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The Psychological Well-Being of Family Members
of Individuals with Schizophrenia

by

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ABSTRACT

The purpose of the study was to investigate how having a relative with schizophrenia impacts on the psychological well-being of family members. The impact of having a family member with schizophrenia was measured three different ways. First, a typical burden scale “The Family Distress Scale”, which will be referred to as “Burden”, was used. Secondly, a newer type of scale called “The Experience of Caregiving Inventory”(ECI), was used. Finally, the number of years the family member has been ill, referred to as “Duration of Illness” was used as a variable involved in the impact of family members’ experiences. These variables were used to examine which measure would best predict family members’ scores on the Psychological General Well-Being Schedule. Also, the relationships between all of these variables were investigated to better understand the experiences of the families studied.

Forty-one family members of thirty individuals with schizophrenia were recruited through the Foothills Hospital and The Schizophrenia Society of Calgary. Family members filled out three self-report questionnaires and answered some demographic questions. Regression analyses indicated that scores on the ECI negative scale, Burden and Duration of Illness accounted for a significant amount of the variance in family members’ scores on the Psychological General Well-Being Schedule. However, the ECI negative scale scores were the only predictor that contributed significantly to the model. Further regression analyses indicated that the ECI negative scale measure was a better predictor than the burden measure, although a high correlation between these measures existed. Duration of Illness’ unique

contribution accounted for 7% of the variance after accounting for the ECI negative scale's contribution. Also, there was a significant relationship, albeit weak, between Psychological Well-Being and Duration of Illness, which indicated higher levels of distress for family members when the individual was ill for a shorter period.

The findings of the study indicate that family members do seem to be significantly distressed due to the impact of having a family member with schizophrenia. There is also support for using newer scales, like the ECI, rather than burden scales which have been the measure of choice in past research.

Further research and clinical programs interested in working with and understanding the experience of families would be better directed by using scales like The Experience of Caregiving Inventory, rather than burden scales. Also, clinicians and researchers may want to pay special or extra attention to family members of individuals experiencing their first onset of schizophrenia, as they may be at more at risk for higher distress levels.

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CHAPTER 1 -INTRODUCTION

Schizophrenia is a life-changing disease that is often referred to as a split from reality, and can be experienced as a complete loss of self. The experience of schizophrenia involves cognitive and emotional symptoms (hallucinations, delusions, grandiosity, inappropriate emotions and disorganized thought) that distort reality, and can, consequently, result in a transformation of self (known inwardly) and of person or identity (known outwardly by others) (Estroff, 1989). It is possible for schizophrenia to take over the person and become the center of one's identity and self, rather than being a condition that is only a part of one's self.

It is a common disease, striking approximately 1 out of 100 people at some point in their lifetime (Torrey, 1983). The age of onset is usually during the late teen years or early adulthood with three quarters of all cases beginning in the 16-25 age group (Torrey, 1983). After the age of 30 onset is less common and after the age of 40 it is quite rare. Typically, the age of onset for men who develop schizophrenia is younger than it is for women. The 16-20 year old age range will consist of more men, whereas first admissions in the 25-30 year old age range will consist of more women (Torrey, 1983). The reason for an adult or late teen onset of schizophrenia is not completely understood. However, some researchers speculate that the stresses of adolescence and early adulthood are responsible whereas other researchers link the hormonal changes of puberty as the possible trigger (Torrey, 1983). In any case, schizophrenia is a potentially mentally disabling disease that strikes its victims later in life after years of adequate or normal functioning. It is not surprising that the onset of schizophrenia can damage the person's developmental trajectory and threaten the identity or

core self of the adolescent or adult (Jackson, McGorry, Edwards & Hulbert, 1996). It is the symptoms of schizophrenia, although not life-threatening, that can be extremely disruptive to the functioning of an individual, sometimes without much improvement even when treated.

The symptoms of schizophrenia are commonly categorized as positive and negative. Positive symptoms include behaviors, thoughts or sensations that are added to the individual's personality that are not normally there, such as hallucinations, delusions, bizarre behavior, and thought disorder (Walker, Davis & Baum, 1993). Negative symptoms include deficits in behaviors, thoughts or feelings that were part of the individual's personality before the onset of the illness. Some examples of negative symptoms include anhedonia, alogia, anergia, blunted affect and social withdrawal (Walker et al., 1993).

Torrey (1983) classifies the experience of the symptoms of schizophrenia into 6 categories: 1) alterations of the senses; 2) inability to sort and synthesize incoming sensations and an inability to respond appropriately; 3) delusions and hallucinations; 4) altered sense of self; 5) changes in emotions; and, 6) changes in behavior. Not all people with schizophrenia experience every symptom and some symptoms may be more profound for some and not for others. A diagnosis is made based on the total symptom picture of each individual. Each category will be elaborated upon briefly to provide an idea of how schizophrenia may be experienced. The DSM-IV criteria for a diagnosis of schizophrenia can be found in Appendix A.

Alterations of the Senses

The alterations may either be manifested through the enhancement or blunting of the senses and all the sense may be affected (ie., an increased acuteness of hearing or vision,

blunting of the experience of pain). The senses may also be flooded with stimuli because the brain is not filtering out irrelevant stimuli. Also, compounding the experience of an overload of external stimuli is an increase in internal stimuli, such as thoughts and memories.

Inability to Sort and Synthesize Incoming Sensations

A person experiencing schizophrenia may not be able to sort and synthesize incoming stimuli and, subsequently, choose a correct response and act on it. This experience may be described or manifested as thought disorder but it also includes visual and auditory stimuli, emotions and actions. There may also be an inability to synthesize two kinds of stimuli together, such as watching television and listening to what is being said.

Delusions

Delusions are false ideas believed by the person with schizophrenia but not by other people in the person's environment and which cannot be corrected by reason. For example, people with schizophrenia might believe that random and even trivial happenings in the environment are directly related to them and are of great significance. Delusions can become very complex and integrated. Consequently, they can become grand ideas of conspiracies and plots against the person experiencing them.

Hallucinations

Hallucinations are experiences of stimuli when there is no initial stimulus at all. A person can have a hallucination that involves any of the five senses and may involve more than

one sense. Auditory hallucinations are the most common hallucination experienced by those who suffer from schizophrenia. There is much variance in the type, the intensity, and the frequency of hallucinations.

Altered Sense of Self

An altered sense of self involves the loss of the ability to know where one's body stops and inanimate objects begin. It is an inability to differentiate oneself and one's body from the environment.

Changes in Emotions

In schizophrenia, changes in emotions usually involve either inappropriate emotions or flattened emotions. Other symptoms associated with flattened emotions are apathy, slowness of movement, underactivity and a poverty of speech and thought.

Changes in Behavior

Changes in behavior are often secondary symptoms that result from the experience of other symptoms that are distorting thoughts, sensations and emotions. For example, people suffering from schizophrenia may act strangely because of certain delusions or hallucinations that they are experiencing. They might refuse to eat because of a belief that the food has been contaminated or poisoned.

Based on the descriptions of symptoms above, it may be easier to comprehend how

devastating and distressing the experience of schizophrenia can be. People experiencing schizophrenia may become quite upset and anxious because of the symptoms they are experiencing. Yet their level of awareness about what is actually happening to them is not as profound as it is for outsiders watching their behavior and personality change considerably. Family members of individuals with schizophrenia have the perspective of an outsider and they have the awareness that something is drastically wrong with their family member. Individuals with schizophrenia view their experiences as reality, whereas family members are aware that their family member's experience no longer has a basis in reality.

At the initial onset of schizophrenia, family members of the individual often experience reactions of shock, distress, denial, anger, guilt or fear. The initial diagnosis or hospitalization can have a huge impact on family members as they are all too aware of the stigma and negative stereotypes that are attached to the group to which their relative may now belong. The family may also be aware of the possibility that schizophrenia can be a life-changing illness for many of those who suffer from it. Often, at this point, the individual with the illness is not aware of the possible results of what has happened to him/her. It is extremely important at this point to support and educate the family members to help them work through their reactions to their "changed" family member.

The ideal, to be strived for, is to support family members so they can eventually learn to deal with their relative's illness confidently and effectively. This is not only ideal for the psychological well-being of the family members, but also to support and to promote the best recovery possible for their relative. Family members can be critical sources of feedback to the individual with schizophrenia. To do this, they can focus on the positive gains and attend to

the characteristics of the individual that have remained the same, rather than focusing on losses or changes in personality. They can encourage and support their relative to take an active role influencing the course of their illness, rather than giving in to the illness and taking on a chronically mentally ill identity.

In the past, family members of individuals with schizophrenia were blamed with causing the illness. Subsequently, their ill relative was typically committed to an institution where they could be protected from their family and the rest of society (Terkelsen, 1990). Due to increased biological and genetic research on schizophrenia and results indicating a biological/genetic component or vulnerability to schizophrenia, the family was finally relieved of the blame and the guilt (Terkelsen, 1990). However, because of the role stress is believed to play in the illness as an environmental trigger, family relationships remain important as they may have a negative or positive effect on the well-being of the individual with schizophrenia, depending on the quality of the relationship. Thus, it is imperative for professionals in the mental health field to develop a better understanding of the experience of family members of individuals with schizophrenia. This knowledge would help professionals to support families in dealing with schizophrenia and to maintain their well-being so they can contribute to the well-being of their ill relative in a positive way.

Statement of the Problem

The problem that this study was designed to address is the lack of consistency in the literature with regard to understanding the experience of family members of individuals with schizophrenia and how it impacts their psychological well-being. Typically, the impact on

family members has been measured by various burden-type scales and/or by scales measuring their distress or psychological well-being in general or in relation to specific symptomology or characteristics of individuals with schizophrenia. This study will address the problem in a different way. The psychological well-being of family members will be measured and then a number of variables will be tested to determine which one best accounts for the distress caused by the impact of having a family member with schizophrenia.

Because of the negative focus of burden scales, some researchers have developed a scale that measure some of the positive aspects or consequences of dealing with a relative who has schizophrenia. This study will compare the usefulness of a typical burden scale, “The Family Distress Scale” (Smith, Birchwood, Cochrane & George, 1993) with a newer scale, “The Experience of Caregiving Inventory (ECI)” (Szmuckler, Burgess, Herrman, Benson, Colusa & Bloch, 1996), as predictors of the psychological well-being of family members.

Another variable that will be investigated in relation to family distress, is the duration of illness, which is the length of time the relative with schizophrenia has been diagnosed with the illness. This is a very important variable to study because it will provide information on how the impact of the illness changes over time for the family. It is unreasonable to assume that all families can benefit from the same support and interventions from professionals. It may be that, over time, the support and services that a family needs can drastically change. Initially, when a family first learns that their relative has schizophrenia, it seems reasonable that the family would experience a high level of distress. Their distress would result from dealing with the fact that their relative has a potentially life-changing illness which is usually a completely novel experience to them. Whereas, a family whose relative has been ill for many

years may have come to an understanding about the illness that has helped decrease the distress, but they would have experienced many more years of burden due to the nature of the illness and the demands of caring for another adult.

The variables that will be used in this study are as follows: scores on “The Family Distress Scale” will be referred to as “Burden”, scores on the “Experience of Caregiving Inventory” negative scale will be referred to as “ECI negative”, scores on the “Experience of Caregiving Inventory” positive scale will be referred to as “ECI positive”, scores on the Psychological General Well-Being Schedule will be referred to as “Psychological Well-Being”, and finally the number of years the relative has been ill will be referred to as “Duration of Illness”. Correlations between all of these variables (Psychological Well-Being, Burden, ECI negative, ECI positive and Duration of Illness) will be investigated to further delineate the relationships between them, thus providing an increased understanding of the experience of family members.

Whereas other research has largely focused on families to examine their influence or impact on their relative with schizophrenia, this study aims reverse the emphasis by examining the impact of an ill member on the family. In 1990 Lefley and Johnson pointed out that families of a person with schizophrenia have, at times, been seen as part of the patient’s problem and, at times, part of the course of treatment; but, it has been a rare occasion that their own psychological needs have been given central consideration. In Perring, Twigg and Atkin’s (1990) review of the literature, they also found that the literature had primarily focused on the effect of family members on the patient’s well-being, as opposed to the effect of the situation on families or carers themselves.

Purpose of the Study

The purpose of this study is to determine the best predictor of the psychological well-being of families who have a member with schizophrenia. The predictors under consideration are Burden, Duration of Illness, ECI negative and ECI positive. Furthermore, all of these variables will be tested to delineate whether there are significant relationships among them. The psychological well-being of families of individuals with schizophrenia is of critical importance to the health of the relative with schizophrenia as reflected in studies on expressed emotion, and, of course, for the family members themselves. The burden experienced due to caring for a relative with schizophrenia has been found to have direct effects on the physical and mental health of the family (Fadden, Bebbington & Kuipers, 1987).

Rationale

This study is important for several reasons. First, it will contribute to an increased understanding about what impacts the well-being of family members. This has implications for determining what resources within themselves and available services would be useful to stay physically and emotionally healthy. This is also important if they are going to provide the majority of the caregiving for their sick relative. If family members are not well physically or emotionally, they will not be in a position to provide high level of quality care for an adult relative with schizophrenia. Secondly, improved family interactions will benefit the relative with schizophrenia by providing a less stressful environment. Thirdly, the results of this study will have direct implications for professionals providing family support and interventions. A clearer understanding of when relatives need more support and what kind of support they need

is critical to contribute to a supportive community and an efficient community mental health system.

This study is different from previous studies in several ways:

1. It uses an alternative measure to burden, which aims to assess the experience of caregiving, that may be more comprehensive and useful.
2. It considers relationships between psychological well-being, the experience of caregiving and burden.
3. It considers whether psychological well-being and/or burden vary with the number of years that the sick family member has been ill.

Hypotheses

Primary Hypothesis:

It is anticipated that:

1. The scores on the Experience of Caregiving Inventory, both negative and positive scale scores will be the best predictor of psychological well-being of family members. High negative scores will account for lower scores on the psychological well-being scale and high positive scores will account for higher psychological well-being scores. (Higher scores on the psychological well-being scale reflect a healthier well-being and lower scores reflect increased difficulties with psychological well-being.)

Secondary Hypotheses:

It is anticipated that:

1. A high level of burden will be associated with a longer duration of illness and a low level

of burden will be associated with a shorter duration of illness.

2. A high level of distress, as measured by the Psychological General Well-Being Scale, will be associated with a shorter duration of illness and a low level of distress will be associated with a longer duration of illness.

Definitions of Terms

Schizophrenia

A group of psychotic reactions characterized by both positive and negative symptoms associated with disturbance in one or more areas of daily functioning of a person's life.

Positive Symptoms

Positive symptoms are usually described as behaviors, thoughts or sensations that are added to a person's personality, in that they are not normally there. Examples of positive symptoms include delusions, hallucinations, thought disorder and bizarre behavior.

Negative Symptoms

Negative symptoms are usually described as a lack of or deficit in characteristics of the person's personality that were there prior to becoming ill. Examples of negative symptoms include blunted affect, apathy, alogia and anhedonia.

Distress

Distress is a subjective experience of discontent and/or discomfort that manifests itself

differently depending on the individual. The level of distress family members are feeling can be measured using depression and anxiety scales. Distress affects overall well being, including both physical and psychological health. It is often measured using scales that assess an individual's psychological well-being.

Psychological Well-being

Psychological well-being is a health- related quality of life measure that is a subjective, psychological dimension (Bech, 1993). It attempts to measure a global psychological concept attained by integrating the different axes of the DSM-IV. The resulting components that are generally measured by health- related quality of life scales are general health, emotional health, vegetative symptoms, autonomy, accomplishment and understanding (Bech, 1993).

Subjective Burden

Subjective burden involves the psychological consequences of the individual's illness for the family (i.e., health problems, distress) (Schene, 1990).

Objective Burden

It is generally accepted that objective burden involves the disruption to the family/household that is due to the individual's illness and is usually observable (i.e., household routines, family relations, finances) (Szmukler, 1996).

Duration of Illness

The number of years since the individual with schizophrenia was first diagnosed with schizophrenia or admitted to hospital because of an acute episode of schizophrenia.

CHAPTER 2: REVIEW OF THE LITERATURE

This chapter presents a review of the literature relevant to family members of individuals with schizophrenia.

