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The Experience of Family Members Living with a Relative With Schizophrenia

by

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ABSTRACT

This study explored the experiences of family members who live with a relative with schizophrenia. Based on the principles of naturalistic inquiry, these experiences were explored through in-depth conversations with twenty first-degree relatives of persons with schizophrenia (PWS). Participants were recruited through the Calgary Chapter of the Schizophrenia Society of Alberta, and also through pre-existing contacts of the researcher. They were purposively sampled for maximum variation in order to gain an understanding of the various experiences of mothers, fathers, brothers and sisters of PWS. The findings emerged as descriptive themes that were expressions of stresses, support and systemic issues. There was a further theme that encompassed participants' responses to living with schizophrenia. The different sources of stress that family members detailed included the symptoms of schizophrenia, familial dissonance, household disruptions, and stigma. Participants also spoke of several sources of support, such as support groups, familial support, and social support. These were described as having alleviated difficulties associated with living with the illness. There were also expressions of concern over the lack of support received by mental health professionals in general. Issues involving the mental health system included personnel, certification, education, respite, and treatment planning. As all conversations elicited emotion, one response was a sub-theme entitled affective dimensions. Further sub-themes included: a process of seeking understanding, accepting the illness and adjusting expectations; coping and managing; expression of gratification; lifelong learning; and advocating. Finally, this study explored expressions of grieving, suffering and hope, with discussion of implications for research, education, and/or practice.

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CHAPTER 1 - THE RESEARCH PROBLEM

I. INTRODUCTION

This study involves an exploration of the experiences of family members who live with relatives with schizophrenia. The past four decades have seen the transfer of care of individuals in mental hospitals to community settings. This deinstitutionalization began with the expectation that treatment for the mentally ill within the community would provide a greater chance for rehabilitation and reintegration. Deinstitutionalization has resulted in many families being the focus of management and care for their mentally ill relatives. Indeed, estimates of ill individuals who live with their families range from 30-65% (Kuipers, 1993; Solomon & Draine, 1995a; Wynne, 1994), with the majority of families remaining involved with their ill relative regardless of whether or not they live together. Many of those individuals who return home are still symptomatic, requiring care, observation and support (Baker, 1993; Goldstein, 1996). Families have been said to serve as an extension of the mental health system, often providing such case management functions as assessment, linkage, monitoring, assistance with daily problems, crisis intervention and advocacy (Saunders, 1999).

It was expected that community mental health (CMH) centres would be able to provide the diversity of treatment and support functions needed to help individuals maintain themselves in the community (Vaccaro, Young, & Glynn, 1993). Unfortunately, the policy has had disappointing results. The current challenges within the CMH system have extensive and multi-level repercussions: they affect the mentally ill individuals, their families, the mental health care system, and communities. The mental health community has subscribed to an “infectious disease” model of illness, in which treatment is viewed as short-term process for dealing with a definite and transitory illness (Bachrach, 1994). Schizophrenia is unable to be viewed as such. It is an illness that is better represented by a chronic illness model, and as such many believe treatment should involve the family, be long term and multi-disciplinary (Bachrach, 1994). Rather than an exclusive focus on curing the illness, goals should include the management of symptoms, and the teaching of coping, living and vocational skills, thereby enhancing the individuals' and family members' quality of life (Farkas, O'Brien, Cohen & Anthony, 1994; Liberman, Vaccaro, & Corrigan, 1995).

Background information regarding the illness precedes a statement of the problem. This is followed by a definition of schizophrenia. The study's purpose and rationale precede a brief history of the relationship between the illness and the family and a discussion of the main issues in the literature. A section on research methods precedes a chapter elucidating my results, which is followed by a concluding chapter dedicated to discussion.

II. BACKGROUND

Schizophrenia is a multi-handicapping, debilitating and lifelong mental illness affecting 1% of the adult population. Direct clinical care costs are extensive. In Canada, individuals with schizophrenia use 8% of all hospital beds and incur direct health care costs of over $2.3 billion each year (Pivik & Young, 1994).

III. STATEMENT OF THE PROBLEM

Although a single family member may exhibit symptoms, receive a diagnosis and undergo treatment, mental illness is undoubtedly experienced by each and every family member. The interdependence characteristic of family systems means every family member is influenced in a particular way. The complexities involved in caring for and working with an ill relative impact, and result in changes to, family members (Judge, 1994). Unfortunately, the experiences of family members are not well understood, despite the fact that a thorough understanding of these experiences is a prerequisite to effective, comprehensive treatment plans and has implications for service provision. In order to develop appropriate family-oriented plans, professionals must understand how family members define their situation, function and cope. In the present research, participating family members were asked to describe their experience of living with a relative with schizophrenia.

IV. DEFINITION OF SCHIZOPHRENIA

The complex, multi-dimensional nature of schizophrenia and its accompanying manifestations dictate that it be conceptualized not merely on a biomedical level, but on a psychosocial level as well. The distinction between disease and illness deserves mention. Traditional biomedical models describe and treat schizophrenia in disease terms, whereas psychosocial models describe illness as the person's experience of altered function or wellbeing. Historically the biomedical models have viewed the course of schizophrenia in a vacuum. A more complete perspective on the factors that influence the course, outcome, and manifestations of schizophrenia is needed, and this involves consideration of the social contexts in which these people live.

It is necessary to view persons as being as important as the illness. Persons with schizophrenia (PWS) should not lose sight of the other aspects of themselves and their lives. It is important that they view themselves, and are viewed by others, as persons who live and cope with a chronic illness rather than as people whose identity is the illness. This approach is built upon the belief that to fully understand illness one must understand overall functioning (Davidson & Strauss, 1995), and is in line with the psychiatric rehabilitation ideology, which emphasizes building upon areas of strength in order to minimize disability.

A. Biomedical

While its symptoms and course vary greatly, the characteristic features of schizophrenia can be conceptualized as falling into two categories -- positive and negative. Positive symptoms refer to the presence of functions and behaviours that otherwise would not normally be present, and include hallucinations, delusions, and grossly disturbed speech and behaviour. Negative symptoms refer to the absence or reduction of functions or behaviours that are usually present and include flattening of affect, difficulties in the initiation of and persistence with goal-directed activities, and poverty of thought and speech (Diagnostic and Statistical Manual of Mental Disorders IV (DSM-IV), 1994). Schizophrenia is marked by cycles of exacerbation and remission. Fortunately, for the majority of afflicted individuals, neuroleptic medication has contributed to the management of the positive symptoms. It should be noted that the side effects of neuroleptic medication are often serious, and as such, negatively impact the PWS' quality of life. The main residual effects of the illness are a consequence of the persisting negative symptoms, which medication does not appreciably reduce (Mueser, Bellack, Douglas, & Morrison, 1993; Tandon, Jibson, Taylor, & DeQuardo, 1995).

B. Psychosocial

The elimination or stabilization of positive symptoms is an essential first step in the rehabilitation of persons with schizophrenia. Effective medication can ameliorate intrusive positive symptoms and improve cognitive functioning, thereby making afflicted individuals more responsive to learning from their environments (Liberman, Kopelowicz & Young, 1994). However, it is important to note that positive symptoms are a surprisingly poor indicator of how persons feel about their lives, or how well they are able to function (Becker, Diamond & Sainfort, 1994). It is the negative symptoms, characterized by their complexity, which are involved in every aspect of psychosocial functioning. They manifest as disabilities such as impaired social adaptation and vocational functioning, and as such they impede development of daily living skills and successful community adaptation (Halford & Hayes, 1991; Liberman et al., 1995).

V. STUDY PURPOSE AND RATIONALE

The purpose of this research is to further explore family members' experiences of living with a relative with schizophrenia. To support, educate and counsel families as they face the demands of the illness, health care professionals need to acknowledge and address the needs of individual family members, including parents and siblings. Furthermore, as it is their experiences that are being explored, there is an immediate need to recognize that family members can indeed offer expertise.

The information provided by the participants in this research may be of benefit to three groups: those responsible for the development of treatment and rehabilitation plans for PWS, professionals who provide the services for family members and, finally, the family members themselves.

While mothers of PWS tend to be the subjects in much of the research I reviewed, I am interested in the experiences of all family members. Mothers were included to corroborate other countries' findings, and in addition I described and contrasted the experiences of additional family members.

VI. LITERATURE REVIEW

My long-standing exposure to the realm of schizophrenia research has provided me with the opportunity to appreciate its breadth, and also to begin a process of synthesis. As a result of my experience, I believe there are certain areas in the literature which are germane to the present study. It would appear logical to group the relevant literature into individual, familial, mental health system, and community themes.

A brief history of the relationship between the family and schizophrenia will precede my literature review. I will first review the literature reflecting important issues from an individual perspective, such as use of medication, stressors, social support and coping skills. Second, I will examine familial level issues, such as coping, stress, and caregiving burden. Third, I will review system issues, such as barriers to care, professionals' collaboration with families, and psychoeducational programs. Finally, I will review the literature on such community issues as rehabilitation and housing problems.

This literature review will illustrate the definitive lack of Canadian data in the area of family members' experiences of schizophrenia. In view of this, American, Australian, British, European, and Scandinavian studies are cited in this literature review.

A. History of relationship between family and schizophrenia

There is a need for literature assessing the impact of schizophrenia on family members, partly because of the assumptions underlying earlier research and beliefs about the relationship between families and schizophrenia. The attempt to identify patterns of family relationships that played a contributory role in the development and course of schizophrenia began in the 1950s. Clinical researchers hypothesized that dysfunctional parenting styles and marital schism contributed to the illness (Clausen & Yarrow, 1955). In the following two decades it was believed the etiology of schizophrenia was rooted in family dynamics, and thus families were viewed as a barrier to the ill individual's treatment (Hatfield & Lefley, 1993; Lively, Friedrich & Buckwalter, 1995). Fortunately, a substantial volume of research has amassed which demonstrates that deviant familial interaction is neither necessary nor sufficient to produce schizophrenia (Halford, 1992). Indeed, rather than having a detrimental effect on PWS, the behavioural family therapy approach more typical today proposes that families are the basic unit of health and, as such, may contribute to the recovery and rehabilitation of ill relatives (Liberman, Kopelowicz, & Young, 1994).

B. Individual behaviour and experiences

1. Use of Medication

Despite the long-standing support for the efficacy of medication in the amelioration of positive symptoms in schizophrenia, up to 85% of PWS will relapse after the first or after multiple episodes (Peuskens, 1996). This alarming relapse rate is due mainly to the "failure to sustain medication regimens" (Dencker & Liberman, 1995; Liberman, Kopelowicz, & Young, 1994; Piatkowska, & Farnill, 1992). Approximately one third of PWS are fully "compliant" with their regimen (Fleischhacker, Meise, Gunther, & Kurz, 1994). However, this portrayal of PWS' failure to adhere to medication regimens as an issue of non-compliance has unfortunately perpetuated blame.

Traditional understanding of this problem has focused on the individual's lack of motivation or resistance to treatment. However, there are many possibilities for the failure to adhere, which include treatment system barriers, such as the lack of access to services and a lack of coordination of multiple elements of the mental health delivery system (Dencker & Liberman, 1995). Further, the lack of a partnership in the treatment collaboration (Kopelwicz & Liberman, 1995), a lack of insight into the importance of the medication (Schwartz, Cohen, & Grubaugh, 1997), denial of the illness (Jeffries, 1996), or the wish to avoid unpleasant side effects such as tardive dyskinesia and weight gain (Fleischhacker et al., 1994; Liberman et al., 1994; Thomas, 1993) have all been cited as reasons contributing to non-adherence.

Part of the source of non-adherence stems from interventions having been applied to individuals. Mental health professionals have traditionally believed that PWS have lacked the capacity to take responsibility for their own care (Wasylenki, 1994). It is important that PWS be viewed as active consumers (Hatfield & Lefley, 1993). Responsible consumers require repeated education about medication effectiveness, side effects, and self-administration. A healthy collaborative relationship between PWS and mental health professionals is a prerequisite for adherence (Munroe-Blum, 1994). Bebbington (1995) stresses that the task in treatment needs to be to mobilize the assets and resources of PWS, including their families, to cooperate in a treatment partnership, sharing responsibilities for adherence to mutually agreed upon treatment plans. Most importantly, interventions of any kind can only be used successfully when they fit with the subjective values and goals of the PWS.

