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HELP SEEKING FOR PARENTS OF INDIVIDUALS EXPERIENCING A
FIRST EPISODE OF SCHIZOPHRENIA

by

Donna Czuchta

A thesis submitted in conformity with the
requirements for the Degree of Master of Science,
Graduate Department of Nursing Science in the
University of Toronto

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ABSTRACT

Help Seeking for Parents of Individuals Experiencing a First Episode of Schizophrenia

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University of Toronto, 1998

The purpose of this triangulated study was to understand parents’ experience of help seeking in response to their child’s first episode of schizophrenia. Twenty participants completed questionnaires related to stigma, parental caregiver burden, uncertainty in illness and help seeking. Findings indicated: 1) as stigmatized attitudes towards mental illness and feelings of ambiguity increased, so did burden; 2) as parental education increased, uncertainty regarding their child’s illness decreased; 3) as the number of symptoms causing distress increased so did burden and lack of clarity regarding their child’s illness. A significant amount of time passed prior to parents seeking help. No relationships were found between indicators of parental help seeking and study variables. A subset of five participants described their help-seeking experience. Three overarching themes emerged: 1) Evolving Change: What does it mean? 2) Continuous help-seeking and 3) Enduring the help seeking: Impact on parents. Implications for practice and research are discussed.
Dedication

To my parents, Anne and John Czuchta, for their tremendous support, love and encouragement they have always shown me. I am so grateful to them.
Acknowledgments

My sincere appreciation and respect is extended to the parents who graciously agreed to participate in this study. Without their involvement this research would not have been possible. A very special thanks to the participants’ children, who agreed to have their parents involved in this study. I deeply admire their courage in overcoming their illness. Many blessings to them for a lifetime full of health and happiness.

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Chapter 1

Introduction and Background

In Canada, mental illness is a significant health problem, and is identified as one of the five serious disease categories along with heart disease, cancer, respiratory disease and stroke (Statistics Canada, 1991). Schizophrenia is a mental illness that affects over 50,000 Canadians each year (Beiser & Iacono, 1990). Illness onset typically occurs during late adolescence or young adulthood (Lively, Friedrich, & Buckwalter, 1995) and characteristically follows a chronic course, with periodic acute exacerbations (Goeree, 1994). Early psychiatric intervention not only significantly aids recovery in first episode psychosis, but may also reduce subsequent chronic symptomatology (Birchwood et al., 1989; Birchwood, 1992; Birchwood & McMillan, 1993; Falloon, 1992).

Families are an extremely valuable resource for individuals with schizophrenia, since family members often encourage their relative to seek treatment in the early phases of the illness (Gamble & Midence, 1994; Rose, 1996). Despite the family's role in early detection, evidence suggests that families delay seeking help for their relatives experiencing a first episode of schizophrenia (Helgason, 1990; Loebel et al., 1992). A number of factors may contribute to the delay of help seeking by the family (Lincoln & McGorry, 1995). These factors include: stigma (Fink & Tasman, 1993), the uncertain nature of the illness (Baier, 1995) and the burden of caring for an acutely ill family member (Lefley, 1987; Rose, 1996).

Society's stigmatizing perception of individuals with mental illness may hinder the help-seeking of families, since family members may attempt to avoid negative labelling of their mentally ill relative (Rose, 1996). The uncertain nature of the illness
during the early phases may cause the family to feel frightened and immobilized. Frequently family members observe behavioural changes in their relative which are difficult to understand. (Baeir, 1995). Significant burden is usually experienced by family members who have a relative with a mental illness. This burden is frequently most intense during the early years of the illness, when parents are faced with confronting the demands of their child’s psychiatric illness (Cook et al., 1994).

At present the contribution of these factors to delay in help seeking for first episode schizophrenia is not fully understood. Examining the factors affecting families and individuals who are initially seeking help, may enable delays in help-seeking to be understood and may ultimately lead to early intervention and improved outcomes for patients and families.

**Study Purpose**

The purpose of this study was: 1) to determine the level of perceived stigma, caregiver burden, and uncertainty in illness that parents experience at the time of their son’s or daughter’s hospitalization for a first episode of schizophrenia, 2) to describe the indicators of parental help-seeking, and to assess the association between indicators of parental help-seeking and the following variables: perceived stigma, caregiver burden, and uncertainty in illness, and 3) to describe the parents’ experience of help-seeking in response to their son’s or daughter’s first episode of schizophrenia.
**Research Questions**

The research questions that guided this study were:

1a) What is the elapsed time between parents’ reports of first noticeable signs and symptoms and the initiation of help seeking (non health professional and psychiatric) for their children’s emerging illness?

1b) How many help seeking attempts were reported by parents prior to their children’s hospitalization for a first episode of schizophrenia?

1c) What is the level of perceived stigma (using the Social Response Questionnaire), caregiver burden (using the Thresholds Parental Burden Scale), and uncertainty in illness (using the Mishel’s Uncertainty in Illness Scale-Parent/Child form) that parents experience at the time of their children’s hospitalization for a first episode of schizophrenia?

2a) Is there an association between indicators of parents’ help-seeking [i.e. number of help-seeking attempts; length of time from first noticeable sign and symptom to seeking help (non-health professional and psychiatric)], and perceived stigma, caregiver burden, and uncertainty in illness at the time of their children’s hospitalization for a first episode of schizophrenia?

2b) Are there associations amongst the study variables: perceived stigma, caregiver burden, and uncertainty in illness, at the time of their children’s hospitalization for a first episode of schizophrenia?

3) How does a parent describe the experience of help seeking for his/her son or daughter who has experienced a first episode of schizophrenia?
Chapter 2

Review of Related Literature

The literature addressing the initial phases of schizophrenia focuses primarily on the neuropsychological, and psychopharmacological aspects of the illness (Bilder et al., 1992; Lieberman et al., 1993; Mayerhoff et al., 1994; Saykin et al., 1994). In a critical review of the literature, Rose (1996) found that few studies have examined the impact of the initial illness episode on the individual and their family. Furthermore, even less literature exists regarding the family's experience of obtaining help for a family member with a first episode of schizophrenia (Lincoln & McGorry, 1995).

For the purposes of this study, literature related to help-seeking in first episode schizophrenia was reviewed, focusing on: help-seeking pathways, help-seeking delay in first episode schizophrenia, early detection of first episode of schizophrenia, perceived stigma, caregiver burden, and uncertainty in illness.

Help-Seeking Pathways: Accessing Mental Health Care

The help-seeking pathway has been defined as the time lapse between the initiation of the help-seeking effort and formation of contacts (Rogler & Cortes, 1993). Freidson (1960) offers a theoretical formulation of the process of seeking help, he states that "the whole process of seeking help involves a network of potential consultants from the intimate and informal confines of the nuclear family through successively more select, distant and authoritative laymen, until the professional is reached" (p. 377).

Rogler & Cortes (1993) further state that the concept of help-seeking pathways implies "the sequence of contacts with individuals and organizations prompted by the distressed person's efforts and those of his or her significant others, to seek help as well as the help
that is supplied in response to such efforts" (p. 555). From an extensive literature review, Lincoln & McGorry (1995) suggest that factors such as the individual's symptomatology, age at onset, and negative stereotypes of mental illness delay the young person from seeking treatment, but the authors do not directly address the role of the family.

**Help-Seeking Delay in First Episode Schizophrenia**

Understanding how psychiatric help is obtained in the early stages of the individual's psychotic illness is critical for early intervention (Lincoln & McGorry, 1995). Research evidence suggests that delays in obtaining effective care occur when psychosis first arises (Lincoln & McGorry, 1995). Studies have found that individuals remain in the community for more than a year with substantial levels of untreated psychotic symptoms (Loebel et al., 1992). In a 20-year follow-up study of 107 patients with schizophrenia, Helgason (1990) found that there were better outcomes for individuals who sought treatment earlier. Individuals who delayed treatment longer were more often admitted to the hospital where they stayed longer than those who received early treatment. This notion is further supported by Loebel et al. (1992) whose study concluded that the duration of illness before treatment is significantly associated with time to remission and level of remission.

The Northwick Park study in England conducted by Johnstone et al. (1986) was developed to describe the nature and selection of individuals experiencing a first episode of schizophrenia, and the difficulties occurring in the interval between onset and admission. In this study, 462 patients between the ages of 15-70 who were thought to have early behavioural changes suggestive of psychosis were referred from nine medical centers in Britain, over a period of 28 months for participation in the study. Participants
and their relatives were assessed by the study's psychiatrists in areas concerning personal data, details surrounding the presentation of the illness, and items of personal and family history.

Results of this study established that for first episode schizophrenia patients, the interval between onset of illness and hospital admission varied widely, and for about one fourth of the patients the delay was more than a year. The reasons for delay in seeking treatment were based on information provided by patients and their relatives. This study highlighted the difficulties and distress experienced by relatives and attempted to identify the families' concerns. Relatives of the patients seeking help described difficulty in obtaining appropriate assessment and treatment services. Some of the relatives suggested that the availability of an emergency walk-in clinic would have provided a stop-gap for the inadequacies in mental health service. Further recommendations included continued education for general practitioners in order to provide them with the necessary skills to identify an individual's first psychotic episode, so that appropriate management could be instigated immediately.

**Early Detection of First Episode Schizophrenia**

Falloon (1992) conducted an uncontrolled preliminary feasibility study concerning early intervention with adults who exhibited symptoms suggestive of schizophrenic disorders. Falloon hypothesized that the outcome of the initial florid episodes of schizophrenia may be improved if the episodes are detected early and effective therapeutic interventions, such as education, comprehensive stress management and neuroleptic medication are implemented.
The study evolved over a 4-year period with the purpose of devising a model of mental health care that focused on providing comprehensive mental health management for all individuals with Axis 1 disorders, in an epidemiological defined population of adults. His sample consisted of individuals living in two British semi-rural areas with a population of 35,000, of which 20,000 were between the ages of 17 and 65. These areas did not have established mental health or hospital-based services, therefore, all the individuals living in this area received their care from local family practitioners (N=16).

Falloon developed a two stage approach to early detection, whereby family practitioners were first trained to recognize prodromal symptoms and then secondly, without delay, refer these individuals for immediate mental health assessment. These assessments were conducted by four teams, comprised of: nurse therapists, psychiatrists, psychologists, social workers, and occupational therapists. Intervention strategies for individuals who were suspected of experiencing a prodrome of schizophrenia included education, comprehensive stress management and neuroleptic medication. Following the assessment, patients and their caregivers were taught how to recognize symptoms so that future episodes could be detected as soon as possible.

The outcome of this study suggested that screening for early signs of psychosis by family practitioners coupled with immediate access to systematic psychiatric assessment, may enable individuals to receive effective clinical management at an early phase of the disorder than is usually possible. This outcome suggests that "initial florid episodes of schizophrenia may be modified when they are detected early and when effective therapeutic strategies are applied with minimal delays" (Falloon, 1992, p. 4). Furthermore, "detection of the disorder at an early stage in its development may delay
and even prevent the onset of the disability" (Falloon, 1992, p. 13). This targeted approach that integrates stress management with low dose drug therapy within an educational framework may enable individuals to avoid developing more severe forms of the illness. Suggestions for future research included a randomized controlled outcome study in order to validate this study's preliminary findings.

A further study by Winefield & Harvey (1994) emphasized the frustration experienced by family members when attempting to access help during the onset of their relative's illness episode. Winefield & Harvey (1994) conducted interviews and administered standardized questionnaires to 121 family caregivers whose relatives had been diagnosed with schizophrenia, on average 14 years previously. An objective of the study was to describe caregivers' needs for additional help. The study found that families were frustrated that help was not readily available during the early phase of the illness, but only when their family member's mental health had deteriorated much further.

This notion is further supported by Grefley & Grusky (1989), who identified family dissatisfaction with mental health services. Their findings indicated that there were inadequacies in the mental health system that were stressful for the family to experience. Families also experienced a lack of involvement during the active phase of treatment. Specifically, families reported a lack of education regarding their family member's illness.

Given that family members are often the first to notice the early signs of a psychiatric problem in their relative (Falloon, 1992; Rose, 1996), this writer believes that mental health services must be responsive to the needs of families during their relative's initial phase of schizophrenia. As one family member states "We all wanted a proactive,
not a reactive plan, one to avoid crisis, not simply to respond to crisis" (Purdy, 1995, p. 757). Rose (1996) concluded that families are requesting to work with professionals in the treatment of their relatives and are in need of support and empathy from health care professionals.

In summary, the literature related to help seeking for an individual experiencing a first episode of psychosis, highlights the influential factors of accessibility of services, and availability of alternative resources in influencing a delay in help-seeking. The importance of early intervention to aid recovery for individuals experiencing a first episode of psychosis is emphasized in the literature.

The Perceived Stigma of Mental Illness

Society's perceived stigma of mental illness is a factor which may influence the help sought by families with a mentally ill relative (Fink & Tasman, 1993). According to Fink (1993), the negative stereotypes of mental illness, and the stigma associated with the utilization of mental health services may inhibit help seeking. As Braff (1992) states "...psychiatric patients in general, and psychotic patients in particular, are terribly stigmatized..." (p. 37). In a pioneering study, Clausen and Yarrow (1955) cited in Rose (1996), examined the impact of mental illness on family relationships and family functioning of 33 wives whose husbands were first admission psychiatric patients. Factors related to the wives' decisions to seek treatment were elicited in a series of qualitative interviews. Findings indicated that all the subjects anticipated and feared that their family member would be rejected or discriminated by others, and were also concerned about the family's status in the community. Study participants' concerns resulted in restricted contact with others outside the family unit, and strained
communication within the family unit. Flynn (1987) and Wahl & Harman (1989) assert that families are not immune to the negative effects of stigma. Stigma is a significant problem for families with a mentally ill relative. Feelings of guilt, shame, and embarrassment have been reported by families which they attribute to the stigma of having a mentally ill relative (Wahl & Harman, 1989).

Individuals with mental illness have the additional burden of being labeled "different" by the general population (DeNiro, 1995; Leete, 1989; Penn et al., 1994). O'Mahony (1982) gathered the study responses of 50 first admission psychiatric inpatients using a semantic differential scale. The results indicated that patients had a negative stereotype of the mentally ill, however they did not apply the stereotype to themselves. The author suggests that the denial of mental illness by patients serves to protect against the negative stereotype of mental illness.

In a qualitative study, Townsend and Rakfeldt (1985) examined the perceptions of 25 first contact patients toward a variety of mental health treatment settings. One quarter of the sample had a diagnosis of schizophrenia or schizophreniform psychosis and were admitted to hospital. The results of this study indicated that outpatient treatment or crisis center treatment were the preferred alternatives to psychiatric hospitalization and also had positive implications for the patient's self-esteem and social contacts.

In efforts to avoid labelling of their family member, families may be less inclined to seek psychiatric intervention in the early phase of schizophrenia. In a study by Beiser et al. (1987), the Social Response Questionnaire (SRQ) was used to measure attitudes toward the mentally ill. This instrument was administered to individuals with schizophrenia, affective psychosis, Crohn's disease, illness free individuals, and their
families. The results of this study found that individuals with psychotic disorders label themselves and are labeled by others more than individuals with Crohn's disease or those who are illness free. Additionally, individuals with psychotic illnesses view themselves more negatively than those individuals with Crohn's disease or those who were illness free but not as negatively as their significant others. Furthermore, when rated by parents and siblings, individuals with schizophrenia had higher SRQ mean scores, compared to family members with a relative who was illness free, had Crohn's disease or affective psychosis.

In summary, the literature related to stigma highlights the role of stigma and societal reactions in determining a family's initial response to a mentally ill relative. Specifically, the literature indicates that there is a negative stereotypic label attached to an individual with a mental illness. This labelling not only negatively influences the individual's self concept but may also contribute to the family delaying help seeking for their relative with a mental illness.

**Caregiver Burden**

Schizophrenia affects all aspects of an individual's life, as well as the lives of their family members (Goldstein, 1995; Lively, Friedrich, & Buckwalter, 1995). The adverse consequences of psychiatric disorders for families, known as caregiver burden, has been studied since the early 1950's (Schene, Tessler, & Gamache, 1994). According to Schene et al., (1994) care giving refers to the relationship between two adult individuals who are typically related through kinship. The addition of the care giving role to the already existing role, is what makes it burdensome (Gallop et al., 1991; Gubman et al., 1987).
Hoenig and Hamilton (1966) were the first to differentiate between objective and subjective burden. Objective burden is defined as "observable, concrete costs to the family resulting from the mental illness...e.g., financial loss" (Maurin & Boyd, 1990, p. 99). Subjective burden is defined as "individuals' personal appraisals of the situation and the extent to which people perceive they are carrying a burden" (Maurin & Boyd, 1990, p. 99).

Review of the literature has consistently found that mental illness produces a significant burden for family members (Carpentier et al., 1992; Gerace, 1988; Howard, 1994; Maurin & Boyd, 1990; Reinhard, 1994). Families describe such reactions as grief, anxiety, worry about the future of their relative and the demands of living with a family member who is mentally ill, which increase over time (Cook et al., 1994; Lively et al., 1995; Noh & Turner, 1987; Spaniol et al., 1984). In addition, families are expected to assume care giving responsibilities which they find burdensome (Johnson, 1990; Lefley, 1987; Maurin & Boyd, 1990).

Significant demands are placed on families during the early onset of the illness. According to Carpentier et al. (1992), not all relatives have the same resources and skills to support their family member with a psychiatric disorder. Families must identify their needs and subsequent treatment resources must be readily available so that caregiver burden may be minimized (Carpentier et al., 1992). There is, therefore, a role for health care providers to collaboratively work with families in identifying the available resources (King & Dixon, 1995). This notion is further supported by Potasnik and Nelson (1984), who found a decrease in caregiver burden when families perceive satisfaction with available social support networks.
The uncertainty associated with an illness may constitute an aspect of caregiver burden that may influence families help-seeking behaviour (Mishel, 1990). Uncertainty, during a first episode of schizophrenia, is experienced by both the parents and the individual with schizophrenia because of the nature of the symptoms and the unpredictability of the course of illness (Baier, 1995). Due to the ambiguous nature of the situation, the individual or their family may find it difficult to decide which, if any, action to take (Mishel, 1988).

In a qualitative research study, Baier (1995) interviewed six persons with schizophrenia and five family members. The purpose of the research was to determine how persons living with schizophrenia and their families describe and live with the uncertain nature of the illness. The results of this study indicated that individuals with schizophrenia and their families experience uncertainty because of the illness symptoms, as well as the unpredictable course of the illness. As a result of this uncertainty, some families felt immobilized, burdened, and frightened, especially when the changes in their family member first began to occur (Baier, 1995). However, for some family members, uncertainty provided an opportunity for hope. Families felt hopeful when they had multiple alternatives and choices in which to reevaluate their child's illness course.

In summary, the literature related to family experiences with mental illness provides evidence that seeking help and caring for individuals with mental illness creates a burden for families. Maurin & Boyd (1990), in their critical review of literature on burden of mental illness in the family conclude that "mental illness produced a significant burden for family members" (p.100). The literature related to help seeking further
supports that early detection and access to treatment resources may reduce the impact of caregiver burden.

**Summary of Literature Review**

In summary, the literature related to family help-seeking highlights various significant factors. Stigma may contribute to delay in help-seeking due to the family’s fear that their relative may be rejected or discriminated against. In order to avoid labelling of their family member, families may be less inclined to seek psychiatric intervention.

Due to the uncertainty surrounding a first episode of schizophrenia, the family may find it difficult to decide which if any action to take. This uncertainty can leave families feeling immobilized, frightened, and burdened by the behavioural changes in their son or daughter. The experience of caregiver burden may facilitate the process of help-seeking in efforts to alleviate the burden that family members may be experiencing.

Given the potential role of the family in procuring early treatment for a first episode of schizophrenia it is essential that an increased understanding of the families experience of help-seeking and related factors be obtained.
Chapter 3

Design and Methods

Overview and Design: Triangulation

Triangulation refers to the combination of both quantitative and qualitative methodologies in one study. This triangulated approach is being increasingly used in the nursing science literature (Breitmayer, et al., 1993; Meyers & Hasse, 1989; Mitchell, 1986). This approach is supported by Duffy (1987), who states that triangulation "when used appropriately, combines different methods in a variety of ways to produce richer and more insightful analyses of complex phenomena than can be achieved by either method separately" (p.133). Goering and Streiner (1996) state that combining both qualitative and quantitative methods serve to extend, compliment, and validate each other's findings "so that each can inform the other as the study progresses" (p. 495). Breitmayer et al. (1993) further state that the combination of both methods allows the varied dimensions of an area of interest to be revealed. Morse (1991) further supports the use of triangulation by stating that it "will strengthen research results and contribute to theory and knowledge development" (p. 122).

For the quantitative component of this study, correlational analysis was used to examine the patterns of association amongst the variables, namely indicators of help-seeking and perceived stigma, caregiver burden, uncertainty in illness. For the qualitative component of the study, semi-structured interviews were used to elicit data regarding the family's help-seeking behaviours for their son or daughter who was experiencing a first episode of schizophrenia.
Setting

This study was conducted at an adult in-patient unit located at a university-affiliated psychiatric facility in a large metropolitan city, located in Ontario, Canada. This unit specializes in the assessment and treatment of individuals experiencing a first-episode of psychosis, predominately schizophrenia or schizophreniform illnesses. The individuals' families are actively involved in the treatment plan.

Sample Selection Criteria

Family members who meet the following criteria and agreed to participate in the study were included in the sample:

1. A parent whose son or daughter was recovering from a first episode of schizophrenia, schizophreniform, or schizoaffective disorder and had been admitted to the Clinical Investigations Unit.
2. The parent was able to read and speak English.

Sample Size

Data were collected over a period of 10 months from 20 parents (mother n=13, father n=7) whose son or daughter was hospitalized in the Clinical Investigation Unit (CIU), at a university affiliated psychiatric facility in Ontario, Canada.

A convenience sample of family members whose son or daughter had experienced a first episode of schizophrenia, schizophreniform, or schizoaffective disorder was selected for the qualitative component. Given the nature and intensity of the data elicited from a qualitative interview, the sample size in qualitative research is usually small (Polit & Hungler, 1991). To address feasibility issues the sample size in the qualitative component of the study was n=5.
Procedures for Procuring a Sample

Once approval from the Office of Research Services was received, the researcher sent a letter to the Vice President of Nursing of the facility (see Appendix A). The purpose of this letter was to obtain permission to conduct the proposed study on the Clinical Investigations Unit within the hospital. A copy of the protocol was enclosed with the letter.

Upon receiving permission from the facility, a letter was sent to inform the Nursing Unit Administrator (NUA) or delegate that the researcher had received approval from the office of research services and the hospital to conduct the proposed study on the unit (see Appendix B). This letter outlined the purpose of the study on the unit and asked for the assistance of the nurse-in-charge on the unit to identify potential participants for the study.

Once the data collection phase of the study had begun, the researcher contacted the nurse-in-charge on the unit frequently to assess if any eligible participants were identified. The sons or daughters (i.e., the identified patient) of the parents (who were the potential participants) were approached by the nurse in charge to request permission to contact their family member in order to seek their participation in the study (see Appendix C). The researcher then asked the nurse-in-charge to approach the family, i.e., the potential participants, to briefly describe the purpose of the study and asked permission for the release of their names so that the researcher could meet with them to further explain the study in detail (see Appendix D).
The researcher met with the potential participants. At this time, the researcher introduced herself and explained the purpose of the study and what participation in the study would involve. The confidentiality of the data and the voluntary nature of participation was emphasized to the participant (see Appendix E). Family members who were willing to participate in the study were asked to sign a consent (see Appendix F).