The Family and Schizophrenia

Currently, in the context of the community integration movement in mental health, individuals with mental illnesses are no longer segregated from the rest of society. Deinstitutionalization has placed much of the responsibility and care of individuals with mental illnesses onto the family. Therefore, families are largely affected by the inadequacies of community care, such as the revolving door syndrome, homelessness among those with mental illnesses, and individuals in the criminal justice system who go untreated (Marsh, 1992). The mental health system that exists to provide services to individuals with mental illnesses has been, at times, less than sensitive and accessible to families in times of need, when they are dealing with crisis situations, legal barriers, and accessing community resources (Marsh, 1992).

When a family learns that their relative has developed schizophrenia they may go through a series of feelings, such as helplessness, anger, despair, and anxiety (Spaniol, Zipple & Lockwood, 1992). Families are suddenly faced with traumatic role changes that are forced on them without perceived warning. Professionals are often as unprepared as families to offer any beneficial help. It has been suggested that families lack support from and communication with mental health professionals (MacCarthy, Kuipers, Hurry, Harper, LeSage, 1989). Numerous studies have found that there is a dramatic difference between a professional's

perception of families' needs and the families' perception of their needs (Spaniol et al., 1992). Thus, families of individuals with schizophrenia may develop fixed beliefs or ways of coping that seem maladaptive, but are functionally useful for them and have been shown to be difficult to change (MacCarthy et al., 1989).

Researchers who have studied the concept of 'burden' or hardship on families have been limited to establishing that burden does exist and that families might benefit and decrease their level of burden through mutual-support groups (Bulger, Wandersman & Goldman, 1993). Services available to families of individuals with schizophrenia include psycho-educational programs, family treatment and support groups. These services may be beneficial to families depending on whether or not they actually meet their needs or if families are able to access them.

Families are faced with many issues and challenging situations, yet they need to be as supportive and resourceful as possible to their family member with schizophrenia. The main areas that have been researched concerning the families of individuals with schizophrenia are expressed emotion, burden and distress. Research on expressed emotion has indicated the significance of family interactions on the health of individuals with schizophrenia. Research on burden and distress are attempts to measure the degree of hardship and negative effects that have been placed on families in the context of a community based mental health system.

Expressed Emotion (EE)

The area that has received the most research attention is the expressed emotion of families of individuals with schizophrenia. EE is a measure of "the affective attitudes and

behaviors of relatives toward a family member with a psychiatric illness” (Kazarian, 1992, p. 51). In particular, expressed emotion is a measure of criticism, hostility and emotional overinvolvement of relatives. The standard method used to assess expressed emotion is the Camberwell Family Interview (CFI) (Kuipers, 1979). A family member is interviewed about factual and historical data concerning the individual with schizophrenia (i.e., events leading up to seeing a doctor, symptomology and their relationship with their ill relative). The CFI is audio taped and is, subsequently, rated by a qualified person. The CFI is scored using frequency type ratings (i.e., critical comments) or scale type ratings (i.e., warmth, hostility, emotional overinvolvement). Family members of individuals with schizophrenia are attributed a high EE rating if they score six or more on critical comments and/or three or more on emotional overinvolvement. The CFI is a time-consuming measure and there has been considerable effort to develop more efficient measures without affecting the predictive value of expressed emotion scales (Vaughn & Leff, 1976). However, at present the Five Minute Speech Sample, or any measure other than the Camberwell Family Interview, has not attained the status of a valid instrument for research or clinical use (Birchwood, 1992).

The link between high EE and the increased likelihood of relapse has been well documented. A high rating of EE in families in various centers around the world has been associated with higher relapse rates in schizophrenia (Brewin, MacCarthy, Duda, & Vaughn, 1991; Kazarian, 1992; Smith, Birchwood, Cochrane & George, 1993). Subsequently, family interventions have been designed and implemented for families to decrease the level of expressed emotion and have resulted in lower relapse rates in comparison to families who did not receive the intervention (Barrowclough & Tarrier, 1990; Kazarian, 1992; Smith et al.,

1993).

Vaughn and Leff (1981) described four characteristics that they found distinguishes high EE from low EE families. High EE families: 1) tended to react to the illness with anger or acute distress, 2) questioned the legitimacy of the illness and may blame their family member for his/her symptoms, 3) were intolerant of symptom behavior and low performance and 4) were highly intrusive in the individual's life. In Kuipers' (1979) review on expressed emotion, she reported findings that high EE families tend to blame the family member with schizophrenia for their illness and behaviors. The family members also emphasized the personal impact the illness has on them rather than the impact on their ill family member. Similarly, Brewin et al.(1991) found that high EE family members made more attributions about the illness to factors that were personal and controllable by their ill relative. This literature indicates that high EE families exhibit certain patterns in their emotional reactions to schizophrenia, attitudes and coping strategies that may contribute to their high EE rating and can be detrimental to the recovery of the individual with schizophrenia.

An individual's symptomology has not clearly been associated with high or low levels of expressed emotion and the research attempting to determine whether positive or negative symptoms contribute to high EE continues (Glynn, Randolph, Eth, Paz, Leong, Shaner, & Strachan, 1990). Families high or low in EE all have to deal with difficult patient behavior at times. While it is unclear what specific behaviors or symptoms are related to EE, the individuals with schizophrenia and their behavior obviously play a role in the family group and must affect family interactions.

It is important to understand the characteristics of high EE families to design

intervention programs effectively and decrease relapse rates. It is also necessary to note that the line between high and low EE ratings is arbitrary and that EE levels are not stable over time (Smith et al., 1993). Families that are not rated high in EE are not exempt from needing intervention programs and support. In fact, Smith et al. (1993) found that a quarter of the families low in EE reported high stress, burden or impaired coping. Furthermore, the high/low EE classification is a research definition used to achieve the maximum prediction of relapse in the nine months following hospitalization (Smith et al., 1993). The question arises whether high EE in families leads to a increase in an individual's symptomology or whether increased symptomology causes an increase in the level of EE. Thus, EE may not be the most useful measure to be using for clinical purposes in working with individuals with schizophrenia and their families. However, the research on EE has quite reliably indicated the critical role the family can play in the recovery of the patient and in contributing to or preventing relapse. Thus, it makes sense that considerable attention and research should focus on working with and understanding families, not only for the well-being of the patients but also for the health of all family members.

Burden of Family Caregivers

Amidst the community care approach of today's mental health system, the bulk of care has resided with family members of individuals with schizophrenia. Consequently, a large area of research in the mental health field has focused on assessing the burden experienced by family members. Research in this area is critical to further understand the needs and experiences of family members and to develop and provide services to support their efforts

in community care (Bulger, Wandersman & Goldman, 1993).

Burden is often the result of the addition of the caregiving role to already existing family roles (Schene, Tessler & Gamache, 1994). Burden is often distinguished into two separate types: objective and subjective. Although definitions may vary slightly, it is generally accepted that 'objective burden' involves the disruption to the family/household due to the individual's illness and it is usually observable (i.e., household routines, family relations, finances) (Szmukler, 1996). 'Subjective burden' involves the psychological consequences of the individual's illness for the family (i.e., health problems, distress) (Schene, 1990).

In the literature, reported relationships between specific personal characteristics and burden have been inconsistent. However, it is claimed that there is a well established trend for greater burden with greater severity of the individual's symptoms (Birchwood & Cochrane, 1990; Gubman, Tessler & Willis, 1987; Noh & Avison, 1988).

Brichwood and Cochrane (1990) found a significant relationship between the patient's behavioral disturbance and family member stress and burden. Behavioral disturbance was measured in two ways. The first consisted of relative's ratings of observed behavior elicited during a personal interview that focused on six behaviors: withdrawal, symptoms, loss of independence, aggression, over activity and medication compliance. The second measure used was the Symptom-Related Behavioral Disturbance scale that measures the patients' behavioral disturbance that is attributable to residual psychotic symptoms. Burden was measured through a personal interview during which relatives were questioned in three main areas: restriction of social and recreational activities, social and family consequences, and feelings of burden and strain. Each question was rated on a four point scale. Stress of the relatives was measured

using The Symptom Rating Test which is a self-report measure of anxiety, depression, inadequacy and somatic complaints. Coping styles of relatives were measured and extensively reported in this study. However, a discussion of coping styles is beyond the scope of this literature review and is not relevant to this study. But, it is interesting to note that coping styles had no independent relationship to burden or stress after the effect of the patient's behavioral disturbance was removed.

The subjects in the study were diagnosed with schizophrenia with a two year history of the illness and they were living with their families. The final sample consisted of 33 males and 20 females with 49 out of 53 individuals living with parents and 4 living with spouses. It is not mentioned how many family members actually participated in the study. So, it is unclear whether it was one member per household or if all family members living in the household participated. Thus, it would be difficult to compare family member results of this study with other studies investigating similar relationships.

In Gubman et al.'s study (1987) 345 individuals with chronic mental disorders who were living at home were compared with 622 individuals who were living in other group settings to investigate factors affecting household complaints. A major problem with this study is that the data was provided to the researchers by 248 case managers in 18 different communities. It cannot be assumed that all case managers have a comprehensive understanding of the difficulties in every household of every patient. Also, the issue of inter-rater reliability was not addressed. All the variables used in this study, dependent and independent, were based on ratings from case managers. However, they were able to include a large number of families in the study. Of the 345 individuals living with family members

30% were living with a spouse, 40.5% with parents and the remainder lived with other relatives. Individuals with schizophrenia living with families had spent considerably less time in hospital (median = 3 months) than those who live in other group settings (median= 3.5 years). The results of a regression analysis identified that behavioral problems were the best predictor of household complaints; more specifically, temper tantrums and bizarre behavior tended to generate household complaints in both settings.

Noh and Avison (1988) investigated factors associated with burden of spouses of discharged psychiatric patients. All patients in the study had been diagnosed as functionally psychotic and they were between the ages of 18 and 65 at the time of discharge. Their family member sample consisted of 163 spouses, 98 of which were male and 65 were female. Burden, measured through a 9 item modified version of Pasamanick et al.'s (1967) "Patient as a problem" scale, was their dependent measure in a regression analysis with psychiatric factors (including the level of symptoms), family environment, stressful life events, mastery and social support as independent variables. The results of an overall regression analysis showed that the patients' level of symptoms, life events and mastery were significant determinants of spouses' perceptions of burden. However, when the sample was split by gender to investigate sex differences, the effect of the patients' level of symptoms and stressful life events was only significant for men. The trend for women, based on these results, was that older women, those with children in the home and women with lower mastery scores were more likely to have higher levels of burden.

Recently, Provencher and Mueser (1997) investigated the relationship between positive and negative symptoms and family burden. Seventy primary caregivers completed self-report

scales measuring their perceived severity of positive and negative symptom behaviors, responsibility attribution, subjective burden and objective burden. Objective burden, subjective burden and the severity of positive and negative symptom behavior were all measured through semi-structured interviews based on modified versions of the Social Behavioral Assessment Schedule. The results indicated a significant relationship between subjective burden and positive and negative symptom behaviors and a significant relationship between objective burden and negative symptom behaviors. Interestingly, contrary to Provencher and Mueser's (1997) hypothesis, increased burden was associated with family members' perceptions that their ill relative was not responsible for their negative symptoms. On the one hand, this seems positive in that family members are acknowledging that these symptoms are related to an illness. On the other hand, family members may be over-attributing their relative's behavior to negative symptoms or may have given up on encouraging their family member to cope with negative symptoms.

Although various measures, methodologies and samples were used in the studies discussed above, the relationship between increased symptomology or behavioral disturbance and burden is quite consistent. This relationship seems to persist throughout these studies even when the focus and intent of each study is different. However, because of the sex difference found in Noh and Avison's (1988) study, the relationship between burden and symptomology or behavioral disturbance may not be straight forward. There may be mediating factors that influence this relationship.

Hoening & Hamilton (1966;1969) found a significant relationship between increased subjective and objective burden of family members with the length of time the relative had

been ill. In Hoenig and Hamilton's 1966 study, they investigated objective and subjective burden in households of individuals with schizophrenia living in the community. Hoenig and Hamilton assessed both objective and subjective burden. Objective burden was measured in 5 areas: finance, health, children, general and their ill relative's abnormal behavior. Subjective burden was measured by questioning the family members as to whether or not they thought the household had suffered a sense of burden over the years. The sample consisted of 62 patients and their households. Hoenig and Hamilton found that objective burden increased if the ill relative had been sick for more than two years. Subjective burden reported by families seemed to increase the longer their relative was ill. Also, Hoenig and Hamilton noted a great discrepancy between reported levels of objective and subjective burden; when objective burden was indicated the level of subjective burden varied considerably. This observation may indicate that these two constructs are actually measuring very different aspects of the impact mental illness has on families.

Although there is no description of the sample of family members who participated in Hoenig and Hamilton's 1969 study, data from family members was gathered on at least 252 patients. The results are similar to their previous study. Their findings indicated that the longer the patients were ill, the incidence of objective burden increased. Results of the analysis of subjective burden indicated less burden initially, with burden levels increasing considerably between the first and second years their relative was ill, then slightly decreasing after 2 years. The 1966 study did not show a decrease in subjective burden over time. It may be that the larger sample size in Hoenig and Hamilton's 1969 study was more sensitive to this trend.

Bulger et al.(1993) studied the relationships between caregiver burden, burden, conflict

and intimacy. Caregiver burden (seen by the authors as equivalent to 'subjective burden') was measured by an instrument developed by Lawton, Kleban, Moss, Rovine and Glicksman (1989) for use for caregivers of aging adults. It is not clear how appropriate this scale is for family caregivers of adults with schizophrenia. Objective burden was measured by a scale developed by Tessler, Fisher and Gamache (1988) that addresses how much help the caregiver provides the ill relative in seven different areas and how much supervision is required by the caregiver in regard to the behavior of the patient in seven different areas. For both scales a five-point Likert-type scale was used for the caregiver to rate their responses. Conflict was measured by Argyle and Furnham's conflict scale developed in 1983. It assesses conflict between normal people in a range of relationships in 15 areas of personal interaction in which conflict is likely to occur. There were 60 participants in the study, all of whom were parents of adults with schizophrenia. Bulger et al. (1993) found that as the age of the caregiver increased, caregiver burden and conflict decreased. They also found that relationships, measured by intimacy and conflict, had a stronger relationship with burden in comparison to the severity of schizophrenia symptoms.

It is important to understand the relationship between duration of illness and burden, and what factors mediate the burden felt by family members. Studies that have investigated the relationship between duration of illness and burden have been inconsistent. Hoenig and Hamilton's (1966, 1969) findings are not surprising as it would certainly make sense that the longer family members provide care for a mentally ill family member, the more burden they feel. Certainly, objective burden increases the longer that a family member requires care (i.e., financially, household responsibilities), but subjective burden is the critical indicator for

ascertaining whether more burden is experienced by family members. The findings forwarded by Bulger et al. (1993) support the argument that although the objective burden obviously increases over time, family members may have become accustomed to the burden and no longer view it as difficult or distressing. Family members may become more educated and knowledgeable about the illness over time and, consequently, more accepting of their relative with schizophrenia and the resulting behaviors or problems.

It has also been reported that families high in EE experience high levels of burden (Scazufca & Kuipers, 1996; Smith et al., 1993). It may be that families high in EE are more apt to deal with the behaviors and symptoms of their ill family member in a negative manner, and are, in effect, contributing to their own increase in perception of burden. On the other hand, it may be that the family members are having to deal with many issues as a result of taking care of an individual with schizophrenia in the community. Poor coping and negative behaviors of family members may partly be a result of the burden family members are taking on in today's mental health system (Fadden et al., 1987). So, working with family members to enhance the effectiveness of their coping skills in dealing with the burden of caring for a relative with schizophrenia has a beneficial effect on the course of the illness (Fadden et al., 1987).

It is quite evident that poor family functioning and feelings of burden is common in families of individuals with schizophrenia. It is also not surprising that families are responding to the responsibility of caring for a mentally ill relative in this manner. Families may be responding to an "abnormal" situation in a very normal way or the best way that they know how. In order to provide families with support and help that meets their needs, scales and

measures need to be identified and better understood that actually tap into the meaningful aspects of their experiences and are attuned to the impact the illness has on their lives.

