the fathers in her study were referred by mothers who had participated in her previous study, *Lifelong maternal care-giving for children with schizophrenia* (Howard, 1994). Knowing that the "story" of caring for an adult child with schizophrenia had already been shared from their spouse's perspective may have influenced the willingness of these fathers to participate in Howard's study. One also wonders if the fathering experience of fathers who agree to participate in research is different from the experience of those fathers who are unwilling to do so.

The second qualitative study that addressed the experience of fathering was Pfeiffer's (2001) study: *The other parent: A qualitative study of fathers of severely and persistently mentally ill adult children*. Pfeiffer (2001) explored the responses of fathers to mental illness in the family, through semi-structured interviews with 28 fathers of children with schizophrenia spectrum disorder. The participants in her study included seven fathers who had participated in a previous study addressing family coping and mental health beliefs at Eastern Pennsylvania Psychiatric Institute (EPPI), as well as fathers solicited through contacts with mental health professionals in in-patient and out-patient settings at EPPI and snowball sampling. Pfeiffer also noted the difficulties she experienced when trying to find fathers who were willing to participate in her study. Although a number of fathers had expressed to a third party a willingness to participate, they refused for various reasons when contacted by the researcher. Those who did agree to participate, however, were very open to
discussing intimate aspects of their lives. Pfeiffer’s study included fathers who were members of support groups and those who were not (one third were members of support groups), fathers of daughters and fathers of sons (one third were daughters and two thirds were sons), as well as fathers who resided with their mentally ill child and those who lived separately (one half of these fathers lived with their child and those who did not still maintained regular contact with their child). As in Howard’s (1998) study, most of the fathers in Pfeiffer’s study were retired (ages ranged from 49 to 84). Twenty-four of the twenty-eight fathers were born before 1936. Fifteen to twenty years had elapsed since their child had been diagnosed. Four themes emerged in Pfeiffer’s study: primary concerns, relationships and supports, professional helpers, and fathering. Some of the primary concerns expressed by fathers in her study were similar to the concerns identified in the research on mothering, others were not.

Similar to the concerns voiced by mothers in the research, the fathers in Pfeiffer’s study expressed concern about their child’s every-day well-being, as well as fears about their child’s future. They feared the recurrence of past psychotic behaviours - behaviours that could compromise their child’s safety or the safety of others. These fathers also expressed feelings of sadness and loss. As in Howard’s (1998) study, many of the fathers in Pfeiffer’s study were moved to tears during the interviews. Two fathers confessed to using alcohol as a form of self medication, three stated that they had required medication and professional help in order to cope. Four fathers commented on support gained through prayer. Several fathers attempted to avoid talking about sensitive emotions. Others used humour to disguise their pain. Clearly, all of the fathers in Pfeiffer’s study were profoundly affected by their child’s illness. They felt guilty about their inability to protect their families
from the effects of the illness and their inability to help their mentally ill child. Although life continued to be difficult, 25 percent of these fathers indicated that the care-giving burden had decreased with the passage of time. Experiences in the early phases of the illness were considered the most painful. After 20 years of living with the illness some of these fathers, now in their senior years, were receiving help from their mentally ill child.

Fathers’ concerns regarding the future were related to increased psychotic symptoms associated with violent, threatening, or suicidal behaviour. Unlike the prevalence of suicide concerns in the research on mothering, only five of the twenty-eight fathers identified suicide as a major concern. Two fathers stated that their child’s death would be a relief. Physical assault, however, was an ongoing concern. One third of the fathers in Pfeiffer’s study had been physically assaulted by their mentally ill child. Assault by a male child was taken more seriously than assault by a female child. Pfeiffer found that fathers were more likely to “forgive and forget” assault by a female child, and consider the aggression a result of illness. The fathers in her study also reported fearing their own anger. They struggled to control their anger in the face of assault by their child. These fathers also expressed anger toward the mental health system, especially when encountering barriers to obtaining help for their child through involuntary hospitalization.

Other concerns regarding the future emerged for fathers in Pfeiffer’s study that were not mentioned in the research on mothering. These concerns included worry about their spouse’s ability to cope in the event of the husband’s death. A few fathers, who were protecting their child from spouses who wanted the child evicted, worried about how their child would be treated when they could no longer provide protection. These fathers were also concerned about their child’s inability to function in a vocation and thus achieve at least
a degree of independence. For some of the fathers in Pfeiffer’s study enabling their child to
be self-reliant was symbolic of successful fathering. One of the surprising findings in
Pfeiffer’s study was the reported prevalence of false accusations of sexual abuse. Three
fathers in this study were accused of sexual abuse by their mentally ill daughter. Two of the
mentally ill sons had expressed sexual attraction to their mothers. Most of the fathers of
daughters expressed fear that their daughters could be sexually victimized because of their
poor judgment and at-risk behaviour.

Regarding relationships and supports, Pfeiffer stated that the majority of fathers in
her study indicated that the experience of living with schizophrenia in the family had not
adversely affected their marriage relationship. Fifty percent of these fathers indicated they
were happily married and their spouse was their main source of comfort and support.
Twenty five percent of the fathers indicated that the stress of living with schizophrenia had
strengthened the relationship with their spouse. One father, who had experienced marital
difficulties prior to the onset of his child’s illness stated, “I would say that dealing with it
has pulled us closer together, because we have to put our heads together all the time and talk
about what should we do about this and what should we do about that” (p. 130). The
twenty-five percent of fathers who were dissatisfied in their marriage, attributed their
dissatisfaction to their wives and not their child’s mental illness.

Other positive outcomes were also noted. Some fathers described becoming more
invested in the family after the onset of the illness. Pfeiffer stated that some of the
participants reported that their child’s illness “had a profound impact on their basic
understanding about the concepts of the innate fairness of life and forced them to question
their basic values (p. 124),” although the impact of this challenge on their personal growth is
Another positive noted by several fathers in Pfeiffer’s study was that their “well” children were sources of support. Twenty-five percent of fathers also reported receiving significant support from their own siblings, a finding which Pfeiffer stated had not been reported previously in the literature.

A finding in Pfeiffer’s study which elicits concern is that, without exception, every father was highly critical of the mental health system in crisis situations. Communication with mental health professionals in in-patient settings proved to be frustrating. Mental health professionals in out-patient settings were considered more helpful. Several fathers, however, were appreciative of individual mental health professionals who communicated an interest in their child. Although fifty percent of the fathers in this study attended at least one session of family therapy, very few fathers claimed to have received any benefit from therapists within the mental health system. It is important to note that these family sessions occurred soon after the initial diagnosis, 15 to 20 years prior to the time of the interviews, at a time when theories implicating parents in the etiology of schizophrenia were still widely held. Unlike mothers, who for the most part felt they received a great deal of support from support groups, fathers tended to have mixed opinions about the benefits of support groups. The majority of fathers in Pfeiffer’s study found support groups uncomfortable or a waste of time, however, a small number of fathers became actively involved. One father stated, “I’m a member, but I don’t go to the functions. It’s mostly mothers” (p. 184).

In her conclusions on fathering, Pfeiffer (2001) pointed out that the fathers in her study need to be understood in the context of men who began their families in the 1950’s and early 1960’s. They grew up during difficult times in which few of them experienced a close relationship with their own fathers. Twenty-four of the twenty-eight fathers were born
before 1936 and grew up with memories of the Depression and World War II. Families at that time were based on a patriarchal structure, and these fathers continued the traditional pattern of going to work and providing the family income, while their wives stayed home to raise the children.

The third study that focused on the experience of fathering was Nystrom and Svensson’s 2004 study: *Lived experiences of being a father of an adult child with schizophrenia*. Nystrom and Svensson utilized a life-world hermeneutic approach to explore and interpret the lived experiences of seven fathers of adult children with schizophrenia who were recruited through branches of the Swedish National Fellowship for Schizophrenia. As noted in the previously reviewed studies of the fathering experience, Nystrom and Svensson stated that it was difficult to find fathers who were willing to participate in their study. The fathers who did participate reported that they were discussing things they had never talked about before. Similar to the participants in Howard (1998) and Pfeiffer (2001), the fathers in this study had been fathers of an adult child with schizophrenia for twenty years or more. All but one of the participants who continues to run his own farm, were retired at the time of the interviews. Their adult children were middle-aged and had been diagnosed with schizophrenia in the early 1980’s.

Nystrom and Svensson’s study was guided by the research question: How does a severely mentally ill adult child affect his or her father’s life situation in short and long terms? An overarching theme of “the struggle to regain control” emerged in the study. Eight aspects of the struggle for control were identified as part of a continuum “from losing control to successively regaining it” (p. 368). The participants described “an initial state of chaos, stress and shock” when confronted with the symptoms of schizophrenia (p. 368). At
the time they felt totally helpless and incapable of caring for their child. One participant described himself as a “broken man” (p. 368). During the help-seeking process these fathers reported feeling disrespected and humiliated by mental health professionals who did not understand their experience and blamed them for their child’s difficulties. Nystrom and Svensson suggested that “it is fair to assume that the early assignment of the role of being a failure as fathers paralyzed for a long time the power of initiative as well as their ability to control the situation” (p. 370).

The initial feelings of shock and loss of self-esteem were followed by a sense of grief and loss as these fathers became increasingly aware of the long term consequences of living with a schizophrenic child. They grieved the loss of who their child may have become and reported experiencing an ever-present sense of worry as they faced a future of uncertainties. These dads worried about what would happen to their child when they would no longer be able to support them. Nystrom and Svensson suggested that the period of grief may have been “necessary in order to regain control and adapt to the situation” (p. 371). Following a period of grieving, the fathers in this study took on the role of “provider of practical support” while their spouses tried to provide emotional support (p. 371).

All of the fathers in this study reported that their relationships with their wives were negatively impacted by the experience of parenting an adult child with schizophrenia. Nystrom and Svensson stated that “the fathers seem to believe that they can control and adapt to the situation far more successively than their wives” (p. 373). These fathers reported that they had participated in family education interventions and all but one stated that these interventions had a negative impact on their marital relationships. They also reported that it was important for them to periodically escape from their stressful family
situations and engage in other activities outside the family. Nystrom and Svensson suggested that these “engagements outside the family might also fulfill the purpose of regaining the control over one’s life situation” (p. 374).

Regarding support, the participants in Nystrom and Svensson’s study reported that support groups with other parents of children with schizophrenia were helpful. Nystrom and Svensson suggested that the fathers in their study wanted “to be listened to in their life-world” and this was only possible with other parents of schizophrenic children. Despite the severity of their experience the fathers in this study cited several positive outcomes. They reported that “their own personality changed for the better” (p. 374). They gained insight into the experience of living with mental illness, “more sympathy with the difficulties of life,” and a greater ability “to cope with other personal crises” (p. 374). In conclusion, Nystrom and Svensson suggested that the process of grieving may be “the beginning of a way back to a meaningful life. The process of regaining control over one’s own life makes it possible to work through the situation …” (p. 375).

In summary, the participants in Howard (1998), Nystrom and Svensson (2004), and Pfeiffer (2001) were all profoundly affected by their experience. Although there were many similarities between the experiences of fathering and mothering an adult child with schizophrenia, there were also differences. Notable among these differences were: the concern about their spouse’s ability to cope, fathers’ reactions to physical assault, having to deal with accusations of sexual abuse, fathers’ fear of their own anger, as well as fathers’ response to their child’s inability to function in a vocation and thus become independent and self-reliant. The participants in Howard, Nystrom and Svensson, and Pfeiffer all reported that their experiences in the early stages of the illness were the most traumatic. These
traumatic experiences associated with the early stage of the illness for the fathers in these studies occurred on average 15 to 20 years ago. Since that time collaborative approaches in working with families have been increasingly emphasized. The findings of these studies lead one to question if the experience of parenting an adult child with schizophrenia is different for fathers today than it was 15 to 20 years ago. If it is, how has it changed?

**Conclusion**

The understanding of schizophrenia and the family has shifted considerably in the research over the past 60 years. Early theories, which developed during the period of institutionalization of the mentally ill, led to assumptions that parents were causal factors in the etiology of schizophrenia and contributed to difficulties in the working relationships between parents and mental health professionals. Within the period of deinstitutionalization, the burden of caring for mentally ill family members fell largely to the family and the focus of research on schizophrenia shifted to factors that were considered part of the vulnerability-stress model of schizophrenia, such as biological factors and the concepts of expressed emotion and family burden. Most of the research based on the vulnerability-stress model addressed the understanding of these factors through deductive approaches.

Over the past fifteen years, inductive qualitative studies began to provide an in-depth understanding of the experience of parenting an adult child with schizophrenia. As noted throughout this review, the participants in these studies were overwhelmingly mothers and the responses of the few fathers that participated in the research were aggregated within the data. The three studies that specifically addressed the experience of fathers, Howard (1998), Nystrom and Svensson (2004), and Pfeiffer (2001) found that, although the experiences of fathers were similar in many ways to the experiences of mothers, there were also
differences. The current study expands the knowledge these studies have provided. The participants in Howard, Nystrom and Svensson, and Pfeiffer's studies were predominantly fathers in their senior years and, at the time of the interviews, an average of 15 to 20 years had elapsed since their child had been diagnosed. The current study addressed the experience of fathers of adult children who had been diagnosed within the past 10 years.
CHAPTER THREE: METHODOLOGY

Design

As noted in the literature review in chapter two, a great deal of research has been directed towards the study of schizophrenia and the family, primarily from deductive, but also inductive perspectives. Over the past 15 years a growing number of inductive qualitative studies have begun to provide an understanding of the experience of parenting an adult child with schizophrenia from the perspective of mothers, however, only three studies were found that have explored the experience of fathering. These studies have employed inductive, qualitative methods. The purpose of the proposed study was to expand the knowledge these studies have provided by exploring the nature and the meaning of the experience of fathers of children who were diagnosed with schizophrenia within the past ten years, a focus which had not been addressed in the research literature. Stebbins (2001) states that an inductive qualitative exploratory approach is appropriate when the purpose of the research is to gain greater conceptual understanding of a little or partially known phenomenon. Exploratory, qualitative research provides an “openness to new ideas and observations” (Stebbins, p.8). “To understand well any phenomenon, it is necessary to start looking at it in broad, non-specialized terms” (Stebbins, p. viii). A qualitative approach allows for flexibility and open-mindedness, two essential aspects of the exploratory process (Palys, 1997; Stebbins). By expanding the knowledge already provided by Howard (1998), Nystrom and Svensson (2004), and Pfeiffer (2001) the current study contributes to the process of concatenation, “a research process and the resulting set of field studies that are linked together, as it were, in a chain leading, to cumulative grounded or inductively
A number of possible qualitative methods could have been used to explore the experience of fathering: ethnography, grounded theory, case study analysis, narrative analysis, or phenomenology. These methods are similar in that they focus on understanding the experiences of others and use “personal descriptions of experience” as their primary data source (Osborne, 1994, p. 179). They differ in terms of purpose and degree of emphasis (Osborne). Ethnography focuses on describing the experience of a group and “is concerned with predictable patterns of thought and behaviour” (Osborne, p. 178). Ethnographic studies present “a socio-cultural interpretation of the data” (Merriam, 2002, p. 9). Grounded theory focuses on inductive development of theory. Using a constant comparative method, grounded theory “aims to develop theoretical explanations of the relationships among categories of data as the research proceeds” (Osborne, p. 181). Case study methods focus on an individual case or social unit and aim to provide a comprehensive description and analysis of everything that can be learned from that case (Merriam; Osborne). Narrative analysis uses stories as data, which are then analyzed psychologically, biographically, or through discourse analysis (Merriam). Phenomenology, specifically hermeneutic phenomenology, systematically “attempt[s] to uncover and describe the structures, the internal meaning structures of lived experience” (Van Manen, 1992, p. 10). This is the purpose of the current study.

Phenomenology, rooted in the philosophies of Husserl and Heidegger, is the study of the life-world as it is experienced pre-reflectively, that is prior to analyzing or classifying the phenomenon (Van Manen, 1992). The phenomenological researcher aims to identify and
describe as richly as possible the phenomenon as people experience it (Colaizzi, 1978). Van Manen states that the starting point of phenomenological research is “everyday experience” (p. ix). Hermeneutic phenomenology goes beyond description to interpret the essential meanings of human experience (Van Manen). In order to do this, the researcher intentionally “attaches” himself/herself to the participant’s life-world and attempts to “become more fully part of it” (Van Manen, p. 5). The purpose of hermeneutic phenomenological research is thus “to borrow other people’s experiences and their reflections on their experiences in order to better be able to come to an understanding of the deeper meaning or significance of an aspect of human experience, in the context of human experience” (Van Manen, p. 62). This is referred to as verstehen and encompasses both empathetic and rational understanding, with the intention of making explicit that which “tends to be obscure” (Van Manen, p. 32). Through interpreting lived experiences researchers relate parts of human experience to the whole of human experience; lived experiences are considered “part of a system of contextually related experiences” (Van Manen, p. 37). Human experience is acknowledged to be infinitely complex; phenomenological research, therefore, never claims to be complete. Through hermeneutic phenomenological methodology, the current study aims to describe as fully as possible the experience of fathers who have an adult child with schizophrenia, and to enrich the understanding of this phenomenon by explicating the essential meaning structures of the experience.

Hermeneutic phenomenological methodology is well suited to research in counselling psychology in that the skills and characteristics of phenomenological researchers are the same as those necessary for effective counselling: relationship skills,
interpersonal communication skills, as well as the ability to understand empathetically (Osborne, 1990). Rew, Bechtel and Sapp (1993) elaborate further on these skills by identifying seven necessary characteristics of phenomenological researchers: a) genuine caring, b) authenticity, c) credibility, d) intuitiveness, e) receptivity as exemplified through an openness to learning, f) reciprocity exemplified through the attempt to minimize power differentials between the researcher and participant, and g) intuitive sensitivity, which enables the researcher “to see and hear accurately” (p. 301). The phenomenological researcher must also be personally interested in the phenomenon and prepared to openly acknowledge his/her motivation in choosing to study the phenomenon.

Bracketing

In phenomenological studies, the researcher, as the primary research instrument, is unavoidably present in all aspects of the research (Osborne, 1990). The researcher therefore begins the research by identifying personal assumptions and presuppositions that may influence the research (Colaizzi, 1978; Polkinghorne, 1991; Van Manen, 1992). Through this process of bracketing, the reader is alerted to the researcher’s perspective and the researcher is enabled to set aside his/her biases as much as possible, and as a result become better able to describe the phenomenon as it is (Osborne, 1994; Polkinghorne; Van Manen). It is therefore important that I begin by identifying myself as a mother of an adult child with schizophrenia with close ties to the phenomenon I wish to study. I began the process of bracketing by writing my own story as a mother of an adult child with schizophrenia and then, together with my thesis supervisor, identified my assumptions and presuppositions.