For those family members who agreed to participate, an appointment was arranged at a mutually agreed upon time to complete the four study questionnaires. A subset of family members who complete the study questionnaires were invited to participate in the qualitative interview. The participants were selected according to their expressed willingness to participate in this component of the study, as well as the ability to clearly articulate their experience of help seeking. All participants were asked to complete the demographic data sheet (see Appendix G) in order to provide information regarding the sample.

**Data Collection**

Data collection took place in a room outside adjacent to the inpatient unit offering privacy and ensuring confidentiality for both the participant and the researcher. Prior to beginning data collection, the researcher briefly reintroduced the purpose of the study and reminded the participants that they may refuse to answer any questions or could withdraw from the study at any time.

The data collection phase of this study consisted of two parts. Part one of data collection addressed research question number one and two. All participants (n=20) were asked to complete part one of the study. Included in part one of the study was the completion of four study questionnaires and the demographic data sheet.
Part two of data collection addressed research question number three. This component of data collection consisted of a one hour interview in which the participant was asked to describe their experience of help-seeking for their son or daughter who had experienced a first episode of schizophrenia. The questions were asked in chronological order as presented in the Turning Point Interview (TPI), however the researcher did use unscheduled probes (i.e. "tell me more about that" and/or "what did it mean to you") in order to have the participant further elaborate when needed. The content of the field notes was used to supplement the participant's verbal descriptions with the participant's nonverbal behaviour during the context of the interview.

**Instrumentation**

**Social Response Questionnaire**

The Social Response Questionnaire (SRQ) (see Appendix H) is a 32 item self-report scale (Beiser et al., 1987). This scale was used to measure the degree of perceived stigma toward mental illness. The SRQ was developed to measure the sick label, and incorporates moralistic attitudes, fear of dangerousness and negative consequences frequently attached to the role of the severely mentally ill. It is a multi-dimensional measure of informal labelling. The SRQ is internally stable for individuals with schizophrenia (Cronbach's alpha = 0.89) and their significant others (Cronbach's alpha = 0.92). The SRQ also exhibits construct validity (Beiser et al., 1987).

The scale is comprised of a list of adjectives that reflect stigmatized attitudes toward individuals with a mental illness. Each adjective is scored on a three-point scale: like someone with a mental illness; somewhat like someone with a mental illness; and not
like someone with a mental illness. A rating of three always indicates the most negative rating, total scores range between 32 and 96. The higher the score the greater the adherence to stigmatized attitudes toward the mentally ill. The scale has been administered to family members and individuals with a mental illness as well as family members and individuals with Crohn’s disease and individuals who are illness free.

Family members are instructed to identify a relative with a mental illness and to complete the scale as it pertains to that individual.

For the purposes of this study, this scale was completed by the parents of individuals experiencing a first episode of schizophrenia, to indicate the degree to which they endorsed stigmatized attitudes toward mental illness. In this study participants were asked to rate people who have a mental illness, not their own child, as was the original intent of the SRQ. The decision to rate the SRQ from a general perspective of mental illness versus a more personal perspective was based on previous clinical experience with the families of this patient population. Clinical experience suggests that parents are sensitive to the application of stigmatized attitudes to their children who are in the early phases of recovery from mental illness. A generalized assessment of stigmatized attitudes takes into consideration this sensitivity.

**Thresholds Parental Burden Scale**

In order to measure family caregiver burden, this study used the Thresholds Parental Burden Scale (TPBS). It is a 29-item self-administered questionnaire, which was developed by Cook and Pickett (1988), (see Appendix I). According to Cook & Pickett (1988) burden “is comprised of a number of stresses and strains encountered in a
variety of life areas by families who deal with the disabled member” (p. 80). The TPBS was designed to be used with parents of children with severe mental illness. The TPBS covers areas such as parental feelings of connection to the ill child, preoccupation, and feelings of ongoing responsibility (Schene et al., 1994). The psychometric properties of the TPBS are well established. The scale has achieved a reliability coefficient of .80 (Cook et al., 1994). Items are scored on a six point Likert scale from strongly agree to strongly disagree. Scores are calculated by summing the scores across the 29 items. Higher scores indicate high levels of burden. The TPBS has been used to study the schizophrenia population and is useful for both research and clinical use (Schene et al., 1994).

**Mishel Uncertainty in Illness Scale—Parent/Child Form**

The measurement of uncertainty has been undertaken in medical/surgical populations (Christman et al., 1988; Christman, 1990; Mishel & Sorenson, 1991; Wong & Bramwell, 1992). However, measurement of uncertainty amongst individuals with a first episode of schizophrenia and their families has not been addressed. In this study, Mishel's (1983) Uncertainty in Illness Scale—Parent/Child Form (MUIS-PC) was used to measure the parents’ level of uncertainty concerning their son’s or daughter's illness. This scale is based upon Mishel’s conceptualization of uncertainty as a cognitive state that occurs when an individual is unable to assign definite values to objects and/or events and/or is unable to accurately predict outcomes. Responses to this 31-item self-administered scale are captured on a five-point Likert scale from "strongly agree" to "strongly disagree" (see Appendix J). An overall score and four factors are calculated.
The four factors consist of ambiguity, complexity, lack of information, and unpredictability factors. Ambiguity, the first factor refers to the absence of cues or vagueness of cues concerning the planning and carrying out of care for the child. Lack of clarity, the second factor refers to receiving or perceiving information about the child's treatment as absent or ill-defined. Lack of information, the third factor relates to the absence of information concerning diagnosis and seriousness of illness. Unpredictability, the fourth factor, refers to the inability to make daily or future predictions concerning symptomatology and illness outcome. The total scale reliabilities (coefficient alpha) are in a moderate to high range (.71-.91). Coefficient alphas for the various subscales have ranged from .72-.81 (Mishel, 1983).

**Turning Point Interview**

In order to collect qualitative data, the primary investigator used the Turning Point Interview (TPI), to enable the participants to describe from their perspective the experience of help-seeking for their son or daughter. The Turning Point Interview is a semi-structured interview and was originally developed to explore the factors that may explain the later onset of schizophrenia in women compared to men (Corin & LeSage, 1997). For the purposes of this study, this instrument enabled family members to describe their own account of the onset of a psychotic disorder and the factors related to eventually seeking professional help for their child.

The interview reviewed hypothesized turning points with the study participants that may have represented significant changes in the health status of their relative. The instrument also elicited data concerning the evolution of their relative's psychotic disorder
(Corin & Lesage, 1997), highlighting areas such as change and effect, help seeking, and consultation with psychiatric services (see Appendix K).

**Help-Seeking Data Information Sheet**

Selected information gathered during the TPI lent itself to quantification. A help seeking data information sheet was generated to collect specific quantitative information related to indicators of help-seeking specifically: 1) number of attempts to seek help; 2) length of time from first noticeable sign and symptom to seeking non-health professional help; 3) length of time from first noticeable sign and symptom to seeking psychiatric help (see Appendix L). The need for such detailed information is supported by the literature so that the initial period of illness can be more clearly understood using a variety of information sources such as the date of onset and end of the first episode of psychosis (McGorry, Singh, & Copolov, 1990).

**Methodological Rigor**

In order to achieve methodological rigor for the qualitative component the researcher addressed the four criteria identified by Lincoln & Guba (1985) that are associated with qualitative research designs, namely: credibility, transferability, confirmability, and dependability.

**Credibility**

Lincoln and Guba (1985) refer to credibility as the degree to which the data are a trustworthy reflection of the participant's experience. The primary source of data in part two of the data collection were descriptions by the parents provided during the interviews. The participants having lived and perceived the phenomenon under study are
considered the "experts" and therefore the most credible source of information (Jasper, 1994). To enhance the credibility of the information provided by the participants, and to avoid personal influence the Turning Point Interview guide was followed during data collection. Clarifying probes were also used to enhance credibility (Sandelowski, 1986).

Elite bias can be a threat to the credibility of qualitative research. Sandelowski (1986) refers to elite bias as the involvement of participants who are often "the most articulate, accessible or high status members of their groups" (p. 32). Sandelowski (1986), further states that the task "of the qualitative researcher is to establish the position of all subjects in relation to the group of which they are members" (p.32). The researcher was aware that this may have posed a threat to the credibility of qualitative findings, however was not evident in this study. All five participants had varied socio-economic status, age, and gender.

To further ensure credibility, the researcher kept field notes in order to record personal biases and feelings that occurred during data collection. This technique provided the researcher with a personal record in relation to the participants’ experiences.
**Transferability**

Lincoln and Guba (1985) state that transferability refers to the degree to which the findings of the study can be transferred to another social situation. According to Lincoln and Guba (1985), the researcher is responsible to provide a thick description of the phenomena under investigation so that the reader can determine whether the findings are applicable to his or her setting.

To ensure transferability of the research findings, the study findings are reported with descriptive detail, specifically during the personal narratives of participants. In doing so, readers are able to arrive at a transferability of findings to their own situations.

**Dependability**

Lincoln and Guba (1985) state that dependability refers to the ability of another researcher to follow the thinking, decisions and methods used by the original researcher. In order to ensure dependability, the researcher described in the research study, the process involved in the transformation of data which lead to the study findings. This includes a description of methods used to collect, analyze, and interpret the data. To further ensure dependability of the findings, readings of the 5 interviews were carried out by two members of the thesis committee. This process assured that all data were accounted for and explored, thus ensuring a consistent approach to the data analysis.

**Confirmability**

Confirmability involves an auditing process that clearly identifies the decision trail used to transform the raw data from the interview to the general categories and themes that form the basis of the study findings. According to Polkinghorne (1989), "the reader must be able to follow the thought processes that have led to the conclusions"
In order to ensure that this criterion is met, the researcher provided details regarding data collection, analysis, and interpretation. Participant excerpts from the interviews were also provided so that the reader can follow the researcher's decision trail.

**Data Analysis**

**Quantitative Data Analysis**

The quantitative data generated from the participants' responses to the study instruments were analyzed according to the Statistical Package for Social Sciences (SPSS). Descriptive and correlational analyses were conducted. Demographic data were analyzed using frequencies, means and range in order to describe the characteristics of the sample. Frequencies of study variables were assessed to determine whether the distribution of any variables was skewed. The variable that captured the time between the first reported symptom to the date of the research interview was highly skewed. Thus, two subjects were deleted to approximate a normal distribution of the data so that the data analysis could be conducted (see Table 1). Coefficient alpha was conducted using SPSS to determine the reliability of the study instruments. Correlational analysis addressed the study's quantitative research questions by correlating scores from the study instruments using SPSS.

**Table 1: Time From First Symptom to Interview**

<table>
<thead>
<tr>
<th>Time (months) From First Symptom to Interview</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>* First Symptom to Interview</td>
<td>34.85</td>
<td>49.11</td>
</tr>
<tr>
<td>** First Symptom to Interview</td>
<td>20.44</td>
<td>22.03</td>
</tr>
</tbody>
</table>

* With outliers (20 participants)
** Without outliers (18 participants)
Qualitative Data Management

Tape recorded interviews were transcribed verbatim using a word processing program. Interviews were typed single-spaced, with a blank line between speakers and wide margins were used to facilitate coding of data. The researcher played the tape back after transcribing, in order to ensure accuracy. Transcriptions were made in duplicate and kept in a locked filing cabinet in the researcher's home. Ethnograph, a computer assisted program for the analysis of text based data (Seidel, Kjolseth, & Seymocer, 1988), was used to facilitate data reduction, storage and retrieval. Following completion of the research study, the interview tapes will be destroyed.

Qualitative Data Analysis

The qualitative analysis used the text from transcribed interviews and field notes, including the researcher's observations during the interview. The researcher used methods of qualitative analysis described by Benner (1985) and Leonard (1989). These methods included thematic analysis and analysis of exemplars.

Thematic analysis involved reading the text of each of the interviews many times in order to arrive at a global analysis. From the global analysis, general categories were identified and a coding scheme was developed. These general categories lead to the identification of themes. Common themes across all five interviews were identified.

An analysis of exemplars was then carried out, whereby, exemplars were extracted from each of the interviews. An exemplar is a vignette of a particular transaction that captures the meaning of the situation. The details and circumstances of a situation, including the participants' reactions to it were coded. This led to the
development of vignettes depicting the participants’ situation, his or her concerns and practices.

All transcribed interviews were analyzed by the investigator and two committee members in order to compare and contrast the derived codes thereby enhancing credibility of the research findings and serving to control bias. Disagreements in interpretation were resolved by returning to the text.

**Ethical Considerations**

**Informed Consent**

Before proceeding with the study, the researcher obtained approval from the Office of Research Services with respect to human rights. To obtain informed consent the researcher required the assistance of the nurse-in-charge to identify potential participants for the study. The researcher explained the purpose of the study to potential participants who agreed to release their names. Study candidates were assured that their participation was voluntary, and that refusal to participate would not affect the care of their family member in anyway.

The participants were informed of the nature of the qualitative interview and its anticipated length. For those subjects who participated in the open-ended interviews, they were informed that the interview was to be tape-recorded and that they had the right to stop the tape recorder at any time. The participants were informed that all information given by the participant was secured under lock and key at all times by the researcher.
The participants were made aware that they had the right to refuse disclosure of any information which created discomfort for them, and the right to withdraw at anytime during the study, without affecting their son’s or daughter’s treatment. The participants were informed that the information they shared with the researcher would be used for research purposes. Participants were also informed who to contact if they had any comments, questions or concerns regarding the study or their rights.

Confidentiality

The study participants were assured that their privacy would be protected during both parts of data collection in order to ensure confidentiality and their anonymity. Corresponding code numbers with the name of the participants was used. The researcher kept the master list linking the code numbers to the identifying data in a locked cabinet for the duration of the study. This list will be destroyed once the study has been completed. However the consent forms will be kept without the identifying codes locked for the required six years.

For those subjects who participated in the open-ended interview, they were assured that their name would not appear on any reports although their direct quotes may be used, and they may recognize their own words. Tape recordings and transcripts would be identified only by code numbers.

Risks and Benefits

Although the researcher conducted both parts of the study in a respectful manner that ensured the privacy for the participant, various items in the study instruments may have raised concern or anxiety in the participants. In addition, in part two of the data
collection process the participant may have become distressed due to the disclosure of sensitive information during the TPI. Therefore, if the participant had become distressed, the researcher would have offered to stop the interview and to reschedule another interview at their convenience. However, participants did not become distressed during the interview. Also, participants always had the right to withdraw at any time and the researcher continually assessed the participant's comfort level during both parts of data collection.

Conversely, participants stated that they benefited from sharing their experiences with the researcher. Participants felt that their interaction with the researcher validated their experience and provided a means of emotional support for them during a stressful time.

**Study Limitations**

This study had certain limitations. The generalizability of the study findings is limited by the small sample size. Different types of help-seeking indicators may have more appropriately captured the parental help-seeking experience. For example, the number of times parents sought help from their family doctor separate from psychiatrists and psychologists, as well as the elapsed time between parents' reports of first noticeable sign and symptom and the initiation of antipsychotic medication, may have further clarified the specific nature of help seeking activities. In addition, the incorporation of more focused qualitative questions that would further elucidate the underlying reasons for delays in accessing help would have been beneficial. Specifically, were the delays related to parental uncertainty regarding their child's presenting symptoms or due to difficulties in accessing help from the health care system? As well, the fact that the majority of
parents who participated in the study had sons limits the generalizability of the study’s findings.
Chapter 4

The Study Results: Quantitative Findings

The results of the study are presented according to: 1) Characteristics of the sample; 2) Relationship of sample characteristics to study variables; 3) Results related to the study’s quantitative research questions

Characteristics of the Sample

Table 2 describes the demographic characteristics of the parents. The majority of the sample was female and the mean age of the sample was 49.7 years. This was a well educated group of parents with a mean of 14.5 years of education. One half of the sample had completed either primary (n=3) or secondary education (n=7), while the remaining half had completed post secondary education. Of the participants interviewed, 14 were employed. The remainder of participants were not employed or retired. The majority of the parents lived with the son or daughter experiencing a first episode of schizophrenia.

Table 2: Demographic Characteristics of the Sample (n=20)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Gender</th>
<th>Age</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td>Female</td>
<td>30-39</td>
<td>13 (65%)</td>
</tr>
<tr>
<td></td>
<td>Male</td>
<td>40-49</td>
<td>7 (35%)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>50-59</td>
<td>8 (40%)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>60-69</td>
<td>4 (20%)</td>
</tr>
<tr>
<td>Age</td>
<td>30-39</td>
<td>10 (50%)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>40-49</td>
<td>10 (50%)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>50-59</td>
<td>6 (30%)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>60-69</td>
<td>5 (25%)</td>
<td></td>
</tr>
<tr>
<td>Education</td>
<td>Primary/secondary</td>
<td>10 (50%)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Post secondary</td>
<td>10 (50%)</td>
<td></td>
</tr>
<tr>
<td>Employment</td>
<td>Employed</td>
<td>14 (70%)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Not employed/retired</td>
<td>6 (30%)</td>
<td></td>
</tr>
<tr>
<td>Occupation</td>
<td>Professional</td>
<td>8 (40%)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Self employed</td>
<td>3 (15%)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Technical</td>
<td>3 (15%)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Homemakers</td>
<td>5 (25%)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Retired</td>
<td>1 (5%)</td>
<td></td>
</tr>
<tr>
<td>Living Situation</td>
<td>Alone</td>
<td>1 (5%)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>With Spouse</td>
<td>3 (15%)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>With Son/Daughter</td>
<td>6 (30%)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>With Spouse, Son/Daughter</td>
<td>9 (45%)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>With Sp., Parent, other Sibling</td>
<td>1 (5%)</td>
<td></td>
</tr>
</tbody>
</table>
Demographic characteristics were also collected from the parents about their hospitalized children (see Table 3). The ages of the children ranged from 17 to 39 years with a mean age of 23.9 years. This mean age is consistent with the findings in the literature. Beiser et al. (1993) state that the early 20's is the peak age when individuals experience prominent psychotic symptoms indicative of a first episode psychosis.

Nineteen out of the twenty participants’ children were male. At the time of data collection, the majority of patients receiving treatment for a first episode of schizophrenia on the Clinical Investigations Unit were male, resulting in a predominately male sample. The composition of the sample may also reflect the higher treatment prevalence rates for males than females for DSM-III-R schizophrenia (DaSilva et al., 1993). Furthermore, according to Hafner & Heiden (1997) and Seeman & Lang (1990) males experience a more severe form of illness, with an increased number of males requiring hospitalization (Seeman, 1982).

Eighty-five percent of the hospitalized children were living with their family, 10% were living with their partner, only one individual was living alone. This was a well educated group of individuals with 55% completing secondary school, and 45% completed post secondary education. At the time of their parents interview, 85% of the children were unemployed. All had received a diagnosis of schizophrenia.
Table 3: Demographic Characteristics of the Participants’ Sons or Daughters (n=20)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Male</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>Male</td>
<td>19 (95%)</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>1 (5%)</td>
</tr>
<tr>
<td>Age</td>
<td>17 – 19</td>
<td>3 (15%)</td>
</tr>
<tr>
<td></td>
<td>20 – 29</td>
<td>14 (70%)</td>
</tr>
<tr>
<td></td>
<td>30 – 39</td>
<td>3 (15%)</td>
</tr>
<tr>
<td>Education</td>
<td>Primary/secondary</td>
<td>11 (55%)</td>
</tr>
<tr>
<td></td>
<td>post secondary</td>
<td>9 (45%)</td>
</tr>
<tr>
<td>Employment</td>
<td>Employed</td>
<td>3 (15%)</td>
</tr>
<tr>
<td></td>
<td>Unemployed</td>
<td>17 (85%)</td>
</tr>
<tr>
<td>Living Situation</td>
<td>Alone</td>
<td>1 (5%)</td>
</tr>
<tr>
<td></td>
<td>Alone w. Partner</td>
<td>2 (10%)</td>
</tr>
<tr>
<td></td>
<td>Lives w. Family</td>
<td>17 (85%)</td>
</tr>
</tbody>
</table>

Relationship of the Sample Characteristics to Study Variables

One relationship was evident between the sample demographics and the study variables. Specifically, an inverse correlation was found between uncertainty in illness and parents years of education ($r = -0.48$, $p = 0.04$), indicating that as the amount of parental education increased, the degree of uncertainty decreased. No other significant relationships were found between the demographic characteristics of the parents and the study variables. As well, no significant relationships were found between the demographic characteristics of the children and the study variables.

Research Questions

Reliability analysis was conducted for each of the three scales used to measure perceived stigma, uncertainty in illness, and caregiver burden (see Table 4). As indicated in Table 4 the coefficient alphas demonstrate an acceptable level of reliability for all scales.
Table 4: Reliability Analysis

<table>
<thead>
<tr>
<th>Scale</th>
<th>Coefficient Alpha</th>
</tr>
</thead>
<tbody>
<tr>
<td>Thresholds Parental Burden</td>
<td>.88</td>
</tr>
<tr>
<td>Mishel Uncertainty in Illness-PC</td>
<td>.83</td>
</tr>
<tr>
<td>Social Response Questionnaire</td>
<td>.83</td>
</tr>
</tbody>
</table>

Table 5 (see pg. 37) describes the mean, standard deviation, range of study variables (omitting skewed data points see pg. 26), and provides results for the following research questions.

**Research Question 1a**

What is the elapsed time between parents’ reports of first noticeable signs and symptoms and the initiation of help-seeking (non health professional and psychiatric) for their children’s emerging illness?

A mean of 4.89 months elapsed before parents sought help from non health professionals and a mean 7.33 months elapsed before parents sought psychiatric help (this includes help from either a family doctor, a psychiatrist or psychologist). In addition, 22.22 months passed from the time parents first reported signs and symptoms of illness in their children to the time of their children’s hospitalization (see Table 5).
Research Question 1b

How many help seeking attempts were reported by parents prior to their children’s hospitalization for a first episode of schizophrenia?

In this study parents sought psychiatric help slightly more than three times (3.39), predominately from family doctors, with subsequent referrals to psychiatrists and psychologists compared to the mean of .89 from non-health professionals (see Table 5).

Research Question 1c

What is the level of perceived stigma, caregiver burden, and uncertainty in illness that parents experience at the time of their children’s hospitalization for a first episode of schizophrenia?

The mean SRQ score (70.7) indicates that parents held some stigmatized attitudes towards those with a mental illness. The mean score of the TPBS (122.4) indicates that parents scored towards the upper range of parental burden. Parents also expressed a moderate amount of uncertainty surrounding their children’s illness, as indicated by the mean score (89.5) of the MUIS-PC. The mean subscales score of the MUIS-PC were also elevated: 40.50 for ambiguity, lack of clarity 21.39, lack of information 13.67 and 13.94 for unpredictability (see Table 5). These scores are elaborated upon further in the discussion chapter.
**Research Question 2a**

Is there an association between indicators of parents’ help-seeking [i.e. number of help-seeking attempts; length of time from first noticeable sign and symptom to seeking help (nonprofessional and psychiatric)], and perceived stigma, caregiver burden, and uncertainty in illness at the time of their children’s hospitalization for a first episode of schizophrenia?

No association was found between indicators of parental help-seeking and the study variables.

**Research Question 2b**

Are there associations amongst the study variables: perceived stigma related to mental illness, caregiver burden, and uncertainty in illness at the time of their children’s hospitalization for a first episode of schizophrenia?

Two associations were found amongst the study variables: 1) a relationship between stigma and caregiver burden and 2) a relationship between ambiguity (uncertainty-subscale) and burden. Specifically, as stigmatized attitudes towards mental illness increased, parental burden also increased (r= .47, p=.05). In addition, as ambiguity increased so did burden. (r= .47, p=.05).

Relationships were also found between the study variables and number of symptoms which caused distress as well as the number of symptoms. Specifically, lack of clarity, an uncertainty subscale, was significantly correlated with the number of symptoms which caused distressed. Indicating that as lack of clarity increased so did the number of symptoms causing distress (r= .55, p=.05). In addition, the data analysis revealed a significant relationship between number of reported symptoms and parental
burden (r=.47, p=.05). As expected, as the number of symptoms that caused distress increased so did parental burden (r=.46, p=.05).