Limitations of 'Burden'

Several scales have been designed to assess the burden of family members of individuals with chronic mental illnesses (Schene et al., 1994; Schene, 1990). It has been suggested that the term 'burden' is negative and damaging and it refutes any positive or rewarding aspects of taking care of an ill family member (Szmukler, 1996). The constructs of "subjective" and "objective" burden have also been criticized. It could be argued that "...each assesses the perceptions of the caregiver, and as such is implicitly subjective, this [objective and subjective] distinction is perhaps spurious" (Schofield, Murphy, Herrman, Bloch & Singh, 1997). Furthermore, Szmuckler and his colleagues (Szmuckler, Burgess, Herrman, Benson, Colusa & Bloch, 1996) outline problems associated with the concept of "burden". Burden fails to recognize possible rewarding aspects of providing care for a relative with schizophrenia that may even serve to counteract the negative aspects.

Another problem with the concept of burden is the fact that it fails to stem from or originate in a psychological or social theory that fully explains the determinants, the mediating influences, or outcomes of "burden". There is also little consistency across studies in the way major constructs are defined and operationalized (Gubman et al., 1987). It is also unclear if burden is a concept solely for parents living with a mentally ill child, or for a spouse or even a child of a mentally ill parent. Whether burden is the same or different, depending on the role of the family member, is vague. There is also the issue of non-relatives living with a mentally

ill person. It would be surprising if non-relatives did not experience burden when it has been quite clear that family members do experience burden to a large degree. Overall, Perring et al. (1990) critique the use of 'family burden' to understand the impact caring for a mentally ill relative as a rather restrictive and narrow conceptualization that interprets the experience of families as mainly disruptions to various areas of family life.

A more appropriate term that encompasses the whole experience of family members or non-relatives caring for an individual with schizophrenia to some extent is 'caregiving'. As a result, Szmukler et al., (1996) developed a self-report measure of the experience of caregiving for a family member with a serious mental illness called the "Experience of Caregiving Inventory" (ECI). The caregiving measure was created based on a stress-coping framework (Szmukler et al., 1996). In this model, stressors due to the patient's illness, behaviors, and disabilities are appraised by the caregiver. Mediating factors, such as social support, have an impact on this appraisal. The carer's appraisal of the stressors interact with the carer's coping strategies resulting in outcomes reflected in psychological and/or physical morbidity or the well-being of the caregiver. Because Szmuckler et al.'s scale is a measure of appraisal, which lies in the 'subjective' domain, a self-report inventory is not only appropriate, but practical in usage.

This scale has another advantage over burden, it assesses not only the negative aspects of caregiving typical of burden measures, but also the positive aspects of the relationship with the person they are caring for. The content of this measure goes beyond direct concerns about their relationship with the person they are caring for to include, for example, stigma and the family's experience with mental health professionals. The construction of the ECI involved

a total of 746 relatives over a four step process that provided feedback and data that helped the authors refine the inventory from 130 items to a final 66 item version and identify 10 statistically reliable subscales. The caregivers included in the study had a variety of relationships of carer to patient: mother, 60%; father, 11%; spouse, 16%, sister, 9%. Just over half (61%) of the caregivers were living with the patient.

To investigate the validity of the ECI, a survey group (n = 359) and a 'clinic group' (n = 63) were tested on measures of coping, level of distress or psychological or physical morbidity (measured by the General Health Questionnaire (GHQ)) and the ECI. A regression analysis was used to measure the extent to which the ECI and coping predicted GHQ scores. The Experience of Caregiving Inventory predicted a large amount of the variance in the participants scores on the General Health Questionnaire in both the survey group ($R^2=0.24$; $p<.0001$) and the clinic group ($R^2= 0.39$; $p<.0001$). Coping only accounted for 10% of the variance over and above ECI for the survey group and 7% for the clinic group. The stress-coping model was also tested and validated on the clinic group. Mediating factors such as family environment, social support, and life events, and stressors, measured through an inventory of caregiving activities and a life skills profile on the ill family member, were tested to ascertain how much of the variance in the ECI negative scale these factors could explain. Forty four percent of the variance of the ECI negative scale was accounted for by the mediating and stressor factors mentioned above, with the major contributors being the Life Skills Profile and the social support measure.

It seems that the ECI measure is reflective of the family members' overall experience and it may be able to account for the distress that they experience directly from the impact of

having a family member with schizophrenia. It has several advantages over the burden scales. First, the ECI acknowledges and measures positive aspects of the caregiving experience. Second, the ECI was developed based on a sound theoretical basis that explains the determinants, the mediating factors and the possible outcomes due to caring for a relative with a serious mental illness. Finally, the ECI does not limit nor imply limitations on who is able to answer the inventory other than anyone who, to some extent, provides care to an individual with a mental illness. It may be that burden is not comprehensive enough to provide researchers or professionals with a useful conceptualization of what family members are experiencing. That is why a more comprehensive measure, acknowledging all aspects of caregiving, might be more useful in understanding the impact of schizophrenia on families.

Summary

Although various measures, methodologies and samples were used, the relationship between increased symptomology or behavioral disturbance and burden is quite consistent (Birchwood & Cochrane, 1990; Gubman, Tessler & Willis, 1987; Noh & Avison, 1988). This relationship seems to persist throughout these studies even when the focus and intent of each study is different. However, the relationship may not be straight forward, as indicated by the sex difference found in Noh and Avison's (1988) study. There may be mediating factors that influence this relationship, such as the severity of the illness, the quality of the relationship between the family member and their relative, the amount of contact and responsibility the family member takes on, or the expectations the family member has of the relative.

Studies that have investigated the relationship between duration of illness and burden

have found inconsistent results. Hoenig and Hamilton's (1966, 1969) finding that measures of family burden increase with the length of illness, is not surprising as it would certainly make sense that the longer family members provide care for a mentally ill relative that more burden is felt. Certainly, objective burden increases the longer that a family member requires care (i.e., financial costs, household responsibilities), but subjective burden is critical to ascertain whether more burden is felt by family members. Over time, family members may become accustomed to the burden and no longer view it as difficult or distressing for them, which may explain Bulger et al.'s (1993) results indicating a decrease in burden for family members with a long duration of illness. Also, family members may become more educated and knowledgeable about the illness over time and subsequently, more accepting of their relative with schizophrenia and the resulting behaviors or problems.

It is quite evident through research that poor family functioning and feelings of burden can often be the situation in families of individuals with schizophrenia. It is also not surprising that families are responding to the responsibility of caring for a mentally ill relative in a potentially negative manner. It may be that families are responding to an "abnormal" situation in a very normal way or the best way that they know how to deal with it. In order to provide families with support and help that meets their needs, scales and measures that actually tap into the meaningful aspects of their experiences and are attuned to the impact the illness has on their lives, need to be identified and better understood.

It seems that the experience of caregiving measure (the ECI) developed by Szmukler et al. (1996) is reflective of the family members' overall experience and it may be able to account for the distress that they experience directly from the impact of having a family

member with schizophrenia. It has several advantages over the burden scales. First, the ECI acknowledges and measures positive aspects of the caregiving experience. Second, the ECI was developed based on a sound theoretical basis that explains the determinants, the mediating factors and the possible outcomes due to caring for a relative with a serious mental illness. Finally, the ECI does not limit nor imply limitations on who is able to answer the inventory other than anyone who, to some extent, provides care to an individual with a mental illness. Current burden measures may not be comprehensive enough to provide researchers or professionals with a useful conceptualization of what family members are experiencing.

Distress of Family Caregivers

High levels of distress seems to be a typical result of having a family member with a psychiatric illness, particularly schizophrenia. The level of distress family members are feeling can be measured using depression and anxiety scales. Distress affects overall well-being, including both physical and psychological health. Psychological well-being is a construct that will be measured in this study to reflect the level of distress in family member participants. Psychological well-being is a health-related quality of life measure that is a subjective, psychological dimension (Bech, 1993). It attempts to measure a global psychological concept attained by integrating the different axes of the DSM-IV. The resulting components that are generally measured by health-related quality of life scales are general health, emotional health, vegetative symptoms, autonomy, accomplishment and understanding (Bech, 1993).

Barrowclough, Tarrier and Johnston (1996) found that 55% of their sample of family

members may have been experiencing a psychiatric disorder and concluded that relatives of individuals with schizophrenia are “at risk” in terms of their mental health. The family members in this study were interviewed while their ill relative was being admitted to hospital during an acute episode of schizophrenia. Most of the family members with schizophrenia had experienced at least one previous episode of schizophrenia (65%) and the mean illness duration was around 6 years. That means about one third of the family members in the study were experiencing their family member having psychotic symptoms for the first time. Interestingly, Barrowclough et al.(1996) also found no significant difference in overall distress between high and low EE relatives or in relatives who could benefit from psychiatric help.

Winefield and Harvey (1993) found that caregivers of a relative with schizophrenia reported higher levels of psychological disturbance and emotionally related health problems than norms from similar populations. In fact 60.3 % of caregivers met the usual criterion for being considered a “case” having a psychiatric disorder. It was also indicated that the level of distress did not differ when the family member lived with their family or elsewhere. Notably, caregivers without adequate family support seemed to be an increased risk of psychological disturbance. A limitation of the study is that participants were self-selected (contrary to Barrowclough et al. (1996), discussed above) because the method used was mail out questionnaires. The majority of the respondents were female carers with sons with schizophrenia with a mean duration of illness of approximately 8 years. However, although there may be some limitations in the generalizability of this study, it seems that family members, more specifically woman caring for sons with schizophrenia, who are willing to take time to complete a mail-out questionnaire are experiencing higher levels of distress than

other comparable group.

Oldridge and Hughes (1992) investigated the psychological well-being of family members who were all living with the family member with schizophrenia. Their study showed a lower prevalence of psychological ill health than in previous studies, yet it was still twice the prevalence rate expected in the general population. However, the study claimed to be investigating the level of stress in carers of long-term schizophrenia sufferers, but family members were included where the duration of illness was only two years and the mean length of duration of illness is not reported. Also, there were only 25 family members who participated in the study. Although it is questionable whether the participants in this study were carers of long term schizophrenia sufferers and the sample size is small, the group of family members investigated had an increased prevalence of psychological ill health.

The results in the literature consistently show that family members of individuals with schizophrenia are at risk for increased distress compared to the general population, resulting in higher levels of psychological difficulties. The differences between Winefeld and Harvey's study and Barrowclough et al.'s study make comparisons more difficult as one study measures family member distress while their relative is acutely ill which can provide very different results than if the ill relative is stable, on medication and living in the community. However, it is clear from the results of these studies that family members of individuals with schizophrenia experience distress across situations and groups.

Research on specific symptomology and distress does not report consistent results. Gopinath and Chaturvedi (1992) found that behaviors related to activity and self-care were reported by family members to be more distressful than aggressive or psychotic behaviors.

Similarly, in Oldridge and Hughes (1992) study, family members reported more distress due to negative symptoms, such as passivity. Yet, Winefield and Harvey (1993) found that turbulent behavior (i.e. aggressiveness, recklessness and destructiveness and substance abuse) contributed significantly to the prediction of caregiver distress.

There are some differences between these studies that may account for the different findings. The majority of the patients in Gopinaths and Chaturvedi's study were female, whereas in Winefield and Harvey's study three quarters of the patients were males. As males in the general population are more apt to exhibit aggressive or turbulent behavior, it would not be surprising that male relatives with schizophrenia may cause more distress due to high levels of aggressive behavior compared to female relatives with schizophrenia. Yet, it is not clear whether family caregivers find the typical negative symptomology (i.e. apathy, flat affect, social withdrawal) or the positive symptomology (delusions, hallucinations, aggressiveness) more distressful.

It has been consistently reported that higher levels of burden and distress is reported by family members of women with schizophrenia compared to men with schizophrenia (Gopinath et al., 1992; Winefield et al., 1993). It is not clear why caring for a woman with schizophrenia is more distressing, but it may be related to different behavioral expectations due to the social roles of men and women.

There has not been consistency in results of research investigating the relationship between distress and specific symptomology. Although some methodological differences may account for the different results, further research would be necessary to support a consistent relationship between distress and either positive symptomology or negative symptomology.

There does seem to be a strong relationship showing higher distress and burden for family members caring for a female relative with schizophrenia as opposed to a male relative.

Distress and duration of illness have shown consistent results in the literature. In one study, distress was higher for younger family caregivers with more education (Gopinath et al., 1992). Perhaps professional and work commitments are a high priority for them and caring for a mentally ill relative proves to be more difficult for them. In another study, Gibbons, Horn, Powell and Gibbons (1984) found that caregiver distress was inversely related to duration of illness. According to their results, distress was higher among newer caregivers whose family member with schizophrenia has only experienced the illness for a short period of time, and are, usually, younger in age.

Higher distress among newer caregivers seems logical because they are experiencing a marked change in their family member's personality due to the symptoms of schizophrenia and changes in the roles and the responsibilities in the family structure. They also, presumably, have less education and knowledge about schizophrenia than those families who have been providing care to a mentally ill relative for years. Thus, their experience is novel and their ability to deal with difficult situations is really being challenged, resulting in high levels of distress.

Noh and Turner (1987) conducted a study investigating the relationship between chronic strain, as measured by burden, and psychological distress among family members of discharged psychiatric patients. All patients in the study had been diagnosed as functionally psychotic and they were between the ages of 18 and 65 at the time of discharge. Of those patients living with relatives, 211 family members consented to be interviewed. The family

members sample consisted of half (51%) male and half female, 77% of whom were spouses and 23% were parents of the patients. Upon examining the hospital records, it was clear that those family members who agreed to be interviewed had relatives who have had chronic mental health problems. Thus, generalizability of these results were restricted to similar families. Psychological distress, the dependent variable, was measured through the General Health Questionnaire. Subjective burden, objective burden, mastery, social support and stressful life events were the independent variables in a regression analysis. Subjective burden was measured by a shortened version of Pasamanick's (1967) "the patient as a problem" index. Objective burden was measured by using four subdimensions of the Personal Adjustment and Roll Skill Scale developed by Ellsworth (1975) and asking family members if there had been any disruptions to their work or school schedules due to their relative's illness. The regression analysis indicated that higher symptom levels in patients were associated with higher distress scores among family members. Subjective burden contributed significantly to the variability in GHQ scores, while objective burden did not. Mastery also significantly contributed to the level of psychological distress in family members, and when mastery was added to the regression, subjective burden was no longer a significant contributor. It was also found, particularly for family members of individuals with schizophrenia (n=90), that community tenure was a significant contributor to their psychological distress. That is, the longer the relative is maintained in the home, the greater the chance of elevated distress levels among family members. This may be the result of chronicity and the continual problems that accompany on-going mental health problems.

Platt and Hirsh found in 1981 (cited in Platt, 1985) that at a given level of objective

burden, family member distress varied considerably. Also, as indicated by Noh and Turner's (1987) research, factors other than burden seem to be better able to account for family member distress. It is questionable how useful burden is in determining the level of distress families are experiencing in relation to having a family member with schizophrenia. Thus, factors that may affect family members' level of distress (psychological well-being), such as burden, the overall experience of caregiving and duration of illness, need to be further understood because of the impact on the patient's illness and the general health of family members.

Summary

This section of the literature review has shown how family members can experience personal difficulties in adapting to and understanding their family member experiencing schizophrenia. The results of the research consistently show that family members of individuals with schizophrenia are at risk for increased distress compared to the general population, resulting in higher levels of psychological difficulties (Barrowclough, Tarrier and Johnston, 1996; Winefield and Harvey, 1993; Oldridge and Hughes, 1992). Although there are some methodological differences in some of the studies, the results are the same indicating higher levels of distress for family members of individuals with schizophrenia across situations and groups.

Research investigating the relationship between family member distress and specific characteristics of the patient has had varying degrees of consistency in the results (Gopinath and Chaturvedi 1992; Winefield and Harvey, 1993; Oldridge and Hughes, 1992). There has not been agreement among researchers investigating the relationship between distress and

specific symptomology. Although some methodological differences may account for the different results, further research would be necessary to forward a relationship between distress and either positive symptomology or negative symptomology. Another reason that there may be inconsistency of results in this research may be because the type of symptomology (i.e. positive or negative) may be arbitrary, rather the important factor may be the severity of the symptoms. There does seem to be a strong relationship showing higher distress and burden for family members caring for a female relative with schizophrenia as opposed to a male relative. Gender differences in this area can probably be explained by social differences in gender expectations and role theory.