2. Stressors

Stress is viewed as integral part of life in the community, and its effective regulation as critical to resolving problems, achieving goals, and maintaining health

(Falloon & Coverdale, 1994). The effects of stress are determined by people's perceptions of the stressor, their resourcefulness in employing coping strategies to buffer the situation, and methods to minimize the stress.

3. Coping Skills

One factor that is believed to impact both the course of schizophrenia and life satisfaction is coping behaviour, or how one manages both environmental and internal stressors. Rather than following a downward and deteriorating course, many persons are able to recover to a significant degree (Davidson, 1992). More energy has previously been devoted to exploring the nature of schizophrenia than to understanding what PWS may do to cope with the illness. The presence of factors that facilitate the improvement process appear to have more to do with the person struggling with the illness than with the illness itself. Research needs to explore the subjective experiences of individuals, as the meaning a person attributes to schizophrenia and its symptoms will have direct implications for how that person confronts and responds to the illness (Davidson, 1992).

In a Danish study, Middelboe and Mortensen (1997) explored strategies for coping with symptoms in long-term mentally ill individuals associated with group homes. Coping was measured by an instrument developed for the study which assessed four aspects of a strategy, specifically the level, direction, target symptom, and effectiveness. The researchers found that participants described five categories of symptom coping, with percentage of individuals using each strategy as part of their entire coping repertoire in parentheses: (a) behavioural control (48%) (i.e., that either involved diversion, or physical change such as sleeping, relaxing, swimming or walking); (b) social change (25%) (i.e., any change in behaviour that results in an increase or decrease in interpersonal contact);

(c) cognitive control (24%) (i.e., any change in attention to certain thoughts or perceptions); (d) physiological change (8%), (i.e., taking medication, drinking alcohol or taking drugs); or (e) symptomatic behaviour (4%) (i.e., behaviour signifying psychopathology, undertaken in order to reduce stress but leading to the impression of symptom exacerbation). The authors suggest that the findings have implications for planning psychoeducational and therapeutic activities. First, they stated that their results confirmed that mentally ill individuals exhibit a wide range of coping strategies to alleviate their symptoms. However, the attempts were seldom described as very effective, which suggests that systematic attempts to improve effectiveness of strategies may reduce symptoms further. The authors recommend that training in coping skills become a goal in psychosocial treatment of mentally ill individuals.

There are several limitations of the study, the first is the lack of diagnostic information provided. While the authors stated that 85% of participants had a diagnosis of schizophrenia with the remainder diagnosed with personality disorders and mood disorders they failed to identify which diagnoses were associated with which coping strategies when discussing the results. Secondly, there was no formal testing of validity and reliability (T. Middelboe, personal communication, November 1, 1998). It is difficult to have confidence in Middelboe's and Mortensen's (1997) findings in the absence of solid psychometric properties.

4. Social support

Social support is correlated with life satisfaction among psychiatric patients (Koivumaa-Honkanen et al., 1996). Deficits in social functioning are key characteristics in schizophrenia (American Psychiatric Association, 1994). Social skills can be viewed as instrumental in achieving social competence. The assumption is that poor social competence contributes to social isolation, decreases people's ability to cope with stressors, and consequently results in an impoverished quality of life (Hayes, Halford, & Varghese, 1995; Mihaljevic, Mandic, & Barkic, 1994). As a result of the young age at which schizophrenia often manifests itself, social skills may never have developed in the first place, or else they may have been lost due to the illness.

In a national schizophrenia project in Finland, Salokangas (1997) studied the living situation, social network and outcome in schizophrenia in a five-year prospective follow-up study. A representative sample of 227 individuals was followed for 5 years. All had contacted public psychiatric services for the first time in their life with regard to a diagnosis of schizophrenia. Detailed standardized interviews were conducted with changes in patients' clinical and functional outcome analyzed by ANOVA according to their living situation and social network. For the purposes of analysis, the subjects were divided into three groups according to their living situation. The primary family group (PRF) consisted of subjects who lived with their parents. The secondary family group (SEF) consisted of those who lived with their spouse or informal partner. The non-family group (NOF) consisted of all other patients who lived either alone or with some other person. The results showed positive changes in clinical state and functional ability as most pronounced in persons living with their spouse (SEF). At the end of the study, the SEF group had fewer psychotic symptoms ($p=0.043$) than the other groups. Furthermore, throughout the follow-up period, SEF patients were found to be in paid employment significantly more often ($p<0.01$) than the remaining patients. The functional and social outcome of men living with their parents was better than that of women in the same situation. Yet, among persons living alone or with some other person, women had better functional and social outcomes than men. Individuals living away from their families were at greater risk of losing their social contacts.

The authors concluded that these latter individuals need special attention from the mental health treatment system. Fostering supportive social networks, active outpatient care and rehabilitative services were recommended as preventive measures. Indeed, family relationships existing at the onset of the illness may be the only lasting relationships. As family members often offer the best possibilities for the individual's care, professionals should strive to preserve and support existing family ties or improve deficient ones. This is an important implication for my research.

In another Finnish study, Viinamaki et al. (1997) examined factors associated with psychosocial recovery in psychiatric patients who had either made at least three outpatient visits during the four months preceding the onset of the study, or who resided in a mental hospital. During a treatment visit each patient was asked to anonymously complete the study questionnaire. This covered demographic information, a subjective capacity for work, financial situation and social support. Social support was measured by the following question on a 4-point scale: "In your opinion, do you receive enough understanding and support in your problems from people closest to you?". Each patient's therapist completed a separate questionnaire on the patient, which covered diagnosis, form of psychotherapy used, frequency of visits, functional capacity, and status of psychiatric symptoms.

Psychosocial recovery was assessed using the Global Assessment Scale (GAS), where recovery was considered to have occurred if lowest GAS score during the preceding year had increased by at least 28 points at the time of the study (n=102). All other participants served as controls (n=982). Comparing the two groups assessed factors associated with psychosocial recovery. Thirty-three percent of both groups were PWS; other diagnoses were depression, personality disorder, and neurosis.

Step-wise logistic regression analysis was used to assess independent predictive outcome factors within the four aforementioned diagnostic groups. As a diagnostic whole, adequate social support was associated with psychosocial recovery ($p<0.05$), whereas financial situation was not. It is important to note that in the logistic regression analysis of PWS (n=371) a high frequency of treatment visits was the only factor associated with recovery (Wald=7.3, $p<0.007$, OR=7.6). These results would appear to be contradictory to Salokangas' (1997) research involving only PWS.

The literature review will progress from the individual level to familial level in the following section.

C. Familial behaviour and experiences

1. Coping Skills

Many relatives are concerned about how to cope with disturbed behaviour (Spaniol & Zipple, 1994). Not surprisingly they also want to bring about a disappearance of the symptoms, but when this does not happen, or when symptoms recur and the problem becomes chronic, then interest in adequate coping strategies becomes a chief concern. It has been suggested that family members' sense of mastery and self-efficacy may affect their ability to cope with their ill relative (Rose, 1996; Solomon & Draine, 1995b). Though caregivers are not able to control their relatives' illness, they are able to manage their response to it. Persons who believe that they can exert some control over their life conditions are likely to direct situations to their own advantage (Reinhard, 1994).

Moreover, the onset of schizophrenia may leave the entire family with a sense of disconnectedness from others, from living and working environments, and from larger purposes in life. One purpose of enhancing coping skills involves the practical issue of how to manage the illness. An additional loftier goal is to foster the restoration of connections. As my literature review will demonstrate, the latter issue has not been well researched.

In an American study, adaptive coping was examined in 225 family members who had the major responsibility of caregiving for individuals with serious mental illness (Solomon & Draine, 1995b). Most of the participating family members were female (n=198, 88 percent), and mothers (n=172, 76 percent). Adaptive coping was measured with a scale derived from an existing coping scale. The resulting questionnaire was tested with a sample from another study of family members who had relatives with severe mental illness and which was reported to have acceptable reliability and validity. Hierarchical regression analysis using five variables that may have contributed to coping was conducted. The five factors were: demographic characteristics of the family member; severity of the illness; the family member's subjective burden and grief; social support; and personal coping resources. Results found that social support was the strongest factor associated with adaptive coping (f=10.03, p<0.001), and a sense of self-efficacy in dealing with the relative's illness was an additional association (t=4.24, p<0.001). The authors recommend that family members use support provided by community-based support groups, and that families form the groups if they do not exist.

One of the study's limitations was that the diagnostic information was inadequate. It was stated that ill relatives had either a diagnosis of schizophrenia (64%) or major affective disorder (not further specified). In addition, similar with much of the existing research on family members and mental illness, most of the subjects were mothers.

Birchwood and Cochrane (1990) studied the strategies and styles of coping in relatives of patients with schizophrenia in the United Kingdom. The researchers showed 31 fathers, 18 mothers, 2 husbands, and 2 wives a set of video-taped interviews in which different behaviours of PWS were role-played. They then asked the family members several questions about the occurrence of those behaviours in their ill relative, and their reactions to those behaviours. Eight categories of coping strategies surfaced: coercion, avoidance, acceptance, collusion, constructive reaction, resignation, reassurance, and disorganized reaction. They further identified the relationship of the coping strategies and variables concerning family burden and to the patient's social functioning. Social functioning was measured with the self-report Social Functioning Scale[1], which has extensive normative data and psychometric validation. Results indicated two significant associations with regard to social impairment: coercion was more commonly adopted by relatives with patients of low social functioning; and the acceptance style was adopted more by relatives of patients with higher social functioning.

One of the limitations of this study was that there was no data on the validation of the adopted coping questionnaire.

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[1] This scale includes the following subscales: social engagement, interpersonal functioning, prosocial activities, recreation, independence, and employment. Patients were trichotomized into three social adjustment groups (high, average, low) at the 33rd and 66th percentile points of the scale.

Magliano et al. (1996) described the development and validation of the Family Coping Questionnaire (FCQ), designed specifically to assess coping strategies adopted by relatives of PWS. The final version of the questionnaire includes items grouped into the following seven subscales: information; positive communication; social interests; coercion; avoidance; resignation; and patient's social involvement. Thirty eight percent of the relatives were men; they were parents in 63% of the cases, spouses in 11% of the cases, and siblings in 18% of the cases. This subject pool is more diverse than in much other research. Factor analysis identified the following three factors as accounting for 71% of the total variance; problem-oriented coping strategies, emotionally focused strategies, and maintenance of social interests in association with patient's avoidance.

The authors suggest that the questionnaire may be helpful in two ways: the targeting and monitoring of psychoeducational interventions in families; and also as part of a general assessment of an individual's environment which is preliminary to all psychosocial approaches to schizophrenia. There is the inherent assumption that patients with similar environments will respond similarly to interventions.

2. Social support

Social support promotes health and wellbeing, reduces exposure to stress, and guards against stress when it does occur, and as a result can be considered as contributing to coping (Lundwall, 1995). In fact, in a study examining predictors of depressive symptomatology among caregivers of persons with chronic mental illness (Song, Biegel, & Milligan, 1997), the researchers found insufficient overall social support to be the most powerful predictor of symptomatology.

Generally speaking, the recognition of the family as an asset in the care of individuals with schizophrenia has brought to the attention of mental health professionals the need to support family caregivers (Hatfield, 1993). It is important to examine the components of social support that facilitate family coping.

Self-help groups are a strong source of social support for family members (Solomon & Draine, 1995b). The groups provide a setting for the sharing of common problems and coping strategies for families. Meetings provide an opportunity for information exchange, and furthermore, family members experience the support and validation of others in similar situations. Coping has been shown to be positively related to affirming social support, the density of the social network, and participation in family support groups (Solomon & Draine, 1995b).

Nurses and other mental health professionals are potential social support resources. Family members report needs for instrumental professional support, such as information about their relatives' illnesses and practical techniques for dealing with aberrant, sometimes threatening, behaviours (Reinhard, 1994). They also seek emotional support, specifically empathy and respect for their concerns and opinions regarding their relatives' rehabilitation (Reinhard, 1994).