The following disclosure of my assumptions and presuppositions regarding the experience of fathering an adult child with schizophrenia begins with my childhood
exposure to assumptions about mental illness and my experience in psychiatric settings as a student in rehabilitation medicine, followed by assumptions and presuppositions which stem primarily from my experience as a mother. Attention is drawn to how I assume the experience of fathers is similar to the experience of mothers, as well as where I expect to find differences.

I believe that early childhood exposure to statements reflecting the stigma of mental illness can leave lasting impressions and influence the ease with which mental illness can be accepted as part of normal life. Although I did not have any direct exposure to mental illness as a child, schoolyard talk referring to the mentally ill as “psychos” or “weirdoes,” left me with impressions that I have not forgotten. These designations implied that people who were mentally ill were dangerous, unpredictable, and definitely people to stay away from. I also recall my father’s comments referring to a family he knew that had a mentally ill son, which implied that having a child with a mental illness was a terrible thing. I believe these early experiences affected my ability to feel comfortable around the mentally ill.

I believe that children today may be more accepting of mental illness than the children of the fifties and sixties. Integration of the mentally ill within the community and the resultant increased exposure of the public to mental illness over the past few decades has, I believe, lessened the stigma of mental illness, although it is still very much present. In addition, increased public awareness and understanding of mental illness, brought about through the educational efforts of organizations such as the Schizophrenia Society, have hopefully contributed to more positive assumptions about mental illness. On the other hand, media depictions of the mentally ill have, and continue to contribute to both negative and positive perceptions of mental illness.
It is my impression that boys may be influenced by the stigma of mental illness differently than girls; boys may be more likely to consider mental illness a weakness. As a mother of five boys, I have repeatedly been impressed with the way boys value strength and easily look down on weakness. Amid the competitive interaction between boys, I have frequently heard “I can do this better than you,” “Look what I can do,” “He’s just a wimp” etc. and witnessed the pushing and shoving to establish who is “the strongest.” It is my impression that boys easily link physical and intellectual prowess to their concept of masculinity. When carried into adulthood these values may significantly influence a father’s ability to accept mental illness, especially in a son.

My first direct exposure to mental illness occurred as part of my occupational therapy training in the early 1970’s. I was required to complete at least two placements in psychiatry and remember feeling uncomfortable with psychiatric patients. Outside of psychiatric settings it had always been easy for me to connect with people and make friends; within the psychiatric setting it was difficult. Being with mentally ill patients required more of me than I was able, willing, or ready to give. I felt inadequate. I remember thinking that I would never choose to work in a psychiatric setting. On reflection, I believe that I was not grounded solidly enough to be able to reach out in any genuinely meaningful and compassionate way to the patients with whom I was working. After graduation, I chose to work in physiotherapy, and did not have any additional contact with the mentally ill until my second eldest son became ill in his adolescent years.

The years prior to my son’s diagnosis were difficult and confusing for both myself and my son’s father. My husband initiated the help-seeking process. It is my impression that fathers may find it easier than mothers to initiate the help-seeking process, especially in
situations where mothers have close emotional ties to their child. Mothers, who I believe have a stronger sense of nurturing, may be more inclined to understand their child’s difficulties in terms of normal developmental adjustment rather than pathology. Mothers may also be more susceptible to doubt their own reactions, especially when fear about safety is a prominent factor. Self-doubt may stand in the way of finding help. Fathers, on the other hand, may have a greater ability to “objectify” situations and be less likely to be overwhelmed by feelings. More goal-oriented than mothers, fathers are also more likely to view helping in terms of action. For fathers, helping may be viewed in terms of protecting and problem-solving. One active way to problem-solve is by involving outside helpers, who are expected to have the knowledge and skills to “fix” the situation. Some fathers, particularly in a traditional patriarchal household, may view the help-seeking role as their responsibility as the “head of the household.” In more egalitarian spousal relationships, which I believe are more common in recent years, the help-seeking process is likely negotiated between parents.

I believe that the initial contact with mental health professionals will greatly affect the ability of mothers and fathers to build effective working relationships within the mental health system. Trust will be undermined if parents sense they are being held responsible for their child’s difficulties. Both mothers and fathers are highly sensitive to feelings of guilt, although I expect fathers may be more sensitive than mothers. When fathers feel judged, they are likely to become less involved in the help-seeking process. On several occasions, both my husband and I felt judged in early interactions with mental health professionals. Although many positive experiences were to follow, the negative experiences are indelibly etched in my memory.
Generally speaking, I expect that fathers, especially professional men, are likely to be treated with more respect than mothers by mental health professionals. I believe that motherhood is undervalued in our society and at times associated with women who are intellectually inferior or incapable in other ways. For both parents, but especially for mothers, the power differential in working alliances with mental health professionals can be intimidating. As a mother, I have experienced being treated in a patronizing way on a number of occasions, and this has contributed to feelings of self-doubt and lack of confidence as a parent.

I also believe that fathers generally will have higher expectations of professional helpers than mothers will. Fathers will expect a high degree of competency, reflected in the ability to provide answers, and are likely to be less comfortable with ambiguities than mothers. Given the difficulty in establishing a diagnosis, fathers may find the help-seeking process more frustrating than mothers. Frustration may manifest itself in reactions of anger, withdrawal, or other ways.

Although the research literature frequently cites examples of the difficulties parents have faced in developing a good working alliance with mental health professionals, I believe there has been a significant shift over the past decade in terms of the approach of mental health professionals to families. Education directed towards working with families has advocated collaborative approaches characterized by respect and recognition of family strengths. There has been a shift away from a deficit model towards a model of empowerment, in which families are enabled to deal with difficulties through accessing and using their strengths. I expect that fathers who feel they have been approached by mental health professionals in a collaborative manner, with respect and recognition of their
strengths, will likely continue to be actively involved in their child's treatment throughout the course of their illness.

I believe that the diagnosis of schizophrenia in a child profoundly changes the lives of both mothers and fathers. The initial reaction to the diagnosis may be accompanied by a profound sense of relief: a new hope for successful treatment — some way of dealing with what until now has been an unknown. The sense of relief will likely be most pronounced in situations where the help-seeking process has been long and painful. Relief, however, will be short-lived unless the child responds quickly to treatment and is able to resume close to pre-morbid levels of functioning.

The process of adapting to life with a schizophrenic child will take time. Throughout this process, I expect that grief and loss, fear, and a confrontation with the existential questions of life will be part of the experience of both fathers and mothers. Although individual differences will likely be apparent, I also expect to find differences between the experiences of fathering and mothering.

I expect that both fathers and mothers will experience an ever-present "ache" inside: the pain of unresolved grief. The ongoing presence of the child will be a constant reminder of what once was, and what could have been. I expect that the expression of grief will be more difficult for fathers than for mothers and that fathers are less likely to process their grief with others. It is still less socially acceptable for males to be overtly emotional than females, although I believe this has changed significantly over the past decade. I expect that many fathers associate masculine strength with emotional self-control. Fathers of an adult child with schizophrenia may find self-control difficult to maintain, for the "ache" inside may be unsettling and unpredictable. Enquiries about their ill child may trigger emotional
reactions. Fathers may find it easier to deal with the uncontrollability by distancing themselves from their grief. Distancing may be reflected in several ways, such as redirecting grief through pouring energy into work or other activities, and withdrawing from the mentally ill child or other members of the family. Withdrawal and isolation will likely become more pronounced when fathers sense the stigma of mental illness. The stigma of mental illness may be felt more strongly by fathers who place a high value on social acceptability. Mothers, on the other hand, will more likely process their grief by talking to others, such as trusted friends and family. Where informal supports are not available, I believe mothers are more likely than fathers to seek help through therapy or support groups.

I expect to find that some aspects of grief and loss may be especially difficult for fathers. Although both parents will grieve the loss of the child they once knew, this loss may be more difficult for mothers, who are more likely to be emotionally closer to their child. Fathers, on the other hand, may experience a greater sense of loss around the dreams and expectations for their child’s future. As indicated by the fathers in Pfeiffer’s (2001) study, losing the dream of seeing their child as independent and vocationally successful may stir up feelings of failure as a father. Feelings of guilt, failure, and disappointment may be compounded if fathers have experienced “blame” from mental health professionals. Fathers of mentally ill sons may feel more accountable for their child’s lack of abilities than fathers of daughters, for sons may be viewed as a reflection of their fathers. The resulting sense of guilt and accountability may incline fathers to be more demanding of sons. Symptoms of the illness that can easily be misinterpreted as irresponsibility or sloth may be less easily tolerated in a son than a daughter.
When mothers and fathers process grief differently, I believe there is potential for misunderstanding and increased tension in the spousal relationship. Misunderstanding, when added to one's personal pain may increase the tendency to be reactive and defensive. On the other hand, some parental relationships may be strengthened by the necessity of working together to solve problems, especially if the course of the illness is punctuated by frequent crises. In egalitarian relationships spouses will more likely problem-solve together and be mutually supportive in challenging situations. When working together becomes too difficult, I expect that one parent may withdraw and leave the care-giving responsibilities to the other parent. Mothers are more likely than fathers to take on care-giving responsibilities. I expect that fathers who have been actively involved in care-giving prior to the child's illness will likely remain more involved in care-giving throughout the child's illness.

I assume that fear will be part of the experience of both mothers and fathers: fear of the unknown, fear of how to manage the unpredictable nature of the illness, as well as fear of the future. Depending on the parent's experience with mental health professionals, there may also be fear of the inability to access appropriate help when needed. Although fear may be equally present for mothers and fathers, fathers may have more difficulty acknowledging their fear due to the social expectation that strong men are not fearful. Fathers may feel the need to protect others in the family by being strong. The difficulty of acknowledging fear may be a reflection of the modeling of their own fathers.

I assume that both mothers and fathers of adult children with schizophrenia will be faced with the existential questions of life: questions about death, freedom, isolation and meaning. How and when these questions are addressed will, to a significant extent, determine the nature and degree of change in a father's life. Fathers in their senior years
may be more likely to address these issues. I believe that the experience of fathering an adult child with schizophrenia also provides the potential for learning how to live life more fully, in deeper and new ways.

Having disclosed my presuppositions, I hope to be able to suspend them as much as possible, in order to be open to the experiences of the participants and “allow the data to speak for themselves” (Osborne, 1990, p. 84).

Participants

Phenomenological methodology emphasizes equality in the research-participant relationship (Rew et al., 1993). The interviewer becomes a participant and the participant becomes a co-researcher (Colaizzi, 1978; Osborne, 1990; Van Manen, 1992). Through a collaborative relationship between the co-researcher, who has experience with the phenomenon, and the researcher, who seeks to participate in the co-researcher’s life-world, it is anticipated that an understanding of the phenomenon will be achieved and the structure of its meaning identified (Osborne).

Six fathers of adult children with schizophrenia volunteered to participate in this study. To meet the criteria for inclusion in the study, the participants were to be biological fathers of an adult child with schizophrenia who had been diagnosed for a minimum of two years and no longer than ten years. A minimum of two years post-diagnosis would ensure sufficient experience with the phenomenon to be able to reflect back on it, while a maximum of ten years post-diagnosis would ensure that these participants could recall their experiences pre- and post-diagnosis. One volunteer, who initially thought that he met the criteria, later mentioned that his son had been diagnosed with schizoaffective disorder. When reviewing the DSM criteria for schizophrenia, he indicated his son’s illness matched
the description. In consultation with my supervisor, it was decided to include this father in the study given the differing opinions concerning the diagnosis of schizophrenia, the mounting evidence for continuum theory (Varma, 1997; Taylor, 1992), and the DSM recognition of schizophrenia spectrum disorders as outlined in chapter one. The themes that emerged in the analysis of the interview with this participant were the same as those that emerged through the analysis of the interviews of the other participants.

In order to be included in the study the participants also had to be interested in communicating their experience of fathering an adult child with schizophrenia and willing to volunteer. They had to be able to articulate their experience. Osborne states that "participants should be people who have experienced and can illuminate the phenomenon" (p. 82). In order to understand the phenomenon as fully as possible, it was important to gather extensive and rich descriptions of specific situations (Kvale, 1983). The participant’s ability to communicate was integral to this process. Participants also had to be willing to commit to two interviews for a total time commitment of approximately three hours.

**Procedure**

Participants were sought through personal networking with mental health professionals at the UBC Schizophrenia Day Program, Burnaby Central Mental Health Day Program, Sherbrooke Day Program (Royal Columbian Hospital), Psychiatric Day Treatment Program (Surrey Memorial Hospital), Melody House Group Home, Riverview Family Resource Centre, Community Mental Health Units, the British Columbia Schizophrenia Society, as well as the Early Psychosis Intervention Program. Notices (Appendix A) describing the study and the criteria for inclusion were sent to mental health professionals in these agencies. Fathers who expressed an interest in participating in the study were asked to
contact the researcher by telephone. As fathers responded, they were briefly interviewed over the phone to determine whether or not they met the criteria for inclusion as outlined in the previous section. Fathers were informed about the rationale and purpose of the study, as well as the time commitment required. The researcher tried to establish an empathic rapport with potential participants during the initial contact. Issues of confidentiality were discussed and interested participants were informed that their participation was completely voluntary and that they retained the right to withdraw from the study at any time. They were also informed that interview sessions would be audio-taped and they would be requested to sign a consent form prior to the initial interview. Potential participants were also given the opportunity to ask questions about any aspect of the study. The first six fathers who volunteered to participate and met the criteria were accepted for the study. An interview was scheduled with those fathers who were accepted for the study at a mutually agreed upon time and location that was private, convenient, and comfortable for the participants. Three participants were interviewed at a community counselling office, two were interviewed in homes, and one was interviewed at an office at UBC. After the interviews were complete, I wondered if the fathers who chose to be interviewed at a private home were emotionally influenced by memories associated with their surroundings. In future research I would recommend that interviews be conducted at a location that is emotionally neutral, such as a community counselling office.

The initial interview began with a review of the rationale and purpose of the study. Participants were reminded of the voluntary nature of their participation and the freedom to withdrawn from the study at any time. Opportunity was given to choose a pseudonym that would be used throughout the study to protect their anonymity. Participants signed two
copies of an ethical consent form (Appendix B), one of which was retained by the participant. A minimally structured interview followed, guided by an orienting statement (Appendix C) which was read to each participant at the beginning of the interview. The interview was audio-taped and transcribed. Every effort was made by the researcher to enter the participant's life-world and to allow the phenomenon to speak for itself. By using the skills of empathetic listening, paraphrasing, immediacy, clarification, as well as open-ended questions the researcher attempted to facilitate a rich description of the phenomenon.

Colaizzi (1978) stresses that the researcher must exercise "imaginative listening" (p. 62), listen "with more than just ears" (p. 64), and be attentive to the nuances and tensions communicated as the participant tells his story. Van Manen (1992) stressed the need for the researcher to be attentive to the silences around the words. As a researcher I strove to be comfortable with ambiguity, attempted to clarify contradictory meanings, and to ascertain where contradictions were the result of miscommunication and where they were a reflection of genuine "inconsistencies, ambivalences and contradictions" inherent in the meaning of the phenomenon (Kvale, 1983, p. 177). Open-ended questions were used to guide the interview and to facilitate more in-depth exploration of topics and issues raised by the participants (Appendix D). Process notes were written immediately after each interview to record non-verbal responses, as well as personal thoughts and feelings "to enhance and extend the description" (Polkinghorne, 1991, p. 183).

The duration of the initial interviews ranged from one and a half to two and a half hours. Participants were encouraged to keep a record of any additional insights that occurred after the interview, and to communicate these insights to the researcher in the follow-up validation interview. After the analysis of the themes and meaning structure was complete,
a copy was sent to each of the participants and a time was arranged for a second interview to validate the findings. One of the participants added some insights that had come to mind after the initial interview. These insights did not change the themes that had emerged through the data analysis. All of the participants validated the findings as an accurate reflection of their experience and expressed a sense of gratitude for the opportunity to participate in the study. Several fathers stated that they felt validated through their experience of participating and that sharing their stories had been therapeutic for them.

**Data Analysis**

The data was analyzed according to the seven steps of phenomenological analysis outlined by Colaizzi (1978). The audiotapes of each interview were transcribed verbatim. The co-researcher’s descriptions (protocols) of the phenomenon were read several times in order to gain a feel for them. Significant statements regarding the experience of fathering an adult child with schizophrenia were extracted from each protocol. The researcher strove to illuminate the thematic meaning of each significant statement. Colaizzi described this step as a “leap from what his subjects say to what they mean” (p. 59). This required incorporating insights gained through process notes, as well as going “beyond what is given in the original data and at the same time, stay[ing] with it” (p. 59). The above steps were repeated for each protocol and meanings were aggregated into “clusters of themes” (p. 59) that were common to the co-researchers. The results of all of the above steps were then integrated into a description of the essence of the lived experience of fathering an adult child with schizophrenia. The findings were then presented to the original co-researchers for validation. New information that emerged during the validation process was taken into consideration in the final report.
Limitations

This study is limited by the degree to which the participants were willing and able to articulate their experience. It is possible that the degree of self-disclosure could have been influenced by the stigma associated with mental illness. It is also possible that fathers who volunteered were highly motivated to share their experience and may not be representative of the population. Given the difficulty noted in the literature in finding fathers of adult children with schizophrenia who are willing to participate in research studies, it is possible that the experience of fathers who do volunteer to participate may be different from the experience of those fathers who are unwilling to do so. It is also inevitable that my biases as a mother of a child with schizophrenia have influenced the process and analysis of the data, despite my attempt to bracket my presuppositions. To minimize personal influences I made every attempt to describe my thoughts, feelings, and reactions through process notes and worked closely with my supervisor. Inevitably, the study was also limited by my lack of experience as a researcher, both in terms of interviewing and analyzing the data. On the other hand, my personal experience as a parent of a child with schizophrenia, may have provided a valuable sensitivity and awareness to the research context. Finally, phenomenological research never claims to be complete. This study represents an initial attempt to give voice and explore the experience of fathers of young adult children with schizophrenia who have been diagnosed within the last ten years.
CHAPTER FOUR: RESULTS

This chapter will begin with a short biographical description of the six fathers who participated in the study. The six common themes that emerged from the stories of these fathers will then be outlined and discussed in detail.