Higher distress among newer caregivers is supported by the literature (Gopinath et al., 1992; Gibbons, Horn, Powell and Gibbons, 1984). This relationship may be explained by the marked change in the ill family member's personality due to the symptoms of schizophrenia and changes in the roles and the responsibilities in the family structure that family members are suddenly experiencing. Newer caregivers also, presumably, have less education, experience and knowledge about schizophrenia than those families who have been providing care to a mentally ill relative for years. Thus, their ability to deal with this type of novel, difficult situation is really being challenged, resulting in high levels of distress.

Burden does not seem to have a straight forward relationship with distress. It would seem to make sense that if a family is feeling a lot of burden, that they would also feel a lot of distress. However, Platt and Hirsh found in 1981 (cited in Platt, 1985) that at a given level of objective burden, family member distress varied considerably. So, it is questionable how useful burden is in determining the level of distress families are experiencing in relation to

having a family member with schizophrenia.

Conclusions

The literature has clearly indicated that families of individuals with schizophrenia face difficulties, not only in their personal adjustment (Spaniol, Zipple & Lockwood, 1992), but also in dealing with the mental health system and accessing services (Marsh, 1992). The importance of the quality of the family environment has been shown to have a strong impact on the well-being of individuals with schizophrenia, and more specifically on their relapse rate as evidenced in studies of expressed emotion. These studies directly point to a need to better support and educate families as part of the treatment and in the best interest of the patient.

However, some researchers are advocating for research that focuses solely on the well-being of the family for the sake of the family members themselves (Lefley and Johnson, 1990; Perring et al., 1990). Studies on 'family burden' and distress have attempted to increase researchers and professionals understanding of the experience of families. Unfortunately, consistent results have been rare to find. However, a strong association between higher burden and increased symptomology or behavioral disturbance has been well supported (Birchwood & Cochrane, 1990; Gubman, Tessler & Willis, 1987; Noh & Avison, 1988). Also, increased distress among newer caregivers has been consistently reported in the literature (Gopinath et al., 1992; Gibbons, Horn, Powell and Gibbons, 1984). However, many important relationships remain unclear, such as the relationship between burden measures and measures of distress (i.e. psychological well-being).

Burden, as an important measure in understanding the impact of schizophrenia on

families, has been criticized for many reasons (Szmukler et al., 1996; Gubman et al., 1987). The concept 'burden' tends to be negative and the scales overlook any possible positive aspects of families' experiences. Burden also lacks a well agreed upon theoretical model that would be useful in designing and testing the model empirically. Burden also tends to be limited for studies on families who are living with the ill family member.

Szmukler et al. (1996) addressed all these limitations of burden in the development of their new measure: The Experience of Caregiving Inventory (ECI). The ECI has some positive subscales, is based on a testable theoretical model and is appropriate for use with anyone who takes on a role as a caregiver.

It would be useful to compare a burden scale with a scale like the ECI in their ability to predict the variance of family members' scores on psychological well-being to determine if the ECI is actually any different or more useful than burden-oriented scales. A scale is only useful if it can serve as an indicator to help professionals understand the impact of a certain experience on a certain group. It would make sense that the more comprehensive the scale, the more indicative it is of the whole experience, rather than just a piece of the whole picture. Thus, it may be that the ECI is a better predictor of family psychological well-being than burden.

It would be interesting to further investigate the relationship between burden, distress and duration of illness. The relationships between burden and distress, and burden and duration of illness have shown mixed results so far. Understanding these relationships would greatly contribute to an understanding about what families go through when a relative is diagnosed with schizophrenia, and how their adjustment and understanding changes over time.

CHAPTER 3- DESIGN OF THE STUDY

The design of this study was a cross-sectional, correlational analysis that examined the effect of having a relative with schizophrenia on the psychological well-being of family members. In this chapter the procedures and method of the study are presented. This will include description of the participants, a description of the measures used, the procedure for recruitment of participants and the collection of the data, the procedures used to analyze the results and the limitations of the research.

Participants

The participants for this study were 30 individuals who met DSM-IV criteria for schizophrenia or schizo-affective disorder and 41 family members of individuals with schizophrenia. There were fewer individuals with schizophrenia than family members in the study because some of the individuals with schizophrenia had more than one family member who participated in the study.

Based on the limited literature in the area using scales like the ECI (Szumkler et al., 1996), one would expect a medium to large effect. Thus, to obtain this effect size with a power of .80, approximately 20 subjects are required (Cohen, 1988). Since the analysis is regression with three independent variables, 30 subjects would be the minimum requirement. Therefore, a sample size of 40 family members would be adequate to test the hypotheses.

Schizophrenia Participants (SP) Schizophrenia participants for the study were identified from the Schizophrenia Disorders Clinic at the Foothills Hospital or through family participation in the Schizophrenia Society of Calgary.

To be included in the study, individuals with schizophrenia met the following criteria:

- (i) They met the DSM-IV criteria for schizophrenia or schizo affective disorder.
- (ii) They were stable outpatients defined by having current living accommodations in the community and not having had an acute episode requiring hospitalization in the past 3 months.
- (iii) They were currently using psychiatric services within the city of Calgary.
- (iv) They were willing to have the researcher contact a family member.
- (v) They were over 18 and under 65 years of age.

The following demographic measures were collected from the individual with schizophrenia for descriptive purposes: age, gender, level of education, source of income, marital status, living arrangements, ethnicity, length of illness, number of hospitalizations, and age at 1st admission.

Age

The mean age of the schizophrenia participants was 29.63 years [$SD=10.35$] with a range of 18 to 53 years.

Gender

In the schizophrenia participant group 20 were males and 10 were females.

Level of Education

Of the schizophrenia participant group 10 had completed some post-secondary education, 3 had completed a college or university degree, 6 had a high school diploma, 9 had some high school, and 2 had completed some junior high school.

Source of Income

Of the schizophrenia participants 8 received AISH (Assured Income for the Severely Handicapped), 4 worked full-time, 6 worked part-time, 4 were unemployed, 3 received social assistance, 2 were students, 1 received disability benefits, 1 received employment insurance, and 1 was a homemaker.

Marital Status

In the schizophrenia participant group 24 were single, 3 were married, 2 were separated, and 1 was divorced.

Living Arrangements

Of the schizophrenia participant group 15 lived with parents, 5 lived with non-relatives, 1 lived with relatives, 3 lived with spouse, 3 lived in supportive accommodation, and 3 lived alone.

Ethnicity

Of the schizophrenia participant group 29 were Caucasian and 1 was Asian.

Length of Illness

The mean length of illness for the schizophrenia participants was 6.02 years [SD=7.89 years] with a range of 0 to 31 years.

Number of Hospitalizations

The mean number of hospitalizations for the schizophrenia participants was 5.33 admissions [SD=18.08] with a range of 0 to 30, with one outlier with over 30 hospitalizations. There were 9 participants who had never been hospitalized.

Age at First Diagnosis/Admission

The mean age at first admission or diagnosis for the schizophrenia participants was 23.50 [SD=7.41 years] with a range of 15 to 45 years of age.

Number of Months Since Last Admission

Of the 21 participants who have had admissions, the mean number of months since last admission was 35.81 [SD=50.85] with a range of 3 to 230 months.

Family Participants (FP) Family members were first degree relatives of the individual with schizophrenia. Family members were included in the study if they met the following criteria:

(i) They had a first degree relative who met the inclusion criteria listed above under schizophrenia participants.

(ii) They had, or attempted to have, regular contact with the family member with schizophrenia approximately once a month.

The following demographic measures were collected from the family members for descriptive purposes: age, gender, relationship to family member, level of education, source of income and marital status and ethnicity.

Age

The mean age of the family member participants was 51.29 years [$SD=9.59$ years] with a range of 26 to 81 years.

Gender

The family member participants in the study consisted of 26 females and 15 males.

Relationship to the Family Member with Schizophrenia

The family member group consisted of 23 mothers, 10 fathers, 2 brothers, 2 sisters, and 4 spouses of the individuals with schizophrenia.

Level of Education

In the family member group, 14 had attained a college/university degree, 4 had completed post-graduate work, 17 had completed some post-secondary education, 3 had a high school diploma, and 3 family members had completed some high school.

Source of Income

Of the family member group 19 maintained full-time employment, 7 were homemakers, 6 were self-employed, 4 worked part-time, 2 were unemployed, and 3 were retired and receiving a pension.

Marital Status

Of the family member group 33 were married, 4 were widowed, 2 were separated, 1 was divorced, and 1 was living common-law.

Ethnicity

There were 40 Caucasians and 1 Asian in the family member group.

Living Arrangements

22 of the family members were living with their family member with schizophrenia and 19 family members were not living with their family member with schizophrenia.

Measures

1. The Psychological General Well-being Schedule (Bech, 1993) was used to determine the level of stress/distress experienced by family members. This scale consists of 24 questions or statements and provides six possible responses, ranging from one extreme (i.e., everyday, all of the time) to the opposite extreme (i.e., none of the time, not at all). The respondent was asked to rate the statements or questions in relation to how they have felt during the past

month. The questions/statements vary from general to specific concerns about physical and psychological well-being. Each answer is rated from 0 to 5, with 0 indicating the highest level of psychological and/or physical health concern and 5 indicating no health concern. The scale has an overall total score, with lower scores indicative of poorer psychological well-being. Dupey (1978) also recommends the use of the following 6 subscales: Anxiety, Depression, Positive Well-Being, Self-Control, General Health and Vitality. This scale was used in the most influential study on health-related quality of life by Croog et al. in 1986 (Bech, 1993). It has been validated by comparing the total score with scales like the Beck Depression Inventory, the Zung Depression Scale and the Hopkins SCL-90 with correlation coefficients around 0.70. The internal consistency has been found to have a coefficient alpha of around 0.90 (Bech, 1993). This questionnaire took about 10 minutes to complete (see Appendix B).

2. The Experience of Caregiving Inventory (ECI) (Szmukler, Burgess, Herman, Benson, Colusa & Bloch, 1996) is a self-report measure that consists of ten subscales: eight negative (Difficult Behaviors; Negative Symptoms; Stigma; Problems with Services; Effects on the Family; the Need to Provide Back-up; Dependency; Loss) and two positive (Rewarding Personal Experiences; Good Aspects of the Relationship). There are 10 sub-scale scores and an overall negative scale score and an overall positive score. For the purposes of this study the overall negative and positive scale scores will be used for the primary analysis, and the subscales will be used only for exploratory analysis. The ECI has good internal consistency with Cronbach alphas ranging from 0.91-0.74. The construct validity of the ECI was verified by two different populations in its ability to predict scores on the General Health

Questionnaire, a finding that was a replication of earlier results (Szmukler et al., 1996). This questionnaire took 10 minutes to complete (see Appendix C).

3. The Family Concerns Questionnaire (FCQ) (Smith, Birchwood, Cochrane, & George, 1993) is a self-report measure that was used as a measure of the degree of burden family members are experiencing. It consists of 46 statements that the family member was asked to rate how descriptive they are of his/her experience on a scale of 1-5, with a 1 indicating 'has not been a concern' and 5 indicating 'always or almost always a concern'. The scale measures aspects of subjective family burden including a broad range of family hardships and consequences, such as worry, fear, tolerance, stigma, and impact on family life. The psychometric properties of the scale are well established (Schene et al., 1994). It was designed for use with first-degree relatives of individuals with schizophrenia and it takes about ten minutes to complete (Schene et al., 1994) (see Appendix C).

Procedures:

There were two routes for recruitment of participants.

1. The schizophrenia participants (SP) were recruited from outpatient programs on Unit 24 at the Foothills Hospital. Clinicians working in the outpatient clinics were asked to identify suitable individuals in their clinics and obtain their permission to give their name to the researcher. The researcher then contacted the person with schizophrenia (SP) who met the criteria for the study. The SP were informed of the nature and purpose of this study and invited to participate. Participation was on a volunteer basis. SP who agreed to participate

signed a consent form. The SP consented to 1) a review of their hospital chart, 2) provide contact information for a family member and 3) provide demographic information.

The researcher then contacted the family member(s). The family member(s) were informed of the nature and purpose of the study and invited to participate. Participation was on a voluntary basis. Family members were asked to sign a consent form prior to any procedures being conducted. Participation involved completing three self-report forms and providing demographic data which took approximately 60 minutes.

The researcher set up appointments to meet with the family members to obtain consent, collect demographic data and to complete the self-report questionnaires. The appointment took place either at the Foothills Hospital or in the participant's home at a time that was suitable to the family member(s).

2. The second route used to recruit participants was through the Schizophrenia Society of Alberta, Calgary Chapter. The Schizophrenia Society was informed of the nature and purpose of the study at one of their meetings. Interested family members and individuals with schizophrenia were invited to contact the researcher. Again, both the individual with schizophrenia and the family members went through the same consent procedures and methods as described above. Whoever contacted the researcher (family member or individual) had to provide permission to contact the other.

Verifying diagnosis from the chart was done by Dr. J. Addington by applying DSM-IV criteria from The Structured Clinical Interview (SCID-I) (Spitzer, Williams, Gibbon & First, 1990, 1992) to the chart. The SCID consists of a semi-structured interview used to make Axis

I and Axis II diagnoses. Dr. Addington has extensive experience in diagnosing individuals with schizophrenia.

Ethical Considerations

Individuals with schizophrenia in this study were outpatients recruited from the Foothills Hospital or volunteers from the Schizophrenia Society of Alberta. It was made clear to them that their participation in this study was voluntary and was not related to their treatment. Permission to invite participants to participate was obtained from their clinicians who only referred individuals who were appropriate for the study and whom they judged to be able to give informed consent. Individuals with schizophrenia had to agree to give their names to the researcher. They also provided permission to confirm their diagnosis through their chart and to contact their family member (see Appendix E for an example of the consent form).

Family members were contacted only with consent of their relative with schizophrenia. Likewise, if family members contacted us first, they gave permission to contact their family member with schizophrenia. A consent form was signed prior to any procedures being conducted (see Appendix F for an example of the consent form). All subjects were informed of their right to withdraw their participation at any time. Any questions asked by subjects were answered in full at the time of obtaining consent or prior to each part of the assessment. Subjects were invited to come to the hospital or the researcher met them at their homes to complete forms at a time that was convenient for them.

There were no immediate or long term risks to the participants. However, if they

experienced distress during the interview, it would have been terminated. This was not a problem for any of the participants.

Confidentiality was assured by assigning a code number to each subject at the time of his/her assessment. Forms and questionnaires were identified only by these code numbers. Only one list containing the names and code numbers of participants was maintained; it was kept in a locked file separate from the numbered data files. The data files were also stored in a locked filing cabinet. No identifiable record will be used for teaching or any other scientific purpose.

This study had ethical approval from the Joint Ethics Committee of the University of Calgary and the Foothills Hospital and the Ethics Committee of the Educational Psychology Department at the University of Calgary.

Data Analysis:

- 1) The variables were tested to determine if the assumptions of normality were met before any analyses were completed.
- 2) Correlational analysis was used to determine the direction and strength of the relationships among the variables. The first step was to determine the strength of the relationships between the dependent variable and the independent variables. Once this had been accomplished, the importance of each of these relationships was then determined with the use of multiple regression indices. The alpha level was set at $p < .05$.
- 3) Those variables that were significantly related to the psychological well-being of family members were entered into a standard multiple regression, which was then used to determine

which independent variables were the best predictors of psychological well-being. The alpha level was set at $p < .05$.

Limitations of the Research

Regression analyses reveal relationships between variables, but do not demonstrate causality (Tabacknick & Fidell, 1989). Any strong relationships between variables that are identified could result from any source, including the influence of variables not currently being measured. This weakness of a correlational study is often referred to as the third variable problem. “The third variable problem refers to the fact that two variables may be correlated not because they are causally related but because some third variable caused both of them” (Christensen, 1989, p. 84). Thus, this study will not be able to make conclusions about a causal relationship between having a relative with schizophrenia and how that impacts the family member(s)’ psychological well-being.

Another limitation involves the limited number of independent variables used to predict the dependent variable, the family member(s)’ psychological well-being. The family member(s)’ psychological well-being is obviously influenced by factors other than their experience caring for a relative who has schizophrenia. Some examples of other factors that might contribute to a family members’ psychological well-being could be other life events, their coping style or their support system. However, this study was solely interested in using only those variables directly related to the experience of having a relative with schizophrenia. There was no intent to account for a huge proportion of the variance in family member’s psychological well-being scores.