Table 5: Mean, Standard Deviation and Range of Study Variables

<table>
<thead>
<tr>
<th>Variable</th>
<th>Mean</th>
<th>SD</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>TPBS * (29 - 174)</td>
<td>122.4</td>
<td>23.3</td>
<td>69 - 154</td>
</tr>
<tr>
<td>UNCERT * (31 - 155)</td>
<td>89.5</td>
<td>14.14</td>
<td>57 - 121</td>
</tr>
<tr>
<td>AMBITOT * (13 - 65)</td>
<td>40.50</td>
<td>8.08</td>
<td>26 - 54</td>
</tr>
<tr>
<td>CLARTOT * (9 - 45)</td>
<td>21.39</td>
<td>6.16</td>
<td>9 - 33</td>
</tr>
<tr>
<td>INFOTOT * (5 - 25)</td>
<td>13.67</td>
<td>2.99</td>
<td>5 - 19</td>
</tr>
<tr>
<td>UNPRETOT * (4 - 20)</td>
<td>13.94</td>
<td>2.86</td>
<td>10 - 20</td>
</tr>
<tr>
<td>SRQ * (32 - 96)</td>
<td>70.67</td>
<td>7.42</td>
<td>56 - 82</td>
</tr>
<tr>
<td>NUSYMP</td>
<td>3.89</td>
<td>1.53</td>
<td>2 - 7</td>
</tr>
<tr>
<td>NUSYMDIS</td>
<td>3.83</td>
<td>1.62</td>
<td>1 - 7</td>
</tr>
<tr>
<td>TIMNONHP</td>
<td>.89</td>
<td>1.18</td>
<td>0 - 4</td>
</tr>
<tr>
<td>TIMPSYCH</td>
<td>3.39</td>
<td>1.29</td>
<td>1 - 6</td>
</tr>
<tr>
<td>SYM2NOH (months)</td>
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Chapter 5

The Study Results: Qualitative Findings

In order to gain further understanding of parental help-seeking a descriptive summary of each of the five interviews is provided. This allows the reader an opportunity to gain a richer understanding of the parents help-seeking experience. Following the descriptive summaries, emergent themes and exemplars will be presented. An exemplar is a vignette, a short description of a particular transaction that captures the meaning of the situation (Benner, 1985). Verbatim quotations of the participants’ own words from the transcribed data are provided. The names of the participants and their family members have been changed to protect their identity.

Interview #1

Mrs. T is a woman in her fifties who works as a teacher. She is presently on a leave of absence from work. She is married and has two children, a daughter with cerebral palsy age 14, and a son, Anthony, age 22. Mrs. T first noticed changes in Anthony when he returned home from his second year of university. At the time she did not place any significance in Anthony’s behavioural changes as she associated these changes with his age. She described Anthony as a very gentle person who had become very argumentative and irritable towards his parents.

Following the completion of his second year of university, Anthony returned home for the summer. At that time, he told his parents that he was smoking marijuana because it helped to clear up things that were bothering him. Mrs. T acknowledged that this was a very stressful time for her family. Working for long periods of time, caring for
a daughter with cerebral palsy and having to deal with Anthony’s drug use were overwhelming for Mrs. T. She decided to take a leave of absence from work.

During the summer, Anthony’s inability to save money and his desire to quit school were often topics of family discussions. Anthony’s parents reached a point where they confronted him. His parents gave him the ultimatum that if he did not change his ways, he was to leave by October, which he did. Over the next six months, it was obvious from his phone calls that Anthony’s behaviour continued to change. Anthony no longer had a social life, instead he spent all of his time meditating. Anthony’s parents pleaded with him for several months to return home. When they saw Anthony during this period, they noticed that his physical health was also deteriorating. He had lost weight because he wasn’t eating. Anthony did not have any money and yet refused to go home. He also continued to insist that marijuana was good because it helped him to see things clearly.

At that point Anthony’s parents knew that something was wrong.

Mrs. T remembers waking up one morning during the summer and knowing that Anthony had schizophrenia. She had read a little bit about schizophrenia and knew of someone who had it. At this time, she described feeling panic stricken but also a sense of relief, in realizing that Anthony had this illness. Mrs. T contacted a unit specializing in schizophrenia and described Anthony’s symptoms to the staff. Once the staff heard about Anthony’s symptoms, they told Mrs. T that he appeared to be a person at risk, and suggested that she contact a Justice of the Peace to place Anthony on a certificate. Her attempt to have Anthony certified was unsuccessful because she was unable to prove that Anthony was a danger to himself.
Over a number of months Anthony’s parents tried to convince him to return home with them. Finally he agreed, however, rather than getting into the car, Anthony ran away from them. His father tried to follow him but was unsuccessful. The police were then called. The following day, Anthony’s father visited the Justice of the Peace, in order to arrange for Anthony to be hospitalized if found. The Justice of the Peace, although sympathetic, still did not believe there was enough evidence to warrant such actions. Anthony went missing for eleven days. On the twelfth night, police were contacted by a woman who had found Anthony on the side of the road appearing quite frightened. Anthony asked the woman to phone police. The police arrived, brought him to the hospital and contacted his parents. Anthony’s parents did not recognize Anthony when they saw him in the hospital. He had hypothermia, was completely dehydrated and had lost weight. While in emergency, Anthony revealed to his parents that he had returned to the woods, instead of waiting for them at the restaurant, because he had seen a sign in a rock saying he should.

Following his admission to hospital, Anthony was placed in intensive care where doctors used intravenous fluids and antibiotics to help stabilize his condition. In fact, according to his mother, by the third day in hospital Anthony was looking “amazingly better, physically”. At this point, his parents met with the nursing staff and explained that they believed their son was suffering from schizophrenia and asked that a psychiatric consultation be arranged. Four days after being admitted to hospital, an attempt was made to have a psychiatrist meet with Anthony. Anthony however refused treatment. Because Anthony was no longer in physical harm and was refusing mental health treatment the hospital discharged him later that day.
The following morning, Mrs. T and her husband visited the family doctor and insisted that he get help for Anthony. He suggested they return home and “if necessary phone the police” if Anthony attempted to leave. In the mean time, the doctor phoned a psychiatrist he knew at a local hospital and arranged a consultation. This local hospital quickly arranged a transfer to a specialized unit where Anthony could get help. At that point, Mrs. T felt relieved and was very thankful that he was finally getting the help he needed.

**Interview #2**

Mrs. P is a teacher in her mid forties. She is separated from her husband and lives with her two sons. Mrs. P and her husband noticed changes in one son Gerard, age 18. The behavioural changes in their son evoked worry and a sense that Gerard was depressed. They also knew that Gerard was taking drugs. Fortunately, Gerard also recognized that he was not well and asked his parents for help. They arranged for a family friend, who was a psychiatrist, to see Gerard on an outpatient basis once a week. Gerard’s outpatient psychiatrist determined that Gerard’s behavioural changes were caused by a combination of depression and substance abuse. Despite this, Gerard’s parents still found it difficult to understand whether the changes in Gerard were the result of a substance abuse problem, an underlying mental illness or, as they described, “an over-rebellious teenager”. In conjunction with the outpatient psychiatrist, Gerard was admitted to a drug day treatment program for twelve weeks and also received help from a private drug rehabilitation counsellor.
Several months later, Gerard’s outpatient psychiatrist recommended a second opinion because it was apparent during their weekly sessions that Gerard was experiencing “some psychotic thinking”. He arranged for an assessment at a clinic that specialized in first episode psychosis. It was the opinion of the clinic staff that Gerard did not have schizophrenia, but rather a substance abuse problem. The staff also recommended that Gerard be taken off the anti-psychotic medication that was prescribed by his outpatient psychiatrist. At the same time, Gerard also decided to stop using all the other drugs. As for Mrs. P, she described feeling relieved that Gerard did not have such a “conclusive diagnosis” as schizophrenia.

Two weeks after the clinic assessment, Mrs. P and her husband met with Gerard’s outpatient psychiatrist. The psychiatrist made them aware that psychotherapy was no longer the best approach and that Gerard was becoming hostile toward him. This occurred while Gerard was off his anti-psychotic medication, and was no longer taking any other drugs.

It was also during this time that Mrs. P began to see increased changes in Gerard’s behaviour which included restlessness and agitation. She described one instance when Gerard returned from school with glazed eyes, hallucinating and talking nonsense. She accused him of taking drugs, which he denied. Mrs. P did not know what was happening. The next morning Gerard managed to go to school. That day, Gerard’s mom received a phone call from the school principal stating that Gerard’s teacher thought he was stoned. The police were called to come to the school because it was a drug issue. Gerard outwardly denied any drug use. When his father picked him up from school, Gerard
insisted that his dad take him to a clinic for a drug screening test to prove that he had not taken any drugs. The results were negative.

Not knowing what to do, Gerard’s parents contacted his outpatient psychiatrist who suggested that they bring Gerard to the emergency department of a psychiatric hospital. After convincing Gerard that he needed help, he agreed to go to the hospital. Working full time and worrying about her son made this time very stressful for Mrs. P. Having been recently separated from her husband, she came to a point where she insisted that her husband share some of the stress. Mrs. P asked her husband to bring Gerard to the emergency department of a psychiatric hospital. Following his emergency assessment, Gerard was admitted to the hospital. Mrs. P described feeling relieved that Gerard was now in a safe place and was receiving the help he desperately needed.

During his hospitalization, Gerard received the diagnosis of schizophrenia. Mrs. P described not feeling relieved with this diagnosis. She would have preferred the diagnosis of bipolar stating that “there are many people who live normal lives with bipolar. You don’t hear too many success stories with schizophrenia. At least I don’t”.

Mrs. P worried that Gerard would be affected by society’s stigma towards schizophrenia. She questioned if an employer could ever find out that Gerard had spent time in a psychiatric facility and if anyone ever truly gets better from this illness and are able to function normally. Mrs. P acknowledged that schizophrenia has received a lot of bad publicity, because people still associate homicide and violence with this illness. She stated that mental illness continues to be buried in a closet and advocated for more education among school administrators regarding detection of this illness. Mrs. P also recommended that there be more advocacy groups for parents who are concerned about
their child’s mental health, so that parents would know who to contact. In light of her recommendations, Gerard’s mother remained optimistic and tried to impart hope and optimism for Gerard and his father.

**Interview #3**

Mrs. Si is a woman in her mid-forties who works in a daycare. She is re-married and lives with her husband and two children, a son and daughter. Over the past six months, she had noticed changes in her son Steve, age 26, which affected his family relations, work productivity and mood.

Mrs. Si described seeing noticeable changes in Steve’s behaviour during the Spring of 1996. Although many of his characteristics remained (quiet, gentle, nice and co-operative), Steve became increasingly “withdrawn”, would pass family members in the streets without saying hello and would come home “and would just sort of glare”. Other changes included spending more time alone in his room, and refusing to eat with the family.

A key event that Mrs. Si attributed to her son’s behavioural changes occurred when Steve was 15. Although Steve’s mother does not know the exact circumstances behind the incident, she was made aware by her cousin that Steve had witnessed a violent “trauma”, which caused him to become withdrawn. Steve was not physically hurt but Mrs. Si felt he was affected mentally. When she found out about the incident 5 years after it occurred, she urged Steve to “go see someone, talk about it because if you don’t, you can’t keep things bottled up, it will get worse”. At the time Steve showed great displeasure in being reminded of the incident stating “Why did you bring that up? I was just - - I was forgetting about it. I don’t want to talk about it”. Mrs. Si recalled that Steve
would “just sit there thinking that I was telling him there was something wrong with him mentally”. At that point she just “left it alone”. Mrs. Si believed that this incident began a cycle of feelings of sadness, anger and repression which continues to this day.

During a regular dental check up in 1996, Mrs. Si was also informed by her dentist that: “Steve needs help. He’s either on drugs, he has a tumor or he’s been through trauma and somebody’s got to help him because it’s out of his hands”. However, despite the growing concern for Steve’s mental health, Mrs. Si still did not know how she was going to get help for Steve.

At first Mrs. Si tried to help Steve help himself. Steve would often complain of muscle aches. Hoping that Steve would share his feelings with a doctor, Mrs. Si suggested that Steve visit his family doctor. After the visit, when the pain had not gone away, Mrs. Si suggested that his pain might have been caused by something else. “Well maybe it’s something else and, you know, are you depressed about something or something on your mind is bothering you?” Steve would not respond to these suggestions. After receiving a call from Steve’s employers informing her that Steve would soon be fired, Mrs. Si decided that it was time she saw the family doctor herself.

At her visit with the doctor, Mrs. Si shared her concerns. The doctor mentioned that he had noticed changes in Steve’s behaviour and had asked the other doctors in his office to pay close attention to Steve if he ever came back. The doctor believed that Steve suffered from schizophrenia and requested that Mrs. Si arrange a follow up appointment for Steve.
A week after the appointment, Mrs. Si still had not heard from the doctor and things continued to get worse with Steve. She phoned the doctor herself. The doctor suggested that in order to avoid a lengthy wait between booking an appointment and the actual consultation, Mrs. Si should bring Steve to a psychiatric emergency unit. Fearing that Steve might be too frightened to go to a hospital specializing in psychiatric care, Mrs. Si brought Steve to a general hospital where he was assessed by a doctor who did not specialize in psychiatry. From there, Mrs. Si and Steve were sent to another hospital which had psychiatrists on staff. After the second consultation, Steve was admitted to the hospital for two days of observation. Mrs. Si recalled that Steve “felt trapped”. After this, the doctors recommended that Steve be transferred to a hospital specializing in psychiatric care. Although Steve agreed with this because “he felt like something was wrong” he still wondered why they just couldn’t put him “into a regular room, regular hospital?”

As for Mrs. Si, although she knew that they were doing the right thing she panicked when they arrived at the psychiatric hospital “because one of the patients rooming with Steve was in his bed; and like I’m frightened because I don’t know this hospital, I don’t know that patient, I don’t know anything about the situation and I’m also doing this to my son, you know, I’m bringing him here. I’m helping him but it frightened me….I felt like ‘oh my goodness, he can’t stay here!’ ”. Mrs. Si also stated that her greatest fear was that Steve would encounter patients who were violent.

Mrs. Si recalled crying when she learned that Steve was psychotic. In addition, Mrs. Si further described feelings of both sadness and anger especially when talking to her mother about Steve’s illness. Mrs. Si recalled feeling angry after one conversation in
particular when her mother said “maybe he’s schizophrenic...you know, you’re born that way. It’s a disease....it’s too bad”.

Mrs. Si would have preferred a diagnosis like depression for Steve, because she felt this type of illness was more common. She remarked that “You hear people talk, oh, I’m depressed today. But you never hear people say, oh, I’m psychotic, have been for the last six months; because that’s a fear that - - psychosis is almost like you think somebody who’s gonna hurt you.”

Finally, Mrs. Si remained hopeful that the work of health professionals, group meetings and counselling would continue to assist the family through this experience. As she reflected, “I didn’t know how I would possibly get Steve to get some help. But I was so happy when [Steve’s family doctor] realized he saw something....He saw that Steve was calling out for help”.

Interview #4

Mr. W is a man in his early fifties who works as an engineer. He lives with his wife. Their son Colin, age 25, lives away from home to attend university. Mr. W first noticed a change in his son in the Summer of 1993. On that occasion, Colin called his parents from the border crossing between Canada and the United States, after attending a concert. Colin suspected that someone was after him and was frightened. Although Mr. W found this incident puzzling they did not seek any help for Colin thinking that “he must have smoked something” at the concert.
In the Spring of 1994, another incident occurred when Colin called his parents from Ottawa, once again feeling scared and paranoid that someone was after him. On this occasion Colin’s mother went to Ottawa followed by Mr. W, one week later. At the time, Colin’s parents suspected that the changes they saw were the result of Colin taking drugs. Once again the incident passed without seeking help.

Over the next two years several isolated incidents occurred which concerned Colin’s parents. On several occasions when they spoke to Colin over the phone they noticed that he would make unusual statements. Specifically, Colin would tell his mother that he thought he was pregnant, or that he was afraid of dinosaurs because they eat people. Mr. W could not understand what Colin was talking about on these occasions.

Early in the summer of 1996, Mr. W and his wife visited Colin again in Ottawa. It was on this trip when they finally realized that Colin needed help. They found Colin agitated and restless. On one occasion while at lunch with Mrs. W, Colin suddenly became very upset and angry and began to curse and swear to a point where Mrs. W was embarrassed. Once again Colin’s parents had difficulty finding an explanation for Colin’s behaviour. “From that point we had to do something for him.” Mr. W and his wife did not talk to doctors, family or friends about seeking help for Colin but rather talked between themselves. They thought the changes in Colin were the result of Colin either experiencing “some mental disorder” or that Colin was using drugs. This uncertainty made it hard for them to share their dilemma with others.
In the later part of summer 1996, Colin’s parents arranged counselling for Colin through their work place. It was their hope that the counsellor would convince Colin to see a doctor and eventually a psychiatrist. However, Mr. W recalled not sharing their suspicions about Colin with the counsellor, and instead, only revealed that Colin was sick and that they did not know what was happening to him. They continued to be unsure if the problem was an underlying mental illness or a drug related problem.

Colin continued to see the counsellor in Ottawa through the summer however, as Mr. W described, things continued to get worse. During subsequent telephone conversations, Colin’s parents learned that he had been suspended from school because he had not fulfilled his course requirements and that he had lost his part-time job. In addition, his girlfriend had also broke up with him because, as she described she “couldn’t deal with him anymore”. At this point, Mr. W and his wife wanted Colin to be home with them, so that they could get him to see a doctor rather than have him struggle on his own. They pleaded with Colin to come home at which time he agreed to do so.

When they arrived home they convinced Colin to see his family doctor. Prior to Colin’s appointment, Mr. W and his wife visited the doctor to inform him about Colin’s unusual behaviour. Upon hearing their description, the family doctor immediately mentioned to Mr. W and his wife different types of illnesses such as manic depression and schizophrenia which matched their description. Colin saw the family doctor on a weekly basis for 3 to 4 weeks.

Colin’s parents were growing impatient because they believed that something was still not right with Colin’s behaviour. They visited his family doctor again to determine what was happening. At that time, the doctor told his Mr. W and wife that he diagnosed
Colin with schizophrenia. Knowing that it was quite a serious disorder, Mr. W insisted that Colin have a second opinion from a psychiatrist specializing in schizophrenia.

Mr. W waited for several weeks to get a report regarding the psychiatrist’s assessment. During this waiting period, Colin’s unusual behaviour increased. He began talking to the TV, writing poetry that didn’t make sense and was very angry and upset. Tired of waiting, and anxious for Colin to receive treatment, Mr. W phoned the family doctor to find out what the results of the second opinion were. Mr. W explained to the doctor’s secretary the things were happening in the house: Colin was yelling in the garage at 1 o’clock in the morning and walking in the middle of the road. Once again, Colin’s parents were left waiting.

Mr. W was eager to understand what was going on. He began reading books on mental illness. He found out about Ontario Friends of Schizophrenia and he and his wife attended a support group at a hospital. In the mean time, Colin’s symptoms continued to worsen. His family doctor prescribed an anti-psychotic medication which failed to help. Colin had a reaction to the medication and was taken to a hospital emergency. After his medications were reassessed Colin was released from the hospital.

Soon after his discharge from the emergency, Mr. W described a critical incident. The family was having supper together when they noticed that Colin was becoming restless. Colin grabbed a knife and pointed it towards Mr. W. Feeling quite frightened, Mr. W grabbed the knife from Colin. His wife started to cry. Colin became increasingly distressed and started shouting, not making sense. Mrs. W was very afraid and attempted to call the police but Colin wouldn’t let her. Instead, Mr. W took his son to the hospital. Colin was discharged from the emergency within hours, and an outpatient
appointment was arranged for him at a specialty clinic in a psychiatric hospital. His parents attended this appointment with Colin at which time he was immediately admitted to the hospital.

Commenting on their help-seeking experience, Colin’s parents stated that they were relieved when Colin was finally getting the help that he needed. They would have preferred, however, for Colin to have received faster help from his family doctor and consulting psychiatrist. In efforts to better understand his son’s illness, Mr. W read many books on schizophrenia. He also commented on the usefulness of parent support groups. He stated that they are very useful “because we [parents] need someone to talk to as does Colin”.

Interview #5

Mrs. A is a woman in her mid-forties, who is a home-maker. She is divorced and lives at home with her son John, age 20. John has a business diploma and is presently unemployed. Mrs. A first noticed changes in her son during the birth of her granddaughter, a week before Christmas, 1996. While at the hospital, shortly after the birth, John, his brother Paul, and their mother were standing together outside the hospital when John suddenly began to cry. When asked what was wrong, John could only say that he did not know. Because this incident occurred during a time when John’s girlfriend had left him, he had just moved to a new home and had just completed school, Mrs. A thought that John ’s behaviour was attributable to “a few things that were bottled up”.
On Christmas eve another incident occurred. During the evening John once again “broke down and started to cry”. After this incident, Paul and John went into the kitchen. Paul approached John at which point John backed away, giving Paul the impression that John was afraid of him.

John asked his brother Paul to take him to a hospital emergency department, which he did. John told the emergency staff that he had not slept in four days. The staff gave him medication to help him sleep and sent him home. Once home however, Mrs. A described John’s behaviour as “erratic”. “...he was jumping up and down [on] the bed, his brother and his Dad were there, and they went in the room with him, they sat with him and they tried to calm him down”.

In early January, John went to his family doctor because of his inability to fall asleep. When he met the doctor, John described himself as feeling sad. After this appointment, the doctor gave John diazepam to help him sleep and asked that he return for a follow up appointment. His doctor suggested then that John see a psychiatrist. Mrs. A recalled that she felt “O.K” with this suggestion because she wanted to get help for John.

At the initial meeting with the psychiatrist, they discussed John’s daily moods and behaviour. Mrs. A recalled that during this time she continued to “to have a positive outlook considering that John was getting the help that he obviously needed...from the medical profession”. After charting his mood for seven days, the doctor prescribed an anti-depressant. In addition, the psychiatrist suggested that they now meet once a week.
After being on medication for three weeks, Mrs. A noticed other changes in John’s behaviour. She recalled one night in March 1997 when John claimed to have ghosts in his room; he opened up all the windows in the middle of the winter to let the ghosts out. Through the night Mrs. A was beside herself, not knowing what to think or do. She contacted the staff of an emergency department, who suggested that she take John to a Crisis Clinic in the morning. The next morning, John and his mother met with two doctors who asked John questions about the ghosts. The doctors’ identified the ghosts as delusions. “Right away I [Mrs. A] thought that was the right illness”. The doctors also recommended that John be put on an anti-psychotic medication.

Following the assessment at the Crisis clinic, Mrs. A felt “fit to be tied”. In addition, Mrs. A remembered that she felt resentful [which she no longer feels] toward John’s psychiatrist. She stated that “he should have maybe even foreseen something coming in”. Mrs. A also believed that her son was “getting overlooked, he’s just missed or he’s fallen through the cracks somewhere and he’s not getting proper attention...To top that off, when Dr. R saw us and knew that John had been into the Crisis Clinic, the first thing he said to me, quite angrily too was, ‘Why didn’t you let me know that John wasn’t getting well?’...meanwhile, we’re seeing this man on an average of five to seven days [a month]...so I built up a little resentment”.