Biographical Synopsis of the Participants

All of the participants in current study were self-selected and volunteered to participate. The researcher received a call from the first father who volunteered to participate over two months after notices about the study had been distributed to support groups and community mental health clinics throughout the greater Vancouver area. Several fathers had indicated an interest in participating to a third party, but did not contact the researcher. The fathers who did volunteer to participate were very open and willing to talk about their experiences. It was clear that they wanted their experience to be helpful to others. Several participants in the current study commented that they considered their own willingness to participate to be atypical of most fathers of adult children with schizophrenia. They were of the opinion that fathers would be unlikely to volunteer to talk about such an emotionally laden experience.

Four of the six fathers who participated in this study were middle-aged, in their late forties and fifties. One father was in his early sixties and another father was in his early seventies. Five fathers had a son with the illness and one had a daughter with the illness. The young adult children represented by these fathers ranged in age between eighteen and thirty-one years of age. Five of the fathers reported that at the time of the interview their child’s illness was relatively stable and he/she was taking steps toward living independently. Of these five fathers, two reported that their child was living independently, but closely
monitored by his/her parents. Three stated that their child was living semi-independently: two in housing provided for mental health consumers and one in the home of an extended family member. Only one of the children represented by the fathers in this study was living at home with his parents. This child was the youngest and the most severely ill of all the children represented by the fathers in this study.

The following is a brief biographical description of each of the six fathers. In order to protect their anonymity each of the participants chose a pseudonym to be used in the study.

**Paul:** Paul is a recently retired father in his early sixties who lives with his wife in the greater Vancouver area. Throughout most of his adult life he has worked in management positions. He has two children, a daughter and a son. His son is twenty-nine years old and was diagnosed with schizophrenia approximately four years ago. Paul had just transitioned into his retirement at the time when his son was diagnosed with schizophrenia. His son has had one hospital admission and at the time of the interview Paul reported that his son's illness was relatively stable. Throughout the course of his illness this son had lived at home and on his own for short periods of time. He is presently unemployed, receiving a mental health disability allowance and living independently in a housing complex supervised by a mental health agency. Paul stated that he is in regular contact with his son and spends time with him at least once a week. As a parent of a mental health consumer, Paul has become very involved in the British Columbia Schizophrenia Society on a volunteer basis. He became aware of the study through a notice distributed through the BC Schizophrenia Society, expressed an interest, and volunteered to participate.
**Rick:** Rick is a middle aged father of four daughters who lives with his family in the greater Vancouver area. For most of his life he has been employed in the manufacturing industry. His third daughter, who was twenty-seven years old at the time of the interview, was diagnosed with schizophrenia approximately eight years ago. This father reported that prior to her diagnosis, his daughter had gone through a tumultuous adolescent period involving illicit drug use. Although his daughter has had several acute episodes of illness, he stated that over the past few years her illness has been relatively stable. She is presently living independently with a partner. At the time of the interview she was employed as a unit clerk in a hospital. Rick and his wife are in regular contact with their daughter. With her permission they monitor the course of her illness and advise her to seek help from mental health professionals as needed. Rick’s wife is a medical health professional. Rick became aware of the study through his wife who is involved with the BC Schizophrenia Society as a volunteer support group coordinator. After reading the notice describing the study, he volunteered to participate.

**Dwayne:** Dwayne is a middle aged father of two sons who has recently retired from a long career as a teacher in special education. He lives with his wife in the greater Vancouver area. His oldest son, who is presently thirty one years of age, was diagnosed with schizophrenia approximately eight years ago. Dwayne reported that his son has had many acute periods of illness involving multiple hospital admissions. Over the past year his son has been relatively stable in terms of his illness, and has been living semi-independently in housing provided for mental health consumers. Both Dwayne and his son have been actively involved within the mental health system on a volunteer basis. Dwayne became
aware of the study through his association with the BC Schizophrenia Society and volunteered to participate.

**George:** George is a middle aged father of three sons who lives with his wife and family in the greater Vancouver area and is employed in the oil industry. The oldest of his three sons has schizo-affective disorder and was diagnosed approximately four years ago. He was twenty years old at the time of the interview. George reported that the course of his son's illness has been lengthy and difficult with multiple hospital admissions. However, within the past year his son has been more stable and has recently transitioned to living semi-independently in the home of an extended family member. Until recently he had been living at home with his parents and brothers. At the time of the interview, George stated that his son was unemployed and in the process of applying for a mental health disability allowance which would enable him to rent his own apartment should he choose to do so. George's son is on medications and is being followed by a community mental health team. George became aware of this study through word of mouth and volunteered to participate.

**Ron:** Ron is a retired father of two sons in his early seventies. Throughout most of his life he has been actively involved in the ranching industry. In his retirement years Ron moved to the coastal region of British Columbia just north of Vancouver where he is actively involved as a volunteer in emergency communications off the coast of British Columbia. Ron's second son was diagnosed with schizophrenia approximately four years ago when he was 24 years old. Throughout his illness he has been treated on an out-patient basis and has recently transitioned into living on his own in an apartment in Vancouver. At the time of the interview Ron's son was unemployed and on a disability allowance. He was in the process of looking into the possibility of going back to school within the near future.
Ron stated that both he and his wife are in regular contact with their son and take turns visiting him in Vancouver to support, encourage, and advocate for him within the mental health system. Ron’s wife became aware of this study through her involvement with the BC Schizophrenia Society. When she told Ron about the study, he volunteered to participate.

**Bob:** Bob is a middle-aged father of three children, two sons and a daughter. He lives with his family in the greater Vancouver area and works with youth within the public school system. His son with schizophrenia is the second child in the family and was eighteen years old at the time of the interview. He is the youngest of all the children represented by the fathers in this study. Bob’s son was diagnosed with schizophrenia approximately four years ago and the course of his illness has been lengthy and very severe. At the time of the interview, Bob stated that his son’s condition continued to be very unstable. He has had multiple hospital admissions. Except for the periods of hospitalization, this father reported that he and his wife have been caring for their son at home throughout the course of his illness. Bob became aware of this study through a notice provided by a family therapist associated with the Early Psychosis Intervention Program. After reading the notice describing the study, he volunteered to participate.

**Common Themes**

Six common themes emerged from the data gathered during one in-depth interview with each of the six participants in this study. The interviews ranged in length from one and a half hours to two and a half hours. At the time of the validation interviews, each of the fathers confirmed that these themes reflected their experience of being a father of a young adult child with schizophrenia. The way in which these themes were experienced by the participants varied according to each father’s individual situation, as well as the severity and
course of his child's illness. The order in which these themes are discussed is not an indication of their relative importance to these fathers' experience or an indication of the order in which they were experienced. Each theme includes quotations extracted from the transcriptions of the initial interview in order to highlight the essence of these fathers' experience. The six themes are:

1. Reflection on Roles and Responsibilities
2. A Sense of Devastation and Vulnerability
3. A Sense of Sadness and Loss
4. A Sense of Frustration with the Mental Health System
5. A Sense of Admiration for their Child
6. A Sense of Having Gained Personally

Refer to page 68 for a table of these themes and their major components.

Reflection on Roles and Responsibilities

Reflection on roles and responsibilities was one of the themes that emerged as part of the experience of fathering an adult child with schizophrenia. The fathers in this study reflected on their roles and responsibilities before the onset of the illness, as signs of illness began to emerge, in the early help-seeking process, as well as after their child was diagnosed. The ways in which these fathers assumed roles and responsibilities varied according to each father's individual situation, as well as the severity and course of their child's illness. Some fathers frequently used the term "we" to include their spouses when reflecting on their roles and responsibilities. All six fathers in this study were committed to parenting their adult child with schizophrenia together with their spouse, although this was reported as being significantly more difficult for some fathers than for others.
## Six Common Themes

<table>
<thead>
<tr>
<th>Reflection on Roles and Responsibilities</th>
<th>A Sense of Devastation and Vulnerability</th>
<th>A Sense of Sadness and Loss</th>
<th>A Sense of Frustration with the Mental Health System</th>
<th>A Sense of Admiration for their Child</th>
<th>A Sense of Having Gained Personally</th>
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<tbody>
<tr>
<td>• Before the onset of the illness</td>
<td>• When receiving the diagnosis</td>
<td>• Loss of who their child once was</td>
<td>• Frustration with multiple inconsistent opinions</td>
<td>• Admiration for their child’s courage and strength</td>
<td>• A more complete understanding of themselves</td>
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<tr>
<td>• As signs of the illness developed</td>
<td>• When facing the realities of living with the illness</td>
<td>• Loss of their child’s potential to be productive</td>
<td>• Frustration accessing resources</td>
<td>• Admiration for their child’s ability to accept the limitations of his/her illness</td>
<td>• A deeper commitment to relationships</td>
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<tr>
<td>• In the early help-seeking process</td>
<td>• In crisis situations</td>
<td>• Loss of dreams for their child’s future</td>
<td>• Frustrating interactions with professionals</td>
<td>• Admiration for their child’s “ways of giving back”</td>
<td>• A greater sense of gratitude</td>
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<tr>
<td>• After their child was diagnosed</td>
<td>• When witnessing the effects of stress on the family</td>
<td>• Loss experienced in father’s present life</td>
<td>• Frustration with discharge planning and leave agreements</td>
<td>• A greater understanding of and sensitivity to mental illness</td>
<td>• A desire to be helpful to others</td>
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<td></td>
<td></td>
<td>• Loss of hopes and dreams for their own future</td>
<td>• Frustration with other parents of mentally ill children</td>
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Reflecting on their roles and responsibilities before the onset of their child's illness helped the fathers in this study make sense of the roles and responsibilities they assumed after the onset of the illness. For some fathers reflection on their own experience of being parented was an important part of this process. As they reflected on their roles and responsibilities prior to the onset of the illness, several fathers experienced an affirmation of their strengths as fathers. These fathers looked back with pride on the ways they have been able to connect with their child and pass on values that are fundamentally important to them. They continue to emphasize these values in their ongoing relationship with their child. These fathers recognized the strengths their child exhibited prior to the onset of the illness and used these strengths to help their child cope with their illness. Some fathers, however, experienced feelings of remorse and regret as they reflected on their fathering roles and responsibilities prior to the onset of the illness. These fathers made intentional decisions to 'father' differently as their child's illness progressed. Personal growth and change became an important part of the fathering experience for these men. The significance of this personal change and growth will be explicated further in the theme: "A sense of having gained personally." The roles and responsibilities these fathers assumed during the help-seeking process and after their child was diagnosed were based on the value they placed on their commitment to relationships (refer to diagram on page 71).

One of the fathers for whom a reflection on his fathering roles and responsibilities prior to the onset of his son's illness was an affirming experience described himself as "a hard-headed cattle-man." He had been heavily involved in the ranching industry in the years prior to the onset of his son's illness. Meeting the challenges of life head-on, taking control and responsibility for oneself, not wallowing in despair in tough
Reflection On Roles and Responsibilities

On reflection some fathers experienced:

Before the onset of the illness
- Affirmation of strengths and values
- Regret and remorse

As signs of the illness developed

In the help-seeking process
- Continued to build on strengths and values
- Intentionally decided to parent differently

Commitment to relationships

After the diagnosis
times, being disciplined, courageous, and determined were values that this father considered to be very important. He strove to instill these values in his sons as they grew up on the ranch. As he reflected on his strengths as a father, this participant took pride in recognizing how these values continue to play an important role in his own life, as well as how they have enabled and empowered his sons to “build something on a very bad situation [living with schizophrenia] and pull themselves out.” He similarly reflected on how the lessons that he and his wife have learned through their ranching experience have helped prepare them to deal with the experience of parenting an adult child with schizophrenia. He put it this way: “We were well equipped for it because - the cattle business - there was a lot of stress and strain in it. We had, - both of us had to work hard and roll with the punches – so we were well equipped to handle it.”

This participant also talked about how he used his knowledge about his son’s strengths prior to the onset of his illness to help his son deal with his illness. For example, one of the skills his son lost when he became ill was the ability to concentrate. This dad reasoned that by getting his son back into playing hockey, an activity in which his son had experienced success in the past, he might be able to help him regain this skill. He described the approach that he took with his son in the following words:

I said to him – Well, why don’t you. You’re a goal tender. He played goal all the way up right through the midgets. I said, ‘You’re a goal tender. You’ve got your gear. You can go to the arena and play drop in hockey’… so he started on that. … He was a lousy player at the start – getting back into things and that, but we still kept talking to him about doing things and everything else.
Fortunately, this participant’s son is able to function at a level that has allowed him to get back into playing hockey with the help of medication, support, and encouragement. This father also talked about how hockey had been a relationship building activity for him and his son before the onset of his illness and continues to be a relationship building activity for them today. He put it this way: “I’ve taken him to the Canuck practices. And we sit there and analyze what Cloutier and the other goal tenders are doing. We try to incorporate some of that stuff into what my son does.”

Another father similarly experienced affirmation of his strengths as a father when he reflected on his fathering roles and responsibilities prior to the onset of this son’s illness. Commitment to relationship and loyalty within relationship are values that permeate the story of his fathering experience. Reflection on his own experience of being parented helped this father make sense of the roles and responsibilities that he assumes as a father. This dad described how he intentionally parents differently than he had been parented, “I’m very close to him [his son with schizophrenia]. … I’m the kind of guy who as long as it’s within reason, everything’s cool, right? Cause I guess that’s something I never had.” He stated that a lot of his time was devoted to relationship with his son prior to the onset of his illness and his commitment to his son continued to be a priority as his son began to show signs of illness. He put it this way, “I would probably walk through a wall for him. I would go through a wall for him … and I would - that’s just sort of the way I view how important he is in my life.”

Another father similarly reflected on the way he was parented to help make meaning of the roles he assumes as a father. He stated, “I raised my children specifically differently. I spent a lot of time with them. I went to sporting events. My dad didn’t do that with me. I
did the opposite to be closer to them.” This father, as a young man, had assumed a major care-giving role for his own mother who had a serious mental illness. As a parent, he became the major care-giver for his son with schizophrenia. He stated that many of the coping skills that he learned while caring for his mother help him care for his son who, at the time of the interview, was acutely and severely ill with schizophrenia.

Some fathers, however, experienced guilt, regret, and remorse as they reflected on their fathering roles and responsibilities prior to the onset of their child’s illness. For example, one father stated, “At that point in time my son and I did not have a very good father-son relationship mainly because I was one of those fellows that was too busy.” Another father similarly looked back on his early fathering role with regret and said, “Normally I don’t act on things. I let things slide.” However, after the onset of their child’s illness each of these fathers became actively involved in the help-seeking process and made relationship-building with their child a high priority.

The fathers in this study also reflected on their roles and responsibilities as signs of the illness began to emerge. Recognizing early signs of illness was reportedly difficult for most of these fathers. They initially tried to normalize their child’s confusing behaviour and make sense of the behaviour in light of their own experiences as young men. Later some of the fathers experienced feelings of guilt as they blamed themselves for not recognizing the signs of illness earlier.

One father, when reflecting on his confusion with what may have been early signs of schizophrenia, described his son as walking “to the tune of a different drummer.” He said, “There was just something odd about him that was hard to describe. There were just things that left you puzzled like: Why did he do that? You know he did some outlandish things
that when I look back - is kind of odd.” At the time, this father tried to normalize his son’s behaviour in order to make sense of it. He said, “I kind of looked at it as him just expressing himself. I kind of stayed out of it and let it work itself out.” However, as his son began to make decisions that were “troubling” in his university years, this father addressed his concerns with his son and tried to give him direction. He compared his son’s behaviour with his own experience. “Yah, 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. So, again, I kind of let that work itself out.” Another father similarly made sense of his son’s unusual behaviour by reflecting on his own experience: “So, I’m 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 seemed like it became more than that.”

Some of these fathers blamed themselves for not understanding their child’s difficulties. For example, one father stated, “I thought for a while there, maybe I was the problem.” This father struggled with self-blame as he recalled his response to an incident that he now thinks may have “really triggered the whole set of problems that carried on.” His son had become “an innocent victim of an accidental shooting which was very traumatic” in his final year of high school. With a heavy sense of guilt this father recalled his lack of involvement following the shooting: “I was very much into what I was doing and quite frankly, in retrospect, wasn’t any help at all in this incident. Certainly I recognize that I should have had him in counselling, but we didn’t.” His sense of guilt increased with the awareness that his wife was left carrying most of the responsibility for helping their son cope with what they were later to recognize as early signs of illness. As his son’s
difficulties increased, this father tried unsuccessfully to give his son direction. He described his feelings in response to what appeared to be his son’s unwillingness to accept direction:

It was very frustrating, because I didn’t have enough empathy for his mental condition. I was wrapped up in what I was doing at work and my wife who was very capable, was carrying the can, but it was taking a toll on her as well. So I was very frustrated and really wasn’t understanding why this guy wasn’t motivated to go to school ...and a good part of it was my fault because I didn’t have a good father-son relationship with him at the time.

This father also reported feeling guilty about misinterpreting early signs of illness as his son’s laziness. He stated, “I must admit that part of my impression was that I thought he was being lazy – just needed a good boot to get going – which wasn’t in retrospect right at all.” The common feeling of most participants related to their failure to recognize early signs of their child’s illness may be best summarized by the father who said: “We always said we should have realized it.”

The fathers in this study also reflected on their roles and responsibilities during the early help-seeking process. When they recognized their child’s need for help, they responded and sought help from various sources, including the public education system, family doctors, psychologists and psychiatrists. Working through the help-seeking process with their spouse became a challenge for some. For example, one father recalled saying to his spouse, “We’re going to make ourselves crazy. ... I would prefer that we do this together.” Despite the difficulties of working together, all of the fathers in this study were committed to finding ways of effectively parenting together with their spouses.
One father reflected on his readiness to respond immediately when he became aware of his son's need for help and described an unexpected midnight call for help from his son who was living outside of the province at the time: "Dad, I'm sick. Can I come home? Something's wrong.' I said, 'I'll be over to pick you up in the morning'.” After his son arrived home, this father, because of his previous exposure to mental illness, recognized the need for professional help. He consulted with his family doctor and then began to work collaboratively with both the doctor and his adult son to convince his son to get help. He described his role in that process: "Well, that's basically the way the two of us worked on it. ... The doctor and I had conversations, then my son and I talked about it too. You know we just talked back and forth.” After a lengthy process involving many conversations and the willingness to let his son make the decision to help himself when he was ready, this father reported that his son, “finally accepted that he would go to the doctor one day and said 'I want to get my life back.'”