CHAPTER FOUR- RESULTS

In order to elucidate relationships between Psychological Well-Being , Burden, ECI negative, ECI positive, and Duration of Illness a correlational analysis was done using Pearson product moment correlations. Then Burden, ECI negative and Duration of Illness, as independent variables and the dependent variable, Psychological Well-Being, were entered into a standard multiple regression analysis to determine which variable was the best predictor. Hierarchical regression analyses were completed to delineate the unique contribution of Burden, Duration of Illness and ECI negative to Psychological Well-Being. A final set of correlational analyses were completed to determine associations between the subscales on both the Experience of Caregiving Inventory and The Psychological General Well-Being Scale with the other variables. (A significance level of .05 was used for all analyses.)

This chapter will be presented in five sections. The first briefly describes the sample. The second section provides descriptive statistics on the variables being tested. The third reports the results of the correlational analyses. The fourth overviews the results of the regression analyses. The last section is a summary of the overall findings of the results section.

Demographics

The family participants in this study consisted of 41 family members, 26 of which were female and 15 were male. The mean age of the family member participants was 51.29 years [SD=9.59 years] with a range of 26 to 81 years of age. The family members who participated

in the study were mothers (23), fathers (10), brothers (2), sisters (2) and spouses (4) of the individual with schizophrenia. Of the 41 family members 22 of them were living with their family member with schizophrenia when the data collection took place.

The family members all had a first degree relative who had been diagnosed with schizophrenia and was currently living in the community. The mean age of the group of individuals with schizophrenia was 29.63 years [$SD=10.35$] with a range of 18 to 53. There were 20 males and 10 females. The mean length of illness was 6.02 years [$SD=7.89$], the mean number of hospitalizations was 5.33 [$SD=18.08$], the mean age at first diagnosis or admission was 23.50 years [$SD=7.41$ years], and the mean number of months since last admission was 35.81 [$SD=51.85$].

Descriptive Statistics and Normality of the Distribution

The mean, standard deviation, skewness and kurtosis statistics for the independent and dependent variables are reported in Table 1. Because the standard deviations for the variables were high, the skewness and kurtosis values, histograms and stem and leaf plots were evaluated to check for normality of the distribution of the variables. When a distribution is normal the values of skewness and kurtosis are between 1 and -1. Most of the variables had high skewness and/or kurtosis statistics and the histograms and stem and leaf plots showed considerably skewed distributions.

Subsequently, the variables required transformation to fulfill the assumption of a normal distribution before the correlational and regression analyses could be completed on the data. The means, standard deviations, skewness and kurtosis statistics for the variables

after the transformations are reported in Table 2. The variables Burden, ECI negative, ECI positive and Duration of Illness were positively skewed and, thus, square root transformations were performed to improve the normality of the distribution. However, the variable Psychological Well-Being was negatively skewed so the transformation first consisted of taking the reflect, then calculating the square root of the data. To reflect a variable, a constant is created by adding 1 to the largest score in the distribution, then a new variable is created by subtracting each score from the constant (Tabachnick et al., 1989). In essence, the negatively skewed variable is simply converted to a positively skewed variable before transformation. All the variables, after transformation, have acceptable skewness and kurtosis statistics required to run the data analyses.

The means and standard deviations of the subscales of The Experience of Caregiving Inventory are as follows: Difficult Behaviors ($M=8.68$, $SD=6.29$), Negative Symptoms ($M=9.37$, $SD=5.84$), Stigma ($M=3.80$, $SD=3.59$), Problems with Services ($M=7.80$, $SD=6.18$), Effects on Family ($M=7.05$, $SD=6.16$), Backup ($M=8.78$, $SD=4.45$), Dependency ($M=7.20$, $SD=4.57$), Loss ($M=8.83$, $SD=4.91$), Positive Personal Experiences ($M=14.37$, $SD=6.13$) and Good Aspects of the Relationship ($M=13.02$, $SD=3.68$). The total possible scores for the subscales ranges from 20 to 32. The subscales Stigma, Effects on Family, Backup, and Problems with services all had skewness and/or kurtosis statistics over +1. Subsequently, these Subscales were transformed by taking the square root to normalize the distribution. After transformation, the means and standard deviations were: Stigma ($M=1.61$, $SD=1.11$), Effects on Family ($M=2.33$, $SD=1.28$), Backup ($M=2.84$, $SD=0.83$) and Problems with Services ($M=2.48$, $SD=1.30$).

Table 1 - Descriptive statistics

Variable	Mean	SD	Skewness		Kurtosis	
			Stat.	Std. Error	Stat.	Std. Error
Psychological Well-Being	79.34	16.84	-1.167	0.369	1.28	0.724
ECI- negative	61.51	30.19	0.972	0.369	0.864	0.724
ECI- positive	27.29	8.24	0.302	0.369	-0.897	0.724
Burden	68.95	42.56	0.983	0.369	0.369	0.724
Duration of Illness	6.02	7.87	1.531	0.369	1.547	0.724

Table 2 - Descriptive statistics after transformation

Variable	Mean	SD	Skewness		Kurtosis	
			Stat.	Std. Error	Stat.	Std Error
Psychological Well-Being	5.02	1.57	0.268	0.369	0.451	0.724
ECI-negative	7.62	1.87	0.4	0.369	-0.15	0.724
ECI- Positive	5.17	0.79	0.064	0.369	-0.957	0.724
Burden	7.93	2.5	0.403	0.369	-0.462	0.724
Duration of Illness	1.97	1.48	0.868	0.369	-0.415	0.724

The means and standard deviations for the subscales of the Psychological General Well-being Schedule were: Anxiety ($M=16.95$, $SD=4.84$), Depression ($M=12.17$, $SD=2.46$), Positive Well-being ($M=12.73$, $SD=3.65$), Self Control ($M=12.61$, $SD=2.76$), General Health ($M=11.05$, $SD=2.70$) and Vitality ($M=13.15$, $SD=3.41$). The total possible scores on the subscales ranged from 15 to 25 with lower scores indicating poorer levels of well-being in that area.

Correlational Analysis

A correlational matrix of the variables is presented in Table 3. The correlations were one tailed tests because the hypotheses for these relationships were directional and there was strong, consistent support in the literature for the direction of these relationships (Gibbons, Horn, Powell and Gibbons, 1984; Gopinath et al., 1992; Hoenig & Hamilton, 1966 & 1969). There was a strong positive correlation between Burden and ECI negative ($r=0.72$, $p<.01$). ECI negative is negatively correlated with Psychological Well-Being ($r=-0.47$, $p<.01$). Higher scores on the negative scale of the Experience of Caregiving Inventory is associated with poorer scores on the Psychological General Well-Being Scale. Burden is also negatively correlated with Psychological Well-Being ($r=-0.32$, $p<.05$). Duration of Illness is significantly correlated with Psychological Well-Being ($r=0.30$, $p<.05$). ECI positive is not significantly correlated with any other variables.

Correlations between The Experience of Caregiving Inventory negative scale subscales and Psychological Well-Being, Duration of Illness and Burden are presented in Table 4. The Experience of Caregiving positive scale subscales were not included because

Table 3 - Correlation matrix

	Burden	Duration of Illness	ECI Negative	ECI Positive	Psych. Well-being
Burden	1	-	-	-	-
Duration of Illness	0.076	1	-	-	-
ECI-Negative	0.723**	-0.067	1	-	-
ECI- Positive	0.126	0.153	0.256	1	-
Psychological Well-being	-0.321*	0.298*	-0.467**	-0.013	1

*p<0.05, **p<0.01, ***p<0.001

none of the variables were correlated with them.

Psychological Well-Being is negatively correlated with Stigma ($r=-0.49$, $p<.01$), Problems with Family ($r=-0.45$, $p<.01$), Dependency ($r=-0.46$, $p<.01$), Loss ($r=-0.32$, $p<.05$) and Difficult Behaviors ($r=-0.43$, $p<.01$). That is, higher scores on the negative subscales indicate poorer psychological well-being. Psychological Well-Being is not significantly correlated with Negative Symptoms, Providing Backup or Problems with Services.

Burden is positively correlated with Stigma ($r=0.51$, $p<.01$), Problems with Family ($r=0.56$, $p<.01$), Dependency ($r=0.52$, $p<.01$), Loss ($r=0.49$, $p<.01$), Difficult Behaviors ($r=0.60$, $p<.01$), Negative Symptoms ($r=0.44$, $p<.01$) and Providing Backup ($r=0.64$, $p<.01$). The only negative subscale Burden is not correlated with is Problems with services.

Duration of Illness is not correlated with any of the subscales of The Experience of Caregiving Inventory negative scale.

Correlations were also conducted to ascertain the relationships between the subscales of the Psychological General Well-Being Schedule and Duration of Illness, Burden, and ECI negative and ECI positive. The results are presented in Table 5.

ECI negative is significantly correlated with the subscales Anxiety ($r=-0.47$, $p<.01$), Positive Well-Being ($r=-0.52$, $p<.01$), General Health ($r=-0.34$, $p<.05$), Depression ($r=-0.44$, $p<.01$), and Self-Control ($r=-0.53$, $p<.01$). The only one it is not correlated with is the Vitality subscale.

Duration of Illness is positively correlated with the Anxiety subscale ($r=.418$, $p<.01$) and the Vitality subscale ($r=.320$, $p<.05$). Burden is only significantly correlated with the Self Control subscale ($r=-.413$, $p<.01$). ECI positive is not correlated with any of the subscales of

Table 4 - Correlations between the Negative Subscales of The Experience of Caregiving Inventory and Psychological Well-Being, Duration of Illness and Burden

Negative subscales of the ECI	Psychological Well-Being	Duration of Illness	Burden
Stigma	-0.49**	-0.06	0.51**
Problems with Family	-0.45**	-0.12	0.56**
Dependency	-0.46**	-0.04	0.52**
Loss	-0.32**	-0.07	0.49**
Difficult Behaviors	-0.43**	0.11	0.60**
Negative Symptoms	-0.18	-0.04	0.44**
Providing Backup	-0.18	-0.10	0.64**
Problems with Services	-0.15	0.01	0.28

*p<.05, **p<0.01, ***p<0.001

the Psychological General Well-Being Schedule.

Regression Analyses

A standard regression was performed with Psychological Well-Being as the dependent variable and Burden, Duration of Illness and ECI negative entered as independent variables. ECI positive was not included in the regression because it did not correlate with Psychological Well-Being. Three hierarchical regression analyses were also performed to help determine the importance of each of the independent variables used in the standard regression model. The results of all regression analyses are presented in Table 6.

The results of the standard regression model indicated that Burden, Duration of Illness, and ECI negative together account for 29% of the variance in psychological well-being scores. However, the results indicated that ECI negative is the only variable that contributes significantly to the equation ($t=2.094$, $p<.05$).

Because of the high correlation between Burden and ECI negative, a hierarchical regression was performed. A hierarchical regression helped to delineate whether ECI negative was the best predictor of Psychological Well-Being or if its effect was diminishing the actual effect of Burden. Burden is correlated with Psychological Well-Being, but it did not contribute significantly to the standard regression model. Thus, two hierarchical regressions were completed using only the variables of Burden and ECI negative. A third regression analysis was performed to determine the importance of Duration of Illness after ECI negative and Burden were entered.

In the first hierarchical regression, Burden was entered first, then the effect of ECI

Table 5 - Correlations between the Subscales of the Psychological Well-Being Schedule and Burden, Duration of Illness, ECI negative and ECI positive

Psychological Well-Being Subscales	Burden	Duration of Illness	ECI-negative	ECI-positive
Anxiety (Free)	-0.27	0.42**	-0.47**	0.02
Depression (Free)	-0.29	0.30	-0.44**	-0.02
Self-control	-0.41**	0.20	-0.53**	-.014
Positive Well-being	-0.30	0.28	-0.52**	0.01
General Health	-0.13	0.17	-0.34*	-0.10
Vitality	-0.28	0.32*	-0.23	0.18

*p<0.05, **p<0.01, ***p<0.001

negative was added. Burden's unique and shared variance accounted for 10% of the variance in Psychological Well-Being and ECI negative still accounted for 12% of the variance in Psychological Well-Being scores above that already accounted for by Burden. Burden was not a significant predictor while ECI negative's contribution was significant ($t=2.372$, $p<.05$).

In the next hierarchical regression analysis ECI negative was entered first and the effect of Burden was added after. ECI negative's unique and shared variance accounted for almost 22% of the variance, whereas Burden added only one tenth of one percent when added into the model. The contribution of ECI negative is significant ($t=2.372$, $p<.05$). Burden did not contribute significantly on top of what was already contributed by ECI negative.

In the final hierarchical regression analysis, ECI negative was entered first followed by Burden and then Duration of Illness. After ECI negative and Burden were entered, accounting for 22% of the variance, Duration of Illness accounted for 7% of the variance in Psychological Well-Being scores.

Summary

The independent and dependent variables were assessed for assumptions of normality. It was found that all the variables had high scores on either the skewness or kurtosis statistic or both. Stem and leaf plots and histograms both indicated that the distributions were significantly skewed. Subsequently, transformations were completed on all the variables, using square root transformations for positively skewed distributions and reflect and square root transformations for negatively skewed distributions.

Relationships between Psychological Well-Being, Burden, Duration of Illness, ECI

Table 6 - Prediction of Psychological Well-Being.

Model	R	R ²	Beta	t	Sig t
Standard Regression					
Burden	-	-	.036	0.178	.860
Duration of Illness	-	-	-.273	-1.93	.061
ECI- negative	0.54	0.29	.422	2.07	.045*
Hierarchical Regression					
1. Burden	.321	.103	-.035	-.167	.868
2. ECI-negative	.468	.219	.492	2.372	.023*
1. ECI-negative	.467	.218	.492	2.372	.023*
2. Burden	.468	.219	-.035	-.167	.868
1. ECI-negative	.467	.218	.422	2.075	.045*
2. Burden	.468	.219	.036	.178	.860
3. Duration of Illness	.539	.290	-.273	-1.933	.061

*p<0.05, **p<0.01, ***p<0.001

negative and ECI positive were examined through Pearson product moment correlations and regression analyses. Three of the variables, ECI negative, Burden and Duration of Illness were able to predict a significant amount of variation in the dependent variable, Psychological Well-Being. Together, these variables accounted for 29% of the variance in Psychological Well-Being scores.

In support of the primary hypothesis, ECI negative was the best predictor of Psychological Well-Being. Its unique and shared variance accounted for 22% of the variation in Psychological Well-Being scores. However, contrary to the primary hypothesis ECI positive was not a significant predictor of Psychological Well-Being. It was not included in the regression model because it was not significantly correlated with Psychological Well-Being.

Results of the Pearson correlations suggest that ECI negative was significantly related to Burden. It was also indicated that there were significant relationships between Burden and Psychological Well-Being and ECI negative and Psychological Well-Being. There was also a small, but significant relationship between Duration of Illness and Psychological Well-Being.

Thus, there was support for the secondary hypothesis that there would be a positive relationship between Duration of Illness and Psychological Well-Being. This relationship, albeit weak, indicates that higher distress levels is associated with a shorter length of illness. The other secondary hypothesis, that Burden would be positively related to Duration of Illness, was not supported by the results.

The results of the correlational analyses of the subscales and the major variables indicated that Psychological Well-Being was related to most of the negative subscales of The

Experience of Caregiving Inventory. Burden was also related to most of The Experience of Caregiving Inventory negative subscales. However, when Burden was tested for relationships with the subscales of the Psychological General Well-Being Schedule it was only related to one subscale. ECI negative was related to five out the six subscales of the Psychological General Well-Being Schedule. So, although Burden and ECI negative are highly correlated, they seem to be measuring something uniquely different from each other. Duration of Illness was correlated with two out of six subscales of the Psychological General Well-Being Schedule, supporting a weak relationship between the two variables.

CHAPTER FIVE

CONCLUSIONS AND DISCUSSION

This study was designed to address the lack of consistency in the literature concerned with the impact of having a relative with schizophrenia and the resulting effect on the psychological well-being of family members. Forty-one family members of individuals with schizophrenia were recruited to study the impact that caring for a mentally ill relative has on family members' level of distress. The psychological well-being (or distress) of family members was measured by a self-report scale, The Psychological General Well-Being Schedule. Then, a number of variables were tested to determine which one best accounts for the distress caused by the impact of having a family member with schizophrenia.