By March, John was unable to concentrate on anything. During the day John was “sleeping a lot. He was in his bed a lot...he appeared to be worsening, talking more about the ghosts. He was doing silly things sometimes too....worrying things”. As an example, Mrs. A recalled finding John standing in the middle of the kitchen squeezing oranges into his eyes.
By the end of April, Mrs. A had talked to a friend who told her of two hospitals which dealt with the type of disorder John was suffering from. She called a social worker at one of the hospitals who informed her that she needed a referral from John’s doctor in order for John to be assessed at the hospital. Unhappy with John’s psychiatrist, Mrs. A returned to their family doctor. Following his assessment of John, the doctor appeared concerned and later that evening phoned Mrs. A. He told her that he had called the hospital and “that things were going to start to move”. Mrs. A recalled that John was “crying a lot, I mean really crying like it wasn’t just a cry, it was a moaning combined with pain cry, and his facial expressions showed that he was like in torture and suffering”.

Mrs. A brought John to the hospital’s outpatient clinic which specialized in psychosis. They recommended that John be admitted to hospital for further assessment. On several occasions, over the next three to four weeks, Mrs. A brought John to hospital. John however, refused to stay any longer than one night. After four weeks, John decided that he needed to go back to the hospital. Mrs. A described John’s decision to return to the hospital: “I’m sure he felt he wasn’t getting any much better; and I think he knew that by going in...well he was hoping ...he would find the help”.

Mrs. A described the entire help seeking process as tedious at times because of the lack of resources and direction. She recalled relying on the support of two friends, one of whom had a child with a mental health illness. Mrs. A stated that she encountered a major barrier when John’s psychiatrist diagnosed John as suffering from depression rather than schizophrenia. But even in that situation, she believed, the doctor was only doing what he believed to be best for John. Mrs. A described herself as feeling great and hopeful about the future. Although the help had not been there in the initial stages of John’s
illness, the staff of the hospital were “magnificent and very supportive...I’m confident that here is where John will be on the road to recovery”.

**Emergence of Themes**

The following themes were present in all of the interviews. The exemplars within each of the themes reflect the experience of help-seeking for parents of individuals with a first episode of schizophrenia. Theoretical knowledge and research findings are incorporated throughout. The three overarching themes and corresponding subthemes that emerged from the data are summarized below.

**Evolving Change: What does it mean?**

The participants identified noticeable change(s) in their children which worsened over time. Parents engaged in a constant search for understanding the changes that were occurring in their children. Parents were also faced with the challenging task of managing the behavioural changes.

**Continuous Help-Seeking**

Parents identified the need to seek help based on the changes occurring in their children. Parents described the ongoing efforts that were necessary to persuade their children that they needed help. They continuously sought help and information from many avenues which included community supports and health care professionals. There was also an urgency to seek help marked by a critical incident that led to hospitalization.
The Help-Seeking Experience: Impact on parents

Parents identified a disruption in family relations related to the behavioural changes in their children. This disruption was characterized by disagreements amongst family members regarding how to manage these changes, and competing demands within the family. In recognizing that their child had an illness parents acknowledged a need for understanding and support. Parents also held certain beliefs about their child’s illness. The entire help-seeking experience evoked a vast array of emotional responses by the parents.

Evolving Change: What does it mean?

“Evolving Change: What does it mean”, was identified as the first overarching theme and is characterized by the following subthemes: a) noticeable change(s) in the child from his/her normal self, b) change(s) in the child worsened over time, c) a constant search for understanding regarding these changes, d) managing changes in behaviour by parents.

Noticeable changes in the child from his/her normal self

Parents described a noticeable change in their children from their normal way of being. This noticeable change was described by all of the parents, and evoked in them feelings of concern, alarm and bewilderment. Noticeable changes were apparent in the child’s mood and behaviour which left the parent with feelings of uncertainty as they struggled to explain these changes. According to Jarboe & Kilts (1998), family and friends may be the first to notice the changes in the individual. Furthermore, the family
can often sense that “something is not quite right, even though they may not be initially certain what the problem is” (p. S4).

Parents noticed mood changes such as, anger and depression and behavioural changes such as, social withdrawal and suspiciousness. These findings are consistent with the prodromal signs and symptoms described by Jarboe & Kilts (1998). The authors state that before treatment contact many of these patients have experienced social isolation and withdrawal. Social withdrawal was also apparent in the Northwick Park study (Johnstone, et al., 1986), who reported that 65% of patients presented with social withdrawal. It was this behaviour that initially alerted families to the awareness of a problem. Similar findings have been cited by Yung & McGorry (1996), in a study of the prodromal phase of psychosis. Study participants, reported experiencing depressed mood, social withdrawal, and suspiciousness. Seventy-six percent of the subjects experienced depressed mood, and seventy-one percent experienced social withdrawal and suspiciousness.

The following excerpts illustrates the children’s emotional and behavioural changes that were described by the parents. Mrs. T first noticed a change in her son after his second year of university in 1995. She described Anthony:

As always a very kind of gentle person and he became very argumentative, very...ahm dark in a way. Talking about how the world was useless and there wasn’t much point being at university. Because the real things that were important weren’t being taught there, [we thought] he’s just being exposed to different ideas now and him finally leaving home...I didn’t think anything of it.
Mrs. P's described the first change she observed in her son: "I guess it was about two and a half years ago when his Dad and I began to become...quite worried that he...was quite depressed".

Another participant, Mrs. Si, recalled the first behavioural changes in the following manner:

He wasn't talking to the family, ahm, he was...was more or less withdrawn... he would not respond unless he would ask the question. And, ah, on the street he wouldn't say 'hi' to his sisters, his sisters said hi to him he would just stare... he wouldn't say hello when he came home and would just sort of glare. I wasn't sure if he was angry or just tired from work. I didn't--I couldn't understand or read his gestures. Ahm, he spent more time in his room...he used to eat with us all the time and then he sort of refused to eat with us, bought his own groceries, whenever I'd cook he would say 'no thank you'. Maybe it was--I felt maybe it was control, controlling his own life, ah, because of his anger or depression or whatever.

Mrs. Si was also alerted by a friend who noticed Steve was not his usual self during a telephone conversation she had with him: "'Hi, Steve, is your Mom there?' There was a long pause. Sort of ... like somebody was breathing heavy, like it was hard work; and then she said 'Steve, is your Mum home?' and he just said, 'NO' "'. Following this conversation when Steve seemed not himself, Mrs. Si's friend told her: "I don't know what's wrong, something's wrong" with your son.
Mr. W described the first changes in his son as follows:

... there was an instance where he called us from Waterloo between Detroit or somewhere crossing into... the border into Canada, that he was scared that somebody is [out] to get him and that somebody is after him and I was quite puzzled.

Mrs. A first noticed changes in her son at the time of her granddaughter’s birth. While she was at the hospital with her family, her son John suddenly began to cry. She recalled that her other son asked John what was wrong, John’s response was “I don’t know”.

**A Constant Search for Understanding**

Parents described a constant search for understanding the changes that were occurring in their children. Three parents attributed the changes in their children to drug abuse, while other parents attributed the changes to developmental characteristics associated with their children’s age. Mrs. T recalled that when she first noticed the changes in her son, both she and her husband attributed them to “his age”. As the months passed, and the changes worsened his parents attributed the changes to drug use. The need to understand the precipitant of these changes is illustrated as follows:

... he continued not to have any social life because he needed to just meditate... that went on... from the June... right through the summer we kept constantly going to see him pleading with him to give this up and come home.

You see, we thought it was the marijuana that changed him like this.
Mrs. P knew that her son was abusing substances, yet she found it difficult to understand the changes she observed in her son. Although Mrs. P describes a number of possible explanations for the changes she was still left feeling quite puzzled with no definitive explanation:

Well I don't, it was really hard to determine whether or not we had a drug addict in waiting, or whether or not there was an underlying mental illness, or whether or not he was just an over rebellious teenager. I mean we really didn't know what we were dealing with.

In an attempt to understand why her son was becoming so withdrawn, Mrs. Si questioned her son: “Are you depressed about something or [is] something on your mind bothering you”. Her son did not respond. Mrs. Si initially attributed the changes in her son to emotional trauma. She had found out from her cousin that Steve had witnessed a violent episode when he was fourteen, approximately eleven years ago. Although he was not hurt, Mrs. Si felt that he was hurt emotionally by it. She concluded that Steve’s behaviour had changed because he had witnessed this violent episode. Ever since Mrs. Si found out that her son had been exposed to this violent episode, she kept a closer eye on him, as she describes:

Well, I was looking for depression or withdrawal, why he's withdrawing from us all. He was just a doer; he finished his high school, got a job, he just kept functioning without having those emotions of laughter and ahm, he couldn't relax after a while, he...become like a robot.

She further stated...“because he was so quiet it was quite hard for me to determine what was wrong with him”.
Mr. W described his belief that the changes in his son were possibly the result of his son taking drugs, however, he remained open to other possibilities. He described arguing with his wife about what was causing the changes in their son. Mrs. W remained adamant that the changes must be drug related:

...at that time we were arguing, myself and my wife...my wife is absolutely sure that this is a result of drugs. And I remember very vividly, we [drove] over five hundred kilometres, we argued about this back and forth. I kept saying, look let's leave open [the] possibility that it could be [a mental illness] even one per cent...it was difficult to convince my wife to even accept possibility of something else other than drugs.

Mr. W and his wife continued to be worried about Colin and struggled to understand why these changes were occurring in their son:

So we got a little bit concerned and worried and we went to see him. And our eyes really opened at that time when we saw [him]... he was a little bit agitated like he couldn't pick out the restaurant, we didn't know again, we thought, what the heck, maybe he smoked something and he had a sip of coke and rum. Whatever happened, I don't know.

Mrs. A believed that the behavioural changes in her son were caused by a number of events that were occurring in his life. As she recalls:

... his girlfriend had just left about maybe a month or so before and, ahm, we had moved to a new address, uh, and he had finished school; it was a few things that was all bottled up. So I figured it was probably all of that.
Mrs. A struggled to understand her son's unusual behaviour. She explained it as follows:

...one night, I was walking through the bathroom to the bedroom and it was around maybe one in the morning, the lights on in the kitchen, I look in the kitchen, C. is standing in the middle of the kitchen. And there was oranges, we had oranges and he was squeezing the orange juice in his eyes! And I didn't understand that. It was really bizarre behaviour. And another time, ahm, he was eating garlic, lots of garlic; garlic bread and anything with garlic in it he wanted to have. It was almost like it was a compulsion to do those things took over, because he had cried so much and he was crying a lot, John felt he had no more tears, and I think this is his way of making his eyes water. He did that with onions too.

**Changes in the Child Worsened Overtime**

All the participants noticed that the behavioural and emotional changes that they observed in their children became worse over time. This observation is consistent with the literature. Specifically, Yung & McGorry (1996) in a study of prodromal psychosis, reported that the majority of participants (19 out of 21) first experienced vague behavioural changes that ultimately lead to the development of overt psychotic symptoms. Mrs. T recalled the process of deterioration that occurred in her son:

...The day he left he was completely strange. He was dancing around; we pleaded with him just sit down and have a talk. Anyway, he walked out and we didn't know where he was going. Five days later he phoned us and he said that he loved us but he needed to [be on his own over the summer]. That sounded very feasible to us... But through the [following] six months it was obvious that from his phone
calls he deteriorated. He continued not to have any social life because he needed to just meditate that went on from June through the summer (of 1996), we kept going to see him pleading with him to give this up and come home.

Mrs. P recalled her son Gerard became increasingly hostile and could no longer tolerate seeing his outpatient psychiatrist. As she described: “Gerard was starting to get sort of hostile towards [his psychiatrist] and [his psychiatrist] is a really nice guy and he certainly would take Gerard back as a patient. But he no longer thought that psychotherapy was...really...the best approach”.

Mrs. Si noticed that the changes in her son’s behaviour began to affect his work performance, to a point where his employment was terminated. As she described:

...I was talking to his supervisors at work without him knowing, because they called me once and I kept in touch. They called me because of his behaviour, he walked out...ah, once to go to night school and didn’t tell them. So I kept in touch with his work and found out they were terminating his...employment there and...told me he would just stand around and stare at people and he would never talk to anybody.

Mr. W recalled the deterioration of his son’s behaviour. These changes were especially evident when he spoke to him over the phone:

...there were a number of times that he didn’t make sense. He would—for example, [make a] statement about, you know, maybe I’m pregnant, you know, dinosaurs eat people, stuff like this. We’re talking, I don’t know how we got to this dinosaur thing, he said, ‘Well, you know, I’m scared of dinosaurs’. I said,
‘come on Colin, what are you talking about’. He said, ‘No, dinosaurs, they eat people, you know’...

For another participant, Mrs. A, she described a decline in her son John’s ability to converse and concentrate which interfered with his social life and school performance. She recalled: “…he had no concentration. John was great TV watcher and reader, a talker, …from a little boy he was talking…That all ceased”.

**Managing Changes in Their Child**

Most of the participants described their continued efforts to manage the changes in their children. According to Caplan (1982) mental illness increases the family’s responsibility to monitor and control its family members’ behaviours. Fisher, Benson, & Tessler (1990) further state that the family’s day-to-day responsibility for controlling behaviour adds a new supervisory role among family members. Different strategies were used to keep their children safe. Some parents encouraged their children to live at home, while others chose to have a “low key approach” by not confronting their children directly with their concerns. Other parents exerted more direct control by modifying their own schedule in order to more closely monitor their children.

Mrs. T recalled an incident when she was alone with Anthony at home and feared doing anything that might upset him:

...I remember, I mean I didn't want to say the wrong thing; I had a real feeling that I could spook him into running, you know. You just had that feeling from him. So I didn't want to say anything, I just...sat with him.
Similar behaviour has been described in the literature as “walking on eggshells” (Chafetz & Barnes, 1989; Lefley, 1987). Ryan (1993), in her study of mothers living with adult children with schizophrenia, referred to this behaviour as “accommodating” to the ill child. In accommodating, parents tolerate difficult illness behaviours in order to maintain a sense of normalcy within the household.

Mrs. Si described her attempts to manage the noticeable changes in her son: “I just sort of got busy and did other things...I wasn't thinking about it as much. I was just keeping an eye on him more. Didn't bring it up, and he wouldn't talk about it”.

Mr. W recalled that he and his wife were quite determined to bring their son home so that he could receive help. Mr. W recalled the first night of their journey home:

…We almost forced him to go with us; he reluctantly went with us, we found [a] motel, it was a nice motel and ah, he didn’t want to sleep, he was agitated, restless, he went to bed, he kept going out smoking, he didn't want to go to bed and eventually later on I was watching TV, he lay down on the bed in [his] clothing and eventually, you know, ah, fell asleep.

In another case, Mrs. P’s managed the changes in her child’s behaviour by modifying her own sleep schedule:

Well I mean, I wasn’t getting any sleep. And one morning I heard him start up my car at three-thirty in the morning. By the time I sort of realized what he was doing, he was gone. I think he just went out to buy some cigarettes and he was back shortly... he smokes and I could smell the smoke coming up from …from his bedroom. I was afraid he was gonna burn the house down. So I was afraid to go to sleep.
In summary, all participants noticed a change(s) in their children which progressively worsened over time. These changes affected both the child’s mood and behaviour. The parents struggled to understand and manage these changes.

**Continuous Help-Seeking**

Continuous help-seeking was described by all participants and is the second overarching theme. It is characterized by the following subthemes: a) identifying the need to seek help, b) persuading their children to seek help, c) seeking help from community supports, d) seeking help from health care professionals, e) urgency to seek help marked by a critical incident/worsening of symptoms leading to hospitalization.

**Identifying the Need to Seek Help**

Three of the parents identified the need to seek help for their children. In two of the cases, it was the children themselves who identified the need to seek help. Quotes illustrating the parent’s perspective are provided followed by the children’s perspective.

Based on the ongoing changes in her son, Mrs. T described her sudden realization that Anthony may have schizophrenia. Specifically she said:

...I woke up one morning and I knew, I just knew, I don't know why or how I knew, but I knew that—I'd read a little bit about schizophrenia, and a friend of mine his brother had it, and I'd never put the two together; and I woke up and I had this idea in my head, I knew this is what Anthony has. And I went to the library and I got some books, now that I knew something was wrong.

Following the realization that her son may have a serious mental illness, Mrs. T contacted a unit at a psychiatric hospital and described her child’s symptoms to the staff.
As she recalls: "...I described the symptoms and she [the nurse] said this seems to be a person at risk, and I said well what do I do about it? So, she talked to me about, seeing a Justice of the Peace..."

Mrs. Si remembered that the decision to seek help for her child came after being alerted by her son's dentist and a personal friend that her son was ill. Mrs. Si recalled her dentists advice: "...I think Steve needs help, he's either on drugs, he has a tumour, or he's been through trauma and somebody's got to help him because it's out of his hands".

Following the dentist's comments, a similar response from a friend and his behaviour at home, Mrs. Si realized that Steve needed help.

In another case, Mr. W decided to seek help for his son based on the pronounced unexplainable changes that he and his wife observed in their son. Mr. W was determined to convince his son to seek psychiatric help and remembered pleading with him: "...look, you have to—you have to go see [a] doctor and not just [a] doctor, you have to see [a] psychiatrist, because we were suspecting something is not right by him..."

In the following two circumstances it was the children that approached their parents stating that they needed help:

Mrs. P described that she and her husband became quite worried that their son was depressed. They also knew that he was abusing substances. She recalled that her son finally approached them and told his parents that he needed some help.

In another case, Mrs. A recalled an incident that arose between her son John and his brother Paul, which was the precipitant that led her son to acknowledge that he needed help:
Mum, it looked like...John thought [Paul] was coming towards him to do something to him. He backed right away from [Paul], just stared back at him. And then he had asked his brother maybe about half an hour after that, "[Paul] take me to the hospital. Take me up to Emergency". And when I just sat down, [Paul] came and said, "Mum, I'm going to take him".

**Persuading Their Children to Seek Help**

For all of the participants numerous attempts were made to persuade their children that they needed help. The need for parents to persuade their children to seek help may be in part, a result of or related to the children’s lack of insight or awareness that help was needed.

Mrs. T recalled a time when she and her husband attempted to seek help for their son. She described their desperate efforts to persuade Anthony to return home so that he could receive help:

...So we felt completely helpless at helping him. We begged him to come home, we kept contact with him, we'd given him money, we'd done everything, you know, and he wasn't budging. And we couldn't understand it, you know. It just didn't make sense if somebody had no money, facing being thrown out at the end of August...he wouldn't budge.

Their efforts to convince their son to come home continued. They knew his whereabouts and kept in contact with him via telephone. As Mrs. T described:

...I phoned him and I persuaded him to come home, and...he just seemed to make the decision; I think he was frightened, think that's what it was. He made the decision
over the phone to come, so I phoned my husband, ahm, he was working, he works in the afternoon sometimes... and he said "Okay, I'll pick him up as soon as I finish". He drove to (city) at eleven o'clock at night, picked him up, came back, we thought breakthrough, you know. Soon as he walked in the house he said, "I've made the wrong decision. I've made the wrong decision, I have to go back". And I mean, Anthony, for goodness sake, you know, just go to bed, calm down. So we persuaded him to go to bed. I couldn't sleep all night. I knew, you know, I thought he was going to take off again.

Anthony did not stay with his parents for long and after awhile returned to his university living accommodation. Despite this, Anthony's parents continued to try to convince their son to return home via telephone with little success. In light of this, they went to visit their son with the intention of bringing him home with them:

We have the car, we said okay Anthony, enough of this now. We tried then... strong arm tactics, you now... we told him to put all the stuff in the car, so he agreed to put the stuff in the car. All his stuff was in the car and we thought okay, you know, he's going to come now. But he ran away... he had a knapsack with him and you know, we thought he's just gonna come in the car. So he didn't; he walked out to the car and he ran like the wind. And we couldn't-- my husband followed him but he just ran away. So we called the Police.

In another case, Mr. W recalled feeling unsure why their son Colin was so reluctant to return home with him. However Mr. W was quite clear that that he and his wife "wanted him to be home with us to really get him to see a doctor". As he further described:
We kept talking...look. Colin, you gotta go--what are you gonna do there, you're debarred, you don't have a job any more, what the heck, you know, [the] best thing for you is to come home, forget about everything, come home and just relax and you will be fine... you have to go to [the] doctor...

Attempts to persuade Colin to return home continued even while his parents were on vacation in Europe. As Mr. W described:

... we kept calling Colin, and finally last day in Paris when we called before we came home, we were talking I remember there...was the telephone booth somewhere here in the motel, and ah, he miraculously, you know, said, "Okay, I'm gonna, you know, I'll agree, I'll come". I was so happy...

In another case, Mrs. P recalled that she had to really “work with” her son to convince him that he needed help. This incident was when her son Gerard was brought to a hospital emergency following an escalation of Gerard’s behaviour. On the advice of Gerard’s outpatient psychiatrist, he was brought to the hospital emergency. With persuasion Gerard agreed to be admitted to the hospital. As Mrs. P recalled “…so finally after really working with him, finally this one morning he said, "I think it's time for me to go", and so we got him in”.

Mrs. Si realized that Steve needed help, but she did not know how she was going to get that help. She hoped that their family doctor would see Steve, realize that something was wrong and activate the necessary help for Steve. As Mrs. Si recalled this wish for help did not transpire:

...in a way I tried [to get] Steve to help himself. Ahm, he told me he had pain in his shoulders and his neck and his head, he always had headaches. And I said,
'Well, see the doctor'. And he did, and I would ask how did it go at the doctor's? And he said, ah, 'Oh, Dr. P. said to me to take Advil because my muscles are sore'. So maybe a week later I asked him, 'did the Advil help'? He said 'no, not at all'. And I said, 'Well maybe it's something else and, you know, are you depressed about something or something on your mind is bothering you? Sometimes the muscles will do that when we're holding on to something'. Then he just had this face like, 'no'. And I said, 'Well, don't be so sure of it'... 

Seeking Help from Community Supports

Parents elicited help for their children from many avenues within the community including: friends, community agencies, and in some instances the police. This is consistent with the theoretical formulation of help seeking by Freidson (1960). Freidson states that the process of seeking help begins with informal consultants until the professional is reached. At times, parents encountered barriers in their search for help.

Mrs. T first described her son's symptoms to hospital staff, who recommended that she contact a Justice of the Peace. Eliciting the help of the Justice of the Peace was very frustrating for Mrs. T's husband. As she recalled:

...he went to find out about it...they more or less said there's no way that you'll get one [Justice of the Peace] anyway because you cannot prove that he's a danger to you see at this point he hadn't really done anything bizarre except going back to where he lived, right? And they said he's twenty..twenty-two, you know, there's no proof that this person is a danger to himself.
Despite these recommendations, Mrs. T and her husband persevered and continued to seek help from the Justice of the Peace. They went back a few days…

…my husband went and told her the story and she was very sympathetic but incredibly still refused to put him on this form one, so that if he was found he would be taken to hospital. She said it's not enough evidence…I think that's wrong, completely wrong. I mean there was evidence at that time, but she said she couldn't. I mean I'm sure, you know, she was sympathetic but she couldn't. Despite their efforts, they were unable to get help from the Justice of the Peace.

Shortly after this, they visited Anthony with the intention of bringing him home. Anthony fled and his parents once again sought help, this time from the Police and encountered more difficulties:

So anyway, we phoned the police from that house and the policeman came, and I didn't realize this…the policeman said to me in that driveway, "If you're telling me that he's…has threatened you or he's threatened himself, are you telling me that?" And I didn't get it. He wanted me to say 'yes, he is a danger to himself' or 'yes he has threatened', then he would have initiated it. But you see, I suppose he couldn't do anything.

Mrs. T was finally able to get assistance from the Police to search for her son after he went missing for eleven days. Mrs. T recalled that the process of finding her son was quite an ordeal:

So, we drove around looking for him all afternoon, so did the police, we went back the next day, we went all around looking for him because it's only a small
place. We toured all the parks, everything. So was the Police looking for him.

They had a picture of him...