Another father, whose son developed signs of illness in his early adolescent years, assumed a strong advocacy role for his son within the education system. He reported facing teachers and administrators who were unwilling to alter their programs to accommodate to the needs of his child and described his reactions as follows: "I was really angry. I was going to make an issue of it and I decided to let it go, because that's not the way to go. It's better to be proactive than just waste it on anger.” Despite feeling alone and rejected, this father reported how he stood firm and did everything he could to help his son graduate:

The school said – don’t bring him in. He’s going to ruin it for other kids. That’s specifically what they said. And I was the only one. ...even my wife gave in. I said
'No'. He's gone there all his life except one course. We helped him... and he went through graduation and he didn’t spoil it for anybody. And it worked out well.

Another participant described his struggle with the responsibility to get his daughter to the hospital for help saying: “I didn’t know if I’d be strong enough to do what’s in my daughter’s best interest.” However, despite his apprehension, this father took action when he recognized that his help was needed. Several fathers who were not successful in getting professional help for their child in the early stages of the illness continued to struggle with self-blame. For example, one father stated:

You couldn’t get my son in to the doctor. Although, - you couldn’t primarily because I wasn’t approaching it in the right way. ...If he needed to be tied down physically I should have done something like that to get him to some professional help a little sooner.”

Finally, the fathers in this study reflected on their roles and responsibilities after the diagnosis was established. They initially made a point of learning as much as they could about the illness. Presently, each father advocates for his child within the mental health system and tries to support his adult child as he/she deals with the limitations of his/her illness. The fathers in this study do what they can to keep their child safe in crisis situations. They also try to help others understand the illness and work together with their spouse to meet their child’s present and future needs.

One father described the period immediately after his child’s diagnosis was established in the following way: “It was really a period of learning. I was – we were – researching schizophrenia like mad.” Another father stated, “When you’re diagnosed with this... you’re going to school as a parent.” As they became aware of possible genetic links
in the etiology of schizophrenia, most fathers began to search their family history: “When he became ill and we learned that there was a genetic predisposition to the illness, we did some - we got hold of family members and tried to find out more.” The discovery of mental illness in their family history increased the sense of self-blame for some fathers. One father stated that, although mental illness was not diagnosed in his family, there was something inside of him that intuitively recognized “something familiar” about his daughter’s behaviour. He said,

I felt a history of this. I don’t know where that came from. I’m trying to put it into words and I don’t know. There’s something that’s been familiar about it from my Dad’s side of the family....I blame my genetics for her condition.

He described his feelings of self-blame and guilt in the following way: “Dr. D., she sat with me and said, ‘You know, it’s not your fault.’ The effect of that statement was quite profound on me. I couldn’t stop shaking. ... I couldn’t allow myself to be exonerated.” Another father stated: “I feel – it’s hard – sort-of embarrassed to have a child that – to myself – that I think it was something I did to produce this, right?”

In the role of advocate within the mental health system, one father stressed the importance of being equipped to work together with mental health professionals. He said, “You’ve got to do your homework. If you’re going to do any fights, you’ve got to research it first. Nobody else is going to do it for you. You’re going to have to do it yourself.” He and his wife and son work as a team to keep their knowledge of schizophrenia up to date: “Between the three of us we do our research and I keep my eyeballs open.”

As their child’s illness progressed, the fathers in this study assumed supportive roles and continue to do so, helping their child deal with the limitations of his/her illness. For
example, one father put it this way: “That’s the ongoing part of being a parent of somebody [with schizophrenia] – trying to continually be supportive without putting yourself in a position where you’re stressed out all the time, right?” This father described his efforts to encourage his child to make use of professional help: “Now I teach my son the steps that we have to take on the advice of a doctor. How we can deal with the situation to make his life the best it could be.” Another father described the difficulty he experienced as he tried to encourage his son to make use of professional help:

We were trying to tell him, “You know, it’s great that you’re recognizing that there’s something wrong. You’re trying to do things to try to help yourself, but you know you need some help as well. There’s professional help available.” You tried to get him – he wouldn’t even go to our family doctor.

Through times of crisis the fathers in this study continue to be actively involved in keeping their child safe. One father described a time when he put himself in danger as he stood firm against his son’s aggression in order to get the help his son needed to stay safe:

He became very angry and aggressive at any suggestions that he needed to be taken back to the hospital. He got really quite angry with me for suggesting that. That wasn’t like him. I actually saw him almost clench his fist as if he was – you know – He was ready to fight me if I pushed it because I just said, ‘Look, you know, you need to go to the hospital and that is all there is to it.’

At times, keeping their child safe meant calling for police intervention. At other times it meant searching for their child when he/she seem to have disappeared. For example, one father reported searching for his son together with the help of friends from his church: “We immediately went downtown. We knew the coffee houses, the bookstores, the public
library. We knew where he hung around and we knew that he must be -- You know -- we had his picture and we were on his trail.”

Several of the fathers in this study also take on active roles to help others understand schizophrenia. Sometimes this means helping to change other family members’ attitudes. For example, one father, with reference to his son who was well, stated, “It took quite a lot of trying to convince him to understand, to take time and look at his brother.” Sometimes the fathers in this study struggle to find a balance of support for their child who is ill and their other children who are well. One father put it this way: “It’s been tough trying to support both boys and kind of keep it equal. Well, you know, you can’t give it all to one son and leave the other son sitting out there.” Another father put it this way: “My kids are like – ‘Why does he get treated this way and I get treated that way?’”

Some fathers have become actively involved in society as advocates for individuals with schizophrenia through the British Columbia Schizophrenia Society, however, their active fathering role has not always been appreciated by their adult child with schizophrenia. As one father put it: “I think he resented initially my getting involved so much with his illness - getting involved with the BCSS, because he felt like I was intruding into his world.”

The fathers in this study also reflected on their roles and responsibility to provide and plan for their adult child’s future. For example, one father described the process of helping his son explore future career options:

What he needs to do is take some computer courses. He needs some help. The computer course thing I can find for him, but finding a job is very stressful for these guys. It is for him – but he needs – we need to find the right notch somewhere. He’s just in that frame now that I think he can handle it.
Another father expressed his concern about what will happen to his son when he and his wife are no longer living: "So, that's one of the worries we're looking at. We're looking at doing – setting up a trust for him ... and see what we can do. ... Then he could be taken care of that way."

All of the fathers in this study are committed to helping their adult child with schizophrenia. They summarized their commitment in the following ways: "As a parent, I think parents should be there through thick and thin." "We're the parents. We feel we know the most. We're doing as much as we can for him." "Our role is still to be the parent and do the best for him." "We're left with what we're left with. We have to make him have as good a life as possible.... that's all we can do."

**A Sense of Devastation and Vulnerability**

Another theme that emerged from the stories of the participants in this study was "a sense of devastation and vulnerability." The word "devastating" was used by all but one of the fathers to describe their fathering experience. The participants reported experiencing a sense of devastation and vulnerability when their child received the diagnosis of schizophrenia, as they began to face the realities of living with a child with schizophrenia, and especially when dealing with crisis situations. Some fathers also reported experiencing a sense of vulnerability as they witnessed the effects of stress within their families, and as they struggled with the limitations of their control over the illness, as well as their limited ability to influence the course of their adult children's life and illness. A sense of devastation and vulnerability was most poignantly felt by the father whose child was the most acutely and severely affected by the illness. The one participant who did not express devastation was the father who described himself as a "take charge kind of guy." He
stressed the importance of being optimistic and described his perspective on life as follows:

"I say, 'Hey, take charge of your life. Don’t let it get you down – because you can’t change what’s happened. You’ve got to equip yourself for the future.'" His determination to be optimistic was reflected in his response to the awareness of the suicide rate among individuals with schizophrenia. He stated: "We just said that our son is not going to be one of them. And that’s what you’ve got to say."

The fathers in this study described the devastation and vulnerability they experienced when their child received the diagnosis of schizophrenia. As one father put it, "When we got the diagnosis, you know, of schizophrenia, well - that was a very devastating diagnosis."

Another father vividly described the impact of hearing the diagnosis at the psychiatrist’s office:

I remember how dark it was in the room. He said, ‘I have tested your daughter and she has schizophrenia.’ When he said that, I just felt like the bottom had fallen out of my world and I felt very sad for my daughter. I felt like it was a death sentence for her and I was mute. I have to say I felt hopeless at that time. I think the other word is powerless. I felt powerless too.

This father said, “It was like falling into a black hole.” He reported fearing the unknown and not knowing who to trust. As questions began to fill his mind, he said to his wife:

We need a – How do we know – that he knows what he’s talking about and things like that? … Maybe we should have a second opinion, because we’re talking about a life altering, you know, life altering actions, if I understood what was going on without understanding fully the implications of it – what was going on – what was going to happen.
Another father described his response when he heard his son's specific diagnosis of catatonic schizophrenia: "Now, that was even more devastating because we were left hanging with the worst possible form - almost near death."

A sense of increasing vulnerability was reported by fathers as they became aware of the realities of living with schizophrenia for their families and their child. One father stated:

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]. Yah, we really didn't know how we could cope with it. Stress - it was very stressful - very, very stressful situation.

As they faced the realities of living with schizophrenia, these fathers reported experiencing periods of hope and despair. They reported how devastating it was to witness periods of deterioration. One father put it this way: "You know, that just killed us - to see him go - deteriorate like that." This father described his despair when his son informed him that he would not take his medication: "He looked at me and he said 'That will be a waste of your time and your money. So, if you think I'm taking that stuff - think again. I'm not taking it.'" In response, this father stated that his "heart just dropped - It was just like - just dropped - a very sickening feeling." Waves of anxiety followed, as this father and his wife began to notice signs of deterioration: "Once we started to see these [signs of illness] happening again, we would get - all the anxiety and stress would just spill out on us." He described the process:
We watched very carefully for the symptoms to kind of reappear. ... Then he would say something – or you would pick up on – a symptom that you had seen in the past. It almost – almost froze you. My wife and I would pick up on them at the same time. I would see her looking at me and I would look at her and it would just - all of a sudden that anxiety just came right back. Your stomach just tightened up. The stress just came on – almost instantaneously. You knew that things were starting to sour and you got worried about how you were going to get him back into the hospital, because that was always the difficulty.

Another father described his despair when he was no longer able to manage his son at home:

It got worse and worse. We had to feed him, dress him, shower him. We had to do everything. We were at our wit’s end and I said, “He’s got to get in the hospital somewhere, right? He has to. We just can’t do this anymore.”

This father reported feeling even more devastated when he encountered what felt like a condescending and judgmental attitude from medical staff at the hospital. His experience will be explicated in more detail in the theme, “A sense of frustration with the mental health system.”

The fathers in this study also reported experiencing a sense of devastation and vulnerability particularly in crisis situations. One father expressed his devastation when he discovered that his son had been arrested:

I mean this – I mean this – to us was the worst possible scenario. I mean – he had never – through all his illness and all – he’d been a strong-willed individual, but he had never been, you know, he’d never been the kind of a person who got in trouble with the law or things like that. So that really broke us you know.
Another father reported experiencing an almost paralyzing sense of fear and helplessness as he prepared to take his daughter to the hospital to get help: “I was dealing in fear. I was trying to resist and at the same time I wanted to help and I didn’t know if I had the strength.” As he headed towards his daughter’s room he stated:

I could not move my hips, my legs. I just looked up there. I couldn’t do it. And my daughter [a daughter who is well] said, ‘What’s going on Dad?’ And I said, ‘I can’t do it.’ She said, ‘This isn’t about you.’ When she said that I thought, ‘Yah, she’s right.’ I just felt better. I went up the stairs.

This father reported that he was “devastated by what was going on” and “very, very worried” about his daughter. On the way to the hospital he “was sitting on pins and needles:” “I was very quiet and I was waiting for her to erupt.”

Another father reported a heart-breaking sense of devastation when his call for police intervention was interpreted by his son as betrayal, abandonment, and rejection. He described what happened: “He [the policeman] handcuffed him and took him away and I can – never forget that scene … that look of him – looking out the window as the policeman drove him away.” Another father voiced a similar sense of devastation when he had to force his son to go back to the hospital against his will: “We brought him back [to the hospital] – forced him back. Just horrible – and he was crying and angry and – It was devastating. It was another major, major blow to us … Then he didn’t want to see us – was holding it against us, right?”

One father struggled to find the words to describe his sense of devastation and vulnerability as he sat with his son in a padded hospital emergency room:
That was really weird. I sat down. I remember sitting down on the – because there’s no bed – it’s just on the floor. And I’m probably - I’m pretty – you don’t see me show my emotions. See - now I get a little emotional, but – it - it – it’s funny – that day I just – I – you know, I ---- As I say, I’m that person that doesn’t walk around and say, I love you. I love you. I love you. And I remember grabbing on to him and just saying, you know, that I love him and actually crying with him, eh? And it was really weird because I don’t do that …but I was just like – devastated.

Another father similarly struggled to control his emotion as he tried to find the words to describe the experience of visiting his son in a locked psychiatric ward:

That was – yah – that was pretty tough. That was pretty tough. We realized, you know, he needed to be there and they were trying to help him get well – get out of there. So, it wasn’t like they were giving him a life sentence, but – yah – that was – pretty heart-breaking to go and visit him there.

Some fathers also reported experiencing a sense of vulnerability as they witnessed the effects of stress in their family. One father stated, “It’s very tiring when somebody is in full blown psychosis and they happen to be around and when they first come home [from the hospital] for the first couple of years. I’m always waiting for the shoe to drop and I find I still am after so many years.” This father worried about the stability of his family. He witnessed his daughters [those who are well] going through what he described as a “period of alarm:” “They wanted nothing to do with her [his daughter with schizophrenia] for quite a while because she was quite off the wall.” He reported fearing the possibility of broken relationships. As he put it: “A lot of times when there are stresses like a child becoming ill in a family, the family breaks up because we grieve in different ways because we just can’t –
we just don’t know how.” Another father similarly described the tension in his family: “I
mean we were all just very, very stressed – very stressed – just on pins and needles.” He too
expressed concern about the effects of this stress in his family. As a teacher in the field of
special education he was aware of “how many families broke up over the pressures and
stress of an illness in the family like this.” He stated:

My wife and I realized that we – that this could affect our marriage too – if we didn’t
– We really felt that we needed to work together – get involved – you know and
avoid – so often one parent would be in denial and the other parent then would have
the whole burden of the illness.

Another participant put it this way: “If your wife’s going to be involved in it, you’ve got to
be involved with it too, whether you like it or not. It’s the only way the two of you will
survive together.”

A similar vulnerability to the fear of broken relationships was expressed by the father
who said, “It felt like the whole family was breaking up” when he witnessed the reaction of
various family members to his son’s difficult and at times bizarre behaviour. He put it this
way: “The other boys were like – ‘Oh, man, I’ve got to get away’ – you know and everyone
would start to separate, which looked like to me – like – wow- this is crazy.” He then
added, “I’m really sometimes surprised that my wife and I are together because it’s that hard
– it’s that difficult on a marriage.” Another father, who has been very involved with the BC
Schizophrenia Society, stated that in his experience there are few couples who are “in it
together.”

Some fathers reported becoming vulnerable to feelings of helplessness as they
struggled with the limitations of their control over the illness. One father put it this way:
“To lose the control is very difficult – It’s really hard when I don’t have control. … I can’t control that situation [schizophrenia]. It’s totally uncontrollable. It’s just – I still try and fight – is the control. It’s an ongoing struggle.” Facing the limitations of their control over the illness led to a pervasive sadness for one father and his wife: “My wife is sad. I am too, because I realize the disease, and I’ve done a lot of reading, I know it’s really somewhat out of our hands. We can make him comfortable. We really can’t do anything.” These fathers also reported feelings of helplessness as they struggled with the limitations of their ability to keep their child safe. One father said:

We’d have sleepless nights – sitting by the telephone. It was – yah – just gut-wrenching to go through those kinds of things. You know when there were crises like this and you knew he was psychotic and he was wandering around out there and there wasn’t a heck of a lot you could do about it.

Some fathers experienced a sense of vulnerability as they struggled with the limits of their ability to influence their child. One participant whose son was unwilling to accept his illness, became very discouraged when his attempts to reason with his child proved fruitless:

The more I – the more we tried to reason with him – that was just counterproductive. You know, he was – even if I – had a long discussion with him and it seemed as if he was coming around, you know, I was making a point. He was seeing – but within half an hour he’d be right back – back to his position.

Sometimes fathers desperately wanted to help and found that they couldn’t because their adult child was unwilling to accept help, leaving them feeling powerless. As one father stated, “He was an adult and he was just refusing any help.”
The sense of devastation and vulnerability experienced by these fathers of adult children with schizophrenia was summarized by the men in this study in a number of ways. One father stated, “Yah – you feel kind of helpless at times. So – so often you just feel like – what can I do? Yah – helpless.” In response to the question, “How has the experience of fathering a child with schizophrenia changed your family life, your work life and/or your leisure life?” one father stated, “That’s a big one. Oh, it’s terrible. That’s where I’m going to break down maybe, but it’s just – It limits you – what you can do – and it’s devastating. ... It’s affected everything.” Other fathers said: “This has messed my whole life up.” “It’s sort of like death, but it’s living.” “It’s probably the most devastating thing you can have in your life.”

A Sense of Sadness and Loss

A sense of sadness and loss was found to be part of the experience of the six fathers in this study. Fathers experienced sadness and loss related to their child’s life, as well as to their own personal lives. Five kinds of losses were identified: loss of who their child once was, loss of their child’s potential to be productive, loss of dreams for their child’s future, loss experienced in fathers’ present lives, as well as loss of hopes and dreams for their own future. These losses were experienced to varying degrees and in different ways.

Each of these fathers reported profound sadness over the loss of who their child once was. This loss was particularly poignant for fathers whose adult children with schizophrenia exhibited a marked decrease in their level of functioning after the onset of the illness, in contrast to their previous levels of functioning. The sense of sadness and loss was heightened with the awareness of the differences between their adult children who were well and their adult child with schizophrenia. Fathers were saddened by their child’s loss of
energy, vitality, and motivation. As one father said, "Now he sleeps all the time. Sort of like, wow, you know, from this active kid who used to get up at 6:30 in the morning and go play hockey to now is really different for me to see." Another father described his son's life as "not much of a life." "It was just kind of existing.... he didn't have that energy and that get up and go and that drive that he had always had." Some fathers experienced sadness at the loss of their child's emotional as well as physical vitality. This was especially the case for fathers of children who exhibited emotional flatness, one of the common symptoms of schizophrenia. One father recalled the sadness he felt when his son stated, "I have no joy in my life. I don't feel sadness. I don't feel joy. I just feel so blah all the time."

Another aspect of "the loss of who their child once was" for some of the dads in this study was sadness at their child's lack of attention to and concern about their physical appearance and self-care. As one father said, "It's really hard for me to see him not care about what his hair looks like. It is really hard for me to see him. You know, he used to really take pride in how he looked." A similar sadness was reflected in the following description:

You know he'll wear the same thing over and over. I mean I do too, but he doesn't wash his. It's like it doesn't matter and that really makes me feel funny because I think, - I've seen him the other way.