The primary hypothesis predicted that the experience of caregiving as assessed by the positive and negative scales of the Experience of Caregiving Inventory (ECI), a newer measure, would be the best predictor of family member distress (measured by the Psychological Well-Being Schedule) due to the impact of caring for a mentally ill relative. Correlations between all the variables: Psychological Well-Being, Burden, ECI negative, ECI positive and Duration of the Illness were investigated to further delineate the relationships between them, thus providing an increased understanding of the impact on family members. Specifically of interest were the relationships between Duration of Illness and Burden, and Duration of Illness and Psychological Well-Being.

Secondary hypotheses predicted that there would be a positive relationship between Burden and Duration of Illness, and that there would be a positive relationship between

Duration of Illness and Psychological Well-Being (lower scores on the Psychological Well-Being Schedule indicating poorer psychological well-being).

Whereas past research has largely focused on families because of their influence or impact on the family member with schizophrenia, this study aimed to focus on family members because of their ill family member's impact on them. Even in 'family burden' or 'family distress' studies, the underlying goal has usually been to understand the family better for the well-being of the patient, rather than for the sake of the family members. It has often been the case, as Lefley and Johnson (1990) pointed out, that families of a person with schizophrenia have at times been seen as part of the patient's problem and at times part of the course of treatment, but it has been a rare occasion that their own psychological needs have been given central consideration.

It was not the intent of this study to account for the total psychological well-being of family members. Instead, the purpose of the study was to determine how much of an impact caring for a relative with schizophrenia has on family members' psychological well-being.

The intent of this chapter is to discuss the results of this study with respect to existing theory and research. The Chapter is divided into five sections. First, the findings of the study will be reviewed and discussed. The second section will discuss the findings of the study in relation to relevant research. The third section will address the conclusions of the study followed by a discussion of the limitations of the study, the fourth section. Finally, the fifth section will provide recommendations for future research and the clinical applications of the conclusions.

The Findings of the Study

The independent variables used in the regression analyses (Burden, Duration of Illness and ECI negative), together accounted for a significant amount of the variance in psychological well-being scores of family members of individuals with schizophrenia. Furthermore, ECI negative was the only predictor that contributed significantly to the model. Hierarchical regression further supported the importance of the negative scale scores on ECI as the best predictor of Psychological Well-Being. The contribution of Burden was found to be redundant with that already contributed by ECI negative. Because Burden and ECI negative are correlated, it is not surprising that there is an overlap between these two variables in their ability to account for the variance in Psychological Well-Being of family members. However, ECI negative was able to account for substantially more variance than Burden.

Thus, the primary hypothesis that The Experience of Caregiving Inventory would be the best predictor of Psychological Well-Being was partially supported. ECI positive, contrary to the hypothesis, was not correlated with Psychological Well-Being, and therefore was not included in the regression model. A variable that is not correlated with the dependent variable will not usually contribute to the model and may, instead, decrease the strength of the model. Thus, the positive experiences of family members, related to caring for a relative with schizophrenia, as measured by the Experience of Caregiving Inventory positive scale, do not seem to be related to better levels of general psychological well-being. This result is surprising, because assessing the positive aspects of the relationship was forwarded as an benefit of using the ECI as opposed to burden scales.

One of the secondary hypotheses predicted that there would be a positive relationship

between Duration of Illness and Psychological Well-Being. This was supported through a weak correlation using a one-tailed test. There seems to be a trend towards a higher risk of distress for family members of individuals experiencing their first onset of schizophrenia. It seems quite reasonable to expect that family members who have been dealing with a relative with schizophrenia for a longer period would become accustomed to the experience and possibly more accepting of it and, subsequently, have lower levels of distress.

The other secondary hypothesis predicted that there would be a positive relationship between Burden and Duration of Illness. A relationship between these two variables was not supported. Burden felt by family members does not seem to increase the longer the relative with schizophrenia is ill. Perhaps family members become familiar with the experience and it is assimilated into their lives as a normal aspect of their family.

Also, there was a highly significant relationship between Burden and ECI negative. It is not surprising that these two scales are related as they are measuring similar aspects of the same situation. However, as indicated by the regression analyses and the correlations of the subscales, these scales are measuring some aspects of the situation that are different from each other.

Further correlations using the subscales of the Psychological Well-Being Schedule and The Experience of Caregiving Inventory (ECI) were conducted as exploratory analysis. The correlations between the subscales of the ECI and the other variables showed that Psychological Well-Being was significantly related to five of the eight negative subscales. The psychological well-being of family members seems to be responsive to issues about stigma, problems with family, dependency, loss and difficult behaviors. Families seem less distressed

about negative symptoms, providing backup and problems with services. It may be that the subscales that are related to Psychological Well-Being are measuring aspects of the situation that have changed. Before the onset of schizophrenia, family members may not have had to think about these issues as much (i.e., stigma, dependency, loss). The subscales that are not related to Psychological Well-Being may be aspects of the situation that family members are familiar with or used to fulfilling (i.e., providing backup) or completely novel experiences (i.e., problems with services).

Burden was significantly related to seven of the eight negative subscales. It seems that these two measures have some general similarities, which is not astounding as they both are attempting to assess the negative aspects of the situation.

Duration of Illness was not related to any of the subscales, which further supports no relationship between Duration of Illness and ECI or Burden. It suggests that the experience of caregiving or level of burden does not seem to vary or change over time. However, because this study was cross-sectional rather than longitudinal and the sample may not have been fully representative of family members of individuals with schizophrenia, it is difficult to make statements about this result.

ECI positive was not related to any of the variables. It is unclear why scores on the positive scale would not have a positive effect on the psychological well-being of family members. Also, it is questionable as to why the positive aspects of the relationship do not seem to increase over time as all family members make adjustments or adapt to the fact that their relative has a serious mental illness. It may be, in part, due to the lack of attention given to the positive aspects of the situation in the past. Mental health workers, in the past, may not

have made a conscious effort to use the positive factors in the situation to facilitate family member well-being and the development of a more positive relationship with their ill relative.

The correlations between the subscales of the Psychological General Well-Being Schedule indicated that ECI negative was related to five of the six subscales. Whereas Burden was only related to one of the six subscales, supporting a unique difference between the two scales. The redundancy of Burden's contribution to the regression model is quite clear from these correlations, as the only subscale it is related to, the Self-Control subscale, is also related to ECI negative. Duration of Illness was related to two of the six subscales supporting a weak correlation between Duration of Illness and Psychological Well-Being. Duration of Illness was related to the only subscale that ECI negative was not related to, the Vitality subscale. Thus, the unique contribution of Duration of Illness seems to be a result of the unique relationship it has with the degree of vitality that family members experience. Again, ECI positive was not related to any of the subscales.

Comparison of Findings with Previous Research

The finding that scores on the ECI negative scale accounts for about 22% of the variance in Psychological Well-Being scores of family members of individuals with schizophrenia is consistent with Smukler et al.'s (1996) results. The ECI negative scale scores accounted for 24% of the variance in the General Health Questionnaire (GHQ) scores for the survey group (n=359) in Smuckler et al's study, which is very similar to the results of this study. The GHQ is comparable to the measure used in this study, The Psychological General Well-Being Schedule, as it assesses similar symptoms such as anxiety, depression and somatic

concerns. In Smuckler et al.'s clinic group (n=63) the variance accounted for was 39% which is quite a bit higher than the results in this study. However, the clinic group was made up of family members of individuals with schizophrenia who had been discharged from hospital just six weeks prior. This study only included family members whose relative had been out of hospital at least three months prior to the study. Thus, the family members in the clinic group of Smuckler et al.'s (1996) study may have been more stressed due to the recent hospitalization of their relative. This would account for higher GHQ scores and a higher percentage of those scores being accounted for by the ECI- negative scale.

Contrary to the primary hypothesis, the ECI positive scale scores did not contribute to the family member's Psychological Well-Being scores. However, this result is similar to Smuckler et al.'s (1996) results. Smuckler et al. explain their result as a response to the bias of psychiatric research in, historically, focusing on the negative aspects of functioning and a lack of scales or measures that determine key factors of positive functioning. While Smuckler et al.'s point is well taken, it also makes sense to predict that positive aspects of an experience should contribute to an overall general feeling about the experience. Thus, the positive subscale of The Experience of Caregiving Inventory does not seem to be reflective of healthier levels of well-being in family members. It may be that, although the ECI's positive subscale is not as useful as a separate measure, questioning family members about positive aspects may contribute to increased openness about the negative aspects of their experience. They may feel less guilt complaining about the negative aspects of the situation when they are answering questions about the positive aspects. Subsequently, the positive scale may be useful by contributing to the validity of the participants scores on the negative scale. Another

explanation may be that the positive scale is not powerful enough to indicate what effect positive experiences in the situation is having on the family members. Also, it may be that the effect, due to positive experiences, on the family member is not being measured on scales like the GHQ or the Psychological General Well-Being Schedule.

Burden was not found to be a significant predictor of family members' psychological well-being scores when ECI's negative scale scores was entered into the model. This is consistent with other studies, in that other variables seem to be more powerful than Burden in a regression model. In Noh and Turner's (1987) study, subjective burden contributed significantly to psychological distress scores, but it did not remain significant after mastery was entered into the model. It seems that burden does account for some of the variation in psychological distress of family members. However, other measures, such as mastery or ECI negative, seem to be able to incorporate the effect of burden and contribute even more to understanding the impact of caring for a relative with schizophrenia.

Although, the ECI's negative scale scores were the best predictor of Psychological Well-Being scores of family members, Duration of Illness was able to account for another 7% of the variance. This is, in part, consistent with Noh and Turner's (1987) finding that community tenure significantly contributed to a model predicting psychological distress. Community tenure is defined as the length of time the relative with schizophrenia has lived in the community since last discharge. Noh and Turner's (1987) study found that the longer the relative with schizophrenia was maintained in the community, the higher the chance of increased distress for the family. In contrast to their finding, the current study found increased distress for family members whose relative had been ill a shorter period of time. Although

duration of illness and community tenure are obviously not identical measurements, their commonality, time, seems to be an important variable to investigate in relation to the psychological well-being of family members of individuals with schizophrenia.

The relationship between number of years the family member has been ill and psychological well-being of family members found in this study is consistent with the results of other studies (Gopinath et al., 1992; Gibbons et al., 1984). These studies found higher levels of distress among newer caregivers. These results indicate that the family members of an individual experiencing a first acute episode of schizophrenia, are experiencing higher levels of distress than family members who have been through it before. Family members of first episode patients are facing a novel life event, and the changes in behavior and personality of their relative, due to schizophrenia, may be extremely fear provoking and stigmatizing. Families who have been through the experience before have had a few years to deal with it, become educated, experienced about what to expect, and possibly more accepting of it.

The variable, Duration of Illness, may have been affected by the distribution of the sample in this study. About one half of the family members in this study had a relative whose onset of schizophrenia was between 0 months and 12 months and the other half of the sample had a relative who has experienced schizophrenia for 2 years or more. However, this distribution is quite similar to that of Gopinath and Chaturvedi's (1992) sample. Gibbons et al.'s (1984) sample consisted of more long term families than short term families yet their results are consistent with both the results of this study and Gopinath and Chaturvedi's (1992). Interestingly, Gibbons et al. (1984) also found that regardless of the length of illness, that family distress levels increased when their relative with schizophrenia met the criteria to be

considered 'psychotic'. Although there is support for a higher risk of distress for family members with a shorter duration of illness, all family members may be more at risk when the ill family member is acutely ill or psychotic.

The secondary hypothesis that higher levels of Burden would be related to a longer Duration of Illness was not supported by the results of this study. There was no relationship between these two variables which is inconsistent with both Hoenig and Hamilton's (1966, 1969) and Bulger et al.'s (1993) results. Hoenig and Hamilton found a positive relationship between burden and duration of illness, whereas Bulger et al. found a negative relationship between these two variables. The implications of the results of this study would be that burden does not change over time for families. This would mean that families whose relative has endured having schizophrenia for a long period of time would feel just as much burden as families whose relative is experiencing their first onset of schizophrenia. It may be that this study did not have a large enough sample size to assess the change in burden over time and the sample may not have adequately represented a range of families in terms of length of illness.

The exploratory correlations resulted in some interesting considerations. Burden was related to the Self-Control subscale on the Psychological General Well-Being Schedule. The less self-control family members feel, the more burden they report. This is similar to the relationship commonly found in the literature between mastery, a measure of the degree of control an individual feels they have to deal with stressful situations, and burden (Noh & Turner, 1987; Noh & Avison, 1988; Smuckler et al., 1996).

The relationship between distress and specific symptomology has been inconsistent

in the literature, some studies reporting a relationship between distress and negative symptoms (Gopinath et al., 1993) while others reporting a relationship between distress and positive symptoms (Winefield & Harvey, 1993). The correlations in this study suggest that there may be a relationship between distress, as measured by Psychological Well-Being, and difficult behaviors as opposed to negative symptoms. Although, the negative symptoms, such as inactivity and lack of self care, may be frustrating for family members, overall they may be easier to deal with than difficult behaviors, such as recklessness and aggressiveness. It should be noted though that the level of symptoms of the ill family member were not objectively assessed, rather the level of symptoms were based solely on the perceptions of family members.

Also interesting to note are the relationships between Duration of Illness and two of the subscales of the Psychological General Well-Being Schedule, anxiety and vitality. As they are both positive relationships, the shorter the duration of illness the more anxiety family members feel. It makes sense that family members may be more anxious when their relative is first experiencing the symptoms of schizophrenia because it is new to them and they are not sure what to expect. Feelings of vitality are lower for family members whose relatives are first experiencing schizophrenia. This finding also seems logical if family members are experiencing more distress, and specifically anxiety, when their relative has been recently diagnosed with schizophrenia, it follows that they may also feel less overall energy and enthusiasm in their day to day functioning.

The Experience of Caregiving Inventory's negative scale scores were related to five out of six of the subscales of the Psychological General Well-Being Schedule. This finding

further supports the scales's ability to be a good predictor of psychological distress. It also suggests that this scale is a comprehensive measure of the impact caring for a relative with schizophrenia has on family members. As Burden was only related to one of these subscales, in comparison The Experience of Caregiving Inventory's negative scale may be a more sensitive measure as evidenced by an ability to extract useful information about the experience of families in this situation. It also indicates that, although the Burden and ECI scales are related, they are different in their ability to predict psychological distress.

Conclusions of the Study

It can be concluded from this study that having a family member with schizophrenia impacts on the psychological well-being of family members. The impact on family members is better measured by The Experience of Caregiving Inventory rather than the burden scale used, The Family Distress Scale. Thus, having a family member with schizophrenia can contribute to family members experiencing psychological or health related problems. The stress of having a family member with a potentially chronic and disabling illness, like schizophrenia, can, potentially impede the functioning of other family members.

Furthermore, the results also indicate a higher risk of psychological or physical health concerns for family members of individuals experiencing their first episode of schizophrenia. Families in this situation may feel completely unsure of what to do and what they are dealing with. They are facing a situation where they may be aware of the stigma and stereotypes associated with an illness like schizophrenia, with very little knowledge to counteract these beliefs and fears. It is critical that the family members are educated about what is happening

to their relative and are provided support and appropriate interventions from the beginning.

The results of this study do not support an increase in burden perceived by family members the longer their relative is ill. It would seem that there is no increase or decrease in levels of burden family members are experiencing over time. It may be that the perception of burden, as a subjective phenomenon, is constant and does not vary over time. That is, if family members find the experience of having a family member with schizophrenia as burdensome at the onset, they will continue to find it just as burdensome in the long run. Also, if family members do not perceive it to be burdensome initially, as years go by their perceived burden will not increase. Studies investigating this relationship have either found an increase in burden over time (Hoenig & Hamilton, 1966;1969) or a decrease in burden over time (Bulger et al, 1993). However, comparisons between studies are difficult due to the inconsistency in the measures and conceptualization of burden.