After searching for Anthony for several days, Mrs. T received a call from police informing her that Anthony had been found by a girl, alive at the side of the road.

Other parents contacted different types of community supports in efforts to deal with the changes occurring in their children. As Mrs. P recalled, ‘it was difficult to determine what was causing the changes’ in her son. However, they were sure that Gerard had a substance abuse problem. To deal with this issue, Gerard was referred to a drug treatment program for 12 weeks. He also saw a private drug rehabilitation counsellor four to five times. Gerard did not feel that the drug counsellor was helping him, so he stopped seeing him. Gerard did however continue to see an outpatient psychiatrist for a period of time.

In another case, Mr. W sought the help of a corporate counsellor through his wife’s workplace. “... the first time that we tried to sort of get some help, perhaps through counselling hoping that she would convince him to go and seek help and see the doctor and eventually [a] psychiatrist”. Mr. W, his wife and Colin continued to see the corporate counsellor for three sessions, however Mr. W felt that the counsellor was not helping Colin. Mr. W went to see Colin’s family doctor for further help.

Mrs. A sought help from two close friends, one of whom had a son with a psychiatric disorder. Mrs. A received tremendous support from these two individuals. She recalled that one of these friends informed her about two hospitals in her area who helped people with psychiatric disorders. With encouragement and advice from this friend, Mrs. A was able to arrange for her son, John, to be seen at a hospital based
outpatient clinic. This outpatient assessment contributed to John’s immediate hospitalization.

**Seeking Help From Health Care Professionals**

At some point during their help-seeking experience all participants contacted a health care professional, namely, their family doctor. Most often, the contact with mental health care professionals was made during the latter part of their help-seeking experience. It was during the contact with health care professionals that parents encountered barriers, experienced substantial frustration, and subsequent delays in activating the appropriate help. This is consistent with findings in the literature. In a study by Winefield & Harvey (1994), family members emphasized the frustration they experienced when they attempted to access help. The study found that families were frustrated that help was not readily available until their family member’s health was severely deteriorated. In the Northwick Park study, Johnstone et al. (1986) described the difficulties that family members encountered in obtaining appropriate assessment and adequate clinical management. In a study of early onset schizophrenia, Hoff et al. (1996) also found that for some general practitioners there was uncertainty regarding appropriate treatment management.

Mrs. T described having to convince health care professionals that her son needed help for his psychiatric illness. She recalled an incident where her son was found by a girl along the side of a road after being missing in the woods for eleven days. The police brought Anthony to the emergency so that he could be physically stabilized. After he was
physically stable the staff were about to discharge him. Mrs. T described her concerns regarding this decision:

...this was on the Monday and I went straight to the, ahm, nurse and I said, I explained to her and I said, "I am pretty sure that this person is suffering from schizophrenia. We have tried to get a Justice of the Peace all day and we've not succeeded". I said. "He cannot leave this hospital without being seen by a psychiatrist". So they asked...a psychiatrist to see him, and the psychiatrist saw him on a Tuesday morning, but Anthony refused treatment. And he was [discharged] that evening and I really, really question that, and I think that was a terrible decision in light of the evidence. Because if we hadn't been there to pick him up, he could have been like many people, gone out onto the street.

In order for Mrs. T to obtain a psychiatric assessment for Anthony she had to return to her family doctor the following day. The family doctor arranged a psychiatric consult for Anthony at a local hospital. Anthony did agree to go to the hospital stating “that it didn’t matter anymore” given that he had “failed his mission”. Following the initial assessment, Anthony was admitted to hospital, but was quickly transferred to a different hospital unit which specialized in first episode psychosis.

In another case, Mrs. P acknowledged that having contacts enabled her to obtain a psychiatric assessment for her son “...we were lucky; I mean we had that connection. I don't know we probably would have gone through our family physician if we hadn't had the connection with [a psychiatrist]”. However, the psychiatrist suggested that Mrs. P seek a second opinion for Gerard from an assessment clinic specializing in psychosis.
Mrs. P described the rationale for this recommendation, as follows: "he told us that from
the previous summer that [Gerard] had patches of, he never called it psychotic thinking or
psychosis, he just said [Gerard] had crazy thoughts sometimes".

At that time the clinic staff identified that Gerard did not have schizophrenia, and
stated that his problems were related to substance abuse. Mrs. P remembered the
assessment findings of the clinic staff: "we don’t think you [Gerard] have schizophrenia,
go off the medication and see what happens". Two weeks after this assessment Gerard’s
outpatient psychiatrist “…wasn’t so sure that things were quite as rosy as the clinic had
said”. He noticed that Gerard was becoming hostile and questioned whether
psychotherapy was the best approach for Gerard. Gerard discontinued seeing his
outpatient psychiatrist stating that "I don’t need this guy anymore, I can solve my
problems myself". Soon after, Gerard experienced an acute exacerbation of his symptoms
and was taken to the emergency department of a psychiatric facility. Gerard had to wait
several hours in the emergency department before a bed became available to him.

Mrs. Si recalled that Steve was complaining of physical ailments so she encouraged
him to go see their family doctor. Mrs. Si was also concerned that Steve was
withdrawing from others. It was unclear if Steve disclosed anything to his family doctor
pertaining to his mental health condition, (particularly his withdrawn behaviour), so Mrs.
Si went to go see the doctor herself:

…I thought maybe Dr. F…would help him, but you can’t help a person unless
they talk. And he [Steve] was not saying. He probably went in there and said ‘I
have headaches, and I get sore backs’. So he prescribed, ah, something to take the
pain away. But he didn’t know anything else because Steve. didn’t say anything.
So that’s when I had to...see the doctor myself and disclosed to him ... “I’m really worried, my son is not responding to us”.

The family doctor disclosed to Mrs. Si that he did notice something different about her son and indicated that Steve may be catatonic. Mrs. Si remembered her response to the doctor’s assessment:

...Oh? and I said, ‘Is that schizophrenic?’ and he says it’s a form of. He said, ahm, ‘What you can do is make an appointment for him, just tell him that I was concerned about him, just tell him when to come in’. So I did that, I said, ‘Dr. F. phoned and wants to see you on...’ such and such a day. And Steve said, ‘Why?’ And I said, ‘Probably follow-up from your physical’.

Steve kept the appointment, but Mrs. Si was unsure of the outcome. Feeling quite “desperate” she phoned the doctor’s secretary wanting some answers. That evening the doctor phoned Mrs. Si at home and suggested that she bring Steve to the hospital emergency in the morning, which Steve agreed to. Getting the proper assessment for Steve was quite an ordeal for Mrs. Si. Unfortunately, the first hospital they arrived at did not have psychiatrists on staff, so they had to take a cab to an alternate hospital to obtain a psychiatric assessment. “...So they cabbed us over there [alternate hospital], a couple of doctors spoke to him, and decided he needed...help and said, ‘Steve, we’ll keep you in here for a couple days for assessment, okay’, and Steve agreed”.

Following this assessment period the staff decided to transfer Steve to a specialized psychiatric hospital Mrs. Si recalled Steve’s response to this decision:

He was willing to be there, he felt safe. He felt like something was wrong, but he says, "Why can’t they just put me into a regular room, regular hospital?" So ah,
on the 14th of February they decided to bring him to (the specialized hospital) because there was a better program for young men his age that are going through it for the first time, and he’d have more to do...more programs.

For another participant Mr. W, his contact with health care professionals began when Colin went to go see his family doctor at the request of his parents. Colin had seen the family doctor a few times but as Mr. W described “nothing really happened”. Prior to Colin going to see the family doctor for the first time, Mr. W and his wife talked with the doctor themselves:

...We went in and he was quite surprised, you know, and we told him, “Look, it's really not for us, it's about our son, Colin”. And we sat down and we expressed our...concerns, we talked about, you know, a number of episodes or rather, you know, unusual behaviour...

Following this discussion, the doctor immediately mentioned certain diagnoses such as manic depression or schizophrenia that might pertain to Colin. After the parents’ appointment with the family doctor, Colin went to see the doctor, a few times. As Mr. W recalled: “…then nothing happened. You know, Colin -said to us that he's fine, that, you know, everything is okay; we kept probing and asking, so what the doctor said, and you know, what you gonna do? Nothing happened”.

A few months had passed and Mr. W and his wife went back to the family doctor to find out what was happening with their son. At this time the family doctor told them that Colin had schizophrenia. Mr. W requested a second opinion from a psychiatrist because he knew that schizophrenia was a serious disorder. Mr. and Mrs. W were unhappy with the family doctor’s response: “Look, I can tell within five minutes if a
person is, you know within five-five minutes, you know, with inappropriate laughing and this and that. I guess he was probing Colin…he was quite sure about-about his diagnosis”.

The family doctor did make an appointment with a psychiatrist for Colin, but made it quite clear to Mr. W that it would take some time. Several weeks later Colin and his mother saw the psychiatrist. It then took several more weeks until Mr. W would receive the results of the psychiatrist’s assessment. During this waiting period Mr. and Mrs. W continued to notice Colin’s unusual behaviour, and became increasingly concerned and frightened.

As Mr. W described: “I became anxious…after all this …we wanted to do something for Colin so that he could finally get treatment”. During this time, Mr. W had to bring Colin to the emergency department because of the side effects he was experiencing from the antipsychotic medication that his family doctor prescribed. Following this emergency assessment an outpatient appointment was made for Colin at a clinic specializing in psychosis. This outpatient assessment led to Colin’s immediate hospitalization.

Mrs. A recalled that her contact with health care professionals began after her son John requested to go to the emergency. John wanted to go to the emergency because he had been having difficulty sleeping for the past four days. Mrs. A also consulted her family doctor, because she was also concerned about John’s mood. John informed the family doctor that he was continuing to have difficulties sleeping. The doctor prescribed medication to help him sleep providing some relief for John, however his sad mood and withdrawn behaviour persisted. As Mrs. A described: “John was always a very talkative
person...Verbally he didn't want to communicate and talk to anyone. So the doctor suggested a therapist for him...a psychiatrist".

John saw the psychiatrist once a week for a few months. It was during this period that the psychiatrist prescribed an antidepressant for John. However, at the same time John was experiencing bizarre thoughts about ghosts. Mrs. A did not know how to handle the bizarre thoughts so she contacted a hospital emergency in the early hours of the morning. They suggested that she bring John to their crisis clinic in the morning, which she did. Mrs. A recalled the content of this assessment:

...they had assessed John for a bit, they talked to him, they talked to me, talked about the ghosts, and ahm, the doctor had said to me then that was the first time I heard the word delusion...So...he's delusional and I right away I thought that was the right illness right there...Something was really wrong. So he had used the word delusional, and as I say, that was the first time I'd really heard that.

At this time, Mrs. A questioned why John's outpatient psychiatrist had not detected John's psychiatric illness. As Mrs. A described:

...I thought that he should have maybe even foreseen something coming in, but I know today he couldn't. But at that time, not knowing anything, I didn't. I couldn't-I couldn't fathom this doctor overlooking...I'm thinking my son's getting overlooked, he's just missed or he's fall[en] through the cracks somewhere and he's not getting proper attention here, you know. And then—and to top that off, when Dr. R. seen us and knew John had been into the Crisis Clinic, the first thing he said to me, quite angrily too, you know, 'Why didn't you let me know that C. wasn't getting well'?
Following the clinic consultation, Mrs. A asked her family doctor to make a referral to an outpatient clinic that specialized in psychosis. She had heard about this clinic from a friend. The referral was made by her family doctor as she recalled: “the doctor was so concerned that day, he called me at nine-thirty that night to let me know that, ahm, he had called and things were going to start to move”. Following this assessment John was admitted to hospital. After several short admissions, John eventually agreed to stay in hospital for treatment.

For the participants there was delay in receiving the appropriate help for their children. Parents had to go back to their primary care provider a number of times to insist that their child needed help. This observation is consistent with findings in the literature. According to Helgason (1990), earlier treatment could most likely be provided if more attention was given to the changes first observed by the patient’s relatives and friends.

Urgency to Seek Help Marked by Critical Incident/Worsening of Symptoms

All participants recalled an escalation in their children’s symptoms which prompted an urgent help-seeking response. For example, when Mrs. T noticed that Anthony’s symptoms were getting worse, she increased her help-seeking efforts. Unfortunately, Anthony had decided to leave home at this time and went missing for several days. Mrs. T contacted the police to help them find Anthony. Anthony was finally found and brought to the hospital by the police as Mrs. T described:

...he was gone for eleven days, and on the Thursday night I get a phone call from the policeman saying a girl had found Anthony. at the side of the road, a girl had phoned the police after finding Anthony. at the side of the road...the girl who saw
him, thank God, she was scared at first, she told the police and I mean, you know, she didn't know who he was, but he'd asked her to call the police. And so she did. And they took him to the Emergency and this policeman phoned us and I phoned my husband and we were there an hour and a half later.

Although Anthony's physical status was stabilized during his hospitalization, his mental health was not assessed. Once Anthony was discharged from hospital, Mrs. T described her urgent attempt to receive help from their family doctor:

...We took him home because it was, ahm, eleven o'clock at night, and it was obvious he was going to run again. So the next morning I went to my--to his family doctor, and I said to him, 'You have... to help me. I can't--we've got to get Anthony in hospital'. So he listened...he said okay, to go back home, make sure, 'if necessary phone the police that Anthony doesn't leave and I will phone the hospital, I know a psychiatrist there'.

Following this insistent plea for help by Mrs. T, Anthony was admitted to hospital and received the treatment he needed.

In another case, Mrs. P described a sudden change in her son’s behaviour that she thought was related drugs:

...we had a nice visit over lunch and I drove him back to school and he came home at five-thirty, wild. Eyes glazed, ahm, talking nonsense, hallucinating, so of course I accused him of having done drugs and he denied ...I'd never seen this wild look before.
The next day, despite still being in this “state”, Gerard managed to attend school. Later in the day, Mrs. P received a call from the school principal stating that he believed Gerard’s behaviour was related to a drug issue and that police should be called in. Instead, Mrs. P was able to arrange for her husband to pick Gerard up from school. Gerard insisted that he had not taken drugs and the following day demanded that his father take him for a drug screening blood test. The results of the test were negative.

During the course of the week, Gerard continued to display unusual behaviour. As Mrs. P described: “One morning I heard him start up my car at three—thirty in the morning. By the time I sort of realized what he was doing, he was gone”. This unusual behaviour prompted Mrs. P to seek immediate help for Gerard by contacting his former outpatient psychiatrist, which lead to his hospitalization:

...Well I thought he was losing it; at this point we started talking, trying to—we called Dr. N, he said “get him down to Emerg at the [the hospital],...but because he's age of majority he had to wait for him to agree”. So finally after really working with him, finally this one morning Gerard said, ‘I think it's time for me to go’, and so we got him in.

One week following her son’s visit with the family doctor, Mrs. Si phoned the doctor’s secretary and asked that the doctor phone her at home. Mrs. Si recalls the telephone conversation with her doctor:

Listen, [Mrs. T], it’s getting worse. I said yes. [Dr. R] ‘What you do is you take him in the morning down to [to the hospital]’. [Dr. R] says, ‘I could make you an appointment [with a psychiatrist], but you might not get in for four...six months or whatever and it’s gone that far. So do that; take him down there’.
Mrs. Si felt she could not wait four-to six months for Steve to be assessed by a psychiatrist. She took her son to the hospital emergency for an assessment, which led to Steve’s hospitalization.

For Mr. W, the urgency to seek help intensified after an alarming incident when his son threatened both he and his wife. The incident occurred one evening shortly after dinner. Mr. W recalled that Colin suddenly grabbed a knife from the dishwasher and pointed it towards him. Although Mr. W was able to retrieve the knife, he felt frightened and could not understand what was happening to his son. Mr. W’s wife began to cry which caused Colin to become increasingly distressed. Colin began shouting without making sense. Mr. W’s wife tried to call police but was stopped by Colin. Mr. W was able to wrestle Colin down to the ground and wait until police arrived. Together with police, Mr. W was able to drive Colin to the hospital emergency.

At the hospital, an outpatient assessment appointment was made for Colin at a specialty clinic and he was discharged from the emergency. Following the assessment at the clinic, Colin was immediately admitted to an inpatient unit, specializing in psychosis.

In summary, all parents identified the need to seek help. They frequently had to convince their child that help was needed. Help was sought from a variety of sources including community supports and health care professionals. All parents describe their help-seeking experience as frustrating and full of delay. Frustration resulted from the parents need to convince health care professionals that their child needed help. Johnstone et al. (1986) recommends that there be continued education for general practitioner’s in detecting a first psychotic episode so that appropriate management can
be instigated immediately. Ultimately, all but one parent experienced a critical incident which led to the child's hospitalization.

**The Help-Seeking Experience: Impact on Parents**

The help-seeking experience had a definite impact on all of the parents. This impact is characterized by the following subthemes: a) disruption in the family, b) illness recognition: need for understanding and support, c) parental beliefs associated with the illness, and d) range of emotional responses to the help-seeking experience.

**Disruption in the Family**

During the course of illness onset and the subsequent help seeking experience, parents described a strain in their relationships with family members which caused a disruption in family life. Disruption in family relations has also been cited in Cook & Pickett (1988). These authors describe that conflict such as increased tension in family relations arises as attempts are made to deal with the ill relative. The disruption in family relations was related to the following factors: a) the behavioural changes in the child, b) disagreements amongst family members regarding how to manage these changes, and c) the competing demands within the family.

**Disruption in Family Relations Related to Behaviour Changes in the Child**

Mrs. A recalled an incident that occurred between her son John and his brother Paul, which was uncharacteristic of how they normally related to one other. Paul described this occurrence to Mrs. A:

‘Mum, it looked like John thought I was coming towards him... to do something to him. He backed right away and just stared back’... Paul had said, ‘John,

Mrs. Si felt her son Steve was angry with his family and blamed them for putting him in the hospital:

…he seems angry-angry with us; he wants out all of a sudden. I wasn't able to come here for a few days, so I think he became angry that I put him in here and he's mentally ill he feels now, and ah, I just don't care, that's what he said over the phone in few words.

Disagreements Amongst Family Members Regarding How to Manage These Changes

Mr. W described that he argued a lot with his wife concerning what was causing the changes in their son:

…we were arguing, myself and wife, going-going to (city) a couple of times, you know, we went there and I had a hard time; you start arguing about this…it was difficult to convince my wife to accept the possibility of something other than drugs.

Mrs. P described:

Well one of the things that became an issue in our house was that, ahm, when the drug usage persisted, my husband wanted to throw him out of the house; the tough love approach, and I must say that's kind of where the beginning of the end of our relationship happened because I wasn't prepared to throw him out on the street.

Mrs. P further commented on the breakup of her relationship with her husband:
...I think one of the biggest things I have always thought this about Gerard, he has remorse, like he feels badly about...ultimately my husband and I split up about four or five months ago and certainly, well, it wasn't all the fault of Gerard, certainly, but it put a damper on the...family relationship.

Mrs. Si acknowledged the discord between herself and her husband who did not believe their son’s condition was severe enough to warrant hospitalization. He felt that Steve was not psychotic, but rather severely depressed.

**Competing Demands Within The Family**

Mrs. Si described having to continue to fulfill her responsibilities at home while trying to find time to see her son in hospital:

I think he's sort of set himself back with anger that--I didn't see him for a few days; I was here every day for a while, but I couldn’t. I had to watch my granddaughter because my daughter got a job, so it was hard for me and, ah, he said to me over the phone, ‘There's one piece of me that’s missing’ I says, ‘What is that, Steve?’ he says ‘there's just something missing’. I said ‘what?’ And he says, ‘My family’.

Mrs. T described that dealing with the changes in her son and her competing demands was a "stressful time for the family":

...we had decided we'd try and get along better with Anthony, too, so we left it at that. But we never wavered from saying frequently that we didn't agree with it [taking drugs]. Well, that was...a very stressful time for the family because I had decided to take a leave of absence because I was just, ah, well I was--I was kind of exhausted with... a) working full-time, b) having, ahm, a daughter with cerebral
palsy. I put it down to well, you know, there were times when you just can't cope with all that.

**Illness Recognition: Need for Understanding and Support**

All participants voiced the need for understanding and support once they realized that their child had an illness. Almost all of the participants were involved and benefited from support groups for parents. As Mr. W described:...“Now my wife and I are going to parent groups at the [hospital] which are very helpful because we need someone to talk to, just as Colin [his son] does”. This need for understanding and support for parents is consistent with the findings of Ryan (1993). In Ryan’s study, participants also recommended that more community support services be available to parents.

Although Mrs. A “felt pretty isolated” when she first noticed the changes in John, she now felt that she had the support she needed: “I mean if I hadn't had support...for the first month of John being ill,...they [health care providers] certainly made up the last few weeks. I've had all the support and it—which in return I'm feeling good for that”.

Mrs. Si described that she had received a mixture of support and understanding from her friends and family. She recalled receiving support from a girlfriend and a lack understanding from her mother:

...when I hear people like my Mum, you know, said ‘Well I hope he's getting good help, where is he’? I said, ‘[the hospital]’. She says, ‘Oh good’. But then she says, "Oh that's too bad". Sometimes I don't want to hear 'that's too bad' because that's negative. I'd rather hear, ‘oh, he's just getting some, ahm,
rehabilitation’ and a girlfriend of mine said that. ‘We all need that sometimes, just a change, a break in his life’. That makes me feel better. But when my Mum—and she also said ‘oh maybe he's schizophrenic’. And I thought... she says, ‘You know, you're born that way. It's a disease’. And that's when she says, ‘Oh it's too bad’ and I just felt a bit angry at her.

She further described how much she values the support she has received from health care providers: “…good professionals, counselling, group meetings, groups, talking it out with no pressure…”

Mrs. P advocated for more parent support groups to be available, as she described it would “be useful, maybe, if there was more publicity about advocacy groups where parents who were concerned about their children would know instantly who they can sort of talk to”.

**Parental Beliefs Associated with the Illness**

It was apparent that during the course of the interviews that participants had certain misconceptions and stereotypes about their children’s illness. In particular, they feared what the future might hold for their children who are now diagnosed with schizophrenia. There was also a fear that their children would be stigmatized by others.
For Mrs. P the fact that her son Gerard was diagnosed with schizophrenia greatly concerned her:

Well I'm not relieved he has schizophrenia. I would prefer bipolar (laughs). Not that I know much about that, but at least, you know, there are a lot of people who live pretty normal lives with bipolar. You don't hear of too many success stories with schizophrenia. At least I don't.

She further states that she would prefer if they would find another name for schizophrenia, given that it has a very negative connotation for herself and others:

I wish they would find another word for it. I mean, they found a new name for manic-depressive illness, bipolar disorder sounds a whole lot better than manic-depression. Why can't they find another one for schizophrenia...people still associate homicide and violence with this disease.

Mrs. P was also very concerned about how Gerard would handle disclosing his illness to others:

Now is he going to be given any counselling about how to...handle, ahm, telling people this...he [Gerard] said the other day, ‘how do I tell people this?’ And I said well you don't go up to someone you don't know, ‘I'm Gerard and I have schizophrenia’. I said, you know, you don't do that. But I said at the same time, if you end up having a, you know, a fairly serious relationship with someone, then it's something that, you know, you would probably want to disclose... but is he given any counselling in terms of how to do that? Without scaring the death out of whoever he tells.
For another participant Mrs. Si she was very concerned for her son’s safety when he was hospitalized on a psychiatric unit, as she described:

I’m frightened because I don’t know this hospital, I don’t know that patient, I don’t know anything about the situation and I’m also doing this to my son, you know, I’m bringing him here. I’m helping him but it frightened me. I said to the nurse, "Can I speak to you for a moment?" And I went out in the hall, I [said], "He might be comfortable, but I’m not comfortable. How is this roommate of his?"

She said, "Oh don’t worry, he’s fine". I started to panic...are there patients here that are violent...