Some fathers were also saddened at changes in their child's appearance due to the side effects of anti-psychotic medication, as was the case with the father who stated:

It was a little disappointing watching him go from that [being very physically fit] to where he is now. He's heavier. You know, he's about two hundred pounds. [I'm] used to seeing him pretty skinny.
Sadness at their child’s loss of relationships and ability to communicate was also a part of the loss of who their child once was. One father noted, “You know he used to be super popular. I mean too popular, but now it’s like - who’s Mark? It’s like - really weird.” Another father talked about the difficulty he experiences when trying to communicate with his son and the sadness he feels at their loss of relationship. He reported that although his child had always been a quiet and rather shy person, there was a marked change at around age fifteen. He recalled how his son would withdraw: “even in our family photos, our trips, he would be standing to the side of the rest of us.” At first this father and his wife tried to make sense of their son’s withdrawal and lack of communication in terms of shyness as a family characteristic. The father, however, experienced a growing and disconcerting sense of loss as his ability to relate and communicate with his child lessened. “Because I’m more outgoing [than my wife] it [the withdrawal] kind of hit me harder. I like to talk .... I just felt I couldn’t respond with him... I couldn’t respond, couldn’t talk to him.” Another father expressed the loneliness he feels when he thinks about his daughters’ loss of relationship with friends. He reported that he can understand her loneliness because of the loneliness he had experienced in his own life.

When I think of her though I feel very lonely - because she doesn’t have a lot of people that she can talk to. I have an innate understanding of the isolation that she has - because she does isolate herself even though she can be quite gregarious. In her way, I think she’s lonely because she can’t talk about - that people will understand what she’s going through.

Another kind of loss experienced by these fathers was the loss of their child’s potential to be productive. For some fathers the loss of the potential to be productive
members of society meant the loss of the ability to work, which they viewed as part of normal adult life. One father put it this way:

He’s not as fortunate as me to be able to just work and have that normal part of life which I had when I was his age. It seems like that’s when I was starting. He’s probably never going to start, not the same as I ever have. His life is a whole bunch different.

The loss of potential to be productive was especially poignant for this father because of the great pleasure he derives from working together with his other sons who are well. He reported that working together with his sons is an important part of their father-son relationship. Some fathers were saddened at the ways in which the negative symptoms of schizophrenia interfered with their child’s ability to be productive. Cautious optimism regarding his son’s work future was expressed by the father who said, “He has a chance to be productive, but he has this motivation problem which comes along with this disease.”

Another father became painfully aware of his son’s loss of potential as he recalled the positive comments he had received from the vice-principal of his son’s school, prior to the onset of his illness when his son was in his graduating year: “Your son, you know, is going to go somewhere. He’s got, you know, ... a lot of qualities that will serve him well if you can get him on the right track.” This father’s sadness and sense of loss was apparent when he stated, “I really did feel he was going to, gonna make a mark in the world. I realize now that that’s not going to happen. I can see that the illness has really taken away a lot of that potential.”

Another kind of loss was the loss of dreams for their child’s future. One father recalled his feelings the first time he took his child to a psychiatrist. His hopes and dreams
of fatherhood had never included the possibility of parenting a child with an illness. In his words:

It was really odd. As a father, as a parent, that I would have a child like that. You only read that in books, or hear it on TV. It’s always other people right? ... I guess for me it was really hard because he’s my first boy and it was like, how would I put the words, very disappointing for me, as a father because I always wanted the perfect child.

One father who recognized that his son had extraordinary skills as a hockey player built hopes and dreams around what his son might be able to do with these skills, only to have his dreams shattered when his son became ill and stopped playing hockey. He put it this way:

Could’ve been, should’ve been.... My kid’s good. He’s good! I guess it was sort of the dream of a father. I strived to have him the best and you know, he was right there, eh? Then all of a sudden he stopped.

Another father expressed a sense of sadness and loss at the thought that his daughter would not have the experience of becoming a mother some day:

She recognizes that it’s [schizophrenia] going to be with her for the rest of her life or at least the possibility. She’s under no illusions about that whatsoever. So much so that I don’t think she’s going to have kids because she worries about it you know. I really feel sad for her.

The loss of dreams of their child’s future was perhaps best summarized by the father who said, “So that image, the image of him being successful – of having a great life, is gone.”
The fathers in this study also expressed a sense of sadness and loss in relation to their own present lives. Lifestyle adjustments were necessary in order for these fathers to meet the needs of their adult child with schizophrenia. One father put it this way:

Maybe we’re not going to have those double incomes...and all this stuff. Our life is basic you know. We have children. We have a child that needs probably more help than our other ones. We’ve got to be there for him. ...Being there for him is having time.

Taking time to meet the needs of their child meant the loss of time for other things for each of these dads.

One father whose son was severely ill experienced a loss of freedom, joy and pleasure in his present life. The degree of care that his son required placed severe restrictions on this father’s life. He stated that as a couple “we feel we can’t go out. We can’t really do anything. So, that makes life not as enjoyable over all.” The restrictive nature of this father’s lifestyle led to a loss of friendships and a deep sense of loneliness. He stated that people “stay away more, and they don’t want to phone as much and we’re basically left on our own.”

Some fathers also expressed a concern regarding their own health, as well as the health of their spouse as a result of the stress of parenting their adult child with schizophrenia. One father put it this way:

I probably retired earlier because of [parenting an adult child with schizophrenia]. I think both my wife and I feel especially those first five years really aged us. My wife...it affected her physically very much, so the stress and everything and the worry, it did age us for sure.
The three fathers who were retired at the time of the interviews reported that as a result of having an adult child with schizophrenia their present retirement lives were significantly different than what they had planned. One father stated:

It’s not our idea of something as a retirement gift. We had intended maybe to move away from the lower mainland, but we’ve since changed our mind. We’re going to stay here...We have adjusted how we might have a retirement life if this hadn’t occurred and pretty well resigned to the fact that we will be some kind of support in there, probably for the duration.

Another loss identified by the participants was the loss of hopes and dreams for their own future. One father talked about having to curtail his dreams of being able to take his family out on boating trips. He had purchased a boat several years ago, but it never got into the water. Another father who loved to travel and had been looking forward to the time when he might have more opportunity to do so in the future stated:

I’m always torn. Like for me, like I want to travel more than my wife, yet I really feel the responsibility [to care for his son] is mine. So I still give up everything to have the responsibility, but I’m quite upset about the fact that I’m getting older and I don’t know, I just won’t be able to do what I want to do.

Some fathers expressed sadness in giving up the hope of having grandchildren. In the words of one dad in reference to his own future: “It’s not going to probably be exactly how you perceived it to be when they’re twenty or thirty...having grandchildren you know, all that stuff.”

Perhaps the impact of loss for these fathers of an adult child with schizophrenia can best be summarized by the response of one father to the question: How would you compare
the severity of the experience of fathering an adult child with schizophrenia with other
difficult experiences in your life? After a few moments of thoughtful reflection he stated,
“This was a huge loss. The death of my father, the death of my mother, other deaths I’ve
been around, I’ve never felt like that.”

A Sense of Frustration with the Mental Health System

A sense of frustration with the mental health system was found to be one of the
themes common to the stories of the fathers in this study. The participants reported
experiencing a sense of frustration to different degrees and in response to different aspects
of the mental health system, depending on their individual situations. All of the fathers in
this study reported that they experienced frustration during the help-seeking process. One
source of frustration reported by most of these fathers was having to make sense of multiple
inconsistent opinions from a variety of mental health professionals. Another source of
frustration was a lack of resources or difficulty accessing resources, especially in crisis
situations. Some fathers reported that their interactions with mental health professionals
became frustrating and difficult. Some reported feeling frustrated in response to decisions
regarding hospital discharge planning and leave agreements. In addition, several fathers
expressed feelings of frustration with other parents of mentally ill children, parents that
appeared to have abandoned their mentally ill adult child. The father of the youngest and
most severely ill child reported the greatest degree of frustration. It is important to note,
however, that although this theme focuses on the frustration experienced by fathers, fathers
also expressed gratitude for specific aspects of the mental health system and in particular,
for the assistance provided by key individuals within the system who were instrumental in
helping them cope with their child’s illness.
Dealing with multiple inconsistent opinions from a number of different mental health professionals was reported to be one of the greatest sources of frustration experienced by some fathers. One father put it this way, "Here's another psychiatrist telling me another story - just a different page. Is this person right? ... So you get these different stories and so you don't know what to believe." Another father stated, "They thought he has all sorts of things, you know, Aspergers and all these other things, but they weren't sure ... and we were seeing lots of different - first of all psychologists then psychiatrists." This father reported that his confidence in the mental health system was severely shaken when, after receiving a diagnosis of schizophrenia from a well respected psychiatrist, he was given a totally different opinion when his son was hospitalized:

They gave us books. It was all related to poor parenting or something to that effect or whatever. They thought he had borderline personality. ... They never said he was mentally ill. They refused to say he was mentally ill. They said it was just behavioural problems relating to either something that happened at school, somebody did something sexually to him, or something at home, or someone did something somewhere to him.

He then added: "We knew it wasn't at home. You know - in our hearts, because we know how we raised our kids." This father reported that the struggle to try and make sense of these multiple inconsistent opinions led to a great deal of discouragement and frustration with the mental health system. He stated, "We just feel through this whole process [help-seeking] more or less we've either had no support, or the support we've had has put us the other way, like ... made us feel worse because they were just - nobody could figure it out."
Some fathers reported feeling frustrated with insufficient resources or difficulty accessing resources. The father who lived on the Sunshine Coast voiced his frustration with the inadequate support available in his area: “It was frustrating trying to get the Ministry of Health and what was available on the coast – was definitely a frustrating situation. It just wasn’t there.” Later in the interview he added, “For the amount of people on the coast [with mental illness] I say the coast is ignored on the mental health end.” Another father voiced similar frustration and difficulty in accessing resources: “There was no easy way to access anything.” He explained further, “You know, it’s fine to say that resources are there, but there was nothing that allowed us to feel like it was part of – not a right – but something that is good to do, part of what we should be doing, or anything like that.” After his daughter was discharged from hospital, this father said he felt stranded without resources:

It was just like, well, she’s finished this program here now, so - goodbye - type thing. I felt very much like we were abandoned at a place where I had no tools to deal with this and I was deathly afraid of losing my daughter. I was deathly afraid of losing my marriage.

Another source of frustration reported by the fathers in this study was trying to access help in crisis situations. One father recalled his frustration when he was told that his son would have to wait months to see a psychiatrist. It had taken a long time to convince his son to be willing to go for help and it was frustrating for this father to think that he might miss what seemed to be a window of opportunity. He called the psychiatrist and said, “My son needs help now – not a month from now or three weeks from now. He’s really – he’s not well.” Accessing police intervention and getting an adult child admitted to hospital was also reported to be frustrating and difficult. One father stated that it was only when his child
was suicidal “that the police were willing to come out and intervene.” After experiencing the difficulty of getting his son transported to hospital, this father expressed how frustrating and difficult it was to have to wait in the hospital emergency department hoping to get his son admitted:

Sometimes when you went to the hospital we have spent up to five hours in emergency to get him hospitalized. And you’re sitting there with someone that sometimes you’re afraid he will bolt on you. That’s one of the things that I’ve really been writing letters and really working on - is to get admissions to have separate admissions for mental illness and to have someone available there to kind of medicate people or to at least help you look after them.

Several fathers also reported feeling frustrated in their interactions with mental health professionals. One father talked about how frustrated he became when the professionals he consulted would not believe his reports regarding his son’s severe functional impairment. He said that as a parent he felt judged, and at times held responsible for his son’s lack of ability to function. He put it this way:

There were bad feelings on our part because a lot of the way through ... we felt we were being criticized. Like, these people [mental health professionals] a lot of them think that they know more, yet, we’re the ones who have been with this person their whole lives.

He reported feeling ignored, devalued, and angry when he sensed that his input was considered irrelevant by the medical staff attending his son:

He did a lot of odd things too that we brought to the doctor’s attention, but she would just not listen to us. Like this is my – the really distressful thing of this whole
episode is that the doctors have to listen to the parents. They would not listen to us. More importantly, they would not listen to him because he told them things and they would not listen to him.

Another father reported his frustration with the mental health staff in a group home when they called to inform him that his son had been missing for over twenty four hours. His response was: “Why in the world didn’t you let me know about this before that – before now - ?” This father reported feeling that the mental health system had ‘let him down.’ Not only had he not been promptly informed of his son’s disappearance, but he also wondered if his son may not have been adequately stabilized on his medication prior to being transferred from the hospital to the group home.

Discharge plans, leave agreements, and decisions affecting mental health allowances were also cited as sources of frustration by the participants. The father of the schizophrenic child who was still a minor reported feeling that his authority as a parent was being undermined when hospital staff tried to convince his son to go to a group home when they knew this decision was contrary to the wishes of his parents. He stated:

They wanted to put him in a group home. They didn’t want us. Like - he’s under nineteen so it ended up they couldn’t do it without our permission, - basically because he is under nineteen. Thank God, OK? Because if he was older they might have been able – They were trying to convince him.

He then described the emotional turmoil he experienced during this process:

I had sleepless nights for weeks. I lost work over it because I was so upset with him being sick to begin with, and then having all these other things running – They’re
going to take him away and the kid is going to end up being in really poor hands because this group home we ended up going to – it was really bad.

Frustration led to despair for this father, as reflected in his statement: “You feel like nothing. Like - you’re just nothing. Makes - like you’re just – I don’t know – nothing. Family members are nothing. It doesn’t matter. Whatever the doctor says is right and is god.”

Another father talked about his frustration and concern regarding premature discharges from hospital and the encouragement given to patients “by the civil rights people” to challenge their commitment when it is not in their best interests. He stated: “I felt that – I think as families, we feel sometimes that patients’ rights supercede their need to be protected. It’s so difficult to get somebody hospitalized and committed. It really is.”

This father also reported becoming frustrated when faced with the hospital staff’s unwillingness to honour his son’s leave agreement. He put it this way, “They let him out of the hospital and he became psychotic right again. I tried to take him back in and they said, ‘There’s no beds’ and I said, ‘That’s your problem. He’s certified. You’re supposed to have a bed for him.’”

Several fathers also expressed frustration with parents of adult children within the mental health system who appeared to have abandoned their child. One father put it this way:

I really get mad at people who have children like this – or that have children that have a problem that I would call mental illness. They just deny it because they would have to put a lot of their time into him ... It’s just a child. This is their life. They’re not there to really help....They wash their hands and don’t want to deal with
that part of it. That’s what I saw at Riverview. I felt like, ‘Where the hell are all these people? Where are all their parents?’ They’re craving for their parents, but their parents are busy. Like, how can you be busy when your child is in this situation? I look at it and say, ‘What is your priority in life?’

Another father expressed similar feelings when he stated:

There’s no sense in saying ‘well I’m not going to acknowledge him or anything.’ I know a lot of people have done that. They’ve walked away from their kids and shut them off and that just ain’t my nature. ...Got a big responsibility to him to help him. You know, it’s just the way I look at life.

Despite these frustrations, the fathers in this study also expressed gratitude for positive aspects of the mental health system as reflected in the following statements: “I think there really are movements in the housing area ...Where they are headed with the housing should be helpful.” “I think there’s a real impetus right now to get family members more involved in the whole process – more involved with the health teams – so on and so forth. So there’re some healthy signs. There are a lot of problems, but there are some healthy signs.” One father also expressed his gratitude for the mental health allowance he expects his son will receive, which will enable him to live on his own. Some fathers expressed a great deal of appreciation to the British Columbia Schizophrenia Society: “If we hadn’t been involved with the BCSS I don’t know how we would have coped.”

Gratitude was also expressed for the psycho-educational program developed through the Early Psychosis Intervention Program. “Awesome” was the word one father used to describe the program. When asked to expand on his experience he stated:
Their approach to it – their understanding and their expertise – everything that goes along with it. I think they have a lot of expertise. Background expertise. I would trust them more than I would any psychiatrist. I don’t know if Len is a psychiatrist or what all his degrees are, but I tell you he puts this disease into laymen’s language. You know – you’re not trying to fight what that word means and this word means. Just lay it on the table ... If you need help – here’s a number.

The names of specific individuals in the mental health system came up repeatedly, associated with statements such as: “You can’t beat her,” “An awesome guy,” “A referral to Dr. - the best advice we ever got,” “She was great.” These individuals were described as “very understanding.” They were reported to have an intuitive sense of how to relate to individuals with mental illness. They provided opportunity to learn about the illness and involved parents “right off the bat.” In crisis situations fathers said these individuals took the time that was necessary to make an accurate assessment. As one father put it, “They didn’t try and kick him out the next day.” Even the father who had the most difficult experience with the mental health system expressed gratitude for specific individual mental health professionals who tried to intervene and provide support for his family. He said, “I’ve got to give it, they tried to help.” Having lived through these frustrating and difficult experiences, the fathers in this study now have a desire to help others: parents, as well as mental health professionals. This will be explicated in more detail in the theme “A sense of having gained personally.”

A Sense of Admiration for their Child

Another theme that emerged from the stories of the fathers in this study was a sense of admiration for their child. All but one father expressed admiration for their child as they
told the stories of their fathering experience. Some expressed admiration for their child's courage and strengths. Several fathers reported feeling a sense of admiration for their child's ability to accept the limitations of their illness and their child's determination to do their best within those limitations. A sense of admiration was also expressed by some fathers for the ways in which their child was "giving back," helping others understand what it is like to live with schizophrenia. The one father who did not report a sense of admiration was the father of the most severely ill child. This father reported that the course of his son's illness had been long and increasingly debilitating. At the time of the interview his son's illness continued to be unstable. He required a great deal of care-giving in contrast to the other adult children represented by the fathers in this study, who were relatively stable and actively taking steps toward independence.

One father expressed admiration for his son's courage and fighting spirit in the following way: "We've admired – I mean – He's fought, you know. He's fought the illness. It's maybe been counterproductive the way he's fought it, but I've had to admire his courage. He has tremendous courage." This father admired his son's efforts to help himself even through the difficult and confusing periods of his illness. He put it this way:

He was always – He was taking books out of the library. He was always reading about psychiatrists. He would often pick up books that were anti-psychiatrists, anti-drug, but he also picked up books on drugs to find out what was in them and what they were supposed to do. So he became quite knowledgeable about what he was taking and what his options were.