3. Stress

It is assumed that family members of PWS experience stress (Baker, 1993; Hatfield & Lefley, 1993). The stress experienced is multifaceted and occurs at the social, economic and psychological levels. Social activities and daily living routines are disrupted, financial support of the ill dependent results, and caregiving burden arises.

Problem with the ill relative's communication ability is a major source of stress for family members (Chafetz & Barnes, 1989). In particular, the withdrawn behaviours characteristic of the negative symptoms often pose the biggest challenge, perhaps because they appear volitional. For instance, one caregiver in the above study stated, "I wish that he would get out of bed and get busy ... I try to keep him busy but he won't do anything I ask him to do ..." (p.64). As stated earlier when defining schizophrenia, one of the characteristic negative symptoms is precisely this difficulty in initiation of activities. However, it should be noted that amotivation is also a side effect of medication. In addition, given that poverty of speech is another negative symptom, the disruption in communication ability noted by family members is not surprising.

a. Stigma

There is clear evidence of the presence of stigmatization of individuals who live with schizophrenia (Farina, 1998; Hatfield & Lefley, 1993; Torrey, 1998). Stigma has been said to be the most critical burden suffered by persons with mental illness (Hatfield & Lefley, 1993). It is an objective and everyday phenomenon. The consequences of social stigma range from difficulties in obtaining employment, housing, insurance, licenses, to the loss of old friends.

In an American study, Wahl and Harman (1989) explored family views of stigma in 487 members of the National Alliance for the Mentally Ill (NAMI). A questionnaire was developed asking respondents to report their views about stigma and its impact. The response rate was thirty-five percent. Questions encompassed several categories, including general questions asking participants the extent to which they felt stigma was associated with mental illness and the extent to which it unfavorably affected ill individuals and their families. Second, a number of ways were listed in which stigma might affect families and might affect their ill relative (i.e. impaired self-esteem, ability to make and keep friends, and success in getting a job), and participants were asked to rate the extent of these possible effects. Third, a number of possible contributors to stigma were listed (i.e. popular movies about mentally ill criminals, jokes about mental illness, and the insanity defense), and participants were asked to rate how much each of them contributed. Finally, possible sources of emotional support were listed for family members to indicate how helpful each was in dealing with stigma and its effects (i.e. factual information about mental illness, talking with mental health professionals, and interaction with other families). Responses involved Likert-type ratings with choices "not at all", "little", "somewhat", "much", and "very much".

Results included most family members reporting that not only their ill relative but the entire family was stigmatized (88%). The percentage reporting "much" or "very much" follows the response in parentheses. The perceived impact of stigma on ill relatives was extensive. The majority reported that their relative's self-esteem was unfavorable affected (76%), as was their ability to make and keep friends, and success in keeping a job (65% and 64%, respectively). Participants reported the following to be perceived contributors to mental illness stigma: popular movies about mentally ill criminals (86%); news coverage of tragedies caused by mentally ill people (82%); violence by mentally ill people (77%); and unfavorable personal experiences with mentally ill people (46%). Participants also responded regarding perceived aids in coping with stigma. Factual information about mental illness (86%); interaction with other families with ill relatives (78%); research findings which establish a biological basis for mental illness (73%); and talking with mental health professionals (49%) were all reported to foster the coping process.

There are several limitations in this study. First, the only diagnostic limitation was that family members provide care to individuals with severe mental illness, "like schizophrenia or bipolar depression". The second limitation stems from the composition of the sample. The families have joined a support organization. It is possible that their greater experience of stigma provided impetus for them to join. Third, participants were further self-selected by choosing to fill out and return the questionnaire. It may be that only those most sensitive to and concerned about stigma responded.

b. Caregiving burden

In an American study, Reinhard (1994) examined the relationships among professional support, caregivers' personal sense of control, and burden and wellbeing in a convenience sample of 94 primary caregivers to individuals with mental illness. Burden was conceptualized as having objective and subjective components, with the objective dimension encompassing such observable effects as financial strain, household disruption, personal activity restrictions, and friction with other family members. Subjective burden included affective dimensions such as guilt, worry, grief, and stigma. Most subjects (68%) were parents of the ill relative. Siblings comprised 15% of the sample, children 12%, and 5% were other relatives, with most subjects female (82%). Two sets of hypotheses were tested after controlling for caregiver characteristics such as age, sex, education, and family income, as well as for the relative's disruptive behaviour. First, higher levels of professional support would be inversely related to burden, inversely related to depression, and directly related to physical health. Second, professional support would affect burden and depression, and physical health indirectly by increasing the caregiver's personal sense of control.

The Burden Assessment Scale (BAS) assessed caregiver burden, and general wellbeing was operationalized as self-reported depression and physical health. Depression was measured by the Center for Epidemiological Studies Depression scale (CES-D). Both scales and the global rating of health were valid and reliable measures. Professional support was measured by asking participants to rate the amount of help received from mental health professionals in instrumental and affective support areas. The family advisory group and psychiatric nurses reviewed all items, with evidence of content validity resulting. Personal sense of control was measured by Pearlin and Schooler's (1978) scale of mastery, which is reliable and demonstrates adequate predictive validity in relation to psychological distress.

The three most commonly reported areas of objective burden were restrictions in personal activity (48%), family stress (45%), and household disruption (43%). Subjective burden reports were higher, with worrying about the future (87%), feelings of loss (54%), and being stigmatized (45%) the most common. However, participants' depression scores were representative of general population scores, and most respondents reported their health as good to excellent. The author concluded that most caregivers felt burdened by their responsibilities, but had not generalized this situation-specific outcome to their global sense of physical or psychological wellbeing.

A major study limitation was that the only diagnostic information provided was that 78% of the respondents provided care to individuals with schizophrenia. It is unclear which results correspond to the relatives of PWS.

McGilloway, Donnelly and Mays (1997) assessed the experiences and mental health status of informal caregivers for former long-stay psychiatric patients in Ireland. A mail survey comprised of two questionnaires, the General Health Questionnaire and the Cost of Care Index, was sent to 72 caregivers. The latter assessed burden on five dimensions of care: physical health and anxiety; personal and social restrictions; the perceived worthiness of providing care; the ill individual's potentially provocative behaviour; and the economic costs of caring. Results showed support for the contention that personal and social restrictions were common, and that the practical demands of caregiving are less likely to be associated with the mental health of caregivers, which concurs with Reinhard's (1994) findings.

Two major limitations of the study are that diagnostic information on the former patients was not provided, nor were psychometric properties for the scales.

Researchers in the United Kingdom studied the psychosocial dimensions of family burden among two groups of caregivers to PWS (Bibou-Nakou, Dikaiou & Bairactaris, 1997). There was a focus on the influence of psychosocial factors, such as the sense of personal control and coping strategies, upon the extent and the perception of burden. PWS were divided into continuing treatment patients (n=31) who had been ill for at least two years, and acute patients (n=21) who had been ill for less than two years. The subjects were predominantly parents (51%), and women (73%). Subjects participated in semi-structured interviews that focused on burden, coping resources used to combat negative symptoms, and styles used to deal with daily problems. Caregivers' mental health was assessed using the General Health Questionnaire. Perceived mastery, coping strategies, and the psychological distress of the caregivers were the dependent measures in a two-way ANOVA, with the patient group and ethnic background as independent variables. The same scale used in Reinhard's (1994) study was used to assess mastery, and exhibited an adequate level of internal consistency.

A significant correlational association between objective and subjective burden and the caregivers' psychological wellbeing was found ($p<0.01$ and $p<0.02$, respectively). Furthermore, mastery and coping were significantly associated with burden and mental health functioning. The continuing treatment caregivers were more likely than the acute caregivers to either use a passive style of coping or to ignore specific problems arising from their interactions with the PWS (ANOVA: $p<0.05$). However, details on sample selection and questionnaire psychometric properties were not provided. Furthermore, as the evidence is correlational, no statement regarding direction of the influence between the psychosocial variables of mastery and coping, burden and wellbeing can be made.

In an American study, Solomon and Draine (1995a) tested the hypothesis that a greater degree of subjective family burden is related to greater severity of the relatives' illness, less availability of social support, and fewer coping resources of family members. The research used baseline data from a random clinical trial of two modes of psychoeducational services for families of persons with serious mental illness. Eighty-eight percent of the sample was female, and 76% were daughters of ill relatives. Family members were assigned to group psychoeducation, individual family consultation, or to a waiting-list control group. It was hypothesized that the two intervention groups would experience decreased burden. Participants were administered a burden questionnaire, a scale to assess their views of the ill relative's current level of functioning, and a social support questionnaire. Social support was measured using the Norbeck Social Support Questionnaire (Norbeck, Lindsay, & Carrier, 1981, 1983).

The four blocks of variables included family characteristics, severity of illness-related stressors, social support mediators, and coping response mediators. The regression model was statistically significant ($p<.05$) in explaining variance in subjective family burden. Thirty-nine percent of the variance in burden was explained by the severity of stressors related to the ill relative's illness and by mediators related to social support and coping capabilities. Having the relative reside with the family member was a significant stressor, which contradicts a conclusion in Salokangas' (1997) research on living situation, social network and outcome.

A limitation was that diagnostic information was stated simply that the ill relative had either a diagnosis of schizophrenia (63.5%) or major affective disorder. A further limitation, once again, was that psychometric properties were not provided for any of the scales or questionnaires used.

In another American study, Bulger, Wandersman & Goldman (1993) explored the burdens and gratifications of 60 parental caregivers to individuals with schizophrenia. In addition to quantitative scales that measured burden, gratification, and patient symptoms, the authors appended four open-ended questions that provided an opportunity to discuss the most difficult aspects of caregiving, rewards from personal growth, parent-child relationship, and the effects of disagreements. Eighty-five percent of the subjects (n=51) were mothers. Psychometric properties of the instruments were acceptable. It is of interest to note that the burden scale was designed for use with caregivers of elderly relatives.

Results indicated that there was a positive element to caregiving. Parents more often had feelings of gratification or intimacy than of burden or conflict. The authors concluded that the emphasis on teaching constructive responses to disturbing behaviour might overlook opportunities to enhance satisfactions of caregiving.

Chesla (1991) identified parental caring practices to PWS in an American qualitative study that used hermeneutic inquiry. Twenty-one parents were interviewed three times over a three-month period regarding stressful episodes and their attempts to cope. The Berkeley Stress and Coping interpretive interview was used to elaborate upon positive and negative episodes of care, their context, what parents considered troublesome, the ways in which they coped, any alternative courses of action they considered, their emotions, and the outcome of each episode. Four qualitatively distinct forms of caring practices were identified: support of the ill relative's wellbeing in spite of shifting symptoms; balancing the ill relative's needs against the caregiver's needs; adoption of professionally prescribed care principles; and remaining personally uninvolved by delegation of care to another family member. These were termed engaged, conflicted, managed, and distanced care, respectively.

The main strength of this study was the detail that emerged from its qualitative approach. As the author stated, if the parents were examined using the "theoretical grid of family burden" the distinct nature and meaning of the burden for parents involved in the different forms of care would be lost. For instance, the parents that practiced the conflicted care and the parents that practiced the managed care would undoubtedly rate as burdened on subjective burden scales. However, the nature of the burden in the two groups was different. In conflicted care parents searched for a reasonable way of relating to the situational demands. They were discontented and had not accepted the illness. On the other hand, parents who practised managed care accepted their situation because they found a way to care through personally constructed "therapies", and also had faith in science. Their burdens stemmed from the endless need for therapy, and thus caring was considered taxing.

The qualitative orientation provided an alternative to the traditional, pathological view of care. Care was not viewed as rigorously attitudinal, but rather as a set of practices that stem from "caregivers' unique backgrounds, ways of being, skills and understandings" (Chesla, 1991).