Mrs. Si further revealed her fears surrounding the illness label her son now has and would prefer like Mrs. P for her son to be diagnosed with depression:

If there’s one medication, and not three pills, he might go along with depression because that’s more common. You hear people talk, ‘oh, I'm depressed today’.

But you never hear people say, ‘oh, I'm psychotic, have been for the last six months’; because that’s a fear that--psychosis is almost like you think of somebody who’s gonna hurt you, automatic, that’s a scary word. Like a psychopath. You know, I hear that about people who kill and that. So, he [Steve] fears what his disease is... I still absolutely have to find out what is a psychopath...

Another participant, Mrs. A, recalled that the doctor used the word delusion to describe why her son was behaving a certain way. She knew the meaning of the word but never thought it could be used to describe an individual:
I mean I know delusional and delusions... means that... you think something there isn't, almost, and ahm, so I knew enough about delusion then, but I'd never had it referred to people...I never really heard anything like that before. So it was all new, all different.

A misconception that Mrs. T had was her belief that street drugs may have been beneficial in alleviating her son's psychosis:

But as Dr. R. pointed out, he could have been smoking marijuana because he would say to us, 'It makes me feel better'. Well if the psychosis was bothering him, perhaps it made him feel better because, I don't know... I mean he always would say it's good, marijuana is good, it makes you see things clearly.

**Emotional Response to Help-Seeking Experience**

Parents described a vast array of emotions during the course of seeking help for their children. For many of the parents they felt overwhelmed with feelings of uncertainty, hopelessness and depression as they struggled to understand why these behavioural changes were occurring in their children. These feelings of uncertainty are consistent with Baier (1995) and Ryan (1993) who state that because of the unpredictability and ambiguous nature of the symptoms, uncertainty arises. Mrs. T described her uncertainty surrounding the possible reasons for the changes in her son: "So you didn't know if it was... all this stuff he'd read... [or]... he's just being exposed to different ideas now... being at university".

Mrs. P described feelings of uncertainty and worry in seeing the changes in her son:
... I mean we really didn’t know what we were dealing with... the feeling of despair he had... I was worried he was suicidal. He never talked about, you know, 'I might as well just kill myself, life's not worth living', it was never that... overt. But at the same time it was something that troubled me.

For Mrs. A there was a sense of feeling hopeless and helpless, unable to provide comfort to her son:

I felt very bad. I did. I felt hopeless. She attributed that because of the number of stresses in his life (i.e. the breakup with his girlfriend, finishing school) that he was going through a depression. She describes that she was feeling hopeless because there was not much I could say to comfort him at all while he was going through this depressed stage... I knew he was hurting, there was pain on his face, there was expressions of pain.

In another case, Mr. W described his feelings of uncertainty... "There was a hell of a lot of uncertainty and plus, you know, us being here and him being physically in the other town”. For Mrs. Si there were feelings of sadness concerning the changes in her son... "I was crying. I couldn’t talk to anyone, but I did talk to my sister, I had to. I cried a lot; I got very depressed”.

Parents commented that it was a very stressful emotional time for them as they struggled to seek the most appropriate help for their children. Mr. W recalled that consulting the corporate counsellor evoked certain emotions in his wife. As he described "...we talked about everything and my wife cried at one point...”

There was also a strong need for parents to continuously convince their children and primary health care providers that they needed help. As Mrs. Si describes:... “I didn’t
know how I would get Steve to get help. But I was so happy when Dr. F realized that there was something [unusual with Steve]”. Mrs. T, described her feelings of panic in attempting to persuade her son Anthony to remain at home so that he could receive help:

“...I was completely panic-stricken. I was just moving from moment to moment by this time...”

Once their children received the appropriate help, parents voiced a sense of relief. Mrs. Si recalled feeling relieved when her family doctor finally helped Steve get the appropriate help:

When he told me to do that, I thought, ‘thank goodness, I've got help’...because it was hard for me to tell Steve we have to as a family, bring you down to the hospital...because he’s blaming me, he wants to blame his family...I kept on putting it on the doctor; the doctor realized you needed some help.

For Mrs. A she described feeling overwhelmed by a number of feelings as she sought help:

I can't even describe it - it was a whole bunch of feelings. There was not real one feeling I can name. At times I felt...hang on...we're strong people, John, you know we'll get through this, you come from good stock...I used everything that I think--...I guess for myself too, I was talking with John., ahrn, we'll get through it, you know, hold on. Meanwhile back on the farm [ I ] was down in tears at the end of the night...I tried hard not to show John...Because I figured if he sees me go a pieces, and he sees his mother breaking down, is it gonna--it's not going to help John any.
When the appropriate help was received, parents described certain emotions in response to the identification of their child’s illness and hospitalization. Looking back on her help seeking experience, Mrs. T recalled “the thing that we regret and to some extent blame ourselves for is that we never thought of anything like this [the illness label]”.

For Mrs. Si the uncertainty continued, even after Steve had received a diagnosis: “I know he's psychotic now, that's what I heard, but I'm wondering why? What did it start from? Was it from depression, anger, sadness, I don't know”. Mrs. Si’s feelings of great sadness were clearly evident when her son was admitted to hospital and diagnosed:

I think I broke down and cried, but I tried to keep the tears in because they all wanted to know, so what happened? My daughter and [my husband were] home; and I find I just couldn’t talk. I said, “They kept him in”. I felt...I wanted to get help from him—for him, have...him kept there at the same time I wanted them to say, ‘you’re okay, go home’, you know, ‘you’re just depressed’. So when the reality hit that hey, he’s really...sick, he needs to stay here, it really...it bothered me. It really bothered me. And it got worse when I found out he was psychotic. The doctors were saying he was hearing voices and getting messages from the TV and the radio. I thought, no!

Although Mrs. Si shared her feelings of fear surrounding her son’s hospitalization, she also described feeling hopeful and relieved that her son was getting the appropriate help:

I'm relieved. He's getting help... he's beginning to realize maybe, question that he might be ill... You see, he's starting to take notes, journals too, and it will help him.
It's gonna help him talk; ahm, talk about past experiences, fears or, you know, talk about happiness...maybe he can become healthy; get in touch with himself and everyone else.

In commenting on her feelings surrounding Gerard’s hospitalization, Mrs. P described feeling both stressed and hopeful:

I knew I would get all weepy...I had just sort of got to the point where I said you take him [her husband] down; you help me share some of this...stress. Because it was stressful...I am pretty hopeful; but what I keep worrying about, I always pride myself on being pretty pragmatic... you know, —it will be pretty devastating if this is the start of repeated hospitalizations.... But I'm quite optimistic and certainly trying to impart that hope and optimism to Gerard, and so is his Dad. Mrs. A revealed that she was afraid and surprised when her son was diagnosed with a psychotic illness:

Well I was fit to be tied. Because I didn't know...what was...[happening]. But this is gone on a grander scale now. It had gotten much widespread...By going from thinking John’s depressed to this doctor saying he’s delusional and he may be psychotic and needs an anti-psychotic...I never really heard anything like that before. So it was all new, all different.

She further voiced her disappointment with the health care professional who was caring for John on an outpatient basis. She felt that he should have detected that something was wrong with John earlier. Mrs. A stated: “I built up resentment against Dr. R myself...I thought he should have known...”. However, once her son was hospitalized, Mrs. A voiced her feelings of hope and support “The staff they are so caring...he is in
good hands...I’m confident that here [the hospital] is where John will be on the road to recovery”.

For Mr. W, he described feeling an overall sense of relief when Colin was admitted to hospital “Thank God he is finally in a place where he can really get the help that he needs”

In summary, all parents described a disruption in family relations as a result of the behavioural changes in their children. In recognizing that their children had an illness parents expressed the need for understanding and support. In addition, the help seeking experience was influenced by certain beliefs associated with the illness that parents held. For example, Mrs. Si brought her son to a general hospital instead of a psychiatric hospital for assessment because she felt it would be less stigmatizing. All participants experienced a vast array of emotions during the help-seeking experience. Although parents experienced frustration and delays in the help-seeking experience, they also described a sense of relief and optimism once their children were hospitalized and were receiving the help that was needed.
Chapter 6

Discussion of Results

This discussion chapter will focus on the interpretation of both the quantitative and qualitative study results. Applicable literature will be interwoven throughout. The quantitative findings indicated a number of significant relationships amongst the study variables. For example, an increase in parental burden was associated with an increase in stigmatized attitudes. In addition, as ambiguity, a subscale of the MUIS-PC increased, so did parental burden. The findings however, did not indicate a significant relationship between indicators of parental help-seeking and the study variables. As will be described later in this chapter, there maybe a number of methodological reasons for this negative finding. The qualitative data however, revealed a number of systemic barriers that impeded parents’ ability to access help. These barriers are highlighted and are discussed further in this chapter (research question #3). In addition, both the quantitative and qualitative data revealed findings which emphasized delay in accessing help and are also highlighted in the discussion.

It is also important to note that parents experienced elevated levels of parental burden, illness uncertainty and perceived stigma. The significance of the variables to the experience of help-seeking is also reflected in the qualitative findings.

Research Question 1a

What is the elapsed time between parents’ reports of first noticeable signs and symptoms and the initiation of help-seeking (non health professional and psychiatric) for their children’s emerging illness?
Study results revealed that there was a prolonged period of time from parents’ reports of first noticeable signs and symptoms to the initiation of help seeking. A mean of 4.89 months elapsed before parents sought help from non health professionals and a mean 7.33 months elapsed before parents sought psychiatric help. In addition, 22.22 months passed from the time parents first reported signs and symptoms of illness in their children to the time of their children’s hospitalization. Results of the Northwick Park study in England conducted by Johnstone et al. (1986) also found that for first episode schizophrenia patients there was a delay between illness onset and hospital admission. For one fourth of the patients the delay was more than a year. Families of the patients described difficulty in seeking help. Specifically, families had difficulty obtaining appropriate assessment and management services. This notion of difficulties in seeking appropriate treatment services has been sited also been sited in Lincoln & McGorry (1995). These authors suggest possible factors which may contribute to delays in treatment… “some general medical practitioners may lack the necessary skills to recognize psychotic illness or in turn may respond inadequately to early warning signs” (p. 1167).

This study’s findings regarding help-seeking delay are also consistent with a study by Bland et al. 1997. The purpose of his study was to: 1) examine the demographic and clinical determinants of seeking help for mental or emotional problems, 2) to determine the proportion of those people with a disorder who sought help, and 3) to determine what categories of professionals are sought by those who receive care.
Although Bland’s study does not directly concern first episode schizophrenia the findings related to severity and delay in help-seeking are relevant for this study. Specifically, Bland found that for individuals with a more severe psychiatric disorder there was an increased rate of help-seeking. Similarly in this study, as the symptoms in the child increased in severity there was a marked urgency to secure help by the parents, as indicated in the second overarching theme of the qualitative findings. Bland and colleagues (1997) also found that 72% of participants with a psychiatric disorder did not seek help for several months before the interview. Reasons for the delay were not discussed. Similarly in this study, parents waited 7 months before seeking psychiatric help.

Factors contributing to the delay in seeking psychiatric help included uncertainty regarding the behavioural changes that parents noticed in their children mistaking the changes for developmental characteristics. It is also possible that time may have elapsed while parents persuaded their children to receive help. Similar findings related to delays in treatment have been sited in Lincoln & McGorry (1995). These authors state that “behaviours manifesting in this age group may convey the impression of normal adolescent turmoil, disguising the first signs of psychotic illness” (p. 1167). Angel (1987) further states that whether relatives see particular symptoms as trivial or serious will influence communication of these symptoms to professionals.
Research Question 1b

How many help seeking attempts were reported by parents prior to their children's hospitalization for a first episode of schizophrenia?

Studies indicate that parents seek help from psychiatric services (Jarboe & Kilts, 1998; Parikh et al, 1997), and in the majority of cases it is the primary care physician who provides these services (Parikh et al, 1997). The literature however, does not document the number of times help is accessed, nor does it address help-seeking from non health professionals. In this study, the mean number of times that participants sought psychiatric help was 3.39 times. The mean for help seeking for non health professionals was 0.89. Nine out of the twenty participants sought help from non health professionals, before or concurrently with seeking psychiatric help. McGorry et al. (1990) recommends that such detailed information is needed in order to more fully understand the period surrounding the early phases of illness.

From the quantitative and qualitative findings it is evident that parents sought help from a variety of avenues including non health professionals, most often from friends and in emergency situations from the police. Parents sought psychiatric help frequently from their family doctor who in some cases referred the child to a psychiatrist. This supports Freidson (1960) theoretical formulation of the process of seeking help whereby there is network of potential consultants from intimate and informal, through distant and authoritative laymen, with professional help being sought last.
Research Question 1c

What is the level of perceived stigma, caregiver burden, and uncertainty in illness that parents experience at the time of their children’s hospitalization for a first episode of schizophrenia?

Perceived Stigma

The mean score (70.7) of the Social Response Questionnaire (SRQ) indicated that participants in this study demonstrated some stigmatized attitudes toward mental illness, in general. It is possible that the stigmatized attitudes observed in this study may be related to the acute phase of illness. Perhaps parents had not had an opportunity to become familiar with the current nature of mental illness and treatment. It may also be possible that parents could more freely express their opinion of mental illness independent of attitudes to their own children.

However, did this degree of stigma observed in this study impact parental help-seeking? According to Clausen (1980) and Fink & Tasman (1993) families may delay seeking help because of fears of stigmatization. This notion is further supported in the qualitative interviews when Mrs. Si stated that she was reluctant to bring her son for help to a specialized psychiatric facility and preferred instead a general hospital setting. When Mrs. Si arrived at the general hospital with her son, the appropriate psychiatric help was not available. Time was then spent transferring Mrs. Si and her son by cab to another general hospital for a psychiatric assessment. Following this assessment a transfer was then made to a specialized psychiatric facility where her son was finally admitted for treatment.
The findings in the present study indicate an elevated mean SRQ scores (70.6), compared to the SRQ mean scores of family members with a relative recovering from a first episode of schizophrenia in Beiser’s (1987) study. In his study, participants were asked to rate the amount of perceived stigma that they held specifically toward their relative. Results of Beiser’s study indicated that parents and siblings reported a mean score of 61.7 toward their relative with schizophrenia. Participants in Beiser’s study demonstrated increased stigmatized attitudes towards relatives with schizophrenia (61.7) compared to participants who had a relative with Crohn’s disease (45.4). It is important to note that in the present study participants were asked to describe people who have a mental illness, not their own child (see p. 20) as in Beiser’s study. Beiser (1987) states that little is known about family labelling and recommends that more longitudinal studies be conducted.

**Caregiver Burden**

The mean scores (122.4) of the Threshold Parental Burden Scale (TPBS) indicated that parents perceived much higher levels of burden compared to the mean burden score of 55.08 in a study by Pickett et al. (1994). In this study, 222 parents of adult children with severe mental illness attending a psychiatric rehabilitation program were studied in order to determine the parents’ degree of care giving burden. The adult children, 51% having the diagnoses of schizophrenia, had been ill an average of six years, and had experienced an average of four hospitalizations at the time of admission to the psychiatric rehabilitation program. Parents in this study participated in in-depth interviews consisting of questions regarding the adult child’s psychiatric history and the impact of the illness on the parent’s life. In addition, questionnaires were administered,
including the TPBS. The TPBS scores ranged from 22 to 81 with a mean of 55.08.
Findings suggest that parents of adult children continue to experience a degree of burden.
Pickett and colleagues (1994) suggest that the help of supportive professionals can assist
families in dealing with their adult’s child illness.

The marked difference between this study’s mean score and the mean TPBS score
in Pickett’s study may be attributed to the different stages of the illness course that the
children were experiencing. This study involved children at their first episode of
schizophrenia, while in Pickett’s study children had experienced the illness for an average
period of six years. The high level of burden in this study is consistent with Cook et al.
(1994) who state that burden is most intense during the early years of the illness when
parents and children are faced with acute psychotic episodes, and encounter frustrations
during attempts to negotiate the mental health system. Furthermore, Cook et al. (1994)
suggest that burden may begin to diminish after five to ten years of illness as parents
enter the stage designated by Tessler, Killian, and Gubman (1987) as “recognition of
chronicity”, whereby burden tapers off as the coping resources and adaptation of the
family increases.

Uncertainty in Illness

The MUIS-PC measured the amount of parental uncertainty concerning their
children’s illness (Mishel, 1987). According to Baier (1995), uncertainty is associated
with mental illness, as well as with chronic physical illness. The mean total score (89.5)
for this study, indicates that parents held a higher degree of uncertainty, compared with
the total mean uncertainty scores for parents of children with spina bifida (83.8), cystic
fibrosis (79.6) or leukemia (70.3).
The MUIS-PC, is comprised of four subscales specifically unpredictability, lack of information, lack of clarity, and ambiguity. All of the mean subscale scores in this study were calculated and compared to other clinical populations. The mean score of the unpredictability subscale indicated that parents were at a similar level of unpredictability than other study populations. For example, parents overall mean score for the unpredictability subscale was 13.9 compared to mean scores of parents whose child had leukemia (13.0) or cystic fibrosis (13.3) (Mishel, 1997).

Parents also indicated a higher lack of information mean subscale score (13.6) compared to parents whose child had cystic fibrosis (10.4) or leukemia (9.9) (Mishel, 1997). One parent Mrs. N, who participated in the quantitative component of the study, commented on “feeling frustrated with the lack of information” that that the GP provided concerning the medications he prescribed their son, who continued to deteriorate. Lack of information for the family has also been cited by Tessler et al. (1991). In their study, the majority of 274 relatives or close friends of discharged psychiatric patients reported that the professional staff did not give them detailed information regarding the individuals illness or include them in treatment planning. Similar findings have also been sited by Rose (1983). Family members were interviewed to gain their perspective of their relatives’ first psychiatric hospitalization. Family members stated that they did not receive adequate information from the hospital staff about their family members mental illness and treatment plan.

In this study, lack of clarity mean subscale scores were similar (21.3) compared to parents whose child had cystic fibrosis (20.7), and higher than parents whose child had leukemia (18.3) (Mishel, 1997), indicating that parents did lack clarity regarding their
childrens' treatment. The elevated mean score for lack of clarity in this study is consistent with both the literature and qualitative findings. For example, Baier (1995) found that parents had lack of clarity about whether the medications used to treat schizophrenia would be effective and whether their relative would be compliant with treatment. In the qualitative interviews of this study, parents also voiced the need for clarity surrounding the medication issue and the chance of relapse as Mrs. P described:

"...what I'm wondering about is do people have relapses even if they are compliant [with medication]?"

In addition, the mean ambiguity subscale score (40.5) for parents whose child was experiencing a first episode of schizophrenia, was higher compared to parents whose children had spina bifida (35.7), leukemia (29.1), or cystic fibrosis (35.2) (Mishel, 1997). Ambiguity refers to the absence of cues concerning the planning and carrying out of care for the child (Mishel, 1997).

The literature on parents' perception concerning their child's mental illness is sparse, particularly for parents whose child has had a first episode of schizophrenia. Mishel (1997) asserts that parents need to receive specific explanations regarding their child's illness, prognosis, and treatment management. Furthermore, uncertainty may be alleviated if parents perceive and accurately understand the information provided.

The results of this study indicated that parents were in need of more information concerning the diagnosis and treatment of their child's illness. Wynne (1986) recommends that families of first episode patients need to tolerate diagnostic complexity given that the early phases of illness can have a mixture of influential factors contributing to the child's presentation. McGorry (1995) addresses psychoeducation in first episode
psychosis and recommends that clinicians acknowledge to relatives that their family member’s illness is treatable, and that the symptoms are familiar to the clinician, given the diagnostic uncertainty associated with first episode schizophrenia. By providing families with information, psychoeducation particularly in a first episode of psychosis, can assist the family in making “sense of what has happened” and identify active coping mechanisms that can be fostered (McGorry, 1995, p. 326). In doing so, the family can experience a sense of relief and retrospective clarity.

Parents viewed this period as an ambiguous and unpredictable time which lacked clarity. A possible explanation for parents elevated levels of uncertainty may be due to the unpredictable and variable course of mental illness. According to Ryan (1993) mothers in her study encountered a degree of unpredictability which seemed to be related to the severity of their children’s symptoms. As Ryan described: “The mothers never knew what they might encounter day to day or even hour to hour” (p. 55).

Schizophrenia remains a poorly understood illness. According to Beiser (1987) families’ approach the illness with many negative images and preconceived ideas. It may be that the general lack of understanding and negative perceptions contributed to the elevated levels of uncertainty seen in this study. It is significant that parents in this study had greater levels of uncertainty regarding schizophrenia than did parents of children with life threatening illness.
**Research Question 2a**

Is there an association between indicators of parents’ help-seeking [i.e. number of help-seeking attempts; length of time from first noticeable sign and symptom to seeking help (nonprofessional and psychiatric)], and perceived stigma, caregiver burden, and uncertainty in illness at the time of their children’s hospitalization for a first episode of schizophrenia?

No association was found between indicators of parental help-seeking and the study variables. The fact that no significant relationships were found amongst the study variables and help-seeking indicators may be due to a number of possible explanations. One primary explanation is the degree of measurement error obtained in the study findings. Two of the subjects were outliers and were deleted to approximate a normal distribution, making the sample size smaller. The removal of the outliers is recommended by Burns & Grove (1993), because the outliers will have a negative influence on the statistical analyses. Even with the removal of significant outliers, a high degree of variability remains in the data related to help-seeking indicators, which may have made the detection of statistically significant relationships difficult.

The data collection with regard to help-seeking data was retrospective for this study. In recalling information retrospectively participants may have resorted to “guesstimates”. According to Tweed et al. (1998), a “guesstimate” is when an individual recalls physician visits, historic patterns of medical illness or other autobiographic data. Participants in this study were asked to recall from memory information pertinent to help-seeking. This information may have been inaccurate.
There may also have been system factors rather than the specific study variables that may have influenced parental help-seeking. Access to mental health services and lack of communication between service providers have been identified as system barriers in the qualitative findings. Parents commented on the amount of time it took to get a proper psychiatric assessment for their children. Difficulties in accessing psychiatric care, especially for emergencies, have also been identified as a barrier in care delivery by family physicians (Craven et al., 1997). Perhaps if there were improved communication between both sectors, the primary care physicians would have an enhanced ability to deliver psychiatric services (Parikh et al., 1997).

**Research Question #2b**

Are there associations amongst the study variables: perceived stigma related to mental illness, caregiver burden, and uncertainty in illness, at the time of their children’s hospitalization for a first episode of schizophrenia?

The quantitative findings indicated a significant relationship between stigma and parental burden. Specifically, as stigmatized attitudes towards mental illness increased, so did parental burden. One parent Mrs. D, who participated in the quantitative component of the study, commented that she did not want her son to be admitted to a psychiatric facility and preferred to manage his symptoms at home. Although not explicitly stated Mrs. D may have perceived the home to be a less stigmatizing environment than the psychiatric hospital. A qualitative study by Townsend & Rakfeldt (1985) supports the notion that psychiatric hospitals are viewed as stigmatizing environments. Subjects in Townsend & Rackfeldt’s study valued less stigmatizing environments such as community support and outpatient care to stabilize psychiatric
crises. Community settings were also less detrimental to self-esteem and self-concept than psychiatric hospitalization.

Despite treatment at home, Mrs. D's son's symptoms of confusion, paranoia and auditory hallucinations persisted. As a result, she took her son to a general hospital where he was admitted and discharged within a few days. Mrs. D felt "that nothing was done for him there". Mrs. D continued to manage her son's behaviour at home and also elicited the help of her son's outpatient psychologist to "prepare" her son for admission to a psychiatric facility. Despite her wish to avoid admission to a psychiatric facility, she knew her son would get the help he needed there.