Some fathers reported a sense of admiration for specific strengths and abilities that they recognized in their child. For example, one father expressed his admiration for his
son’s ability to write poetry. He said, “He’s really good at rhyming. He’s really good at, you know, this punk rap stuff – really good at it – really. His poems – He can make poems that are just unreal. He could go to Hallmark cards and – they’re better - Like he’s incredible.” Another father admired his son’s ability to play hockey. He stated, “He’s an awesome hockey player. He still helped me coach hockey this year – awesome skater.”

Another father expressed his admiration for his child’s ability to advocate for herself: “She advocates very well for herself and she sets boundaries very, very well – without anger – just lays it out – this, this, this and this.”

Most of the fathers in this study reported a sense of admiration for their child’s ability to accept the limitations of their illness. For example, one father stated that accepting the illness allowed his child to “get on with her life.” He put it this way: “She is a beautiful spirit. She’s just a – The fact that she’s gone through a number of things is one thing. The other thing is that she’s faced them. She’s accepted them.” This father described his daughter as a “hero”:

She’s my hero because I watched [her] not just get this disease that was a life long sentence and go through a cycle of sadness – the grief cycle – the anger and the loneliness – watching because she couldn’t talk to us about it…. When she went and she accepted what was going on and embraced it – and not try to fight it, I could not believe the strength of that.

Some fathers also reported a sense of admiration as they witnessed their child’s determination to do the best they could within the limitations imposed by their illness. For example, one father reported feeling a sense of admiration when his son came to the point where he was willing to accept his illness and assume responsibility to take medications in
order to function optimally within the limits of his illness. This father stated, “We have never from that day had to say, ‘Son, have you taken your medicine?’” Another father similarly expressed admiration for the responsibility his son is taking to care for himself when he said, “He’s able to look after himself. He’s quite responsible in that way.” This father also expressed admiration for the steps his son is taking to move toward independence. He put it this way:

What he’s trying to work himself towards now is finding some part-time work.
Make a little money. He wants to buy this Macintosh computer and start this whole business and take some courses and making music business which he has researched.
He’s got the smarts to make it work.

Admiration for his son’s determination to do his best prompted another father to say: “I’m proud of the kid actually. I’m really proud of him. I mean he’s gone out there. It looks like he’ll beat the odds.” “He still has the problem, yet he plays hockey.”

Some of the fathers in this study reported feeling admiration for the way in which their child was “giving back”, helping others understand what it is like to have schizophrenia. For example, one father expressed his admiration for his son’s openness, honesty, and willingness to talk about his illness. He described a conversation that his son had with “the ice-man” after one of his son’s hockey games: “So, my son told him bluntly, ‘I hear voices and flashes and - he [the ice-man] says, ‘You mean that television ad I see is actually true?’” Another father spoke with admiration when he described how his son is “giving back” through his work as a volunteer. He said, “My son’s been involved with the Canadian Mental Health Association as a volunteer - Goes downtown Vancouver a couple of times a week - Answers the telephone - Gets information to people.” A proud and
thrilling moment occurred for this father when he heard his son speak at a mental health conference as a participant in a panel that included several mental health consumers, chief executive officers of the health region, as well as the provincial Minister for Mental Health.

This father described his experience in the following way: “There he [his son] was. He was ready. He had a suit on and he looked like a million dollars and he just had this air of confidence and I thought he’s gonna be fine. And you know what? He was just great! He really was great!” After his son had spoken about the positives that he saw in the mental health system, as well as “his concerns and what he would like to see,” the Minister for Mental Health said, “I need to hear from more people like you.” The pride and admiration this father felt at that moment was expressed in the following way: “He just blew me away – He really did and it reminded me of some of the things he was capable of doing before he became ill. And – He was just on that night. He really was.”

Another father reported a sense of admiration as he witnessed his daughter’s determination to do the best she could in her job as a hospital unit clerk. He stated, “She listened. She read. She did what she had to do.” “As a unit clerk she makes a great surgeon. She doesn’t go in just to punch a few keys. She had to learn a little bit more. That’s just her nature.” The theme of ‘a sense of admiration for their child’ may, however, best be summarized by the father who said: “I’m prouder than hell of the kid that he’s come as far as he has.”

A Sense of Having Gained Personally

Another theme that was common to the experience of fathers in this study was a sense of having gained personally. Some fathers stated that through their experience of fathering a child with schizophrenia they gained a more complete understanding of
themselves. This increased self-understanding reportedly encouraged some fathers to move
toward personal growth and change. Some fathers talked about having gained a deeper
commitment to building relationships within their families. Some fathers reported having
gained a greater sense of gratitude, as well as a greater understanding of, and sensitivity
toward, mental illness. All of the fathers in this study reported having gained a desire to use
their fathering experience in a way that would be helpful to others.

Some of the fathers in this study reported that their experience of fathering an adult
child with schizophrenia resulted in a greater understanding of themselves. For some fathers
this increased self-understanding helped them to make meaning of their fathering
experience. For example, one father reported having gained a greater awareness and
understanding of his strength as a father. He put it this way:

I look at myself as this [having a child with schizophrenia] is what's been given to
me. I made it through with my mother. She was difficult too. Some things were
similar – the suicide part and looking after her when I was younger. So, I just feel
like – I have to compliment myself and say I'm a strong person - because it just
makes me realize when – when I talk to other people who couldn't do it [parent a
child with schizophrenia].

For this father, the awareness of his strength led to a greater sense of meaning and purpose
in his life as reflected in the following statement:

Maybe – I don't know what you believe in – but maybe ... maybe a lot of us are just
more accepting. Maybe we can handle these types of things [parenting a child with
schizophrenia]. For whatever reason, we're stronger people or less biased toward
mental illness. I don't know. Like different reasons. I just feel like maybe there's a
reason. We feel we know a lot of people who couldn't [parent a child with schizophrenia].

Another father similarly reported having gained an awareness of his strength as a father. He put it this way: "I figure I've done a fair job. Both my boys have survived and turned into pretty good straightforward characters." In response to the question, "Have there been any ways in which this experience has been positive?" this father immediately answered, "Yah – I think the wife and me are both proud of what we’ve both done – and that’s positive.” Another father stated: “I think we’re very good parents, me and my wife – put a lot of time into our kids.” As a result of his fathering experience, he also reported having gained a new perspective on his priorities as a father. He stated, “As you go on, you understand that it really doesn’t matter what they [your children] do. It’s what you do for them.”

Some fathers reported that the increased self-understanding that they had gained through the experience of fathering a child with schizophrenia influenced them to make major personal and life-style changes. For example, one father stated that watching his daughter deal with her illness increased his awareness of the changes he wanted to make in his own life. He stated: “As my daughter got feeling a little bit better, I knew that there was something missing with me. I’d always felt like there was something missing – but it’s really helped me.” Although he felt devastated when his daughter was diagnosed with schizophrenia, this father reported that his experience with his schizophrenic daughter prompted him to come to grips with issues from his own past that had long remained hidden. He stated, it “became a portal and a gateway for me to be able to accept some of the things that happened in my life to me.... It allowed me to be human about what has happened to
me." The ensuing process of dealing with his own issues reportedly started him on a journey toward healing and personal growth. He put it this way: “I think if I hadn’t been blessed with these opportunities [witnessing his daughter’s growth through the struggles she’s gone through] and also the other opportunities with my other daughters and my wife, I would be afraid to look at growth.” Through his fathering experience, this father stated that he gained an awareness of his need to learn how to be emotionally supportive to his family, and subsequently did “a lot of work in that area over the last couple of years.” He summarized his personal growth in the following statements:

I could probably be available for her [his daughter] today if she needed something. I know I can ... I’m learning to be present, to listen, to try to hear what’s going on and I’m learning how to empathize without putting a story together. I could walk into a room now where I don’t know people, feel comfortable, talk to them and look at them. I could not do that before ... I didn’t want them to know who the heck I was. This father reported that one of his personal goals today is “not to stop growing because I want to be able to appreciate until my last breath — I guess — comfort’s not the word — and not inspiration, but healingness. I want my family to feel connected and I want to feel connected. It doesn’t have to be happy, but wholesome.”

Another participant also talked about the ways in which he has changed through his fathering experience. He stated, “I think my son taught me a lesson — taught me that I can’t live my dreams through him.” This father also expressed an ongoing desire to continue working on being more understanding and empathic, “trying to feel what my son feels.” In addition, he reported that through his experience of fathering a child with schizophrenia he
has gained a new perspective on the role of control in his life, which has enabled him to become more self-accepting and genuine. He put it this way:

I guess I try and control it [the effects of schizophrenia] by knowing as much as I can about it. It satisfies my control because if I know enough about it, it feels like I have some control over that situation. I can help. So, I guess, my help becomes a control – but I’m doing it in a totally different fashion than – I would normally do my control. So, it’s really interesting, but I feel good – so it doesn’t lose that personality that I own.

Some fathers reported that they gained personally through discovering the depth of their love for their schizophrenic child. One father put it this way, “Certainly we probably love him as much, if not more, because you just – It’s something we’ve been through together.” Another father said: “We know – we really see that you love your child, I guess – and that you know you love your child because you’ve gone through so much hell and you’re going to bat for him and doing everything you can to keep him as best you can.”

As he thought about how he had changed through the experience of fathering a child with schizophrenia, one father reported that he had gained a new awareness of his ability to change. He put it this way: “I think it’s a real eye opener to me to see how I can change. … What I do know is that I’m willing to do it – It’s a fight between who I am and what I need to do for this child, right?” This father stated that, in his opinion, in order to be helpful as a father, personal change was a necessary part of the process: “I don’t think you can help yourself – this situation [schizophrenia] – if you aren’t open and honest and actually do have some changes.”
The fathers in this study also reported having gained a deeper commitment to the relationships in their family, especially their relationship with their spouse and their child with schizophrenia. For example, one father talked about how his experience of fathering a child with schizophrenia has strengthened his commitment to his marriage. He stated, “I made it my purpose that the stress of my daughter being ill wasn’t going to break us up.” Other fathers made similar statements: “It’s changed my wife and my relationship. We’re a lot closer than we were.” “I think, if anything, all of this experience strengthened our marriage – brought us closer together. We certainly have a common - common problem – needed to work together to deal with it.”

Some fathers reported that their fathering experience resulted in a deeper relationship with their schizophrenic child. For example, one father stated: “You know, in a positive way, it has made me develop a father-son relationship that I should have developed a long time ago.” This father described how he used fly fishing to help him deepen his father-son relationship:

Fly fishing is therapy. There isn’t a psychologist or counsellor around that can be as good as fly fishing ... It is getting out – trying to get the line out – the fly – on the water. Whether you catch something or not doesn’t matter. It’s a good way of getting away from everything – and my son and I have been out. Yah – we go out and we do this sort of thing - ... Yah, this works.

Another father talked about how he treasures the windows of opportunity when he is able to build relationship with his son. He described one of his recent opportunities in the following way: “There was that window of about a month where he really did [communicate with his dad]. He just talked endlessly about his whole life ... I felt
extremely relieved ... sometimes relief can be more than being happy to me.” Another father communicated the depth of his desire for relationship with his son when he said, “I crave that relationship.”

Some fathers also reported having gained a greater sense of gratitude through their experience of fathering a child with schizophrenia. For example, one father expressed his gratitude for the ways in which his schizophrenic child has helped him. He said, “She’s been an incredible help to me. ...She’s allowed me to look at myself and realize that I take things for granted. ...I feel like I’ve been given a gift, you know.”

Another father reported having gained a profound sense of gratitude for loyal friends who stayed committed to his schizophrenic son over the years. He stated: “They were amazing people. They would even go and visit him at Riverview Hospital when he didn’t want them to. They said, ‘You were a friend in good times and you’re a friend in bad times’.” This father also expressed gratitude for supportive friends who gave “hands on” help when his son seemed to have disappeared. He described their help: “It was their idea. Let’s go – let’s, you know - Where do you think he is? What can we do? And they just got in – We had people knocking on doors. It was amazing.”

Another way in which the fathers in this study reported having gained personally was in their sensitivity toward, and understanding of, mental illness. For example, one father stated that he has gained an understanding of his son’s behaviour. He put it this way: “I understand him a lot more than I did before – at least I think I do. I understand his reactions.” He also talked about how the sensitivity and understanding that he has gained has influenced him. He said, “I become softer when I think deeply about how he is compared to how I get up every morning.” Another father who experienced a severe
depression as part of his experience of fathering his child with schizophrenia, reported that he and his schizophrenic child gained a mutual understanding of what it was like not to be able to function, to be alone, and to have difficulty relating to others. He described their mutual understanding in the following ways:

My daughter helped me – because she understood that when I was frozen, I couldn’t think an hour ahead. I couldn’t think a minute ahead. I just didn’t know how to function. ...I see in her that aloneness ... I’m just saying I have a compassion – that I have an empathy for -- [her aloneness].

This father also reported that through his experience of fathering a child with schizophrenia he has gained a sense of meaning around the struggles of life. He put it this way:

Watching my daughter go through the process of learning to accept her illness, being able to relate to it and then trying to operate in it – what’s the word – function with the illness – the growth that she’s had to go through. I’ve looked at the struggles ... understanding that everything has a struggle... but you can have growth from them and she’s grown.

Another father reported that the sensitivity to mental illness that he has gained through his fathering experience has helped him in his work with “troubled” kids. He stated, “I’m actually more educated in that I see some troubling – kids - and other people don’t see it – because I have a schizophrenic. Because I’m involved with a lot of schools I do see some kids starting that way.” Another father summarized the sensitivity and understanding of mental illness that he has gained in the following way:

In a positive way I’ve learned a lot about a disease that’s around and the challenges there are to try and – not lick the disease, but handle it in terms of families. ...We’re
all trying to deal with this situation [living with schizophrenia] as a normal part of
life. It’s just a different way of dealing with things.

Finally, all six of the fathers in this study reported having gained a desire to be
helpful to others as a result of their experience of fathering an adult child with
schizophrenia. One father stated that his experience has given him “a ton more compassion
for the struggles of people.” Another father stated that he wanted to find ways in which his
experience could be helpful to both other families living with schizophrenia, as well as
professional helpers. He said, “I want to help other people. I don’t want them to go through
what I went through.” His message to mental health professionals was: “The most
important thing is that you must listen to the parents because the parents are paramount in
knowing about their child and what to do and what the changes are and everything
throughout life.” Participating in this study was one way that fathers hoped that they could
help in some way. One father stated, “If I can help ten of those people who didn’t come to
Riverview to see their kids through this somehow – I don’t know – if it’s any part of it – I’ve
done my part.”

Some fathers found a way to be helpful to others by becoming involved with the
British Columbia Schizophrenia Society (BCSS). For example, through the BCSS, one
father has been able to help direct other families who are in the help-seeking process get
connected with “doctors who know more about this stuff.” He has also been involved in
supporting educational initiatives, “trying to get a plan together to aim down the road – to
future people coming out [of medical school] – you know – graduating – so that there’s
more empathy – to know what to do with these guys [individuals with schizophrenia].”
Another father stated, “I got totally involved [in BCSS] – really worked hard to remove the
stigma of mental illness. ...I go into schools and do presentations... go in and tell our stories...to help people understand mental illness.” One father talked about a way in which both he and his son have been able to help others. He explained it this way: “I’m on the mental health advisory board for our hospital region and so is my son. He’s on that advisory too as a consumer from Canadian Mental Health Association. So, we just happened to arrive there in different ways.”

A sense of having gained personally may best be summarized by the following responses to the question, “Have there been any ways in which this experience has been positive for you?”: “Well, my marriage is much stronger. The relationships in the family are stronger. I have met some wonderful people. I have been able to work with some wonderful people within the BCSS. We have had wonderful support from the couples group in our church and I think – I’m more compassionate - less judgmental.” “I’m so grateful that my daughter has my wife. I’m so grateful that I’ve been a part of that, you know. So grateful that she’s got family.”

The six themes that have emerged from the stories of the participants in this study are similar in some ways to the findings of previous studies that have focused on the experience of parenting an adult child, however there are also differences. These similarities and differences, as well as the implications of the findings, will be discussed in the following chapter.
CHAPTER FIVE: DISCUSSION

This final chapter begins with a restatement of the purpose of the study followed by an essential structure, a condensed overview of the experience of fathering a young adult child with schizophrenia as described by the six participants in this study. The results of the current study will then be compared to the existing research literature that has focused on the experience of parenting a child with schizophrenia. The chapter will conclude with a discussion of implications for counselling practice, implications for mental health policy, implications for family practitioners and psychiatrists, as well as implications for future research.

The purpose of the current study was to explore and describe the experience of fathers of young adult children with schizophrenia who have been diagnosed within the past ten years. The research was guided by the question: “What is the nature and the meaning of the lived experience of fathers whose young adult children have been diagnosed with schizophrenia?” A hermeneutic phenomenological approach was used to gain as rich an understanding as possible of the subjective experience of the six fathers who participated in this study.

The Essential Structure of the Lived Experience of Fathers of Young Adult Children with Schizophrenia

The experience of fathering a young adult child with schizophrenia profoundly affected the lives of each of the six participants in this study. As they told their stories, each of the participants reflected on their roles as fathers prior to the onset of their child’s illness, as well as the roles and responsibilities they assumed later as their child became ill. Reflecting on these early roles and responsibilities helped these men make meaning of the
roles and responsibilities they later assumed after the onset of their child’s illness. For some fathers this “reflection back on their early fathering” was an affirming experience. They took pride in the ways they had built their relationship with their child, as well as how they were able to model and pass on values that later helped their child deal with the limitations of his/her illness. These fathers continued to look for ways to stay connected and foster a closer relationship with their child as their child’s illness progressed. They also looked for ways in which their child’s strengths could help them cope with their illness. For some fathers, however, the “reflection back on their early fathering” resulted in feelings of regret and remorse. These fathers experienced a period of significant personal growth and change as they made decisions to parent differently as their child’s illness progressed. All of the fathers in this study at the time of the interview, were actively involved in their schizophrenic child’s life and made the relationship with their child a high priority. They reported that finding ways to parent together with their spouse was initially a challenge. Although more difficult for some than for others, all of the participants were committed to their marital relationships and together with their spouse, worked hard to find ways to effectively support each other.

As early signs of their child’s illness began to develop, most of the fathers struggled to make sense of what was happening. They tried to normalize their child’s behaviour and make sense of unusual behaviour in light of their own experiences as young men. Later, some fathers struggled with guilt as they blamed themselves for not recognizing the signs of illness earlier. However, when they recognized the need for help, all of the fathers in this study became actively involved in the help-seeking process. They sought help from various sources including the public education system, family doctors, psychologists, and
psychiatrists, depending on their individual situations. For most of the fathers the help-seeking process was difficult. It was especially challenging for fathers of adult children who were unwilling to accept help. Some of these dads who were unsuccessful in getting help for their child early in the help-seeking process later struggled with feelings of self-blame.