In an American study, Howard (1994) studied lifelong maternal caregiving for children with schizophrenia. The principles of naturalistic inquiry and a grounded-theory design provided foundation for the methods in the study. Purposive sampling guided participant selection. Participants were asked, "Begin from the beginning and tell me about your caregiving experience with your ill child". A model was developed to organize descriptions of caregiving. Maternal care was described in terms of watching, working, and waiting. Watching meant vigilance and how mothers gave attention to their child. Working referred to the physical and psychological tasks inherent to caregiving. Finally, waiting referred to times when mothers were less active in working activities, yet thought about, hoped for, and also feared for the future of the child. Further results included the elucidation of four stages of caregiving, which the author stated is useful in understanding both problems and processes of caregiving. In stage 1, entitled "perceiving a problem", mothers encountered difficulties and dilemmas. Stage 2, "searching for solutions", was described as learning about the diagnosis, yet having little understanding about the illness. Stage 3, "enduring the situation", involved finding some meaningful support and increasing understanding about schizophrenia. Stage 4, "surviving the experience", involved the recognition of ways to care for the self in the face of sorrow and continued caregiving, and was described as a time of acceptance, hope and determination.

The finding that mothers lacked understanding about the illness has implications for health care providers in general. The author suggests that evaluation studies are indicated, perhaps through accrediting bodies that review psychiatric hospitals and services. In addition, direct help in the home is a noteworthy need and congruent with nursing practice methods.

In another American study, a phenomenological examination of the experience of caring for an adult son with schizophrenia, Tuck et al. (1997) interviewed seven mothers and two fathers who were primary caregivers. Participants expressed intense dissatisfaction with initial mental health evaluations. Specifically, caregivers stated that the diagnosis itself had little "explanatory or predictive value" for the family. Professionals did not recognize the families' need for follow-up on diagnosis with a description of the "situated meaning of the diagnosis". Parents wanted to know what the diagnosis meant for both the ill relative's and the family's future. Indeed, the need to know about the illness was a recurring theme in the interviews.

The authors recommend that after the diagnosis is made at the initial consultation with mental health care professionals, caregivers receive education about schizophrenia, its prognosis, and available resources in the community.

LIMITATIONS OF CAREGIVING LITERATURE

Although much quantitative research has been undertaken in this area, it is difficult to have faith in some study findings when information is not provided regarding the instruments' reliability and validity. In addition, the diagnostic group in some studies is not restricted to schizophrenia. This makes interpretation of the results difficult, as the authors do not specify which diagnoses are associated with which results. Furthermore, most studies that include family members are based on information provided by women, typically mothers. I believe that relatives have separate needs and experiences, and as such research should focus upon all persons who provide care.

As is evident from this literature review, with the exception of the studies by Chesla (1991), Howard (1994), Tuck et al. (1997), and the mixed-methods study by Bulger et al. (1993), quantitative research has predominated in family caregiving studies. There has been a focus on the rational and technical aspects of care (Chesla, 1991; Le Navenac & Vonhof, 1996) and within these conceptualizations empirical studies have often identified family members and PWS at risk for negative outcomes in both mental and physical health. However, this focus on risk factors has neglected what the experience means to the family. Illumination of the broader experience of family members, including how they perceive and define the illness, as well as how they have undertaken the care, is warranted. Le Navenac and Vonhof (1996) comment that the contextual aspects of caregiving are often "packaged in the literature according to the type or number of mediating variables, such as physical, emotional or financial problems, as opposed to their qualitative aspects" (p. 8). It would appear that the importance of interpretive, qualitative work lies in its ability to correct and extend theoretical constructions about care, which is a multi-dimensional experience (Le Navenac & Vonhof, 1996). In spite of the awareness that schizophrenia can impose an extensive burden on families, studies have not yet examined how family members participate in managing the illness, or how they experience the impact on their lives.

Indeed, Chesla (1991) states that a major problem in conceptualizing care as a burden is that it systematically disregards most of the meaning of care. Recent research has been embodied by conceptions of the family as burdened by care, yet it is unnecessarily limiting to study burden as the dominant experience of the family. As Bulger et al. (1993) posit, it behooves us to study additional aspects of family members' experiences such as caregiving gratification. Furthermore, caregiving practices could adopt a broader approach and focus on easing the suffering of the ill member or enhancing self-empowerment of all involved. These experiences are important because they likely influence approaches to caring and thus may impact the course and outcome of schizophrenia.

Plager (1995), as cited in Tuck et al., (1997) called for qualitative approaches to health research "... to elucidate the meaning of the family's life world, their lived experience, their situatedness, their concerns and what matters to them" (p. 67). Simply stated, humans act toward things on the "basis of the *meanings* that the things have for them" (Ellis & Flaherty, 1992). Furthermore, Wright, Watson and Bell (1996) propose that an exploration of family members' beliefs about etiology, treatment, prognosis, and mastery, control and influence is a prerequisite to "creating a context for change". In addition, it has been stated that family members have served as "expert witnesses", and that they are expert on their experiences (Thorne & Robinson, 1989). This provides further support for their participation in the present research.

The next section of the literature review will proceed to health system issues.

D. MENTAL HEALTH SYSTEM

Family members' experiences with their ill relative are likely influenced by the mental health care system in the area in which they live (Goldstein, 1996). The studies reviewed herein are American, Australian, British, European, and Scandinavian. As a result of differences between the Canadian system and the systems in other countries, I believe there is a clear need for research in a Canadian context. A brief introduction to the importance of the system to families who live with PWS precedes a review of dominant issues in the literature.

The mental health system ought to treat not only acute episodes, but also provide lifelong care by linking different treatments and rehabilitation services (Bachrach, 1994; Wasylenki, 1994). A comprehensive, multidimensional approach is necessary, continuously offered, assessed and coordinated over time and over different settings, and adapted to individuals and their particular needs (Peuskens, 1996). Moreover, a critical component of an effective service system is open communication with families, including soliciting and accepting their involvement (Hatfield & Lefley, 1993).

1. Barriers to care

Talbott (1996) asked experts in the mental health field to cite the top ten barriers to care of the mentally ill. Methodological details are unclear. Dr. Talbott did not respond to email requests for further information. Responses cited ranged from service deficiencies such as too little focus on rehabilitation and restrictive admission policies of community programs, to the lack of continuity of care, non-compliance, stigma, and inadequate housing. Nowhere in the literature reviewed in this research paper did researchers ask ill individuals what they perceived as the top barriers to effective care. Practical issues would have undoubtedly surfaced, in my view. Individuals have an important role to play in the planning and delivery of programs (Munroe-Blum, 1994; Wasylenki, 1994). The needs and wishes of PWS have often been ignored by service providers, with the result that many mental health services have been ineffective. Professionals and ill individuals often have very different perspectives on needs (Comtois et al., 1998). Expanded involvement of PWS could include participation in planning, operational roles in more traditional service delivery systems and support for consumer-initiatives such as self-help and peer support programs (Jeffries, 1996; Wasylenki, 1994). The concept of primary health care invites full community participation, and the development of the necessary arrangements through which individuals, families, and communities can undertake accountability for their health and wellbeing (Alma-Ata, 1978).

Furthermore, eliciting the involvement of the families of individuals with schizophrenia is an important component to well-planned services (Barrowclough & Tarrier, 1992; Smith, 1992; Wasylenki, 1994). Their views are often different from their ill relatives' and a critical prerequisite to service development. Their participation has the potential to attract the larger community which may have difficulty in identifying with ill individuals, but which may more easily provide support, both personal and financial, in response to appeals from family members.

2. Collaboration

As a result of the often chronic and relapsing nature of schizophrenia, the existence of a collaborative relationship based on open and ongoing communication between mental health professionals and families is of critical importance. Collaboration requires a shift from therapeutic models of viewing families in which deficits are the main concerns to competence models which focus on strengths (Hatfield, 1994; Marsh, 1994). The impact of the illness on families is often profound and deserves special attention. However, there is little research based on inquiries with families, on what the families need and want from professionals. The investigations that do exist are most often conducted by advocates such as Hatfield (1994).

Research suggests relatives experience dissatisfying contact with professionals (Hell, 1997; Howe, 1995; Marsh, 1994) and, specifically, it is most often relatives associated with self-help groups that express the greatest disappointment with the service system (Hell, 1997; Johnson, 1990; Thorne, 1993). It is not possible to deduce whether the relatives felt freer to voice their dissatisfaction and to speak about the stress they felt than relatives not affiliated with a self-help group, or whether conversely, it was pre-existing higher levels of stress and dissatisfaction that led to their joining a group.

Both families and ill individuals have reported professional indifference to their experiences (Hell, 1997; Howe, 1995). The dissatisfactions most often mentioned by family members encompassed what they perceived as alienation from the treatment process, insensitivity to family needs (Rose, 1996), early release, and difficulties in discharge planning (Johnson, 1990).

Kane (1992) suggested that professionals need to give up the dominating role they have assumed in the traditional relationship. Not only should professionals take caregivers' viewpoints seriously, but in addition to reacting in crisis situations they should also act in non-crisis times. Both relatives and ill individuals themselves are able to assess early signs of relapse, and this information can be used with professionals to prevent the development of more serious symptoms (Kuipers, 1993).

3. Psychoeducational programs

There is often a discrepancy between the professionals' understanding of schizophrenia and the reality of the illness experienced by ill individuals and their family members (Howe, 1995). A framework of provision has developed which has been shaped by academic debate, economic consideration, and civil liberties ideology, rather than by recognition of the needs of those having to live with schizophrenia (Howe, 1995). Families should receive baseline knowledge that enables them to achieve necessary expertise and provide a properly supportive network for their ill relatives (Chafetz & Barnes, 1989; Chesla, 1989; Howe, 1995; Kuipers, 1993). Family members are disempowered if they are deprived of essential information about schizophrenia. Indeed, all successful intervention studies have included an educational component, and perhaps most importantly, the chronic nature of schizophrenia dictates a need for information throughout the course of the illness. Psychoeducational programs are designed to educate family members about schizophrenia, its treatment, and to emphasize learning, problem solving, and communication (Reinhard, 1994).

Family members of patients with a diagnosis of schizophrenia were surveyed to determine their understanding of their relative's illness and its implications for the family

(Gantt, Goldstein, & Pinsky, 1989). At least one family member of each of 45 patients with schizophrenia was interviewed. Patients had been admitted to the inpatient services of a voluntary psychiatric hospital in the city of New York. The objective was to determine the need for, and content of, a proposed psychoeducation program. The researchers explored the accuracy of the families' knowledge of the diagnosis, at what point they were given a diagnosis, and if information regarding medication and therapy had been provided. Fifty-three percent of all the families interviewed knew the correct diagnosis, 68% had no understanding of the etiology of schizophrenia, and 24% had no knowledge of what the early symptoms of their relatives' illness were. Moreover, 51% of families had no understanding of the chronicity of schizophrenia, and 71% did not receive information about medications. The authors concluded that their data support the need for the implementation of a psychoeducation program, yet there was no description of study methods, nor statement of the actual sample size!

In an Australian study the perceived needs and tasks undertaken in the caregiving role were examined in interviews with 121 family caregivers to PWS (Winefield & Harvey, 1993). Researchers asked patients in outpatient and suburban outreach clinics if their "closest relative" could be approached for participation in the study. Sixty-five percent gave consent for this approach, and the consent rate among "caregivers" was 64 percent. A series of interview questions explored the amount and type of help received by the caregiver to "deal with troublesome behaviour" by the patient. Twenty-nine percent of caregivers had no contact with the patient's medical advisors, while the remaining caregivers rated their confidence in expressing their needs to the patient's doctors (51%), ease of contacting staff (22%), and helpfulness of staff (41%). Further, a checklist of needed improvements to services asked for 3-point ratings (very useful, might be useful, and not at all useful) regarding caregivers' views on the usefulness of eight possible improvements. Respondents rated the following as very useful: earlier professional intervention when patient begins to relapse (90%); how to lobby politicians for more funding for services (67%); more information about causes and treatment of schizophrenia (65%); more information about how families can cope with disturbed behaviour (64%); education of police about how to treat mentally ill persons (62%); better supervised accommodation available (61%); more day programs in own area (59%); and more meetings with patients' doctors (49%).

A major limitation of Winefield and Harvey's study is the lack of information on the nominated relatives that declined to participate. Highly isolated and burdened families may be among nonparticipants, and this bias would result in an underestimation of the level of burden. Furthermore, the generalizability of this study is limited due to subject composition. As members of self-help groups they may have been self-selected for distress.