The quantitative findings also indicated a second association amongst the study variables. Namely, as ambiguity a subscale of MUIS-PC, increased so did the amount of parental burden. Similar findings were found in the qualitative findings. Specifically, Mr. W commented on the stressful nature of not knowing what was wrong with his son and the strain of attempting to help his son from a distance. "There was a hell of a level of uncertainty and plus, us being here and him being physically in the other town".

Another relationship emerged in the data between uncertainty and years of education. This finding indicated that as the amount of parental education increased, the degree of uncertainty decreased. This relationship may reflect that increased parental education was associated with an increased awareness regarding mental illness and knowledge of appropriate treatment for their children. Mrs. P provides evidence of this in the qualitative findings:

I've done all the networking that I could to try and make sure that he gets the best help possible...this whole question of access...I live my life very anonymously,
but when it benefits me I make sure I pull all my cards. It’s a terrible thing to say...the son or daughter of a single mom with a grade eight education, living in public housing downtown Toronto is not going to be treated the same way as a professional with a better education. Hate to say it, but it’s true.

Commenting further on education, Cook et al. (1994) in her study of developmental stages and family burden among parents of offspring with severe mental illness found a significant relationship between burden and education. Parents with more formal education were found to have lower parental burden resulting from less cognitive preoccupation with their child, and in addition, felt less ongoing responsibility for the child. Cook et al. (1994) comment that “education may act as a buffer against burden related to psychological connectedness to the offspring” (p.446).

Furthermore, lack of clarity, a subscale of the MUIS-PC and number of symptoms which caused distress were also related. Indicating that as the number of symptoms that caused distressed increased so did parents lack of clarity. Evidence of parents’ lack of clarity was also found in the qualitative interviews, As Mrs. Si described: “I know he’s psychotic now, that’s what I heard, but I’m wondering why? What did it start from? Was it from depression, anger, sadness, I don’t know”.

In addition, the number of symptoms which caused distress was also found to be related to burden. As the number of reported symptoms which caused distress increased so did parental burden. This finding is consistent with the Cook et al. (1994) who state that burden is most intense during the early years of illness which is marked by acute psychotic symptoms and help-seeking attempts. In addition, Cook et al. (1994) offer an explanatory model of parental burden. Specifically, Cook and colleagues (1994)
postulate that the intense level of burden begins to diminish after five to ten years of illness. In their formulation, burden tapers off consistently throughout the life course as the coping resources and adaptation of the family increases.

**Research Question #3**

How does a parent describe the experience of help-seeking for his/her son or daughter who has experienced a first episode of schizophrenia?

Three overarching themes emerged related to parents' experience of help-seeking. Specifically: 1) Evolving Change: What does it mean? 2) Continuous Help-seeking, and 3) The Help-Seeking experience: Impact on parents. Consistent with the quantitative findings, parents encountered delays during the course of their help-seeking experience. The qualitative findings offer a number of perspectives regarding the nature of delay.

**Evolving Change: What does it mean?**

Within the theme of evolving change: what does it mean?, the subthemes revealed that a significant amount of time passed before parents were able to seek help for their children. This length of time before parents were able to seek help, may have been due to the parents underlying feelings of uncertainty. It is clear that parents not only had a high score on the uncertainty measure but also voiced their uncertainty about what was causing the changes in their children in the qualitative interviews. Not knowing why the behavioural and emotional changes were occurring in their children, it was difficult for parents to determine if help was warranted, and if so, what type of help was required.
The qualitative findings indicate that parents attributed the changes in their children's mood and behaviour to either developmental characteristics of their children, as Mrs. T described: "he's just being exposed to different ideas now and him finally leaving home...we tried to say...it's his age and so on..." or to their children's substance abuse. As Mrs. P described "it sure looked like he [her son] was stoned".

It was also apparent that the changes in their children evolved gradually and over time became worse. This gradual pattern of change is consistent with the findings of Yung & McGorry (1996). In their study of the initial prodrome of psychosis, the majority of patients (19 out 21) first experienced non specific symptoms then developed more marked changes and finally symptoms of psychosis emerged. The gradual development of changes were also found in the quantitative findings of this study where 7.33 months passed from when the parents first noticed the first symptom in their child, to the date where the symptoms became so severe that parents initiated psychiatric help.

Prior to receiving appropriate help, parents had to manage the behavioural and emotional changes in their children. The notion of managing relatives' behaviour is supported by an exploratory study by Horwitz & Reinhard (1992). In their study of family management of labelled mental illness in a deinstitutionalized era, the authors found that families must deal with behaviours most families rarely encounter. In addition, families must also apply social techniques few families ever have to consider. For example, when confronted with violent behaviour, Reinhard (1994) comments that families may have to consider calling the police to help manage the situation, as in the case of Mr. W in this study.
Continuous Help-Seeking

The second overarching theme focused on the process of continuous help-seeking. Seeking help for their children was not an easy endeavor for parents. At times not only did they have to persuade their children that they needed help, but also had to convince health care professionals, most often the primary health care provider that their children were in need of help. A combination of these factors, namely locating and securing the most appropriate help for their children, as well as the need to persuade and convince their children of the need for help, inevitably resulted in delays in getting treatment. The need to continuously seek help underscores a critical issue namely, the presence of system barriers in accessing appropriate help.

The quantitative data revealed that parents sought psychiatric help a mean of 3.39 times for their child. The majority of psychiatric help was from family doctors, subsequent referrals to psychiatrists in five of the cases, and in three cases referrals to psychologists. Prior to their hospitalization, three of the participants’ children were seeing a psychiatrist on a regular basis, primarily for supportive psychotherapy. The mean time between parents initiation of psychiatric help and the study interview was 12.56 months.

As indicated in the study findings, most of the study participants (n=11) sought help from their family doctors which is consistent with the literature. According to Lin et al. (1996) and Parikh et al. (1997), family physicians are the most common source of help for individuals with mental health disorders. Craven et al. (1997) obtained descriptions of how family physicians detect and manage mental health problems in their practice. In addition, Craven and colleagues (1997) obtained descriptions of perceived barriers to the delivery of optimal mental health care. Convenience samples of 10-12
physicians were chosen with a mixture of rural, urban and university settings. The study confirmed the importance of family physicians in the detection and management of mental health problems. Craven et al. (1997) findings revealed a range of problems commonly encountered by family physicians which are reflected in the present study.

Overall, family physicians in the Craven et al. (1997) study identified the problem of detecting mental health problems in family practice settings, including the undifferentiated nature of presenting problems. Similar findings were evident in this study’s qualitative findings. There was a high level of uncertainty concerning the apparent changes in the child. Many of the parents attributed the changes to drug use, or to their child’s age. In one case, the psychiatrist who was caring for Mrs. P’s child on an outpatient basis requested a second opinion for her son, because of the ambiguous nature of her son’s symptoms.

Difficulties in the relationship with local psychiatric services, accessing psychiatric care (especially for emergencies), and poor communication with mental health providers were among those difficulties consistently identified by Craven’s (1997) study as barriers to the delivery of mental health care. This study’s qualitative findings provide evidence of similar barriers. For one participant, Mrs. Si, her son’s family doctor suggested that she just bring her son to a hospital emergency, because as he described it could take “four [to] six months...” to make an appointment with a psychiatrist and by then “it’s gone too far [her son’s mental health deterioration]”.

For another participant Mr. W, weeks had passed before his family doctor received the assessment information from the referring psychiatrist. As Mr. W recalled he was anxiously awaiting the results from the family doctor’s secretary and inquired how
long it would take to get the report back from the psychiatrist assessment “after all
this…we wanted to do something for Colin so that he could finally get treatment”. In the
meantime, Colin symptoms continued to get worse.

Another participant Mrs. T and her husband had to go to the Justice of Peace
twice in efforts to seek assistance in accessing help for their son who had gone missing.
Having no success with their attempts, Mrs. T had to contact the police in efforts to find
her son.

Given the different types of barriers parents encountered during their help-seeking
experience, parents provided recommendations about preventative actions. Mrs. P stated
that given that “mental illness continues to be buried in the closet. [she recommended]
more education among school administrator’s about how to spot this [illness]”. She
further states that “this is a illness that hits kids from the ages of 16-25… that means
school administrators should at least be familiar with the symptoms of a psychotic
episode”. Mrs. A recalled her experience with her family doctor who thought her son was
experiencing depression rather than psychosis and therefore prescribed an antidepressant.
In light of this, Mrs. A recommended improved detection skills of health care providers
to distinguish first episode psychosis from other mental health illnesses.

The need to persuade their children to get help was an ongoing pursuit for parents.
The children’s lack of insight that help was needed may have contributed to parent’s
ongoing efforts to persuade their children that they needed help. According to Lincoln &
McGorry (1995), lack of insight is prominent in this patient population, and may play a
part in treatment delay.
The help-seeking experience: Impact on parents

In the final overarching theme, the impact of the help-seeking experience was described by parents. Once again, issues emerged which may have influenced treatment delays. At the forefront is the impact of stigma, as well as varied emotional responses of the parents in attempting to seek help. The qualitative findings indicated that parents held certain misconceptions regarding the illness and experienced a range of emotional responses. According to McGorry (1995) families, like members of the general community possess a negative stereotype of schizophrenia and mental illness. During the first episode when parents are presented with the notion that terms such as schizophrenia and mental illness could apply to their children, it can be threatening and potentially shattering.

The effects of stigma on delaying parents’ help-seeking attempts were apparent. Two parents in the study were more inclined to seek help from a general hospital instead of a specialized psychiatric hospital. The appropriate treatment resources were not available at the general hospital which resulted in either discharge or a transfer to a psychiatric facility.

The entire help-seeking experience evoked a wide range of emotional responses by the parents such as: guilt, sadness, frustration, relief in their attempt to access help, and may have contributed to the increased amount of parental burden documented in the quantitative findings. Lefley (1987) comments on the guilt that the family may experience in response to feeling that they should have sought help earlier, or for lacking the foresight that might have prevented an unimaginable decompensation [in their relative] regardless of whether it occurred at home, at school or in another city. Mrs. A
commented on her feelings of guilt: "it was a feeling also of maybe a wee bit of guilt, too...[because] mums are supposed to make the kids feel better...and make everything better".

Mrs. A recalled her feelings of sadness during her attempts to seek help. At times she "felt strong, urging herself and John to hold on and hang in and they’d get through this" and other times she would be "in tears at the end of the night”. She recalled, making sure that John never saw her in tears because she “figured if he sees me go to pieces...he’s the one that’s ill, and he sees his mother breaking down, is it not going to help John any”.

Mr. W commented on the frustration he felt by not receiving “faster medical help” from his family doctor. The feelings of frustration that Mr. W felt towards his family doctor, has also been cited by family doctors. Family doctors also feel frustrated with difficulties accessing and obtaining support from the psychiatric community. Craven et al. (1997) cite the numerous difficulties that occur at the clinical interface between psychiatry and family medicine. The groups of family physicians interviewed in his study indicated that even in centres with a large number of psychiatrists, “none of the groups felt they had good access to psychiatric consultation, advice and back up” (p.948). Craven et al. (1997) recommended that further studies be conducted to explore this issue in greater depth.

Once help was obtained, some participants voiced a mixed sense of relief, because they finally arrived at the necessary help and as a result knew what was causing the changes in their children. Mrs. P describes both her reaction and that of her son’s. “I think he’s [her son Gerard] relieved that he now knows that this is an illness and it’s not just
that he’s been rebellious and difficult and weird”. On the other hand, “I’m [Mrs. P] not relieved he has schizophrenia”. Mrs. Si described her feelings of relief once her son had been admitted to a specialized psychiatric hospital: “I’m glad I did. I’m relieved he’s getting help”.

The combination of both the objective and subjective findings in this study provide valuable insight into the process of help seeking for parents attempting to secure help for their children. The findings highlight the relationship of stigma, parental caregiver burden, and uncertainty during the process of help-seeking. However, what relevance do these findings have for health care? Is our system of health care effective if parents struggling to seek help for their children, are faced with feelings of uncertainty and overcome by burden? In addition, they are left to deal with feelings of frustration and sadness in efforts to seek help. Why must families have to convince health care providers that help is needed? The findings from this study speak directly to the need for government and health care professionals to improve access to mental health services for consumers and providers of primary health care. Health care should provide just that, a caring supportive environment for families, one which promotes health and has resources for early detection of mental illness and prompt appropriate intervention. If this does not occur, individuals and their families will suffer at the expense of their family members’ further psychotic decompensation, resulting in longer hospital stays, and increased utilization of limited resources.
Chapter 7

Summary, Implications and Conclusions

Summary

The purpose of this study was to enhance our understanding of help-seeking for parents of individuals experiencing a first episode of schizophrenia. The research questions that guided this study were:

1a) What is the elapsed time between parents’ reports of first noticeable signs and symptoms and the initiation of help-seeking (non-health professional and psychiatric) for their children’s emerging illness?

1b) How many help-seeking attempts were reported by parents prior to their children’s hospitalization for a first episode of schizophrenia?

1c) What is the level of perceived stigma, caregiver burden, and uncertainty in illness that parents experience at the time of their children’s hospitalization for a first episode of schizophrenia?

2a) Is there an association between indicators of parents’ help-seeking [i.e., number of help-seeking attempts; length of time from first noticeable sign and symptom to seeking help (non-health professional and psychiatric)], and perceived stigma, caregiver burden, and uncertainty in illness at the time of their children’s hospitalization for a first episode of schizophrenia?

2b) Are there associations amongst the study variables: perceived stigma related to mental illness (using the Social Response Questionnaire), caregiver burden (using the Thresholds Parental Burden Scale), and uncertainty in illness (using the Mishel
Uncertainty in Illness Scale-Parent/Child form), at the time of their children’s hospitalization for a first episode of schizophrenia?

3) How does a parent describe the experience of help-seeking for his/her son or daughter who has experienced a first episode of schizophrenia?

Data was gathered from 20 parents with a child who was hospitalized for a first episode of schizophrenia. Participants were asked to complete questionnaires related to stigma, caregiver burden, uncertainty in illness and help-seeking. A subset of five participants described their help-seeking experience using a semi structured interview format.

Descriptive quantitative data regarding delay in help-seeking revealed that a mean of 4.89 months elapsed before parents sought help from non health professionals. Furthermore, a mean 7.33 months elapsed before parents sought psychiatric help. In addition, 22.22 months passed from the time parents first reported signs and symptoms of illness in their children to the time of their children’s hospitalization.

In this study, parents sought psychiatric help slightly more than three times (3.39) predominately from family physicians, with subsequent referrals to psychiatrists and psychologists. The mean number of times parents sought help from non-health professionals was .89.

Findings from the study instruments indicated that parents held a degree of stigmatized attitudes towards mental illness. Parents also experienced parental burden as measured by the TPBS. The MUIS-PC indicated that parents did experience uncertainty regarding their children’s illness.
The quantitative data from the questionnaires revealed: 1) a significant relationship was also found between stigma and parental burden; as stigmatized attitudes towards mental illness increased so did parental burden; 2) as ambiguity (a subscale of the MUIS-PC) increased so did parental burden; 3) an inverse correlation between uncertainty and years of parental education; as parental education increased the degree of parental uncertainty regarding their child's illness decreased; 4) as lack of clarity (a subscale of the MUIS-PC) increased so did the number of symptoms causing distress; 5) a significant relationship between number of reported symptoms and parental burden; as the number of symptoms that caused distressed increased so did parental burden. Further findings from the MUIS-PC subscales revealed that parents whose child had a first episode of schizophrenia experienced a high degree of ambiguity and a lack of information regarding the illness.

No significant relationships were found between indicators of parental help seeking and study variables. As previously stated, there maybe a number of methodological reasons for why associations were not found. Perhaps more relationships amongst the study variables would have been evident with a larger sample size for the quantitative component of the study.

Using thematic analysis, three main themes emerged from the qualitative data. Similar to the quantitative findings, the qualitative findings emphasized delay in help-seeking. The overarching themes are as follows: 1) Evolving Change: What does it mean? 2) Continuous Help-seeking and, 3) The help-seeking experience: Impact on parents. Findings suggest that parents experienced frustration and uncertainty as they attempted to seek help for their children in the earliest phases of a schizophrenic illness. Help-seeking
was experienced as a continuous process influenced by uncertainty regarding evolving symptoms, stigmatized attitudes, parental burden and availability of mental health services.

Implications for Practice

This study provides a description of parents’ help-seeking experiences that may assist other families who find themselves in a similar situation. The results highlight the lack of resources that are available to families who are faced with the challenge of obtaining help for a child with a first episode of schizophrenia. This study may provide a beginning incentive for the development of resources and programs designed for accessing help in early schizophrenia.

Increased collaboration between the primary health care sector and the psychiatric community must occur in order to improve resource utilization especially with regard to referrals and the communication of treatment recommendations. Improved access to community supports, such as a public health directory would assist families to know who to contact for assistance and support.

Health care professionals must continue to develop effective interventions in the early detection and treatment of individuals experiencing a first episode of schizophrenia. According to Lieberman & Soebel (1993) “treatment strategies should be geared to early identification and intervention with patients and subsequent prevention of possible relapses” (p. 67). By addressing the areas voiced by parents, namely, enhanced assessment by health care professionals, especially in primary care settings, improved outcomes for individuals experiencing this type of mental illness can occur.
The results of this study highlight the impact of certain variables on help seeking. For example, parents held some stigmatized attitudes toward mental illness. Study findings suggest that these stigmatized attitudes may have contributed to a delay in help seeking and contributed to increased burden. Attempts must be made by the government and health care providers to de-mystify the stigma of mental illness by marketing campaigns to educate the public at large. In a study by Wahl & Harman (1989), it was found that families reported that factual information about mental illness was most helpful in dealing with the issue of stigma. Educating families is a key intervention in combating stigma. Flynn (1987) asserts that when addressing the notion of stigma with families, it is the responsibility of health care providers to respond to families with sensitivity, understanding and wisdom.

The participants in this study described feelings of uncertainty regarding their children’s illness. Health care providers can decrease parental uncertainty by providing more information regarding their child’s illness and prognosis. Acute crisis hospitalizations can be prevented by early detection skills and ongoing assessment skills especially in primary care settings. As health care providers, we must listen to families’ concerns at the earliest phase of their relative’s illness. It is well documented that earlier detection leads to a better outcome (Falloon, 1992; Lieberman & Sobel, 1993; Lincoln & McGorry, 1995). Education plays a large part in early detection, especially in the teaching sector. Education in primary care settings and schools can facilitate prevention by focusing on the detection of early warning signs. To address the issue of parental uncertainty in the earliest phase of the illness onset, education pamphlets in schools and
family doctor's offices should be made available to increase the awareness of possible early warning signs.

The findings of this study have specific implications for nursing practice. Given primary care settings are frequently the first source of professional help that parents seek for psychiatric services (Bland et al., 1997; Craven et al., 1997; Parikh et al., 1997), mental health nurse practitioners are vitally important to the early detection and assessment of first episode of schizophrenia.

To address the burden of stigmatizing attitudes held by parents, it is essential that nurses initiate educational programs that will demystify mental illness and provide factual information to facilitate earlier intervention. Ongoing public education can also be established through information booths by public health nurses and by educating parent groups at local schools. Nurses can also explore with parents their perceptions surrounding mental illness and offer support and hope especially in parent groups in community health settings.

The provision of home visits that focus on rapid assessment and referral by community mental health nurses, may reduce parental burden, uncertainty and feelings of isolation, while facilitating earlier intervention. Early detection of psychosis is likely to reduce the need for crisis admissions, and may decrease the need for police intervention (as described in the second qualitative theme) (McGorry, 1995). The community mental health nurse can also play a role in family consultation. According to Bernheim (1989), the goal of family consultation is to educate and support families. Reinhard (1993) suggests that through family consultation a strengthening of family members' capacities
to attend to their own needs as well as those of the ill relative can contribute to reduced family burden.

**Implications for Research**

This study has provided an increased understanding of the process of help-seeking for parents of individuals experiencing a first episode of schizophrenia. By generating findings related to uncertainty in illness in first episode schizophrenia, the study results extend the uncertainty in illness theory developed by Mishel (1988). Further testing of the four subscales of the MUIS-PC is required to determine if distinct dimensions of the MUIS-PC exist for the first episode schizophrenia patient population. Initial results of this study suggest that the MUIS-PC and the TPBS have very good levels of reliability for parents of individuals experiencing a first episode of schizophrenia. Further studies need to be conducted to substantiate the reliability of findings in this study and to further assess the validity of these instruments in the first episode schizophrenia population. Further exploration of the relationship between stigma and caregiver burden, in the first episode patient population, should also be conducted. A longitudinal study that examines the evolution of stigmatized attitudes could provide valuable data about these attitudes and the impact on burden. In addition, further consideration should be given to elucidating detailed appraisals of parental coping mechanisms to reduce parental burden.

Future research should also address how increased collaboration between primary health care providers and the psychiatric community could be fostered to promote a stronger alliance that would better meet the needs of the first episode schizophrenia patient population. Intervention studies are needed to explore clinical strategies to enhance earlier detection of first episode schizophrenia in the primary health care sector.
Intervention studies are also needed to increase clarity and provide information to parents regarding signs and symptoms of psychosis. The role of the primary health care provider in minimizing parental burden and uncertainty should also be investigated.

A future study might address young people’s perspectives of first episode schizophrenia. Strauss (1989) underscores the value of understanding the subjective experience of mental illness. He acknowledges that by listening to individuals discuss the meaning of illness and how they have recovered, mental health service providers will be able to more fully understand the subjective experience and implement individualized interventions (Strauss, 1989).

With the provision of research findings that address the issues inherent to readily accessing efficient and effective care, health care providers will be better equipped to promote positive outcomes for individuals experiencing a first episode of schizophrenia.

**Concluding Statement**

This study offers an increased understanding of the help seeking experience for parents whose child has experienced a first episode of schizophrenia. The findings describe the persistent measures that parents take in order to seek help for their children. The findings also highlight the role of stigma, parental caregiver burden and uncertainty in the help seeking process. As health care providers we must listen and respond to the needs of families as we assist their children to access immediate and effective help that will provide the foundation for an optimal recovery.
References


Appendix A

Letter to the Vice-President of Nursing at the Participating Hospital

Dear Nancy Johnston:

I am a registered nurse enrolled in the graduate program in the Department of Nursing Science at the University of Toronto. In partial fulfillment of the Master of Science in Nursing program at the University of Toronto, I am conducting a study under the joint supervision of Dr. Beth McCay and Dr. Ruth Gallop. I am now writing to ask your permission to conduct this study on the Clinical Investigation Unit at the Clarke Institute of Psychiatry.

The purpose of this study is to gain an understanding of the experience of help-seeking for parents of individuals experiencing a first episode of schizophrenia. All participants in the study will be asked to complete four questionnaires related to stigma, caregiver burden, uncertainty in illness and help-seeking data. A subset of participants will be asked to participate in a semi-structured interview that will focus on their help-seeking experience.

If you agree, I will ask the nurse in charge on the CIU to assist me in identifying potential participants for the study. I am enclosing a copy of my thesis proposal for your consideration. I would greatly appreciate the opportunity to conduct the study at your agency and I would be glad to meet you and answer any questions you may have. I can be reached at (416) 340-8490. Additional concerns may be directed to Dr. Beth McCay at (416) 979-4747 (ext. 2550)

Thank-you for your time and I look forward to hearing from you at your earliest convenience.

Sincerely,

Donna Czuchta, RN., MSc. (Cand.)
Appendix B

Explanation for the NUA and the Nurse-in-Charge on the Participating Unit

Dear ____________:

I am a registered nurse currently enrolled in the graduate program in the Department of Nursing Science at the University of Toronto. In partial fulfillment of the Masters of Science in Nursing program, I am conducting a study under the supervision of Dr. Beth McCay and Dr. Ruth Gallop. I have received permission from the Vice President of Nursing to conduct this study on your psychiatric unit. I would like to request your assistance to recruit prospective subjects for the study. The purpose of the study is to gain an understanding of help seeking for parents of individuals experiencing a first episode of schizophrenia.