After their child was diagnosed, each of the fathers in this study made a point of learning as much as they could about the illness. Some fathers struggled with feelings of self-blame as they became aware of possible genetic links in the development of schizophrenia and recognized mental illness in their family of origin. They advocated for their child within the mental health system, and provided support and encouragement on an ongoing basis. Some fathers became actively involved in helping others understand mental illness through their involvement with the BC Schizophrenia society. All of the fathers expressed the desire to let their experience be helpful to other families members living with mental illness, as well as mental health professionals.

The fathers in this study experienced a sense of devastation and vulnerability at various points in the course of their child’s illness. Hearing that their child was diagnosed with schizophrenia was a devastating experience for most of these dads. Even though several years had passed since receiving the diagnosis, these fathers vividly recalled their experiences at the time. The sense of devastation and vulnerability was most poignantly experienced by the father of the youngest and most severely ill child whose illness continued to be unstable at the time of the interview.

Throughout the course of their child’s illness, these fathers experienced periods of hope and despair. It was particularly devastating to witness periods of deterioration, times when they became vulnerable to feelings of anxiety and helplessness. As they witnessed the
effects of stress on other family members, they worried about the stability of their families. Some fathers struggled with the limits of their control over the illness, as well as their limited ability to influence the course of their adult child's life. Crisis situations, which at times involved accessing emergency intervention, were also devastating experiences for some fathers as they struggled with the inadequacies of the available support systems and the need to provide safety, sometimes at the expense of being misunderstood by their child. All of the fathers in this study reported that the experience of fathering an adult child with schizophrenia had dramatically changed their lives.

A sense of sadness and loss was central to the experience of fathering an adult child with schizophrenia for the dads in this study. Some fathers expressed a sense of sadness and loss as they reflected on their child’s lack of self-care and the contrast between their child’s present level of functioning and how they functioned prior to the onset of their illness. They were saddened by the loss of their dreams for their child’s future. Sadness was also expressed as they reflected on the losses they experienced in their own lives. Supporting and caring for their adult child resulted in significant life-style adjustments for these fathers, as well as the loss of hopes and dreams for their own future.

At various points in the course of their child’s illness the fathers in this study experienced frustration with the mental health system, especially in the help-seeking process. Some fathers become frustrated as they tried to make sense of multiple inconsistent opinions from various mental health professionals. The father with the most severely ill child became extremely frustrated as he tried to work with mental health professionals who seemed insensitive and judgmental. Several fathers became frustrated with the lack of resources or difficulty accessing resources especially in crisis situations. Some fathers
expressed the frustration they experienced as they witnessed what appeared to be parental abandonment of other mentally ill children by their parents. However, despite their frustration, the fathers in this study expressed gratitude for specific aspects of the mental health system such as mental health allowances and housing for mental health consumers. They were also grateful for the assistance provided by key individuals within the system who were described as very caring, understanding, knowledgeable, and willing to take the necessary time to provide thorough assessments.

All of the fathers in this study whose young adult child with schizophrenia were relatively stable at the time of the interview, expressed a sense of admiration for their child. They admired their child’s courage and strength as their child accepted the limitations of his/her illness and found ways of living within those limitations. They also admired the ways in which their child was taking responsibility for him/herself and moving toward independent living. Several fathers expressed admiration for their adult child’s willingness to be open and honest with others about their illness and the ways in which their child was "giving back" by helping others understand mental illness.

The fathers in this study also experienced a sense of having gained personally. For some fathers this meant gaining a more complete understanding of themselves - their strengths and abilities. Several fathers reported that gaining a more complete understanding of themselves moved them toward personal growth and change. Some dads expressed having gained a sense of gratitude for the support they received from others and for things they had often taken for granted. In addition, they reported having gained an understanding of, and sensitivity to, mental illness that has given them a compassion for others who are living with mental illness. They also expressed having gained a deeper commitment to
relationships within their family. All of the fathers reported having gained a desire to let their experience of being a father of a young adult child with schizophrenia be helpful to others.

**Comparison to the Literature**

This section will begin with a discussion of the similarities and differences between the findings of the current study and the findings of the three previous studies that have explored the experience of fathers of adult children with schizophrenia: Howard (1998), Nystrom and Svensson (2004), and Pfeiffer (2001). A comparison to the findings of the studies that have addressed the experience of parenting an adult child with schizophrenia primarily from the perspective of mothers will follow.

The findings of the current study confirm the findings of Howard (1998), Nystrom and Svensson (2004), and Pfeiffer (2001), that fathers of an adult child with schizophrenia are profoundly affected by their experience, and that the early years of their child’s illness are the most difficult. Nystrom and Svensson characterized this early period as a time of helplessness, stress, chaos, and shock. Pfeiffer described the first few years as extremely traumatic. Howard drew attention to the high degree of stress experienced by family members due to the significant time gap between the onset of signs of illness and the establishment of a diagnosis. One might expect that the duration of this traumatic period might be shorter now than in previous decades as a result of the increased awareness of schizophrenia and the advent of newer and more effective antipsychotic medications, however, there is insufficient data to determine if this is the case. The findings of the current study also confirm the findings of Pfeiffer, as well as Nystrom and Svensson, that
fathers of adult children with schizophrenia experience cycles of hope and despair and live with an ever-present underlying uncertainty, alert for signs of deterioration.

The findings of the current study expand the understanding of the sense of sadness and loss reported by fathers of adult children with schizophrenia in previous studies. Five kinds of losses were identified by the fathers in the current study: the loss of who their child once was, the loss of their child’s potential to be productive, the loss of dreams for their child’s future, the losses in their own lives, as well as the loss of hopes and dreams for their own future. Some of these losses were also reported in Howard (1998), Nystrom and Svensson (2004), and Pfeiffer (2001), others were not, or were described somewhat differently.

Howard reported a sense of sadness and suggested that the concept of “chronic sorrow” could be used to describe the experience of the participants in her study. Losses were implied, but not specifically identified in her discussion of the disruption of family life and the constant concern about their child’s future. The fathers in Pfeiffer’s study expressed sadness at the loss of hopes and dreams for their child’s future, as well as the loss of their child’s potential to be productive. Pfeiffer’s participants believed that productivity through “gainful employment” would allow their children “to achieve independence and be self-reliant” (p. 108), which was symbolic of successful fathering for these men (p. 108). The participants in the present study also expressed sadness at the loss of their child’s potential to be productive, however, they did not view this loss with a sense of failure. Instead, this loss challenged them to find ways to encourage and support their child to do the best they could within the limitations imposed by their illness. Perhaps fathers of adult children with schizophrenia today are less likely than fathers of previous generations to view the
independence gained through vocational success as symbolic of successful fathering in part
due to the increased awareness and understanding of the negative symptoms of the illness.
For example, lack of motivation and energy may be more likely understood as part of the
illness rather than as a character flaw or learned behaviour.

In Nystrom and Svensson's (2004) study, in addition to expressing sadness at the
loss of their child's potential, the participants described "a loss of capability to care in an
adequate way for their son or daughter" (p. 369), as well as a significant loss of control and
loss of self-esteem. These researchers suggested that negative interaction with mental health
professionals which resulted in "the assignment of the role of being a failure as fathers"
profoundly affected their participants' self-esteem and "paralyzed for a long time their
power of initiative" (p. 369). As a consequence of this loss of self-esteem, Nystrom and
Svensson stated that some of the fathers in their study "had been struck by [psychosomatic]
illness and fears of being mad themselves" (p. 370). This finding was not reported in the
current study. The fathers in the current study struggled with feelings of guilt, self-blame,
and lack of control. However, these feelings were not linked to their interaction with mental
health professionals. Although the father of the youngest and most severely ill child in the
current study did describe being blamed for his child's behaviour by mental health
professionals, he remained convinced that he was not responsible for his son's behaviour
and his experience did not deter him from staying actively involved in his son's care. This
difference between the findings of Nystrom and Svensson and the current study is
encouraging, as it may be an indication that the effects of some of the early theories that
have implicated parenting as a causal factor in the development of schizophrenia are
becoming less prevalent.
The participants in the current study, as well as Howard (1998), Nystrom and Svensson (2004) and Pfeiffer (2001) expressed concern about how their children would manage in the future, after the death of their parents. The loss of who their child once was and the loss of dreams for their own future were, however, not specifically addressed in the three previous studies of the fathering experience. Perhaps these losses are more poignant in the early stages of the fathering experience. The children represented by the fathers in the current study had been diagnosed for eight years or less, whereas the fathers in the previous studies had been living with their child’s illness for fifteen to twenty years or more. Perhaps fathers today are also more aware of planning for their future retirement years.

A sense of frustration with the mental health system was another finding common to the experience of participants in the current study, as well as participants in the studies conducted by Pfeiffer (2001) and Nystrom and Svensson (2004). However, only some of the sources of frustration reported in the current study were similar to those reported in previous studies, such as the frustration these dads experienced in the help-seeking process as they tried to make sense of early signs of the illness and the frustration around trying to provide safety for their child during acute psychotic episodes. Unlike the participants in Pfeiffer’s study, who were reported to be frustrated with the lack of answers from mental health professions, the fathers in the current study reported becoming frustrated with multiple inconsistent opinions. Unlike the participants in Nystrom and Svensson’s study, most of the participants in the current study, with the exception of the father of the youngest and most severely ill child, did not feel disrespected, humiliated, and blamed for their child’s behaviour in their early contacts with mental health professionals. In the current study, the participants’ struggle with self-blame appeared to be related to their lack of success in
accessing help for their child in the early stages of their child’s illness, as well as their awareness of possible genetic links in the etiology of schizophrenia, not to being blamed for their child’s behaviour by mental health professionals. As noted previously in the discussion of “losses,” this difference is encouraging and may be another indication that early theories implicating parenting as causal factors in the development of schizophrenia are less prevalent.

Pfeiffer (2001) and Nystrom and Svensson (2004) also raised concerns related to trying to provide safety during acute episodes of the illness that were not reported in the current study. In Pfeiffer’s study the participants voiced concerns about physical assault by their child, false accusations of sexual assault, and fathers’ fears of their own anger in confrontations with their child. In Nystrom and Svensson’s study the participants expressed fears of potential violence by their schizophrenic children. These differences between the findings of Pfeiffer, Nystrom and Svensson, and the current study may reflect differences in the severity of the illness, the efficacy of newer anti-psychotic medications, or differences in the relationships and styles of interaction between fathers and their schizophrenic children.

Some of the fathers in the current study reported a struggle to gain control over their sense of emotional vulnerability, as well as the struggle to accept the limits of their control over the illness and the course of their child’s life. The struggle to regain a sense of control was also reported by Pfeiffer (2001), as well as Nystrom and Svensson (2004), although the participants in these studies described their struggle to regain control somewhat differently. In the current study fathers reported that gaining an understanding of the illness, as well as an understanding of their child’s reactions, helped them to accept the limits of their control and that uncertainty was part of living with the illness. In Nystrom and Svensson’s study,
however, the struggle to regain a sense of control was the central theme of the experience of fathering an adult child with schizophrenia. These researchers suggested that a major factor contributing to the experience of lack of control was the disrespect, humiliation, and resultant loss of self-esteem experienced by the participants in their contact with mental health professionals. The fathers in their study regained a sense of control through finding "a balance between grieving and adaptation" (p. 363). The participants in both Pfeiffer's and Nystrom and Svensson's studies, reported that becoming more involved in activities outside of the family, such as professional activities, helped them regain a sense of control, a factor that was not reported by the participants in the current study.

Perhaps the struggle for control is more difficult for men who have experienced being blamed for their child's illness. Perhaps a sense of control is a more prominent issue for men who became parents at a time when a more authoritarian style of parenting with a greater emphasis on control was a societal norm. Most of the fathers in the current study were on average twenty years younger than the fathers in the above-mentioned studies, and therefore began their parenting at a time when social norms reflected a more egalitarian form of parenting.

A finding that was not reported in the previous studies of the fathering experience was "a reflection on roles and responsibilities." Perhaps this theme emerged in the current study as a result of the way the participants were invited to share their experience through the orienting statement and/or as a result of the questions that were asked. The orienting statement in the current study invited the participants to describe their experience as a story, beginning with when they first noticed signs of the illness. Questions were asked regarding what it was like in the early stages of the illness and how the participant's experience
changed after the diagnosis was established, as well as in the months and years that followed. Other questions that may have contributed to the articulation of this theme were: How do you think your experience as a father of a child with schizophrenia has influenced your view of yourself? and As you reflect on your fathering role and your partner's mothering role before and since your child was diagnosed with schizophrenia, have these roles changed and if so, how? As discussed in chapter four, reflecting back on their early experience of fathering helped the participants in the current study make sense of the ways in which they assumed roles and responsibilities after the onset of their child's illness. This reflection ultimately led to an intentional commitment to prioritize relationship-building with their child throughout the course of his/her illness.

Another factor to consider in the development of this theme is that perhaps this reflection on roles and responsibilities is more likely to be part of the experience of fathers who are raising their child when societal expectations of parenting emphasize more egalitarian roles and responsibilities than in previous decades. The fathers in the current study described taking on both a practical providing role, as well as a nurturing role with their schizophrenic child. Pfeiffer (2001), on the other hand, described the roles of the participants in her study as characteristic of the traditional pattern of fathers in the 1950’s and 60’s, based on a patriarchal structure where fathers went to work to provide the family income, while their wives stayed at home and provided the primary nurturing role for their children. The participants in Nystrom and Svenssion’s study similarly described their roles as providers of practical support and their wives as providers of emotional support. Howard (1998) also reported that although the fathers in her study were actively involved in caring for their child, they considered their wives to be the primary care-givers and viewed
themselves as care-giving helpers. It may also have been easier for fathers in the current study to reflect back on their roles and responsibilities than it would have been for the participants in the studies by Pfeiffer and Nystrom and Svensson, who felt judged and blamed for their child’s illness.

A sense of admiration for their child was another finding in the current study that was not reported in previous studies. A number of factors may have contributed to this difference. As was pointed out in chapter four, all but one of the fathers in the current study experienced a sense of admiration for their child. The father who did not report a sense of admiration was the participant whose child was the youngest and most severely ill at the time of the interview. The five participants who did report a sense of admiration were fathers whose adult children with schizophrenia were relatively stable in terms of their illness at the time of the interview, actively taking steps toward becoming more independent, and no longer living with their parents. The experience of fathers whose schizophrenic children are living at home, as was the case for many of the participants in the previous studies, may be different from the experience of fathers whose children are living in supervised housing for mental health consumers. It is also possible that the children represented by the fathers in the current study were able to function at a higher level than the children represented by the fathers in the previous studies. Insufficient information was provided to determine if this is the case. Other factors such as the utility of newer antipsychotic medications, as well as the availability of more and better community support and resources such as supervised housing for adult mental health consumers, may also have contributed to this difference.
An additional factor that may possibly have contributed to the sense of admiration experienced by the participants in the current study was the intentional focus that the fathers in the current study placed on continued relationship-building with their child. The bond that these fathers had with their child may have allowed them to work together with their child to a degree that might not otherwise have been possible, and, as a result these fathers may have gained a greater understanding of, and admiration for, their child’s accomplishments in the face of considerable obstacles and challenges.

Another finding that emerged in the current study was the theme “a sense of having gained personally.” Although some of the ways that fathers in the current study reported having gained personally were mentioned in the previous studies of the fathering experience, the current study expands the understanding of these gains. This may be the result of having asked direct questions about positive outcomes and change, such as, “Have there been any ways in which this experience has been positive for you?” “How has the experience of fathering a child with schizophrenia changed your family life?” and “How have your relationships with your spouse/partner, friends, or work colleagues changed since the onset of your child’s illness?”

The fathers in the current study reported that through their experiences they had gained a more complete understanding of themselves which moved them toward personal growth and change. They also reported having gained a deeper commitment to relationships within their families. Although parenting together with their partners had been stressful, they were committed to finding ways to parent together and most of the participants reported that the relationship with their partner had grown stronger. These fathers also reported
having gained a greater understanding of, and sensitivity toward, mental illness, as well as a
desire to use their fathering experience in a way that would be helpful to others.

Similar positives were reported in the previous studies of the fathering experience
although not to the same extent. In Howard’s (1998) study, one father reported having
gained an increased commitment to his wife and children, as well as an increased
understanding of mental illness. Pfeiffer (2001) stated that the majority of the twenty-eight
fathers in her study indicated that the experience of living with schizophrenia in the family
had not adversely affected their marital relationships, however, only twenty-five percent of
her participants reported that their marriage had been strengthened as the result of their
experience. Some of the participants in her study also reported that they had become more
invested in their family and that their experience had caused them to reevaluate their belief
about the fairness of life, resulting in a search to finding happiness in new ways. The
participants in Nystrom and Svensson’s (2004) study reported that their personality had
changed for the better, but did not elaborate on that change. They also reported having
gained insight into the realities of living with mental illness which led to “more sympathy”
(p. 374) and a greater ability to cope with crisis.

A sharp contrast between the findings of the current study and the findings of
Nystrom and Svensson (2004) was the report by the participants in Nystrom and Svensson’s
study that their marital relationship was negatively impacted by their experience of
parenting an adult child with schizophrenia. All, but one of the participants attributed this
negative impact to the effect of early family interventions sessions during which these men
reported feeling disrespected, humiliated, and blamed for their child’s difficulties by mental
health professionals. This contrast between the findings of Nystrom and Svensson and the
current study further emphasizes the possible negative impact of early theories implicating parenting as a causal factor in the development of schizophrenia. Other factors which cannot be compared because of insufficient data, may also have contributed to these differences, such as the duration and severity of the illness, and the effects of living with a schizophrenic child for fifteen to twenty years.

In summary, the findings of the current study confirm and expand the understanding of the devastation and vulnerability, as well as the sense of sadness and loss experienced by fathers of adult children with schizophrenia reported by Howard (1998), Nystrom and Svensson (2004), and Pfeiffer (2001). The sense of frustration with the mental health system reported by most of the participants in the above-mentioned studies, as well as the participants in the current study, although in different ways, suggests a need for continued reevaluation and change. The differences between the findings of the current study and the findings of the above-mentioned studies of the fathering experience suggest that the impact of early theories implicating parenting as a causal factor in the development of the illness may be declining. The findings in the current study which were not reported in previous studies suggest that reflection on roles and responsibilities may be an important part of the meaning making process and could possibly contribute to a greater commitment to family relationships. The findings also expand the awareness of ways in which the experience of fathering an adult child with schizophrenia could lead to a sense of having gained personally.