In an American study, Main, Gerace and Camilleri (1993) examined siblings' perspectives on information sharing concerning schizophrenia in family members. Semi-structured qualitative interviews were conducted with a convenience sample of 11 adult siblings. Questions focussed on information sharing, specifically the following: (a) what were you told about your sibling's condition; (b) who was initially involved in talking with you and your other siblings; (c) over time, what are the things you are your siblings have been told? By whom? What kinds of questions have they had? and (d) are there things about the condition or concerns that you have decided not to share with other members of your family?

Results showed a variation in siblings' needs and desire for information about schizophrenia. Approximately half of the siblings desired information about schizophrenia, whereas the other half preferred not to seek it. It appeared family members were often at different stages in their readiness to accept information. The authors suggested that mental health care providers need to understand that although a family may not seem interested in receiving information at a particular stage of an individual's illness, there may be interest in information acquisition in the future. Furthermore, the authors concluded that the information offered to siblings who sought it was often inadequate and confusing. This concurs with other research findings on the subject.

Information sharing between families and professionals has helped families in anticipating and preparing for situations that schizophrenia presents, in addition to managing the stresses involved (Main, Gerace, & Camilleri, 1993; Wynne, 1994). A lack of information has resulted in family members displaying unrealistic expectations of the needs and chronicity of the illness (Gantt, Goldstein & Pinsky, 1989). Moreover, this has manifested itself as increased stress and in turn resulted in some family members displaying counterproductive behaviours. For instance, research suggests residual negative symptoms present particular difficulties for families (Birchwood & Cochrane, 1990). Even when positive symptomatology has subsided, the negative symptoms of schizophrenia that result in social withdrawal, apathy, and self-neglect can cause families frustration (Solomon & Draine, 1995b). Some relatives fail to recognize these symptoms as stemming from an illness, and instead may attribute them personally to the individual and criticize ill members for being lazy and selfish (Goldstein, 1996).

As mentioned earlier, there is a need for Canadian research into health system issues that may affect family members of PWS. The development of any psychoeducational program is best understood within the cultural context of the health delivery system of the country in question. The United States does not have a national health system in which mental health services are guaranteed to all. Rather, multiple treatment systems exist in different communities, some supported by private insurance mechanisms, and others by public funding, often with minimal coordination of these systems (Goldstein, 1996). It would be interesting to see how the experiences of family members in Canada compared to those in America, Britain, and Europe.

The next, and final, section will review community level issues.

E. COMMUNITY

1. Rehabilitation

Health is not merely the absence of symptomatology, but involves competent functioning in the community. Pender's (1996) definition of health is in accordance with the rehabilitation model, as she states that health includes "building on strengths, enhancing resources, and fostering resilience to enhance prospects for effective living" (p. 29).

Psychiatric rehabilitation can be defined by its purpose, which is the improvement or sustaining of the quality of life of people with psychiatric disabilities. This is accomplished by assisting them in the development of their ability to live successfully in the community and to participate to the maximum extent in recreational, social, vocational and educational pursuits (Farkas et al., 1994). The intention of rehabilitation is to empower individuals, or encourage them to take advantage of their assets by building upon wellness. Individuals are taught to take an active part in managing their illness and controlling their lives (Runyan & Faria, 1992). The individual is helped to adapt to life in spite of the disabilities the illness presents and also to prevent the development of handicaps that are the social disadvantages resulting from the disability. One aim is to develop compensatory skills that may limit the extent of the disabilities.

a. Vocational rehabilitation

Work plays a number of important societal roles. Not only is it a "normalizing experience" (Harding, Strauss, Hafez, & Lieberman, 1996), but it has directly associated improvements in activity, social contacts, and remuneration. Further, it provides daily time structure and routine, and the foundation for enhanced autonomy and self-esteem, illness self-management, community tenure, and quality of life (Drake et al., 1994; Peuskens, 1996; Van Dogen, 1996). There is a general consensus that less than 15% of PWS are able to attain and maintain competitive employment (Harding, Strauss, Hafez, & Lieberman, 1996).

Vocational rehabilitation (VR) is posited to alter the course of the illness, resulting in fewer psychiatric admissions, more productivity, and a better quality of life (Lehman, 1995). It is designed to facilitate the ability to work, incorporating procedures designed to prepare the individual for, or for reintroduction to, productive employment. VR programs are one aspect of the rehabilitation process, with the goal being the restoration of individuals' optimal functioning within the workplace. Transitional employment (TE), the more traditional vocational program, employ the "train-place" approach where individuals are trained prior to placement in temporary community jobs. Supported employment (SE) programs are more typical of today and employ the "place-train" approach. Proponents of the latter programs believe that the relatively poor success rate of the TE programs stems from two of its characteristic features: first, the time-limited nature of the support, and second, the transfer of learning required from training to work situations. More often than not individuals with schizophrenia require ongoing services and support, such as training in the skills necessary to maintain employment, once they secure competitive employment.

Success rates of VR programs have not been encouraging, as most programs do not meet their objectives (Bond, 1994). While quantitative analyses have determined that VR outcomes are generally discouraging, it is not understood why the rates are so low. Qualitative research may aid in the elucidation of the barriers to successful performance in the workplace. Furthermore, the specific challenges that work poses and how individuals cope in the workplace may be explored. Rehabilitation programs are faced not so much with a disability that must be cured, but with an environment to which we must try to adapt. Therapeutic interventions need to aim to adapt the individual to their immediate environment, and also at adapting the environment to the person (Dauwalder & Hoffmann, 1992).

2. Housing

Some researchers believe that housing is so pivotal to the success of the community rehabilitation of individuals with schizophrenia that safe, decent, affordable housing is a prerequisite to the development of life skills that foster independence (Dzurec & Bininger, 1992). Baker and Douglas (1990) found that the perceived quality and appropriateness of housing environment significantly affected short-term community tenure. Indeed, the fit of individuals with their environments is a key tenet of the CMH movement.

The housing issues experienced by those with schizophrenia are three-fold: first, there is the practical difficulty of the lack of availability of affordable housing; second, difficulties arise as a consequence of objective stigma; finally, when individuals relapse they may lose their accommodation and damage deposit, and therefore need to "start over". Social prejudice against mental illness has a direct impact on individuals' lives. Janacek (1991) reported on an American study:

> Despite our program's being a good neighbor and an unmitigated success, we have had difficulties, basically concerning community acceptance. I have had to file a suit before the Eighth Circuit Court of Appeals to remain in the neighborhood. The community believes that our program is bad for real estate values, that our residents are dangerous, and that we have established a "mental health ghetto". This is certainly not the case. Our residents remain approximately six months, and 80% of them advance to independent living. Furthermore, none of our residents has ever been arrested, let alone charged with any crime against any neighbor or citizen.
>
> (Janacek, 1991, p. 16)

Some posit that many American mental health programs appeal to landlords because they are willing to guarantee annual leases for supervised apartments (Hatfield & Lefley, 1993). Persons who receive federal entitlements, Supplementary Security Income or Social Security Disability Insurance, are often more reliable sources of rental revenue than persons holding jobs from which they can be fired. Perhaps with the proper education and salesmanship, more landlords can be taught to appreciate persons with a history of mental illness.

VII. SIGNIFICANCE OF THE STUDY

This literature review is testament to the breadth of existing issues. One conclusion that can be drawn from the literature is the need for Canadian research that endeavors to describe in-depth the experience of family members of PWS. Rather than study the family as a unit, it was my desire to further understand the experiences of the individual within the family. Moreover, this desire influenced my choice of method. Qualitative methods are best suited to glean this information (Creswell, 1994; Denzin & Lincoln, 1994).

Specifically, research regarding the experiences of siblings and fathers is warranted. An understanding that extends beyond that of mothers' experiences to those of all family members' experiences is a prerequisite to effective, comprehensive treatment plans and, additionally, has implications for service provision. Mental health professionals need to be able to offer effective services, resources, and support to all involved in the care and management of ill relatives. Furthermore, family members' are able to provide expertise.

Information provided by participants in this study may be of benefit to three groups: those responsible for the development of treatment and rehabilitation plans for PWS; professionals who provide the services for family members; and finally, family members of PWS.

CHAPTER 2 - METHODS

I will state my grand tour question and study subquestions, outline the principles of naturalistic inquiry, briefly describe fundamentals of qualitative methods, and follow with a statement of entry and access. I will provide a description of participant recruitment and selection, followed by data collection. A discussion of ethical issues will precede a description of data analysis. A description of the steps I took to ensure the trustworthiness of my inquiry will conclude this section.

I. STUDY DESIGN

A. Grand tour question and study subquestions

The grand tour question is a statement of the study question in its most inclusive form. This question is stated as broadly as possible to guard against limiting the inquiry (Creswell, 1994). The sub-questions are of a tentative nature, and serve to narrow the focus of the investigation. My grand tour question was, "Describe your experience of living with a relative with schizophrenia". The sub-questions were as follows:

1. "What does schizophrenia mean to you?"
2. "What presents difficulty in living with a family member with schizophrenia?"
3. "What do you find gratifying about your experience in living with a family member with schizophrenia?"

After conversations with the first two participants it became apparent that the order of the sub-questions needed to be changed. One participant suggested that the question, "What does schizophrenia mean to you?" be posed at the end of the conversation. More often than not it evoked tears, or at a minimum long pauses and heavy sighs. I wondered aloud whether it was too weighty a question to be asked at the outset. The participant who made the suggestion concurred, and felt that it was easier to have "warmed up to it" with an examination of the other questions first. Furthermore, she added that the placement was logical, as posing it at the end of the conversation seemed to "naturally flow". This granted an opportunity for participants to provide summary comments. Thus I posed the question, "What does schizophrenia mean to you?" at the end of the conversation. Changing the order of the questions is an example of the emergent design that is indicative of naturalistic inquiry.

B. Principles of naturalistic inquiry

A paradigm can be defined as a systematic set of beliefs, together with accompanying methods (Lincoln & Guba, 1985). Among the qualitative options ranging from hermeneutic phenomenology to ethnography, I chose to use naturalistic inquiry (Lincoln & Guba, 1985; Guba & Lincoln, 1989). As it is an approach with clearly articulated steps to follow, it is of merit to novice researchers such as myself.

Naturalistic inquiry asserts that multiple socially constructed realities exist (Guba, 1990; Lincoln & Guba, 1985) and that the researcher is not removed from participants in the activity of inquiring into these constructions. Siblings, mothers, and fathers undoubtedly manifest differing realities, and I explored each. Moreover, this mode emphasizes the interactive and inseparable nature of the "inquirer" and the "object of inquiry" and, as such, the findings of the investigation are a creation of the inquiry process (Lincoln & Guba, 1985). Finally, similar to Bergum (1991), I prefer to call the interviews "conversations" to reflect the implication of a discussion.

C. Qualitative methods

I employed qualitative methods in this research. Miller and Crabtree (1994) suggest the adoption of methods that keeps the researcher "open and intimate" with the text. Qualitative methods are inductive in that they begin with observations of reality, formulate insights or understandings, and then may result in generating hypotheses or building theories (Lincoln & Guba, 1985). This method emphasizes the importance of context in all aspects of an investigation, from conception to publication of results. Both the researcher and the methods are considered embedded in the findings. The researcher is always "in the picture", influencing everything that is seen and told, and serving as an instrument for data collection and analysis (Lincoln & Guba, 1985). The researcher tries to avoid imposing presumptions and preconceived notions. The growth of understanding begins with trying to comprehend the meaning of participants' experiences.

Naturalistic inquiry is an appropriate qualitative means to understanding the meaning of experiences. As it places an emphasis on the comprehension of human meaning ascribed to some set of circumstances (Lincoln, 1992; Lincoln & Guba, 1985) it is the paradigm of choice from within I will address my research questions.

II. ENTRY AND ACCESS

Prior to initiating this research I had three years experience as a psychiatric research assistant. I worked with PWS and their families on two projects and, in so doing, I developed an interest in how families experienced and managed the illness. I regularly attended the monthly meetings of the Schizophrenia Society of Alberta, initially as a means to recruit participants in the two projects, yet eventually as a result of my interest in many aspects of the illness. For the present research I accessed sixteen participants through the Society, and in addition four acquaintances unaffiliated with the Society participated.