The inclusion criteria for the sample of participants are:

1) a parent whose son or daughter has been admitted to the CIU at the Clarke Institute of Psychiatry, and has the first episode diagnosis of schizophrenia, schizophréniform, or schizoaffective disorder or is assessed by the first episode psychosis outpatient clinic.

2) are able to read and speak English.

All 20 anticipated participants in the study will complete study questionnaires related to caregiver burden, uncertainty in illness, stigma related to mental illness, and help-seeking data. In addition 5 selected participants in the study will partake in a semi structured interview which will focus on their experience of help seeking during their son or daughter's first episode of schizophrenia. It is anticipated that the interviews will be conducted in a room on the unit that offers privacy for the researcher and the participant.

I will require your assistance to identify potential participants for the study. I will be contacting the unit frequently to see if potential participants have been identified and would like to meet with me. When a suitable participant has been identified, I would appreciate if you could seek permission from the patient for their family member to meet with myself (see attached copy). Upon obtaining the patient's agreement for me to meet with their parent I will ask you to approach their parent and briefly describe the purpose and nature of the study. If you could then ask for permission for the release of their name so that I may meet participant to explain the study further (see attached copy).

I would be very pleased to meet with you to answer any questions or concerns you may have. I can be reached at (416) 340-8490. If there are no questions or concerns, then I would like to thank-you for your assistance with my study.

Sincerely,

Donna Czuchta R.N., MSc (cand).
Appendix C

Nurse-in-Charge's Explanation of the Study to the Patient

Hello Mr./Mrs________________:

A registered nurse, Donna Czuchta, who is a graduate student at the University of Toronto is conducting a study to see what your parents experience of help-seeking was like for you prior to you coming to hospital. If you have any questions regarding this study Donna would be able to meet with you. Would it be alright to ask your parents (mother/father) if they would like to meet with Donna to hear about the study?
Appendix D

Nurse in Charge's Explanation of the Study to the Participant

Hello Mr./Mrs______________:

A registered nurse, Donna Czuchta, who is a graduate student at the University of Toronto is conducting a study to understand your experience of obtaining help for your son or daughter during his or her first episode of schizophrenia has been for you. If you agree she would like to learn what the experience of help-seeking has been like for you. She would like to tell you more about the study to see if you might be interested in participating. Hearing more about the study does not obligate you to participate. Would it be alright to give your name to Donna Czuchta so she can arrange a time to tell you about the study.
Appendix E

Explanation to the Participant

Hello Mr/Mrs. ____________________.

My name is Donna Czuchta and I am a student at the University of Toronto. I am a registered nurse who is completing a Master of Science degree at the Faculty of Nursing. I am doing a research study under the supervision of Dr. Beth McCay and Dr. Ruth Gallop at the Clarke Institute of Psychiatry. This research study is to understand the experience of help-seeking for parents of individuals experiencing a first episode of schizophrenia. I would like to explain the study to you so that you can decide if you would like to participate.

Your participation in the study would take approximately 20 minutes of your time, while your son or daughter is hospitalized on the CIU at the Clarke Institute of Psychiatry. I will ask you to complete four study questionnaires related to stigma, your perception of your son or daughter's illness, your experience of providing care, and help-seeking data. You may also be asked to participate at a later date in a 1 hour interview with myself to describe your experience of help-seeking for your son or daughter who is presently in hospital. There are no right or wrong answers to your questions, and during the interview you may ask for information if the questions are not clear.

It is anticipated that this study will provide an increased understanding of parent's help-seeking experience and will ultimately improve care in this area. If you agree to participate you will never be personally identified in any study results. If you agree to take part you may withdraw and or refuse to answer any questions at anytime, which will in no way influence your son or daughter's care.

Do you have any questions about the study? Would you be willing to participate in this study?

If yes, would you please read and sign the consent form.

If no, thank you for time.
Appendix F(a)

Participant Informed Consent Form

I agree to participate in the study conducted by Donna Czuchta, under the supervision of Dr. Beth McCay and Dr. Ruth Gallop at the Clarke Institute of Psychiatry. The aim of this study is to better understand the help-seeking that led to hospitalization for my son or daughter.

My participation in this study involves the completion of four study questionnaires related to my experience of help seeking, stigma, uncertainty in illness and caregiver burden.

The justifications and the possible risks of this study have been explained to me by Donna Czuchta. I understand that I may feel temporarily distressed reviewing my son or daughter's history, on the other hand I may feel relieved. My participation in this project is voluntary and I may withdraw at any time. I understand that my agreement or refusal will not jeopardize the present or future care of my son or daughter provided at the Clarke Institute of Psychiatry. I also understand that my answers are confidential.

To assure that my answers will remain confidential, a numeric code will be used instead of my name, and the data will be kept in a locked cabinet in a locked office. I understand that my name will not appear on any written recordings of the interview(s). I understand that my name will not be identified in any reports of the study.

If I have any questions regarding the study I can reach Donna Czuchta at (416) 586-4541. Additional concerns may be directed to Dr. Beth McCay at (416) 979-4747 (ext. 2550).

Family member signature ______________________________
Witness ______________________________
Date ______________________________

I have been given a copy of this form to refer to and keep for my personal reference.
Appendix F(b)

Participant Informed Consent Form

I agree to participate in the study conducted by Donna Czuchta, under the supervision of Dr. Beth McCay and Dr. Ruth Gallop at the Clarke Institute of Psychiatry. The aim of this study is to better understand the help-seeking that led to hospitalization for my son or daughter.

My participation in this study involves the participation in a semi-structured interview with a research interviewer to describe my experience of help-seeking for my son or daughter who is presently in hospital.

The justifications and the possible risks of this study have been explained to me by Donna Czuchta. I understand that I may feel temporarily distressed reviewing my son or daughter's history, on the other hand I may feel relieved. My participation in this project is voluntary and I may withdraw at any time. I understand that my agreement or refusal will not jeopardize the present or future care of my son or daughter provided at the Clarke Institute of Psychiatry. I also understand that my answers are confidential.

If I choose to participate in the semi-structure interview, I agree to have this interview audiotaped. To assure that my answers will remain confidential, a numeric code will be used instead of my name, and the data will be kept in a locked cabinet in a locked office. I understand that my name will not be identified in any reports of the study. I understand that while excerpts from the interviews will be used in the report of the study, these may be identifiable to me, but not to others.

If I have any questions regarding the study I can reach Donna Czuchta at (416) 586-4541. Additional concerns may be directed to Dr. Beth McCay at (416) 979-4747 (ext 2550).

I also agree to participate in the semi-structured interview if selected.

Family member signature

Witness

Date

I have been given a copy of this form to refer to and keep for my personal reference.
Appendix G (Part I)

Demographic Data of the Participating Parent

1. Sex: (please circle) Female Male

2. What is your present age _____ years

3. Completed years of education _____ years

4. Are you employed yes/no.
   If you are employed what is your occupation ________________________.

5. Living situation (please circle one) alone
   alone with spouse
   living with son/daughter
   living with spouse and son(s)/daughter(s)
   living with spouse, and/or parents/siblings

6. Prior to hospitalization how much time did you spend with your son/daughter per week?
   Number of hours _____/week
   Number of days _____/week

7. Predominate language(s) spoken at home ________________________.
Appendix G(Part II)

Demographic Data of the Ill Family Member

1. Sex: (please circle) Female Male

2. What is your son or daughter's present age ______ years

3. Completed years of education ______ years

4. Is your son or daughter employed yes/no.
   If employed what is their occupation ________________________.

5. Living situation (please circle one) alone
   alone with spouse
   living with family

6. Predominate language(s) that your son or daughter speaks at home ______.
Appendix H

Social Response Questionnaire

The object of this questionnaire is to find out how you describe people who have a mental illness. The following list of words consists of adjectives that are sometimes used by persons to describe those with a mental illness. Please indicate an X beside each adjective according to how much it reflects your feelings about a person with a mental illness.

<table>
<thead>
<tr>
<th>Adjective</th>
<th>Like Someone With A Mental Illness</th>
<th>Somewhat Like Someone With A Mental Illness</th>
<th>Not Like Someone With A Mental Illness</th>
</tr>
</thead>
<tbody>
<tr>
<td>Weak</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reliable</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Relaxed</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Different</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Co-operative</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self-Reliant</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Non-Productive</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bad</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Predictable</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Healthy</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not OK</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Worthless</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Normal</td>
<td></td>
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<td></td>
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<tr>
<td>Hopeless</td>
<td></td>
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<td></td>
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<tr>
<td>Safe</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Well-Adjusted</td>
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<td></td>
<td></td>
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<tr>
<td>Unreliable</td>
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<td></td>
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<tr>
<td>Strong</td>
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<td></td>
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<tr>
<td>Tense</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Difficult</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Helpless</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mixed Up</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Good</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unpredictable</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sick</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>OK</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Valuable</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Abnormal</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Optimistic</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dangerous</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A Misfit</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Productive</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
**Appendix I**

**Threshold Parental Burden Scale (TPBS)**

We are interested in your feelings and experiences in helping your child to cope with his or her problems. For each statement, please circle the letter that best describes how you feel.

<table>
<thead>
<tr>
<th></th>
<th>Strongly agree</th>
<th>Moderately agree</th>
<th>Slightly agree</th>
<th>Slightly disagree</th>
<th>Moderately disagree</th>
<th>Strongly disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(a)</td>
<td>(b)</td>
<td>(c)</td>
<td>(d)</td>
<td>(e)</td>
<td>(f)</td>
</tr>
<tr>
<td>1.</td>
<td>I will always be prepared to take financial responsibility for _________.</td>
<td>a</td>
<td>b</td>
<td>c</td>
<td>d</td>
<td>e</td>
</tr>
<tr>
<td>2.</td>
<td>One of the hardest things about dealing with _________ is that his or her problems are so unpredictable.</td>
<td>a</td>
<td>b</td>
<td>c</td>
<td>d</td>
<td>e</td>
</tr>
<tr>
<td>3.</td>
<td>_________ needs me much more than any of my other family members.</td>
<td>a</td>
<td>b</td>
<td>c</td>
<td>d</td>
<td>e</td>
</tr>
<tr>
<td>4.</td>
<td>I worry about what the future will bring for _______.</td>
<td>a</td>
<td>b</td>
<td>c</td>
<td>d</td>
<td>e</td>
</tr>
<tr>
<td>5.</td>
<td>Sometimes, I feel that my life and ________'s life are inseparable.</td>
<td>a</td>
<td>b</td>
<td>c</td>
<td>d</td>
<td>e</td>
</tr>
<tr>
<td>6.</td>
<td>Sometimes, I feel that _________ is not really troubled but instead is just being lazy or uncooperative.</td>
<td>a</td>
<td>b</td>
<td>c</td>
<td>d</td>
<td>e</td>
</tr>
<tr>
<td>7.</td>
<td>Sometimes, I find it hard to stop thinking about ________ and his/her problems.</td>
<td>a</td>
<td>b</td>
<td>c</td>
<td>d</td>
<td>e</td>
</tr>
<tr>
<td>8.</td>
<td>I feel that _________ tries to manipulate me.</td>
<td>a</td>
<td>b</td>
<td>c</td>
<td>d</td>
<td>e</td>
</tr>
<tr>
<td>9.</td>
<td>If I don't help _________, no one else will.</td>
<td>a</td>
<td>b</td>
<td>c</td>
<td>d</td>
<td>e</td>
</tr>
<tr>
<td>10.</td>
<td>I wish _________ would show better grooming and personal hygiene.</td>
<td>a</td>
<td>b</td>
<td>c</td>
<td>d</td>
<td>e</td>
</tr>
<tr>
<td>11.</td>
<td>I can't imagine life without _________.</td>
<td>a</td>
<td>b</td>
<td>c</td>
<td>d</td>
<td>e</td>
</tr>
<tr>
<td>12.</td>
<td>I often feel mixed up about how much I should be doing for _________.</td>
<td>a</td>
<td>b</td>
<td>c</td>
<td>d</td>
<td>e</td>
</tr>
<tr>
<td>13.</td>
<td>I continue to hope that _________ will be like his or her old self again.</td>
<td>a</td>
<td>b</td>
<td>c</td>
<td>d</td>
<td>e</td>
</tr>
<tr>
<td>14.</td>
<td>Of all my family, I feel the most closely connected to _________.</td>
<td>a</td>
<td>b</td>
<td>c</td>
<td>d</td>
<td>e</td>
</tr>
<tr>
<td>15.</td>
<td>I feel embarrassed over the behavior of _________.</td>
<td>a</td>
<td>b</td>
<td>c</td>
<td>d</td>
<td>e</td>
</tr>
</tbody>
</table>
Appendix I (TPBS con’t)

<table>
<thead>
<tr>
<th>Strongly agree</th>
<th>Moderately agree</th>
<th>Slightly disagree</th>
<th>Slightly agree</th>
<th>Moderately disagree</th>
<th>Strongly disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>(a)</td>
<td>(b)</td>
<td>(c)</td>
<td>(d)</td>
<td>(e)</td>
<td>(f)</td>
</tr>
<tr>
<td>16. Because I spend so much time helping __________, this causes hardships for my other children. a b c d e f</td>
<td></td>
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<tr>
<td>17. No matter how hard it is to control his or her behavior, __________ will always be welcome in my home. a b c d e f</td>
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<tr>
<td>18. My family and I often have disagreements about my involvement with __________. a b c d e f</td>
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<tr>
<td>19. Sometimes, trying to deal with __________'s problems makes me feel helpless. a b c d e f</td>
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<tr>
<td>20. Nobody understands __________ as well as I do. a b c d e f</td>
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<tr>
<td>21. I feel useful when I help __________. a b c d e f</td>
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<tr>
<td>22. I feel that I'm more committed to __________ than to my spouse. a b c d e f</td>
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<tr>
<td>23. I can never plan to do things with other people unless I first stop and think about whether or not __________ will need me. a b c d e f</td>
<td></td>
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</tr>
<tr>
<td>24. Sometimes, I'm not sure where __________ fits in as part of the family. a b c d e f</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>25. I would sacrifice my life to save __________. a b c d e f</td>
<td></td>
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</tr>
<tr>
<td>26. One of the hardest things about __________’s problem is worrying about whether or not the worst symptoms will occur again. a b c d e f</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>27. No matter what else happens in __________’s life, I know that I will always be responsible for him/her. a b c d e f</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>28. I'm not sure how much I should expect __________ to help around the house. a b c d e f</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>29. I feel that __________ is too dependent on me. a b c d e f</td>
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</tbody>
</table>
Appendix J

MISHEL UNCERTAINTY IN ILLNESS SCALE--PARENT/CHILD FORM

Instructions: Please read each statement. Take your time and think about what each statement says. Then place an "X" under the column that most closely measures how you are feeling about your child TODAY. If you agree with a statement, then you would mark under either "Strongly Agree" or "Agree." If you disagree with a statement, then mark under either "Strongly Disagree" or "Disagree." If you are undecided about how you feel about your child, then mark under "Undecided" for that statement. Please respond to every statement.

1. I don't know what is wrong with my child.
   - Strongly Agree
   - Agree
   - Undecided
   - Disagree

2. I have a lot of questions without answers.
   - Strongly Agree
   - Agree
   - Undecided
   - Disagree

3. I am unsure if my child's illness is getting better or worse.
   - Strongly Agree
   - Agree
   - Undecided
   - Disagree

4. It is unclear how bad my child's pain will be.
   - Strongly Agree
   - Agree
   - Undecided
   - Disagree

5. The explanations they give about my child seem hazy to me.
   - Strongly Agree
   - Agree
   - Undecided
   - Disagree

6. The purpose of each treatment for my child is clear to me.
   - Strongly Agree
   - Agree
   - Undecided
   - Disagree

7. I do not know when to expect things will be done to my child.
   - Strongly Agree
   - Agree
   - Undecided
   - Disagree
8. My child's symptoms continue to change unpredictably.

<table>
<thead>
<tr>
<th>Strongly Agree (5)</th>
<th>Agree (4)</th>
<th>Undecided (3)</th>
<th>Disagree (2)</th>
<th>Strongly Disagree (1)</th>
</tr>
</thead>
</table>

9. I understand everything explained to me.

<table>
<thead>
<tr>
<th>Strongly Agree (5)</th>
<th>Agree (4)</th>
<th>Undecided (3)</th>
<th>Disagree (2)</th>
<th>Strongly Disagree (1)</th>
</tr>
</thead>
</table>

10. The doctors say things to me that could have many meanings.

<table>
<thead>
<tr>
<th>Strongly Agree (5)</th>
<th>Agree (4)</th>
<th>Undecided (3)</th>
<th>Disagree (2)</th>
<th>Strongly Disagree (1)</th>
</tr>
</thead>
</table>

11. I can predict how long my child's illness will last.

<table>
<thead>
<tr>
<th>Strongly Agree (5)</th>
<th>Agree (4)</th>
<th>Undecided (3)</th>
<th>Disagree (2)</th>
<th>Strongly Disagree (1)</th>
</tr>
</thead>
</table>

12. My child's treatment is too complex to figure out.

<table>
<thead>
<tr>
<th>Strongly Agree (5)</th>
<th>Agree (4)</th>
<th>Undecided (3)</th>
<th>Disagree (2)</th>
<th>Strongly Disagree (1)</th>
</tr>
</thead>
</table>

13. It is difficult to know if the treatments or medications my child is getting are helping.

<table>
<thead>
<tr>
<th>Strongly Agree (5)</th>
<th>Agree (4)</th>
<th>Undecided (3)</th>
<th>Disagree (2)</th>
<th>Strongly Disagree (1)</th>
</tr>
</thead>
</table>

14. There are so many different types of staff, it's unclear who is responsible for what.

<table>
<thead>
<tr>
<th>Strongly Agree (5)</th>
<th>Agree (4)</th>
<th>Undecided (3)</th>
<th>Disagree (2)</th>
<th>Strongly Disagree (1)</th>
</tr>
</thead>
</table>

15. Because of the unpredictability of my child's illness, I cannot plan for the future.

<table>
<thead>
<tr>
<th>Strongly Agree (5)</th>
<th>Agree (4)</th>
<th>Undecided (3)</th>
<th>Disagree (2)</th>
<th>Strongly Disagree (1)</th>
</tr>
</thead>
</table>

16. The course of my child's illness keeps changing. He/she has good and bad days.

<table>
<thead>
<tr>
<th>Strongly Agree (5)</th>
<th>Agree (4)</th>
<th>Undecided (3)</th>
<th>Disagree (2)</th>
<th>Strongly Disagree (1)</th>
</tr>
</thead>
</table>
17. It's vague to me how I will manage the care of my child after he/she leaves the hospital.

<table>
<thead>
<tr>
<th>Agreement Level</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Undecided</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
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<td>(5)</td>
<td>(4)</td>
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</table>

18. It is not clear what is going to happen to my child.

<table>
<thead>
<tr>
<th>Agreement Level</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Undecided</th>
<th>Disagree</th>
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19. I usually know if my child is going to have a good or bad day.

<table>
<thead>
<tr>
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20. The results of my child's tests are inconsistent.

<table>
<thead>
<tr>
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21. The effectiveness of the treatment is undetermined.

<table>
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22. It is difficult to determine how long it will be before I can care for my child by myself.

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23. I can generally predict the course of my child's illness.

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24. Because of the treatment, what my child can do and cannot do keeps changing.

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25. I'm certain they will not find anything else wrong with my child.

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</table>
26. They have not given my child a specific diagnosis.

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<thead>
<tr>
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27. My child's physical distress is predictable, I know when it is going to get better or worse.

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28. My child's diagnosis is definite and will not change.

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29. I can depend on the nurses to be there when I need them.

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<tr>
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30. The seriousness of my child's illness has been determined.

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<tr>
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</table>

31. The doctors and nurses use everyday language so I can understand what they are saying.

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Appendix K

Turning Point Interview (TPI)

As explained to you in the consent form, I would like to ask you questions related to the help-seeking you sought for your son or daughter. All your responses are confidential.

FIRST TURNING POINT

Change and Effect

Perhaps you could go back in time to the very beginning, when you noticed something changing in _________ when the trouble first began?
(note date-time line).

Could you highlight some of the main events, changes or happenings since the beginning?
(note date-time line).

What did you first notice anything different about him or her (behaviours, perceptions)?

When would you say that he or she was his or her normal self?

What did you notice? What was happening at that time?

Despite these changes, in what way or ways was _________ the same?

How did you understand or interpret this change?

How did you feel about it?

How did you react?

What was the most troubling for you at the time (explore the reasons)?
Appendix K (TP! con't)

Help-Seeking

Did you talk with someone at that time about the changes you were perceiving?

Or did you prefer to keep people from knowing about the problems? Why?

Did you seek help at that time?

If not why?
If yes

Whose decision was it to seek help?

How did this person react? What was his or her response?

What was your reaction to this response?

Did you ask someone else for help?

How long did this first period last?
Appendix K (TPI con't)

SECOND TURNING POINT

Change and Effect

How did things evolve after that?
(1. Stability; 2. Improvement; 3. Deterioration)
(for 2 and 3, explore concrete signs and behaviours as perceived by the respondent).

When did things get better (or)
When did things get worse?
When was it?

Can you tell what was happening?

What was it that was troubling _________?
What was _________experiencing at that time?
Specific perception of change in _________.

How did you understand or interpret the situation at that time?

What were some of the feelings or reactions you had?
Did a name come to mind to describe that type of problem?
Did you have an idea what could have caused this problem?
Did you consider this problem serious?

At that time, did these problems interfere with: _______'s
-socioal life?
-school performance?
-work life?

At that time, were the problems affecting how _________ was getting along with other people?

When would you say that he or she was his or her normal self?
(Sudden or gradual deterioration?)

What did you notice? What was happening at that time?

How did you understand or interpret this change?

In what ways was _________his or her normal self?

How did you feel about it?
How did you react?

What was the most troubling for you at this time? (explore the reasons)

**Help-Seeking**

Did you talk with someone at that time about the changes you were perceiving (experiencing?)

Or did you prefer to keep people from knowing about the problems? Why?

Did you seek help at this time?

If no: Why?
If yes: From whom? (specify the status and the nature of the link with the respondent).

How did this person react? What was his or her response?

What was your own reaction to this response?

Did you ask someone else for help?

How long did this first period last?

**Following the First and Second Turning Points:**

How did things evolve after that and until the decision to consult psychiatric services?

Identify perceived "Turning Points" (toward improvement or worsening)

For each "Turning Point" document:
- perceived or experienced signs and symptoms
- In case of a worsening, explore interpretations, coping and help-seeking

Just before the decision to consult psychiatric services:

How did you understand or interpret the situation at that time?
- perceived or experienced signs and symptoms
- In case of a worsening, explore interpretations, and help-seeking
Appendix K (TPI con't)

Consultation of Psychiatric Services

How was the decision to consult psychiatric services?

What were the circumstances?

Who made the decision? Why?

Did other people agree?

How did ______ react?

How did it work out?
Appendix L

Help-Seeking Data Information Sheet

When did you first notice behaviour changes reflective of the symptoms of an illness in your son/daughter?

Please specify the date ____________________.

Please specify the symptoms __________________________________________.

When did you first notice behaviour changes reflective of the symptoms of an illness in your son/daughter that caused you distress?

Please specify the date ____________________.

Please specify the symptoms __________________________________________.

What date did you first seek help from non-health professionals for your son or daughter ____________.

How many times did you seek help from non-health professionals ____________.

When did you first seek psychiatric help for your son or daughter ____________.

How many times did you seek psychiatric help for your son or daughter ____________.

What diagnosis did your son or daughter receive after you sought psychiatric help _________________.