Finally, the relationship found between Burden and ECI negative is not surprising as the focus of both these scales is on the negative aspects of the situation. However, Burden seems to be only assessing a part of what ECI negative is measuring. The burden scale used is focused on the behavior of the ill relative and the ECI focuses on how much the family member is thinking about a certain issue. This difference may be the reason that the ECI is better able to draw on the distress family members are feeling. The behavioral aspects addressed on the burden scale seem more like objective measures and may not motivate family members to really assess how they feel and think about it.

Limitations of the Study

There are several limitations of this study. Due to the sample size (n=41) there were some limitations to the variables that could be investigated, such as differences in family members' experiences associated with their relationship to the ill family member and gender differences, both concerning the gender of the ill family member and the gender of the family member themselves.

Although many studies aim to identify and use only "primary caregivers", the intent of this study was to investigate the psychological well-being of all family members (mother, father, sister, brother, or spouse) who have had regular contact and involvement with the ill family member. It would be interesting to understand the experience of non-primary family caregivers to discern how they perceive their role or relationship with their relative. Different family members are going to deal with the situation in very unique ways. The fact that there usually is a 'primary caregiver', as forwarded by other studies, supports the notion that the caregiving is not being evenly distributed between family members and it would be interesting to investigate why this is happening. Even though certain family members may not be considered primary caregivers, they are also impacted or affected by the illness. However, due to the sample size this study was not able to address any possible differences due to the type of relationship (parent, sibling, spouse), but instead investigated all family members as one group.

The use of self-report questionnaires may also have its limitations. There are possible advantages of self-report questionnaires such as, low risk of interviewer bias and increased honesty of the participant. However, self-report questionnaires limit the depth of the questions

and answers. Also, the questions, although standardized, cannot ask for clarification or probe into a specific area and, ultimately, they may not address some important, relevant information. Also, the commitment required of the participant is low, which may result in participants not taking the measure seriously or they may strive to provide the results/answers that they think the researcher is looking for (Christensen, 1991). However, these limitations are minimized by the use of questionnaires with good construct validity and validity checks embedded in the questions that helps guard against subject error.

It was not possible to randomly select participants for this study, because the participants, not only had to meet certain inclusion/exclusion criteria, but also had to be willing to participate voluntarily. Consequently, the participants who were selected for this study were selected on the basis of whether they volunteered and whether they met certain criteria. Because of this restriction there may be some built-in-bias in the data (Christensen, 1991). Family members who were willing to volunteer time for the study may be families that are more supportive and involved with their family member with schizophrenia. Family members who are not as involved and willing to help may have answered the questionnaires very differently from those who participated. On the other hand, family members who are not involved in the treatment of their relative or have not accessed services for themselves, may have not experienced considerable distress. They may have had an easier time dealing with schizophrenia and continuing with their lives. Thus, the generalizability of the results of this study is limited to family members who are actively involved in helping and supporting their family member or those who have accessed services to deal with schizophrenia.

Suggestions for Further Research and Clinical Implications

Further research may be better directed by the use of a more comprehensive scale and perhaps more sensitive scale, such as the ECI, to develop a better understanding of the impact caring for an individual with schizophrenia has on families. It is not to say that burden is not a useful conceptualization, as it does seem to assess some of the same aspects the ECI measures as indicated by their high correlation. However, it is lacking in its theoretical foundation. Burden is limited in its power to explain the experience of families as a whole due to its narrow conceptualization. This does not mean that the ECI fully explains the experience of families, but that it is more effective than burden because it encompasses a larger conceptual framework of the experience. To further validate and improve the usefulness of the ECI, more research should be done involving the positive scale to delineate the role of positive experiences for family members and how these experiences relate to caregiving.

Further research would also highly benefit from the use of qualitative measures, such as semi-structured interviews or focus groups, to contribute to a more in depth, fuller understanding of the experience of families. Although useful and practical for research and clinical use, quantitative measures of any human experience is bound to fall short of the actual experiences of people. If future research is going to continue to acknowledge that the experience of families caring for a relative with schizophrenia is important in its own respect, then more qualitative studies are necessary. Qualitative research would be able to address specific, in-depth details about what is involved in caregiving, differences in coping styles between family members, gender differences, cultural differences, and the emotional and psychological impact on family members.

Research investigating the changes families go through over time in response to the impact of having a relative with schizophrenia, would benefit from a longitudinal study. A longitudinal study would provide a comprehensive understanding of how the coping and response styles of a family change over time from their relative's first onset to periods of recovery and through possible relapses. Because the nature of a mental illness, like schizophrenia, involves periods of wellness, variability in prognosis, and acute episodes, families will respond very differently to the same questions at different times. Although, cross-sectional studies, such as this one, attempted to recruit families of individuals with schizophrenia that are at a similar level of functioning, due to the individual variability in the manifestation of this illness, it is impossible to assume that families are dealing with the same situation at the same time. Thus, a longitudinal, qualitative study would be an ideal way to understand how families are impacted by their relative and how families change and adapt over time.

For clinical use, it seems that the ECI may be a better choice than a burden scale if the clinician is interested in using a quantitative measure to assess the impact on family members of caring for an individual with schizophrenia. The ECI acknowledges the positive aspects of the experience, providing the clinician with the opportunity to use the positive aspects that family members indicate on the scale, to build on the strengths and positives of the family and the situation. The ECI also provides clear subscales that would be helpful to a clinician working with families to identify specific areas to work on together. The Experience of Caregiving Inventory would also be useful as an outcome variable when evaluating programs that involve work with family members of individuals with schizophrenia.

Another implication for clinical work is that family members of individuals experiencing their first acute episode of schizophrenia are probably going to be more distressed than families of individuals who have been ill for a long period of time. Thus, clinicians need to be extra sensitive to families in these situations and be prepared that they will need more time, support and guidance to get through this experience.

Ultimately, the impact that caring for a family member with schizophrenia has on the psychological well-being of family members can effect how they can deal and cope with other aspects of their lives. Increased psychological distress is going to affect many areas of life, such as job performance, personal and professional relationships, dealing with other stressful life events and the quality of family relations, including the relationship with the ill family member. As indicated by research, a stressful family environment can contribute to a possible relapse of the ill family member. Poorer psychological well-being of family members is bound to make it more difficult for them to deal with their family member with schizophrenia in positive, helpful ways. Thus, it is crucial for professionals to keep in mind that the impact that schizophrenia has on the well-being of family members, not only follows them into other areas of their lives, but also affects their present and future ability to cope with their family member with schizophrenia.

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Appendix A

DIAGNOSTIC CRITERIA FOR SCHIZOPHRENIA (American Psychiatric Association, 1994)

- A. *Characteristic symptoms:* Two (or more) of the following, each present for a significant period of time during a 1-month period (or less if successfully treated):
- (1) delusions
 - (2) hallucinations
 - (3) disorganized speech
 - (4) grossly disorganized or catatonic behavior
 - (5) negative symptoms, i.e., affective flattening, alogia or avolition
- Note:** Only one Criterion A symptom is required if delusions are bizarre or hallucinations consist of a voice keeping up a running commentary on the person's behavior or thoughts, or two or more voices conversing with each other.
- B. *Social/occupational dysfunction:* For a significant portion of the time since the onset of the disturbance, one or more areas of functioning such as work, interpersonal relations, or self-care are markedly below the level achieved prior to the onset (or when the onset is in childhood or adolescence, failure to achieve expected level of interpersonal, academic, or occupational achievement).
- C. *Duration:* Continuous signs of the disturbance persist for at least 6 months. This 6-month period must include at least 1 month of symptoms (or less if successfully treated) that meet Criterion A (i.e., active-phase symptoms) and may include periods of prodromal or residual symptoms. During these prodromal or residual periods, the signs of the disturbance may be manifested by only negative symptoms or two or more symptoms listed in Criterion A present in an attenuated form (e.g., odd beliefs, unusual perceptual experiences).
- D. *Schizoaffective and Mood Disorder exclusion:* Schizoaffective Disorder and Mood Disorder With Psychotic Features have been ruled out because either (1) no Major Depressive, Manic, or Mixed Episodes have occurred concurrently with the active-phase symptoms; or (2) if mood episodes have occurred during active-phase symptoms, their total duration has been brief relative to the duration of the active and residual periods.
- E. *Substance/general medical condition exclusion:* The disturbance is not due to the direct physiological effects of a substance (e.g., a drug of abuse, a medication) or a general medical condition.
- F. *Relationship to a Pervasive Developmental Disorder:* If there is a history of Autistic Disorder or another Pervasive Developmental Disorder, the additional diagnosis of Schizophrenia is made only if prominent delusions or hallucinations are also present for at least a month (or less if successfully treated).

Name: _____ ID#: _____
Relationship: _____ Date: _____

The Psychological General Well-being Schedule

This questionnaire asks about how you feel and how things have been going with you. For each question check the appropriate box that best applies to you.

1. How have you been feeling in general? (during the past month)

- in excellent spirits
- in very good spirits
- in good spirits mostly
- I have been up and down in spirits a lot
- in low spirits mostly
- in very low spirits

2. How often were you bothered by any illness, bodily disorder, aches or pains? (during the last month)

- every day
- almost every day
- about half of the time
- now and then, but less than half the time
- rarely
- none of the time

3. Did you feel depressed (during the past month)

- yes - to the point that I felt like taking my life
- yes - to the point that I did not care about anything
- yes - very depressed almost every day
- yes - quite depressed several times
- yes - a little depressed now and then
- no - never felt depressed at all

4. Have you been in firm control of your behavior, thoughts, emotions, or feelings? **(during the past month)**

- yes, definitely so
- yes, for the most part
- generally so
- not too well
- no, and I am somewhat disturbed
- no, and I am very disturbed

5. Have you been bothered by nervousness or your “nerves” **(during the past month)**

- extremely so - to the point where I could not work or take care of things
- very much so
- quite a bit
- some - enough to bother me
- a little
- not at all

6. How much energy, pep, or vitality did you have or feel? **(during the past month)**

- very full of energy - lots of pep
- fairly energetic most of the time
- my energy level varied quite a bit
- generally low in energy or pep
- very low in energy or pep most of the time
- no energy or pep at all - I felt drained, sapped

7. I felt downhearted and blue **(during the past month)**

- none of the time
- a little of the time
- some of the time
- a good bit of the time
- most of the time
- all of the time

8. Were you generally tense or did you feel any tension? (during the past month)

- yes - extremely tense, most or all of the time
- yes - very tense most of the time
- not generally tense, but did feel fairly tense several times
- I felt a little tense a few times
- my general tension level was quite low
- I never felt tense or any tension at all

9. How happy, satisfied, or pleased have you been with your personal life (during the past month)

- extremely happy - could not have been more satisfied or pleased
- very happy most of the time
- generally satisfied - pleased
- sometimes fairly happy, sometimes fairly unhappy
- generally dissatisfied, unhappy
- very dissatisfied or unhappy most of the time

10. Did you feel healthy enough to carry out the things you like to do or had to do (during the past month)

- yes - definitely so
- for the most part
- health problems limited me in some important ways
- I was only healthy enough to take care of myself
- I needed some help in taking care of myself
- I needed someone to help me with most or all of the things I had to do

11. Have you felt so sad, discouraged, hopeless, or had so many problems that you wondered anything was worthwhile? (during the past month)

- extremely so - to the point that I have just about given up
- very much so
- quite a bit
- some - enough to bother me
- a little bit
- not at all

12. I woke up feeling fresh and rested (**during the past month**)

- none of the time
- a little of the time
- some of the time
- a good bit of the time
- most of the time
- all of the time

13. Have you been concerned, worried, or had any fears about your health? (**during the past month**)

- Extremely so
- very much so
- quite a bit
- some, but not a lot
- practically never
- not at all

14. Have you had any reason to wonder if you were losing your mind, or losing control over the way you act, talk, think, feel or of your memory? (**during the past month**)

- Not at all
- only a little
- some - but not enough to be concerned or worried about
- some and I have been a little concerned
- some and I am quite concerned
- yes, very much so and I am very concerned

15. My daily life was full of things that were interesting to me (**during the past month**)

- none of the time
- a little of the time
- some of the time
- a good bit of time
- most of the time
- all of the time

16. Did you feel active, vigorous, or dull, sluggish? **(during the past month)**

- very active, vigorous every day
- mostly active, vigorous - never really dull, sluggish
- fairly active, vigorous - seldom dull, sluggish
- fairly dull, sluggish - seldom active, vigorous
- mostly dull, sluggish - never really active, vigorous
- very dull, sluggish every day

17. Have you been anxious, worried, or upset? **(during the past month)**

- Extremely so - to the point of being sick or almost sick
- very much so
- quite a bit
- some-enough to bother me
- a little bit
- not at all

18. I was emotionally stable and sure of myself **(during the past month)**

- none of the time
- a little of the time
- some of the time
- a good bit of the time
- most of the time
- all of the time

19. Did you feel relaxed, at ease or high strung, tight, or keyed-up? **(during the past month)**

- Felt relaxed and at ease the whole time
- felt relaxed and at ease most of the time
- generally felt relaxed but at times felt fairly high strung
- generally felt high strung but at times felt fairly relaxed
- felt high strung, tight, or keyed-up most of the time
- felt high strung, tight, or keyed up the whole month

20. I felt cheerful, lighthearted (**during the past month**)

- none of the time
- a little of the time
- some of the time
- a good bit of the time
- most of the time
- all of the time

21. I felt tired, worn out, used up, or exhausted (**during the past month**)

- none of the time
- a little of the time
- some of the time
- a good bit of the time
- most of the time
- all of the time

22. Have you been under or felt you were under any strain, stress, or pressure? (**during the past month**)

- Yes - almost more than I could bear or stand
 - yes - quite a bit of pressure
 - yes, some - more than usual
 - yes, some - but about usual
 - yes - a little
 - not at all
-

Score = _____

EXPERIENCE OF CAREGIVING INVENTORY

The following pages contain a number of statements that commonly apply to persons who care for relatives or friends with a serious mental illness.

We would like you to read each one and decide how often it has applied to you over the past one month.

If it has never happened or rarely happened you would CIRCLE the number 0 or 1. If it has happened sometimes, then you would CIRCLE the number 2. If it has happened often or seems to have happened nearly always, then you would CIRCLE the number 3 or 4.

It is important to note that there are no right or wrong answers. Also, it is best not to spend too long on any one statement. Often your first reaction will usually provide the best answer. While there seem to be a lot of statements, you will find that it won't take more than a moment or so to answer each one.