III. PARTICIPANT RECRUITMENT AND SELECTION

Participants were family members of PWS. The title of my research states that participants were family members “living with” a relative with schizophrenia. This is actually a mode of being. The ill relative need not have resided in the family home in order for the family members to participate in conversations. The first participant was a woman previously known to me who works at the Schizophrenia Society. After completion of the conversation I asked her if she could recommend any families that may be able to offer different perspectives on living with schizophrenia. She provided me with a list of several families to contact. It was anticipated that participants be selected using purposive sampling (Lincoln & Guba, 1985; Field & Morse, 1985). Selection of participants proceeded only after the conversation with the preceding participant had been taped and analyzed. I continued by asking each successive participant to refer me to families that could offer me different perspectives. However, given that only one family had an ill female relative it is possible that the sample was not truly purposive. Perhaps participating families simply "knew" other families with ill males.

According to Lincoln and Guba (1985), maximum variation sampling is selected in ways that provide the most encompassing range of information possible. Exceptional cases are not suppressed, and multiple realities are unearthed. The procedures of purposive sampling depend on emergent, not *a priori*, design. Thus, each successive participant was chosen either to gather knowledge that extended, supported or refuted existing findings (Lincoln & Guba, 1985). Findings were elaborated through conversations with individuals of varying ages and with different lengths of experience with schizophrenia.

I had hoped to be conversing with both the mother and father, in addition to any siblings in each family. However, I ended up seeing both the mother and father in only three of twelve families, and only two brothers in total. I conversed with fourteen women and six men. As an aid to clarification the table in Appendix A provides information on the families. Seven mothers, seven sisters, four fathers, and two brothers of PWS participated. This gender disparity could be interpreted in several possible ways. One could posit that emotive reasons underlie the imbalance, or perhaps that the verbal abilities of females contributed. However, I believe there was a straightforward explanation. Two mothers were widows, and one was divorced. Although there were twelve brothers who were potential participants, only two lived in Calgary at the time of my data collection and hence the imbalance.

IV. DATA COLLECTION

A. Field notes

Throughout the data collection process I maintained field notes. These consisted of a list of potential participants, methodological notes, and comments regarding conversations. The latter included the date, time and place of conversation, together with any emotional reaction I experienced during the conversation. My field notes were often written in my car immediately after the conclusion of a conversation because I personally found this an ideal time for capturing my first impressions. The field notes provided context during the analysis of each conversation and in addition were a reminder of my frame of mind at the time of the conversation.

B. Reflexive Journal

Every conversation evoked intense emotion. Tears were commonplace, both in the participant and in myself. As I listened to these intensely private and moving stories I was often overcome with both awe and sadness. After the completion of each conversation I felt emotionally drained and unsettled to a certain degree. I discovered early in the data collection process that I had to ensure I had several hours after each conversation to be alone. This allowed me to reflect upon and digest the story at my own pace through immersing myself in an unrelated activity as a form of "escape". This private time allowed me to enter each conversation refreshed and clearheaded.

The tone of one conversation warrants specific mention. Although I attempted to bracket my preconceived notions with all participants, I did experience difficulty doing so with one individual. I am a person whose self-awareness extends to knowing that when personally confronted in an aggressive manner, I do not cower meekly in a corner. Rather, I probe my inquisitor to try to understand how the conversation evolved into its present state.

This particular individual had rescheduled our appointment three times, and perhaps I should have interpreted this to mean that he did not want to speak with me. However, not only did his explanations of why he needed to reschedule seem authentic, but also he promptly and consistently returned my phone calls. When we finally did meet I perceived him to be in an aggressive and angry state. Within the first five minutes of our meeting he wondered aloud what I would do if the conversation upset him to the point where it would "force him to throw the chair through the wall". I quickly stated that we did not have to have the conversation if he had decided against doing so. However, he did insist on speaking with me, yet clearly interpreted our conversation as an opportunity for him to "vent his anger". Each time I posed a question he interpreted it as an interruption and requested that I not speak.

V. ETHICAL ISSUES

Ethics refer to ideals demonstrating how people should relate to each other in specific circumstances, to principles of conduct that guide those relationships, and to the kind of reasoning one is involved in when thinking about such ideals (Smith, 1990). The ethical issues of privacy, confidentiality, and anonymity are of particular importance in qualitative research. Privacy is control over others' access to oneself and associated information. Confidentiality is agreement with a person about what will be done with their data, whereas anonymity refers to the lack of identifying information that would indicate which individuals provided which data (Miles & Huberman, 1994). Every attempt to secure participants' confidentiality was made; however, I explained my intention to publish the findings as the information gathered will be used to partially fulfill thesis requirements.

A. Anonymity

Given that qualitative research pursues vivid descriptions of the lives of those studied, anonymity is a difficult process. The detail description provided in qualitative conversations is not a route to disguising an individual's identity. In order to attempt to prevent the identification of the participant, I used pseudonyms and changed identifying information. Miles and Huberman (1994) recommend the use of member checks to confirm or elaborate on interpretations to help with anonymity issues, as participants can often detect information that would identify them. Participants in this research were offered access to records of their conversations, and member checks were performed.

B. Informed consent

I explained the study and its rationale to participants. As it is impossible to know in advance where the conversation may lead in a qualitative interview (Miles & Huberman, 1994), explicit mention was made of the right to withdraw from the project, to end the interview, or to ask that audiotaping stop at any time. Although all participants would consent at the start of the study, the consent may become invalid as researchers may have new ideas, and questions head in new directions (Boss et al., 1996; Kopelman, 1997). The determination of informed consent is particularly difficult in qualitative designs, and Ramos (1989) suggests an alternative notion of consent. "Ongoing consensual decision-making" is better suited to the emergent nature of qualitative research. A copy of the consent form is located in Appendix B. Had my research headed in a new direction, I would have employed ongoing consensual decision-making.

C. Risks and Benefits

In-depth interviewing "opens up what is inside people" (Patton, 1990) and, in so doing, is likely more intrusive and involves more reactivity than quantitative methodologies. Given that naturalistic inquiry explores fundamentals of humanness, it may be assumed that conversational topics may cover sensitive issues (Boss, Dahl, & Kaplan, 1996). Indeed, some conversations in this research did elicit emotional and distressing reactions. As mentioned in the consent form, if requested I was willing to provide participants with referral to counseling services.

However, a possible benefit was that these conversations provided an opportunity for participants' voices to be heard, and thus a degree of relief felt. Indeed, several participants specifically stated that they felt "better" after our conversation, and knowing that the area was being researched. Furthermore, other family members may benefit from their experiences.

VI. DATA ANALYSIS

Data analysis in a naturalistic study must include the simultaneous process of collection and analysis of data (Lincoln & Guba, 1985). These authors state that the process of data analysis is one in which "the constructions that have emerged (been shaped by) inquirer-source interactions are reconstructed into meaningful wholes" (p. 333).

The purpose of this form of data analysis is twofold. The first is to code the data to enable category recognition and analysis. The second is to develop a data filing system that will provide a flexible storage system. I used the word processing software WordPerfect to transcribe verbatim the conversations in the study from audio-tapes. These transcripts were then imported into Q.S.R. NUD*IST, a qualitative data analysis software program. Software supports the processes of coding data and theorizing about the data and, as such, some believe computer-assisted analysis is more efficient than unassisted analysis. Q.S.R. NUD*IST is a tool that I found helpful in the creation of ideas, the management of categories and question posing. For example, in my early stages of analysis I questioned whether gender differences in emotional responses were appearing. It should be noted, however, that some individuals believe there are inherent limitations to computer-assisted analysis, such as its potential to stunt creativity.

Although dated, the process espoused by Colaizzi (1978) is based on similar fundamentals as the computer program I used. This author suggests that the first step in the coding process involves the extraction of "significant statements", and is followed by the formulation of meanings. The next step in analysis involves the organization of these meanings into clusters of themes and, finally, a validation of the themes by referral back to the original transcribed conversation.

Transcription and analysis of the first conversation was completed prior to the initiation of the conversation with the second participant, allowing analysis to proceed in an orderly fashion. However, there was one exception to this procedure. I spoke with a mother and father who requested that I conduct their conversations one after another during the same visit to their house. Their request did not allow for transcription prior to the conversation with the second participant.

A. Data management

The conversations were audio-taped and then transcribed, in their entirety, within 24 hours of completion. Transcribing proved laborious, and after the transcription of two conversations I considered hiring someone to complete upcoming transcriptions. However, I decided to continue personally transcribing the tapes, and eventually found it a helpful step in preliminary data analysis. The extra exposure to the data during transcription aided analysis by increasing my awareness of the data.

B. Process of using software

Following transcription I printed off and read the transcripts. I then recorded my initial perceptions and remarks in the margins. The transcripts were then imported into Q.S.R. NUD*IST for coding and analysis. The first step in coding in Q.S.R. NUD*IST involves labeling "free nodes". These are basic, not yet categorized themes. Development at the level of free nodes was followed by organization into an "index tree". These are "tree" structures of category and subcategory. They provided a visual aid that enabled me to search for patterns in coding and build new codes. Using Q.S.R. NUD*IST expedited the process of categorization into themes and patterns.

Data analysis resulted in the compilation of a large quantity of free nodes in NUD*IST. These themes are listed in Appendix C and the basis for reduction to the main themes is illustrated to the reader. I used three guidelines in my decision to collapse to four themes and their associated sub-themes. First, the number of documents containing reference to a specified theme was noted. Second, the number of text-units (i.e., the number of lines coded for a specific theme) was considered. Finally, I added a final condition for inclusion into the discussion of results; that the participant presented the particular theme with intensity. If I perceived that the individual wanted me to understand the associated theme, I considered the theme as being important for inclusion in my results. Thus, the themes explored in the Results chapter were coded in numerous documents, at a large number of text units, and were presented with intensity by the participant(s).

VII. TRUSTWORTHINESS

Conventional, positivist science applies the following criteria to inquiry: internal validity, the degree of accuracy of the findings and whether reality is reflected; external validity, the degree to which findings can be generalized to other settings similar to the one in which the study occurred; and reliability, the extent to which findings can be replicated by another inquirer (Denzin & Lincoln, 1994). The criteria of validity and reliability are addressed in qualitative research, yet the terms trustworthiness and authenticity are used.

I propose that naturalistic inquiry needs to meet analogous criteria to quality criteria of the positivist paradigm. In Table I the analogous criteria and techniques used to ensure trustworthiness are illustrated.

Table I - Positivistic and Analogous Naturalistic Terms, And Associated Techniques to Establish Trustworthiness

Positivistic Term	*Naturalistic Term*	*Technique*
Internal Validity	Credibility	1. debriefing 2. member checking
External Validity	Transferability	3. thick description
Reliability	Dependability	4. audit trail
Objectivity	Confirmability	5. audit trail

In naturalistic inquiry, trustworthiness criteria include credibility, transferability, dependability, and confirmability (Guba & Lincoln, 1985; Lincoln, 1992). Together with descriptions of the criteria, I will describe the steps I took to establish the trustworthiness of my inquiry. Credibility, the first criterion, can be defined as sufficient representation of the multiple realities and can be ensured by debriefing and member checking. As a method of debriefing I conversed confidentially with fellow student colleagues during regular Qualitative Interest Group (QUIG) meetings. Discussions of my themes, conclusions and analyses enabled unearthing of my implicit knowledge and interpretations.

Furthermore, this venue provided an opportunity to find alternative explanations and explore the emerging design.

Performing member checks is considered the most critical technique for establishing credibility (Guba & Lincoln, 1989). This is the process of testing preliminary categories of data and interpretations with the participants from whom the original conversations were collected. This enables the researcher to assess the intent of the information, and in addition, provides a chance for the participant to correct any possible misinterpretations or provide further information. I performed member checks with all but one participant in my research.

The second criterion, transferability, can be established by thick description. Lincoln and Guba (1985) describe thick description as the provision of "sufficient information about the context in which an inquiry is carried out so that anyone else interested in transferability has a base of information appropriate to the judgement" (pp.124-25). The description must detail all a reader may need to know to understand the findings, and it is important to note that findings are not part of the thick description. I used purposive sampling to provide as extensive a database as possible in order to facilitate transferability judgements.