The findings of the current study were also compared to the findings of studies that have focused on the experience of parenting an adult child with schizophrenia primarily from the perspective of mothers. A number of similarities were found. Regarding forms of
care-giving, the fathers in the current study, like the parents in Chesla’s (1991) study who practiced engaged care, were actively involved with their child. They tried to understand their child’s world, worked to engage their child in the real world, and were interested in fostering their child’s self-esteem. They also affirmed their child’s strengths and supported their child as they strove to live within the limits imposed by their illness. Like the parents in Chesla’s study who used managed care, it was important to the fathers in the current study to inform themselves about the illness and to find ways to help their child regain some of the skills they had lost.

Like the participants in Tuck et al. (1997), the fathers in the current study found it difficult to recognize early signs of the illness. They attempted to normalize confusing behaviour, became frustrated with the inability of mental health professionals to identify the problem and were greatly impacted by the diagnosis. Similar to the findings of Tuck et al., Milliken (2001), Pauch (1996), and Thorpe (1994), the fathers in the current study experienced devastation, uncertainty, as well as periods of hope and despair as they struggled to make sense of their experience. Like the mothers in Milliken, Crisante (2000), Vatri-Boydell (1996), the fathers in the current study experienced frustration with the mental health system as they tried to protect and find help for their child, particularly in crisis situations. They also tried to assess their child’s strengths and needs in order to find appropriate programs and activities for their child, similar to the experience of the mothers in the studies by Pauch and Thorpe. The findings of the current study support the findings of Milliken, Pauch, Thorpe, Tuck et al., and Vatri-Boydell that grief and loss is part of the experience of parenting an adult children with schizophrenia. All of the losses identified by
fathers in the current study were reported in the studies of the mothering experience when
taken together.

The following differences were noted in the comparison between the findings of the
current study and the findings of the studies based primarily on the experience of mothers.
The participants in Tuck et al. (1997), reported a lack of self-confidence as a result of their
experience, a finding which was not reported in the current study. Perhaps the struggle with
a lack of self-confidence may be more characteristic of the experience of mothers than
fathers. The fathers in the current study also did not report the degree of misunderstanding,
blame, and stigma, reported by Milliken (2001) and Vatri-Boydell (1996) or the over­
whelming demands of care-giving on an ongoing basis that were reported by Pauch (1996),
Thorpe (1994), and Vatri-Boydell. The mothers in the studies by Pauch, Thorpe, and Vatri-
Boydell reported that care-giving became an all consuming experience. In Thorpe’s study
mothers described feeling abandoned, isolated, and in great need of support. This degree of
abandonment, isolation and need for support was not reported in the current study. These
differences lead one to question whether the children represented by these mothers were
more severely ill than the children represented by the fathers in the current study and/or if
the support needs of mothers are different than the support needs of fathers. With the
exception of the father of the most severely ill child, most of the fathers in the current study
did not express a great need for support. Most of the fathers in the current study felt
supported by their families and several received a great deal of support from their
involvement with the BCSS.

Another difference was found when comparing the findings of the current study with
the findings of Pauch (1996). Pauch reported that the mothers in her study returned to
patterns of mothering that they had used when their child was young. For these mothers this meant "picking up the pieces", doing for their child what he/she could not do for themselves. This finding was not reported in the present study, although one wonders if direct questions about the day to day care of their child may have revealed a similar finding given that the fathers in this study reported taking on both practical and nurturing roles with their child.

The most noticeable difference between the findings of the current study and the studies based on the perspective of mothers is the absence, for the mothers, of a sense of admiration for their child and the absence of a sense of having gained personally. Perhaps the children represented by the mothers in these studies were more severely ill than the children represented by the fathers in the current study. Perhaps the demands of care-giving were too all consuming that it was not possible to consider having gained personally. As noted in the comparison with the previous studies of the fathering experience, this difference may also be partly accounted for by the questions that were asked in the current study. A number of additional factors may also have played a part in this difference such as the degree and effectiveness of support, as well as the availability of housing and financial options.

**Implications for Counselling Practice**

The findings of the current study suggest a number of implications for counselling practice. It is clear that the experience of fathering an adult child with schizophrenia had a profound impact on the lives of the fathers in the current study. Consistent with the recommendations of Howard (1998), Nystrom and Svensson (2004), and Pfeiffer (2001), helpers need to be aware of this impact and seek to understand fathers' "life-world"
(Nystrom & Svenssion, p. 363) by sensitively and actively listening to fathers as they tell the story of their experience. The participants in the current study wanted helpers to understand that they loved their child, wanted to help, and knew their child in ways that a professional never can. Counsellors need to recognize, and value the contributions of fathers. This is consistent with the recommendations of Perkins, Nieri and Kazmer (2001) who recommend that family members be included in clinical decision-making. They state that when patient concerns regarding confidentiality restrict the sharing of information with family members, the benefits of working in collaboration with family members need to be revisited as the clinician’s therapeutic relationship with the schizophrenic patient becomes stronger.

Fathers in the current study reported that they struggled to make sense of the early signs of illness and experienced a sense of devastation and vulnerability. Validating and normalizing feelings of confusion, helplessness, and devastation may be an important way of helping fathers. In the help-seeking process most of the fathers in the current study stated that they were frustrated by receiving multiple inconsistent opinions from a number of different professionals. As pointed out by Perkins, Nieri and Kazmer (2001), this suggests that it is important for helpers to be aware that fathers who seek help may already have experienced negative interactions with other professionals, and therefore, establishing a relationship of trust may be challenging. Remaining tentative about opinions that are uncertain, and normalizing the difficulty of establishing a diagnosis may be important. It may also be helpful for helpers to enquire about possible negative help-seeking experiences and provide a safe environment where these experiences can be processed. Validating feelings of guilt and defensiveness without judgment may be an important part of allowing fathers to feel safe and begin to regain a trusting relationship with mental health
professionals. The fathers in this study repeatedly mentioned the names of specific individuals within the mental health system who provided invaluable help and support. These individuals were described as knowledgeable, caring, and willing to take time to provide accurate assessments and not come to quick conclusions. Helpers need to take note of what these fathers are saying. As Nystrom and Svensson recommended, there is a need for education of professionals about “caring” (p. 378).

The participants in the current study reported that after their child received the diagnosis of schizophrenia they entered a period that one father described as “a time of researching schizophrenia like mad.” Consistent with the recommendations of Howard (1998), Nystrom and Svensson (2004), Perkins, Nieri and Kazmer (2001), as well as Pfeiffer (2001), counsellors need to anticipate this desire to learn about the illness and be prepared to supply accurate and current information for fathers. Reference lists and informative websites may be helpful for fathers at this time. Several of the fathers in this study reported that the support provided by the BC Schizophrenia Society was invaluable. Referrals to the BCSS should be readily available to fathers, as well as information about psycho-education sessions provided by the Early Psychosis Intervention Program. Helpers who are involved in providing psycho-education sessions to parents should take note that the information provided needs to be readily understandable, as one father in the current study put it - “in layman’s language.” Given the difficulties reported by fathers in the current study around safety and crisis intervention, practical information about how to assess risk, as well as how and when to call for emergency intervention may also be helpful. The participants in the current study also drew attention to the difficulty they experienced with involuntary hospital admissions. Debriefing these traumatic situations and validating the commitment, courage
and strength it takes for fathers to take action may be helpful, especially in situations where fathers face being misunderstood and rejected by their child.

The participants in the current study found that reflecting on their fathering roles and responsibilities prior to their child’s illness and as the illness progressed helped them to make meaning of the roles and responsibilities they assumed throughout their child’s illness. For some fathers this reflection on their fathering roles led to an affirmation of their strengths as fathers, while for others it led to decisions to parent differently. Counsellors may be in a position to facilitate this reflective process by inviting fathers, to tell their fathering stories using questions similar to those that were asked in this study, such as, “As you reflect on your fathering role before and since the onset of your child’s illness, have these roles changed and if so, how?” “How has your life changed?” Helping fathers increase the awareness of their strengths through questions such as, “How have you coped?” and “What’s kept you going?” may help this process. Fathers who experience feelings of regret and remorse could be invited to consider what, if anything, they might like to do differently.

The fathers in this study reported that parenting an adult child with schizophrenia with their spouse was challenging. Counsellors may be able to provide a safe environment where couples can address these challenges and gain an understanding of each other’s emotional responses. This process may help to lessen defensive reactions and provide a framework in which couples can be more supportive of each other. The participants in this study also expressed concern about the effects of stress on other members of the family. Providing a safe context within which to determine and respond to the needs of all family members may be helpful. These recommendations are consistent with those of Pfeiffer, who
suggested that helpers provide a safe place "where sensitive topics can be discussed without fear of recrimination" (p. 222).

A sense of sadness and loss was reported to be central to the experience of the participants in the current study. Counsellors may be in a position to help fathers identify losses and work through the grieving process. According to Grams (1996), listening and validating the emotions attached to the stories of loss is helpful to facilitate movement through the process of grief and eventually "glean the wisdom" from the experience. He states that the process of grief is "emotional, not logical" and "story telling is the language of grief" (p. 3).

A sense of admiration for their child was another theme that emerged from the stories of the fathers in the current study. The participants who expressed a sense of admiration were fathers of adult children who were relatively stable in terms of their illness and their children were actively taking steps to move toward independence. Counsellors may be in a position to help fathers recognize their child's courage and strength and in so doing foster a sense of admiration. Timing, however, may be important. Questions that attempt to explore areas of courage and strength may be inappropriate with fathers whose children are severely ill. The one father in this study whose adult child was still severely ill did not express admiration for his child. Exploring strengths with this father may have increased his awareness of his child's losses rather than his strengths and resulted in a greater sense of discouragement.

Finally, all six of the fathers in the current study expressed a sense of having gained personally. Asking questions such as "Have there been any ways in which this experience
has been positive for you?” may help fathers make meaning of their experience. Counsellors need to be sensitive to appropriate timing when asking this question. Given a trusting and caring therapeutic relationship at a stage where fathers are not in crisis, this question may facilitate new insight into their experience and be a source of encouragement, as well as possibly lead to a greater sense of gratitude and a stronger sense of self.

**Implications for Mental Health Policy**

One of the sources of frustration with the mental health system voiced by some of the fathers in the current study was the difficulty experienced when trying to access help in crisis situations, such as involuntary hospital admissions. The suggestion was made that mental health consumers and their parents might receive help more expeditiously if hospital emergency departments had separate admissions for mental health emergencies. Consistent with the recommendation of Pfeiffer (2001), the findings of the current study suggest a need for re-evaluation of the effectiveness of crisis interventions and commitment procedures.

**Implications for Family Practitioners and Psychiatrists**

Many of the implications for counselling practice also apply to family practitioners and psychiatrists who may be the first helpers contacted by fathers and their families in the help-seeking process. The participants in the current study reported that the medical professionals they found most helpful were those who demonstrated that they cared and took time to make an accurate assessment. The fathers in the current study also reported that they wanted to be helpful. As one father put it: “We’re the ones who have been with this person their whole lives.” In addition to taking time, one of the ways that medical professionals may demonstrate caring and a desire to make an accurate assessment may be to recognize
the expertise of fathers and find ways to involve them in the process of assessment and diagnosis.

Several fathers in the current study also reported a sense of frustration when receiving multiple inconsistent opinions from mental health professionals. As noted in the previous section, it may be important for family practitioners and psychiatrists to normalize the difficulties in establishing a diagnosis and be aware that fathers and their families who are seeking help may already have experienced frustration in the help-seeking process. Immediately after receiving the diagnosis the fathers in the current study indicated that they wanted to learn as much as possible about the illness. Some fathers indicated that they experienced difficulty accessing resources. Family practitioners and psychiatrists are in a position to meet this need by providing current and accurate information, as well as referrals to agencies such as the BC Schizophrenia Society and the Early Psychosis Intervention Program. The findings of the current study also indicate that fathers of adult children with schizophrenia and their families are profoundly affected by their experience. Family practitioners and psychiatrists need to be aware of the services provided by counsellors/therapists who are sensitive to the effects of mental illness. When appropriate, referrals could be instrumental in helping to support, enable and empower fathers and their families as they come to terms with the realities of living with a mental illness in the family.

**Implications for Future Research**

As has been repeatedly mentioned, very few studies have explored the experience of fathers of adult children with schizophrenia. The current study is the only study known to the researcher that has focused exclusively on the experience of fathers of young adult
children with schizophrenia who have been diagnosed for eight years or less. Given the small sample of participants, more research is needed to support and expand the findings. It is also important to note that all of the fathers who participated in the current study were volunteers. Therefore, it is possible that the findings may only reflect the experience of a homogeneous group of fathers and not be representative of the experience of most fathers of young adult children with schizophrenia.

The participants in the current study were all middle class Caucasian men. Five of the six participants lived within the Greater Vancouver Area, where acute psychiatric facilities are available 24 hours a day. The one participant who did not live in Greater Vancouver lived only a few hours traveling time away from Vancouver. Consistent with the recommendations of Howard (1998), more research is needed to expand the understanding of the fathering experience by including fathers from different cultural or economic backgrounds, as well as fathers who live in rural areas with limited access to acute psychiatric care.

One of the findings in the current study was that through the process of reflecting on their roles and responsibilities prior to the onset of their child’s illness, as well as in the early stages of the illness, the participants gained a greater understanding of themselves and the roles and responsibilities they assumed as their child’s illness progressed. Longitudinal research would be helpful to gain an understanding of the roles and responsibilities fathers assume over the course of a child’s illness.

The participants in the current study also reported that the early years of the illness were the most difficult. They struggled to make sense of early signs of illness, and became frustrated with the responses of mental health professionals. Similar findings were reported
in Nystrom and Svensson (2004) and Pfeiffer (2001). More research is needed to expand the understanding of the experience of fathers at this early stage, in order to gain insight into what, if anything, can be changed to facilitate the help-seeking process in a way that is less traumatic and more helpful to fathers and their families.

All of the participants in the current study reported that the experience of fathering an adult child with schizophrenia produced increased stress in their relationships with their spouse. Despite the increased stress, every one of these participants reported that they were committed to finding ways to parent together with their spouse and that as a result of their experience they became more committed to family relationships, including their relationship with their spouse. Research aimed at gaining insight into the dynamics of the working relationship between partners who have an adult child with a mental illness in the early stages of the illness, as well as throughout the course of their child’s illness, may be helpful to other families and to professionals as they strive to support and empower this population. Several fathers in the current study also reported that they struggled to find balance in their relationships with their other children who were well. More research is needed to gain an understanding of the effect on father-child relationships with children who are well, when one child in the family has schizophrenia.

It is clear from the findings of the current study that the participants considered a sense of sadness and loss central to their experience. More research is needed to confirm and expand the understanding of the losses these fathers identified, as well as what, if anything, fathers find helpful in the grieving process. Several sources of frustration with the mental health system were identified in the current study, such as the frustration fathers experienced as they tried to access help in crisis situations, as they dealt with hospital
discharge planning and leave agreements, as well as the frustration experienced in the interaction with some mental health professionals. Additional research may provide a more thorough understanding of these sources of frustration and ultimately identify more helpful ways to work with families of the mentally ill.

Two additional themes, 'a sense of admiration for their child' and 'a sense of having gained personally' emerged in the current study that were not reported as themes in the previous studies. Perhaps fathers who have a sense of admiration for their child and sense that they have gained personally are more likely to volunteer in research studies. Perhaps fathers who are more involved in parenting, as was the case for the fathers in this study, are more likely to have experienced a sense of admiration for their child and a sense of having gained personally. These fathers may not be representative of most fathers of adult children with schizophrenia. Research with a larger sample, using questions similar to those asked in the current study, may serve to confirm and expand the knowledge of these aspects of the fathering experience and provide greater insight into effective ways to enable and empower families living with mental illness.

Finally, the themes of this study emerged from the voices of fathers of adult children with schizophrenia themselves and the results were shared with the participants. All of the participants expressed gratitude for the opportunity to participate in the study and for the opportunity to validate the findings. Several of the fathers reported that participating in the study had been a therapeutic experience for them. In future research it is recommended that results be similarly shared with the participants. Providing the opportunity for participants to validate the findings and provide feedback respects and honours their position as the true experts on their experience.
REFERENCES


APPENDICES
Confidentiality:

Your identity will be kept strictly confidential. A pseudonym will be used in the transcripts and in the communications of findings to insure 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.

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 at the numbers listed above.

Contact for concerns about the rights of research subjects:

If you have any concerns about your treatment or your rights as a research subject, 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 have received a copy of this consent form for your own records.

Your signature indicates that you consent to participate in this study.

________________________  ______________________
Subject Signature          Date

________________________
Printed Name of Subject

Version: December 5, 2003
Appendix C
Orienting Statement

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

There is a lack of knowledge about the experience of fathers whose young adult children have been diagnosed with schizophrenia. I am interested in learning about your experience as a father of an adult child with schizophrenia. My main questions are: “What has the experience of fathering a child with schizophrenia been like for you? How have you made sense of your experience and in what ways have you and your life been changed by this experience?

If you wish, you may describe your experience as a story beginning with when you first noticed signs of the illness. What was it like for you then? How has your experience changed over the years? What impact have these changes had on your life? Throughout the interview I may ask you 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?

Version: December 5, 2003
Appendix D
Interview Questions

General Research Questions:

What has the experience of fathering an adult child with schizophrenia been like for you? How have you made sense of your experience and in what ways have you and your life been changed by this experience?

Possible Additional Interview Questions:

- What was it like in the early stages of the illness, when you first began to notice signs of the illness?
- How did you decide that help was needed?
- What was the help-seeking experience like?
- How did your experience change after the diagnosis of schizophrenia was established, in the months following the diagnosis, several years later?
- How do you understand/make sense of your son/daughter’s illness?
- Has the image of your child changed, if so, how?
- How has the experience of fathering a child with schizophrenia changed your life (family, work, leisure)?
- How have your relationships with your spouse/partner, friends, or work colleagues changed since the onset of your child’s illness?
- How do you think your experience of fathering an adult child with schizophrenia has influenced your view of yourself?
- How would you compare the severity of the experience of fathering a child with schizophrenia to other difficult experiences in your life?
- What kinds of support have you found helpful, or not helpful?
- What, if anything, would have been helpful in terms of support or information from medical or mental health professionals and significant others in your life?
- As you reflect on your fathering role and your partner’s mothering role before and since your child was diagnosed with schizophrenia, have these roles changed and if so, how?
- Have there been any ways in which this experience has been positive for you?

Version: December 5, 2003