Female version

Experience of Caregiving Inventory (ECI) 1994

*G Szmukler, P Burgess, H Herrman, A Benson, S Colusa, S Bloch
University of Melbourne, Victoria, Australia*

0 = never
 1 = rarely
 2 = sometimes
 3 = often
 4 = nearly always

PLEASE CIRCLE

During the past month how often have you thought about:

- | | | |
|-----|--|-----------|
| 1. | your covering up his illness | 0 1 2 3 4 |
| 2. | feeling unable to tell anyone of the illness | 0 1 2 3 4 |
| 3. | his difficulty looking after money | 0 1 2 3 4 |
| 4. | having to support him | 0 1 2 3 4 |
| 5. | what sort of life he might have had | 0 1 2 3 4 |
| 6. | his risk of committing suicide | 0 1 2 3 4 |
| 7. | I have learnt more about myself | 0 1 2 3 4 |
| 8. | I have contributed to others' understanding of the illness . . . | 0 1 2 3 4 |
| 9. | being unable to do the things you want to do | 0 1 2 3 4 |
| 10. | how health professionals do not take you seriously | 0 1 2 3 4 |
| 11. | his dependence on you | 0 1 2 3 4 |
| 12. | helping him to fill in the day | 0 1 2 3 4 |
| 13. | I have contributed to his wellbeing | 0 1 2 3 4 |
| 14. | that he makes a valuable contribution to the household . . . | 0 1 2 3 4 |
| 15. | the effect on your finances if he becomes more seriously ill . | 0 1 2 3 4 |
| 16. | dealing with psychiatrists | 0 1 2 3 4 |
| 17. | him always being at the back of your mind | 0 1 2 3 4 |
| 18. | whether you have done something to make him ill | 0 1 2 3 4 |
| 19. | that he has shown strengths in coping with his illness | 0 1 2 3 4 |
| 20. | I have become more confident in dealing with others | 0 1 2 3 4 |
| 21. | how family members do not understand your situation | 0 1 2 3 4 |
| 22. | that he is good company | 0 1 2 3 4 |
| 23. | I have become more understanding of others with problems . | 0 1 2 3 4 |
| 24. | how he thinks a lot about death | 0 1 2 3 4 |
| 25. | his lost opportunities | 0 1 2 3 4 |
| 26. | how to deal with mental health professionals | 0 1 2 3 4 |
| 27. | feeling unable to have visitors at home | 0 1 2 3 4 |
| 28. | how he gets on with other family members | 0 1 2 3 4 |
| 29. | backing him up when he runs out of money | 0 1 2 3 4 |
| 30. | how family members do not understand the illness | 0 1 2 3 4 |
| 31. | how he deliberately attempts to harm himself | 0 1 2 3 4 |
| 32. | I have become closer to some of my family | 0 1 2 3 4 |
| 33. | I have become closer to friends | 0 1 2 3 4 |
| 34. | I share some of his interests | 0 1 2 3 4 |
| 35. | I feel useful in my relationship with him | 0 1 2 3 4 |
| 36. | how health professionals do not understand your situation . . | 0 1 2 3 4 |

0 = never
 1 = rarely
 2 = sometimes
 3 = often
 4 = nearly always

PLEASE CIRCLE

During the past month how often have you thought about:

- | | | |
|-----|--|-----------|
| 37. | whether he will ever get well | 0 1 2 3 4 |
| 38. | feeling the stigma of having a mentally ill relative | 0 1 2 3 4 |
| 39. | how to explain his illness to others | 0 1 2 3 4 |
| 40. | others leaving home because of the effect of the illness | 0 1 2 3 4 |
| 41. | setting his up in accommodation | 0 1 2 3 4 |
| 42. | how to make complaints about his care | 0 1 2 3 4 |
| 43. | I have met helpful people | 0 1 2 3 4 |
| 44. | I have discovered strengths in myself | 0 1 2 3 4 |
| 45. | feeling unable to leave him home alone | 0 1 2 3 4 |
| 46. | the effect of the illness on children in the family | 0 1 2 3 4 |
| 47. | the illness causing a family break-up | 0 1 2 3 4 |
| 48. | his keeping bad company | 0 1 2 3 4 |
| 49. | how his illness effects special family events | 0 1 2 3 4 |
| 50. | finding out how hospitals or mental health services work | 0 1 2 3 4 |
| 51. | doctors' knowledge of the services available to families | 0 1 2 3 4 |
| 52. | the difficulty getting information about his illness | 0 1 2 3 4 |

During the past month how often have you thought about him being:

- | | | |
|-----|---|-----------|
| 53. | moody | 0 1 2 3 4 |
| 54. | unpredictable | 0 1 2 3 4 |
| 54. | withdrawn | 0 1 2 3 4 |
| 56. | uncommunicative | 0 1 2 3 4 |
| 57. | not interested | 0 1 2 3 4 |
| 58. | slow at doing things | 0 1 2 3 4 |
| 59. | unreliable about doing things | 0 1 2 3 4 |
| 60. | indecisive | 0 1 2 3 4 |
| 61. | irritable | 0 1 2 3 4 |
| 62. | inconsiderate | 0 1 2 3 4 |
| 63. | behaving in a reckless way | 0 1 2 3 4 |
| 64. | suspicious | 0 1 2 3 4 |
| 65. | embarrassing in appearance | 0 1 2 3 4 |
| 66. | behaving in a strange way | 0 1 2 3 4 |

Appendix D
FAMILY CONCERNS QUESTIONNAIRE

NAME: _____ ID#: _____ DATE: _____

We are interested in assessing the impact of your relative's illness on you and your family. We would very much appreciate it, if you would respond to the questions below and on the following pages. Please be as frank and honest as possible in your replies. Your answers will remain confidential.

What is your age? _____

What is your gender (circle) MALE FEMALE

What is your relationship to the patient (wife, husband, mother, father, son, daughter, brother, sister, etc.) _____

Is your relative who is ill currently living with you?

YES, ALL THE TIME PART-TIME NO, NOT AT ALL

If your relative is not living with you, how long has it been since you shared the same house?

Please respond to each question by circling the appropriate number:

- Checking "DNA" means that the behaviour or problem has never occurred with your relative.
- Checking an 1 would indicate while the behaviour or problem has occurred you and your family have not been bothered by or concerned about it while your relative has been living with you.
- 2 means that you have only been bothered by the behaviour occasionally or infrequently.
- 3 indicates that it is regularly a source of concern.
- 4 means that it often is a source of concern.
- 5 means that you are almost always or always concerned about or bothered by the behaviour or problem described.

Regarding your relative's behaviour when living with you:

	DOES NOT APPLY, HAS NEVER HAPPENED	HAS NOT BEEN A CONCERN	INFREQUENTLY A CONCERN	REGULARLY A CONCERN	OFTEN A CONCERN	ALWAYS OR ALMOST ALWAYS A CONCERN
1. How much trouble has your relative been at night (being noisy, wandering about etc.)?	DNA	1	2	3	4	5
2. Has your relative been a nursing problem (i.e. bedridden, incontinent, needing to be fed or bathed)?	DNA	1	2	3	4	5
3. Has your relative's safety been a source of worry (for example wandering off by himself/herself, using the car etc.)?	DNA	1	2	3	4	5

	DOES NOT APPLY, HAS NEVER HAPPENED	HAS NOT BEEN A CONCERN	INFREQUENTLY A CONCERN	REGULARLY A CONCERN	OFTEN A CONCERN	ALWAYS OR ALMOST ALWAYS A CONCERN
4. Has your relative's behaviour caused you to fear for the safety of others?	DNA	1	2	3	4	5
5. Has your relative caused any difficulty by being unco-operative?	DNA	1	2	3	4	5
6. Does your relative represent a strain by relying and depending on you or people in the home too much?	DNA	1	2	3	4	5
7. Has your relative's constant restlessness, noisiness or talking been upsetting to you or the family?	DNA	1	2	3	4	5
8. Has your relative's frequent body symptoms or complaints worried you?	DNA	1	2	3	4	5
9. Has your relative been a problem because of sexual, rude, or objectionable behaviour?	DNA	1	2	3	4	5
10. Has your relative's behaviour caused you any embarrassment because he speaks or behaves oddly?	DNA	1	2	3	4	5
11. Has your relative caused any trouble with the neighbors?	DNA	1	2	3	4	5
12. Is your household work or routine upset by your relative?	DNA	1	2	3	4	5
13. Are the social or leisure time activities of the family interfered with because of your relative?	DNA	1	2	3	4	5
14. Has anyone in the household had to stay away from work because of your relative?	DNA	1	2	3	4	5
15. Has anyone in the household had to stay away from school because of your relative?	DNA	1	2	3	4	5
16. Has your relative's behaviour caused you much worry (overall)?	DNA	1	2	3	4	5
17. Has your relative been a physical strain on you?	DNA	1	2	3	4	5
18. Does your relative require excessive amount of attention or companionship?	DNA	1	2	3	4	5
19. Are the children ashamed because of your relative?	DNA	1	2	3	4	5

	DOES NOT APPLY, HAS NEVER HAPPENED	HAS NOT BEEN A CONCERN	INFREQUENTLY A CONCERN	REGULARLY A CONCERN	OFTEN A CONCERN	ALWAYS OR ALMOST ALWAYS A CONCERN
20. Are the children afraid of your relative?	DNA	1	2	3	4	5
21. Do you feel ashamed because of your relative?	DNA	1	2	3	4	5
22. Are you afraid of your relative?	DNA	1	2	3	4	5
23. Has your relative been an emotional strain on you?	DNA	1	2	3	4	5
24. Has your relative's quiet or non-communicative behaviour been upsetting to you or the family?	DNA	1	2	3	4	5
25. Has your relative been a financial strain on you?	DNA	1	2	3	4	5
26. Has your relative's lack of interest in doing things or seeing people been upsetting to you or the family?	DNA	1	2	3	4	5
27. Have you or other members felt neglected because of your relative's illness.	DNA	1	2	3	4	5
28. Has your relative's irritability or argumentativeness been upsetting to you or your family?	DNA	1	2	3	4	5
29. Has your relative's difficulty making decisions been a burden on you?	DNA	1	2	3	4	5
30. Has your relative's illness made it difficult to plan for the future?	DNA	1	2	3	4	5
31. (If spouse) Does your husband/wife's lack of interest in sex upset you?	DNA	1	2	3	4	5
32. Has your relative's lack of energy or fatigue become a burden on you?	DNA	1	2	3	4	5
33. Has your relative's sleep problem been upsetting to you?	DNA	1	2	3	4	5
34. Has your relative's appetite change caused problems for you?	DNA	1	2	3	4	5
35. Has your relative's constant worrying and nervousness been distressing to you?	DNA	1	2	3	4	5
36. Has your relative's hopeless attitude caused you to feel discouraged?	DNA	1	2	3	4	5

	DOES NOT APPLY, HAS NEVER HAPPENED	HAS NOT BEEN A CONCERN	INFREQUENTLY A CONCERN	REGULARLY A CONCERN	OFTEN A CONCERN	ALWAYS OR ALMOST ALWAYS A CONCERN
37. Do you worry about what will happen to your relative in the future?	DNA	1	2	3	4	5
38. Do you worry about the medications that your relative is taking?	DNA	1	2	3	4	5
39. Has your relative's behaviour caused you to fear for your own safety?	DNA	1	2	3	4	5
40. Has your relative's behaviour caused you to fear about the safety of your possessions and property?	DNA	1	2	3	4	5
41. Has your relative caused any trouble with the police?	DNA	1	2	3	4	5
42. Has your relative caused any embarrassment with friends?	DNA	1	2	3	4	5
43. Has your relative's illness reduced the enjoyments and outlets in your life (e.g. hobbies, interests, forms of relaxation)?	DNA	1	2	3	4	5
44. Has your relative's illness affected relationship or contact you have with friends, relatives, etc.?	DNA	1	2	3	4	5
45. Has your relative's illness reduced the number of holidays and breaks you can take?	DNA	1	2	3	4	5
46. Has your relative's illness affected or reduced the times when you can go out (e.g. pub, cinema, walks etc.)?	DNA	1	2	3	4	5

Appendix E

The Psychological Well-Being of Family Members
of Individuals with Schizophrenia

INDIVIDUAL PARTICIPANT CONSENT FORM

RESEARCH PROJECT: The Psychological Well-Being of Family Members of Individuals with Schizophrenia

INVESTIGATORS: Dr. Jean Addington, Laurie Martens.

This consent form, a copy of which has been given to you, is only part of the process of informed consent. It should give you a basic understanding of what the research project is about and what your participation will involve. If you would like more details about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

1. PURPOSE OF THE RESEARCH: The purpose of this research project is to understand the effect on family members of having a family member with schizophrenia.

2. PROCEDURES: There will be 30 individuals invited to participate in this study. Participation in this study will involve one interview which will cover:

1. Giving permission to the researcher to look at your hospital chart in order to confirm your diagnosis.
2. Giving the researcher permission to contact one or two of your immediate family members.
3. Providing the researcher with some general information about yourself.

None of these tasks can be considered part of your treatment.

3. DESIGN OF THE STUDY: This study has a correlational, cross-sectional design. Data will be collected on one occasion to determine the predictors of family members' psychological well-being who have a relative with schizophrenia.

4. RISKS: There are no known risks to these procedures beyond those encountered in daily life. Should you feel fatigued or stressed by the demands of the questions you may take a break, postpone the interview to another time, or refuse to continue.

5. PARTICIPANTS INVOLVEMENT:

- 1) The researcher will contact you by phone.
- 2) A meeting at the hospital will be set up at a time suitable to you for an interview that will take a maximum of 20 minutes.
- 3) The interview will involve you answering questions about your age, level of education, employment status, length of illness, number of hospitalizations and age at first admission. You will also be asked to provide contact information for your family members.

6. BENEFITS: There are no direct benefits to you from participating in this research.

7. ALTERNATIVES: You may choose not to participate in this research. Just as there are no risks or benefits to participating, there are no risks or benefits to not participating. Neither participating or refusing will affect any decisions about your treatment or your involvement in your treatment program.

8. ACCESS TO INFORMATION: Your name and the information obtained from the research will be kept confidential. This will be ensured by a number of safeguards.

(I) You will be interviewed in a private office.

(ii) Your records will be identified only by a number and not by your name.

(iii) Your records will be kept in a locked file cupboard in a locked office.

(iv) No information concerning your identity will be used in any published reports.

9. COSTS: There are no costs associated with participation in this study.

Your signature on this form indicates that you have understood to your satisfaction the information regarding your participation in the research project and that you agree to participate as a participant. In no way does this waive your legal rights or release the investigators, sponsors or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time without jeopardizing you health care. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation. If you have any further questions please contact:

Dr. Jean Addington 670-4836

If you have any questions concerning your rights as a possible participant in this research, please contact the Office of Bioethics, Faculty of Medicine, The University of Calgary at 220-7990.

(Name of Participant)

(Name of Witness)

(Signature of Participant)

(Signature of Witness)

(Investigator)

(Signature of Investigator)

(DATE)

A copy of this consent form will be given to you. Please keep it for your records and future reference.

Appendix F

The Psychological Well-Being of Family Members
of Individuals with Schizophrenia

FAMILY MEMBER PARTICIPANT CONSENT FORM

RESEARCH PROJECT: The Psychological Well-Being of Family Members of Individuals with Schizophrenia.

INVESTIGATORS: Dr. Jean Addington, Laurie Martens.

This consent form, a copy of which has been given to you, is only part of the process of informed consent. It should give you a basic understanding of what the research project is about and what your participation will involve. If you would like more details about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

1. PURPOSE OF THE RESEARCH: The purpose of this research project is to understand the effect on family members of having a family member with schizophrenia.

2. PROCEDURES: There will be 40 family members of individuals with schizophrenia invited to participate in the study. Participation will involve one interview during which you will be asked to provide some general information about yourself and complete three short self-report questionnaires.

This assessment can be done in one or more sessions if you prefer. You can have breaks in the sessions if you want. The appointments will be made at a time suitable to you. None of these tasks can be considered part of your family members' treatment.

3. DESIGN OF THE STUDY: This study has a correlational, cross-sectional design. Data will be collected on one occasion to determine the predictors of family members' psychological well-being who have a relative with schizophrenia.

4. RISKS: There are no risks to these procedures. Should you feel fatigued or stressed by the demands of the tasks you may take a break, postpone the tests to another time, or refuse to continue.

5. PARTICIPANTS INVOLVEMENT:

- 1) The researcher will contact you by phone.
- 2) A meeting will be set up at a time and place (Foothills Hospital or your home) suitable to you for one interview that take no longer than one hour.
- 3) You will be asked to provide the researcher with some demographic information about yourself, including your age, relationship to family member, level of education, employment and marital status.
- 4) Then there will be three short self-report questionnaires to fill out. Two of them directly concern your role or relationship with your family member with schizophrenia or schizo-affective disorder. The third one directly asks questions about yourself concerning your general well-being.

6. BENEFITS: There are no direct benefits to you from participating in this research.

7. ALTERNATIVES: You may choose not to participate in this research. Just as there are no risks or benefits to participating, there are no risks or benefits to not participating. Neither participating or refusing will affect any decisions about your family member's treatment or his/her involvement in the treatment program.

8. ACCESS TO INFORMATION: Your name and the information obtained from the research will be kept confidential. This will be ensured by a number of safeguards.

(i) You will be interviewed in a private office.

(ii) Your records will be identified only by a number and not by your name.

(iii) Your records will be kept in a locked file cupboard in a locked office.

(iv) No information concerning your identity will be used in any published reports.

9. COSTS: There are no costs associated with participation in this study.

Your signature on this form indicates that you have understood to your satisfaction the information regarding your participation in the research project and that you agree to participate as a participant. In no way does this waive your legal rights or release the investigators, sponsors or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time without jeopardizing your health care. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation. If you have any further questions please contact:

Dr. Jean Addington 670-4836

If you have any questions concerning your rights as a possible participant in this research, please contact the Office of Bioethics, Faculty of Medicine, The University of Calgary at 220-7990.

(Name of Participant)

(Name of Witness)

(Signature of Participant)

(Signature of Witness)

(Investigator)

(Signature of Investigator)

(DATE)

A copy of this consent form will be given to you. Please keep it for your records and future reference.