Dependability, the third criterion, is analogous to the conventional criterion of reliability and refers to the stability of the data over time. An audit trail was conducted by an individual external to my research. This fostered dependability, and heavily relied on adequate records kept during the course of the study. Documentation of the conceptual development of my research left evidence that was used to reconstruct the process by which I reached my conclusions. The audit trail consisted of six types of documentation:

raw data; data reduction and analysis products; data reconstruction and synthesis products; process notes; materials relating to intentions and dispositions; and instrument development information (this list was developed by Halpern, and reported in Lincoln & Guba, 1985, pp. 319-320). For the audit procedure the auditor randomly selected and listened to one audio-tape to ensure the accuracy of my transcription. A list of my themes and their accompanying definitions was provided to enable coding of the conversation. After the completion of coding, the auditor and I met to ensure an acceptable level of agreement was found. There was 89% agreement and following a discussion regarding her findings, a letter of attestation was written and is included in Appendix D.

Confirmability, the fourth criterion, is concerned with ensuring interpreted categories have basis in the data and are not simply researcher's concoctions. Guba and Lincoln (1989) maintain that it must be possible to track data to its sources, and that the logic underlying interpretations is both explicit and implicit. Again, this can be done through following an audit trail.

Guba and Lincoln (1985) recommend the use of a reflexive journal, a technique with applications to all of the above four criteria. I used this journal to record information about "self and method" (Guba & Lincoln, 1985). It is the heightened awareness of the researcher's consciousness that is of critical importance to the success of research. Bracketing is a required process of reduction and it involves uncovering our "original awareness" of a lived experience (Beck, 1994). Researchers expose their presuppositions about the phenomenon under study so that they can deliberately abstain from them. While it is recognized that it is impossible for the researcher to be completely free of bias in reflection on the experience under study, it is possible to control it. The process of bracketing involves setting aside one's beliefs about the phenomenon under study in order to see the phenomenon as it is. The goal is to control bias and thus involves researchers making their beliefs, biases, and assumptions explicit at the outset, and for the duration of the study. I used my reflexive journal to foster this process.

VIII. SUMMARY

My literature review provided support for the need for qualitative research involving all family members. Twenty participants who live with a relative with schizophrenia were interviewed to explore their experiences. Verbal consent was obtained prior to taping conversations either at the participant's home or workplace. I selected participants who varied in age, and had lived with the illness from five to over twenty-five years. The transcribed conversations were stored, coded, and analyzed with Q.S.R. NUD*IST software.

CHAPTER 3 - RESULTS

I. INTRODUCTION

The results of my conversations are presented in the following chapter. In total I interviewed twenty family members of persons with schizophrenia (PWS). In Table II, demographic characteristics of the study participants are detailed. I will explain each of the four main descriptive themes that emerged from the conversations and provide definitions for each. The main themes were: stresses; support; system issues; and responses. Each of these themes will be illustrated with quotes from the conversations.

Table II - Characteristics of Study Participants

Characteristic		#
Relationship to PWS		
	Sister	7
	Mother	7
	Brother	2
	Father	4
Age Range		
	20 – 29	2
	30 – 39	2
	40 – 49	4
	50 – 59	5
	60 – 69	5
	70 – 79	2
Affiliated with Schizophrenia Society		
	Yes	16
	No	4
Years Living with Schizophrenia		
	1- 5	4
	6 – 10	3
	11-15	2
	16 – 20	3
	20 +	8

II. PRESENTATION OF DESCRIPTIVE FINDINGS

A. STRESSES

Family members detailed several different sources of stress that arose from the prolonged and protracted challenges of living with an ill relative. The symptoms of schizophrenia, familial dissonance, household disruptions, and stigma were the main sub-themes.

1. Symptoms

The symptoms of the illness vary greatly within and between individuals. Some PWS are rarely symptomatic and experience few episodes, while others experience severe and repeated relapses. It is important to note that the side effects of medications are similar to illness symptoms. Family members described the strain of symptoms, both positive and negative, on their daily life. One mother described her son's thought disorder:

> MS: It was just unfortunate that he has one of the most severe forms of schizophrenia and his major symptom is thought disorder, which is one of the most disabling of the symptoms. It simply means that not on any given day is he fully aware or in touch with what's going on. Nor can he react rationally very often to what is happening to him. It's a very, very difficult symptom to deal with.

A sister described her brother's memory lapses, and that he loses "chunks of time" with no recollection of what has transpired:

> SL: But, you know, the time – the whole um, consciousness of how much time is going by, and the sequence of events that have happened, he remembers snatches of it.... Even a couple of months ago when he was really bad again. He phoned me and said, Sandra, I don't remember anything. I remember waking up and thinking I should have breakfast, but I don't remember another thing until about 11 o'clock at night.

A father described his son's delusions:

> RT: There were times when Grant really didn't want to be around me at all. He thought I was evil, and this whole thing started when he had a delusion that the milkman was a vampire... The milkman brought the milk, and Grant took the milk and put it out on the deck. Well, I didn't want the milk out on the deck so I went and picked it up, and he said, that's BAD. I said, there's nothing wrong with this, and I took a drink right out of the box. And he just backed away from me and said, you're evil.

One sister, who resides with her ill brother with her two children, described the ways her brother acted on his delusions and his hallucinations:

> DS: ... One of Andrew's latest to protect us from the demons is to fill up the bathtub... I thought, why is he always having baths at, like, three in the morning? And then Tanya (her daughter) told me he leaves the tap running and fills up the bathtub with water. He has things about water running ... somehow it wards off demons.

This description illustrates to the reader how his symptom management would result in disruptions in their house.

A mother described her son's delusion that it had been broadcast publicly that he had AIDS:

> ST: I said, well Grant, why aren't you at work today? He said, I can't go to work, and I said, why? He said, well because Mom, they all think I have AIDS. I said, Grant, nobody thinks you have AIDS. He said, yes they do, yes they do, because my manager broadcast that over the outside speakers and inside speakers and I heard him... say that to the whole mall, to all of those people, that Grant Thompson had AIDS... And from there it went to David Letterman saying that he had AIDS, and everybody in the world heard it.

It is important to recognize the unpredictable nature of the symptoms in schizophrenia. Some participants suggested that this, in and of itself, is a sufficient strain to warrant ongoing education regarding coping mechanisms.

2. Familial Dissonance

Familial dissonance can be defined as the dissension among family members regarding management issues of their ill relative, symptomatic behaviors, and/or treatment particulars. The family members in this study described varying degrees of disagreement.

One sister described the differing opinions of her mother and father with respect to the care of her two brothers with schizophrenia. She linked it to the generation, the 1960s, and society's general unreceptivity to mental illness. She described how her mother's denial complicated matters:

> CP: Then to have something wrong with them that you couldn't see, was both devastating and also mental illness was just not acceptable. And consequently my mother and father certainly were at odds about what SHOULD be done. And so that caused quiet friction. You know, ah, my father really tried to get David into an institution.... My mother wouldn't go along with it. She said, oh, he just needs love.

After her father's death, the same woman was made guardian to her ill brothers, and the dissonance then extended between her and her mother.

> CP: And how do you, particularly after my father died, tell your mother you're taking over and this is how it's going to be done?... There was tremendous hostility and struggle, and she would not give up the financial. She controlled that so I had to go through her for everything. So her frustration would be that when I said I had just spoken to Richard's social worker and he'd like to go to camp in the summer and it will be $400... And she would say, what do you think I'm made of? And it wasn't about the money. It was about her frustration, probably both guilt and frustration. Guilt that I was doing it, and frustrated that maybe she couldn't and that was her only way to control the situation, which didn't make it a pleasant situation.

The same woman continued to describe her mother's denial about her brother's illness. She further described how her mother would undermine attempts at obtaining care for her brother:

> CP: And then she thought if she moved him out, into his own place, sort of in B.C. somewhere (motions with hands), and he lived independently, he would be fine. He'd get a job and that would be that... He was all over the place, and then he'd come back. He lived with me most of the time... What ended up happening is that she kicked him out so he could no longer live there and so he had no place to go. Any doctor's appointment I'd set up she would make sure she undermined it and he didn't follow through. So finally he lived on the street.

Another sister described one brother's visits during holidays and his comments about how to manage their ill brother:

> SN: ... When he comes home at Christmas time or holidays, my brother's pretty outspoken and he sort of thinks he knows how things should be. And I see this happening, not just in our situation, but in lots of families. When someone comes in suddenly on a holiday, or whatever, and says, OK, I can see how this ought to be dealt with, and I have the best answer. Just leave it to me. When they haven't been there on a daily basis and seen the ins-and-outs, and what's been working and what hasn't, and they think they have all the answers.

Another sister described a similar situation in her family:

> DK: Steven's reaction to Michael was, um, we really should get him doing something. Get a job, or he really should be taking courses. And, because he doesn't live with him, except on a sporadic basis where he'll see him a couple of times a year, he doesn't have the same understanding of Michael as Mom and I do. And even Paul, sometimes, doesn't have it. I actually got annoyed with Paul, because he'll say, well, Michael's like a write-off. And I'll say, Michael's not a write-off. He didn't mean that as he's no good as a human being, but as in, he'll never DO anything. And I said, he does PLENTY.
> EM: He just defines it differently.
> DK: Yah, but that's the incorrect way of looking at it. But I think those are just defensive reactions to looking at it.
> EM: Do you?
> DK: Yah, I do. I think they don't want to deal with the emotional reality of where Michael's at. If you cut that off by saying, oh he's a write-off, or oh, he should be working, it's pretty much like you're --. One says he's a write-off, and there you eliminate your responsibility to him as his brother, because you're saying, oh well, he's not going to change... Your expectations drop to zero. But, if you say, he should be doing this or that, you're going the other way. It's pushing him BEYOND what he's capable

> of, as opposed to just dealing with him and interacting with him, and accepting him where he is.

Acceptance of her brother, exactly where he is in life right now, is of critical importance to this woman, and was a pervasive theme in our conversation.

Another woman described her disapproval with her parents' decision to have her ill brother live with them in the family house:

> SL: I would have definitely done it differently. But they made the choice that this is what their life would be. They would have him in their house and care for him. I think they have totally crippled him by letting him stay at the house. There is no chance that he will EVER, EVER live without them. He's got them where he wants them... They have no choice now but to let him stay there. He has been dependent for too, too long.

3. Household disruptions

Individuals described many instances of ill relatives' bizarre and erratic behaviour causing household disruption. This sub-theme overlaps with two particular emotional reactions: frustration and fear.

> ST: So, our house was in absolute chaos. He would be up at night and he would cook. It was right in the middle of the night. One time he was – he wrote for a long, long time. In the middle of the night he decided he had to burn all this and put it in the fireplace and burned it and forgot to open the flue and our house was filled with smoke. Ah, those kinds of very frightening things started to happen.
> EM: Do you mean, frightening safety-wise?
> ST: That, and of course it was obvious how very, very sick he was and we knew he was sick, the doctors knew he was sick, everybody in the world knew he was sick, but he didn't know he was sick and we couldn't get help for him. So, now we had to wait for him to attempt suicide...

One sister, who lives in the same house as her ill brother, described a similar frustration:

> DS: He has no short-term memory so you can say something five hundred times a week and it doesn't sink in... His restlessness is annoying too... He constantly paces, constantly, constantly, in and out, in and out... I

> recognize that it's just superficial things he does that annoy me. Like when I'm cooking every night and he's hanging over me, and when's supper, and what are we going to have? Then he eats a sandwich and not supper. You know, things that kids do. It's like having another child. A grown man who's just like a little kid.

Another sister described the restrictions she experienced as a result of her brother's attempt to cope with certain symptoms:

> BH: When he was awake he was reading a book. And I couldn't make any noise because it would bother him. So I was basically trapped. I felt like I was in a cage with him. He said that if he wasn't reading a book or if he wasn't, um, keeping his mind occupied with something he would get racing thoughts.

The above quotes illustrate that disruptions are perceived and expressed by any family members living in the same house. As mentioned, two potential emotional responses are frustration and fear.

4. Stigma

Stigma, for the purposes of this research, can be defined as society's negative attitudes towards those with a mental illness such as schizophrenia (Link, Mirotznik, & Cullen, 1991). It is a complicated issue, and one that undoubtedly provokes intense emotion. Family members described perceived stigma in a variety of ways. One mother speaks:

> PJ: There are many handicapped people. Ah, a mental handicap in society is so rarely understood. It's very easy to take care of somebody who's blind, or can't speak, or hear. I shouldn't say it's very easy. Of course it's not very easy, but society copes with it... There is an awful lot done, and rightly so, for the physically handicapped people. There is still not enough done for the mentally handicapped. And it is not recognized correctly. The Schizophrenia Society has been pushing and pushing that this is a disease. It has got to come out into the open... I'm not ashamed to have a son with schizophrenia.

A sister described the impenetrable shroud of secrecy that exists in her family as a result of the stigma she perceived to exist:

> SL: I NEVER talk about this. EVER. I have to protect my family. People are so cruel, so we find that it's best just not to talk about it outside the family. People just don't understand. Our family is intensely, intensely private. So when people ask me what Randall is up to now, I just say, oh, he's good. He's just in between things now. We make sure we're not in a position to hear the heartless and callous comments, because you KNOW they're spoken.

A comment by another mother illustrated the stigma, in addition to the lack of support, she perceived to exist in the mental health system. She also commented on the resulting dilemma parents face:

> ST: There's no question about the stigma in the mental health system. When we ask our people (PWS affiliated with the Schizophrenia Society) where they feel the most stigmatized, it is from the very SECOND they enter the hospital door. And, you see, family members are put in a vice because we can't, we cannot raise too much hell. Because our son is going to be in there ... if I haven't been nice and accepted all your crap, then what is going to happen to my son when he's in there?

Another mother commented on receiving similar treatment:

> AN: Simple things, like Robbie going to the desk for permission to do something, and being ignored. And it wasn't just Robbie this happened to, but every one of them. They went to the desk, they were only allowed on THAT side of the desk, and they were ignored five, ten, fifteen minutes. They did that to Robbie when I happened to be there (sighs). I just quietly moved over beside him and said, has anyone helped you yet? No. I said, oh. In a loud voice, I said, excuse me. We're waiting for service here. My son has a problem and he needs help with it, and I want that service RIGHT NOW. I'm standing there, thinking to myself, I'm not this kind of a person. I don't LIKE this kind of a person. That he, a grown man, has to have someone else do that for him. It's soul-destroying to be put in that position.

These comments suggest that some professionals display a certain attitude when communicating with ill individuals, and that family members desire that this communication be respectful and sensitive.

Interestingly, only one individual, a father, commented on the progress of societal views on mental illness:

> BT: I think, in general, we in society are far more accepting of people that are not 'normal'... and this goes before my time, but if you had a person with a physical handicap you kept him in the house. You were embarrassed to take them out into public. If they had a mental handicap they were sheltered and kept away from the public. I think the public is far more accepting of people who do not fit the definition of 'normal'. So they integrate better. So I think it's easier for the people with schizophrenia in society now than it was in the past.

B. SUPPORT

There are several sources of support for family members of PWS. Support groups such as the Schizophrenia Society, familial support, and social support all provide relief for relatives who live with schizophrenia. Furthermore, mental health professionals are potential sources of support for family members and their ill relatives. Perhaps not surprisingly, as sixteen of the individuals with whom I spoke are affiliated with the Society, there was much discussion of the strength that was gleaned from the Schizophrenia Society.

1. Support groups

Support groups have been shown to provide support to many family members living with a mental illness (Solomon & Draine, 1995b). Indeed, the majority of the participants in the present research referred to the degree to which they rely upon, and glean strength and comfort from the Schizophrenia Society. The opportunity to share experiences with fellow members is reportedly therapeutic, as Kuipers and Westhall (1992) reported that relative groups are a particularly effective way to deal with emotional issues.

Family members commented on the learning that resulted from shared experiences for which the Schizophrenia Society provides a venue. One father commented:

> RT: It helps a lot when you can talk to people who have gone through what you're going through and learn from them what they went through, and how they handled it and how we can handle it better.

Other family members mentioned that they adapted coping mechanisms learned from fellow Society members. Moreover, one father described the Society as a "salvation", after commenting on the rejection and stigmatization he and his family felt from their church:

> RH: That is one of the nice things about the Schizophrenia Society in Calgary, because we found that that was our salvation. We really didn't get ANYTHING in the church we attended because we were treated like a pork chop at a bar mitzvah. We'd run in and no one knew who we were...

A mother criticized the hospital support groups, commenting on the lack of practical advice they offered, and contrasted information provided by the Schizophrenia Society:

> ST: We also took part in the support groups from Hospital B and Hospital D, neither of which did one damn thing for any of us. Um, they did give you a little bit of information. But first of all, it wasn't as good as what we got at our Society, wasn't thorough, and gave you NO practical advice, except structure. You must structure your days, they said. I say, great, you come and do it! He is in bed until 5 o'clock every afternoon. How would you like to try structuring that? You know, it was just dumb.... We give practical advice on how to help.

Several other family members expressed the need for sensible and practical suggestions about how to manage the illness on a daily basis, particularly in the first few years following initial diagnosis.

Another mother of a son who has had schizophrenia for over 25 years spoke of the sense of worth she gained after joining the Society. Being given something constructive to do positively impacted both herself and her son.

> AN: And, of course, in 1980 the Schizophrenia Society began, and I have been active there since September of 1980. That helped save me and helped save my son, because it helped take my emotional distress away from him. I was given work to do instead of sympathy.

Again, another mother expressed gratitude for the support provided by the Society. Furthermore, she explained how her involvement with the Society enabled her to maximize access to mental health services for her son.

> MS: The last ten years or so, it (the Schizophrenia Society) has been one of the most supportive things happening in my life. It keeps me very busy in a very concrete, practical way. As a result of the work I do for the Chapter I meet a great many people throughout the city, ah, so I become more and more familiar with the mental health system and how to access it...

A mother of a son with schizophrenia stated that both she and her husband had enjoyed meeting the people in the Society.

> GH: ...It does create a certain camaraderie of people when you live through that... You understand where people are coming from and the pain that they've been in. All of them, like us, seem to feel that by helping, it has helped them. I think I've learned a lot about life because of this illness.

A sister commented on the relief felt after attending Society meetings, and in knowing she was not alone in experiencing certain feelings:

> SN: Sometimes people don't want to burden others by talking about the illness, and that may be why they don't go to Society meetings... There's a lot of frustration and despair and helplessness, and to talk to someone else about it is wonderful. You feel guilty because you can't DO anything (for your ill relative), and when another person is saying, I feel the same way, and I can also tell you that there's not a lot you can do. That's a big relief, you know.

On the other hand, a sister spoke of her family, including her ill brother, disaffiliating themselves from the Society:

> DK: He's never really hooked into any other services related to the Friends of Schizophrenia Society. And although Mom and I attended a few sessions, I guess because he's quite independent in his own mind about a lot of things, he didn't really feel the need to bond with a lot of other schizophrenics. As in, he does want to be a part of whatever Society YOU'RE in, not necessarily only a part of THAT Society.

This family had decided it wasn't necessary for their family to be a part of such a support network, and yet she added that the Society provided useful information and focus for people who want and need that resource to gather information.

These quotes illustrate that there were two types of benefits that family members glean from support groups: benefits from resulting relationships and benefits resulting from information. The latter benefit reflected an increase in information about schizophrenia in the following ways: knowing how to advocate more effectively for the PWS, an increased ability to cope emotionally, having more information available regarding the illness, and finally, more information about services and interventions. Benefits resulting from relationships stemmed mainly from the sense of camaraderie.

2. Familial support

Several individuals described the strength they gleaned from other family members. A sister described the strong bond she feels with both of her parents in their united care for her ill brother:

> SN: I have to say, my parents are terrific. I'm not surprised my mom is, and most moms are. But my dad is right in there too. He spends so much time with Dennis and he takes him down to Unsung Heroes (a Schizophrenia Society group meeting for PWS)... And my dad has a long day at work ... I'm tired after a day at work and my dad is twice my age (laughs)... He has totally embraced every venue for helping my brother any way he can... I don't know what we'd do if my dad wasn't there.

The same woman illustrated her commitment to her brother's care when she described her decision to move back to Calgary after living in Europe:

> SN: After the schizophrenia diagnosis, weekly phone calls with my parents weren't really sufficient for me to feel comfortable about being away from them. I decided to move back to Canada and to actually live here and at home with them. Um, to support my parents ...

A father referred to the "net" that should be in place to "catch" ill individuals when they struggled, and speculated that it would ameliorate the effects of the illness:

> BT: I really think it's important for Sam to have a net to catch him when he's in trouble. But I also think it's important for a family not to abandon their kid. How much the support ... that you get from the family or society in general, what tempering effect does that have on the illness? ... It's not just medication that helps ...

He then illustrated awareness of his own behaviour towards his son under less than optimal circumstances:

> BT: I know that I've had times that I've gotten under Sam's skin. He'll be climbing the walls. He doesn't know what to do, and doesn't know how to deal with it. He's so passive and he's so frustrated, and if I did that day after day, it would harm him.

A mother described the importance of the bond between her ill son and the rest of the family:

> MS: As I said, he lives at home with me. His sister lives here with her two children, and that can be a fairly trying situation for a lot of people. And we find it remarkable that Andrew copes with that, partly as I said because he has maintained from the first, from the very first since he became ill, he has maintained a very strong bond with the family. He has also maintained a constant love and affection for all of us.

One mother with whom I spoke had no immediate family members, except both a daughter and son diagnosed with schizophrenia. She described her son's supportiveness when her daughter intermittently goes off her medication:

> VL: ... the results of her illness are quite different from my son's, it seems. Now, what we have been going through my son has been observing. And he said, you know, this is one lesson. I will NEVER go off my medication because I know the effects that it can have on everybody. Also, a very interesting thing. He has been most supportive. Well, we meet everyday for coffee, and for weeks all he'd talk about was, well, have you seen Allison? What are we going to do? How are we going to handle it? And, and, he would come up with a solution.

On the other hand, one mother described the damaging impact of the illness on family unity:

> AN: Robbie was diagnosed in '78, and in 1980 my one daughter and her family moved to B.C. and my other daughter went to Australia for a year.
> EM: Oh my!
> AN: And it was, ah, it was pretty hard for him, especially.
> EM: And you, too.
> AN: Well, it was hard for me, but harder for him because he felt that they had rejected him (pause). And, ah, you really can't reason that well with someone who's ill with a mental illness... I had kind of written my girls off at that point, and I was very (pause) I concentrated very hard on Robbie. I couldn't handle anything else. I thought, if you want to walk away from this you walk away. I just haven't got time for this.

In some instances, the upheaval was only temporary, as the continuation of the above quote illustrates:

> AN: And so there was a big rift there that took a lot of time to heal over, and now we are just very, very strong. And they have never (pause) they weren't turning their back on Robbie. They had their own personal, um, situations that were causing them problems, and ah, they were looking for their own survival. It's just that I couldn't accept it at that time. So now we have this wonderful family support system.

Some conversations revealed how difficult a long-standing lack of familial support can be. One sister described the reasons she was made guardian to two of her brothers with the illness, and the incredible challenges she faced as a result of the lack of familial support she received from her siblings. Moreover, she stated her mother's attitude proved to be a challenge every step of the way. I attempted to clarify an earlier statement that she found guardianship particularly straining:

> EM: So, would you say the fact you were made guardian to your two brothers, and having your mother resist every decision you made regarding their care, was one of the most difficult things about living with schizophrenia?
> CP: I don't think being a guardian was the difficult part. It would not have been difficult had I had some family support. Even if they had said, we don't want anything to do with this, but we will support your choices 100% of the way. But instead, they just said nothing. It wasn't just that they put their heads in the sand, but also that my mother fought me.

Close to the end of our conversation, the same sister concluded what serious mental illness can do to a family, like hers, that doesn't unite in the process of providing care.

> CP: To sum it all up, I guess, having someone mentally ill in the family, especially that many years ago, it's so disruptive. It really cuts through the heart of the family, and unless you're really mature as a family, it can break a whole family apart. It can pit one against another and make them really at odds.

She alluded to the impact of societal attitudes in the generation that her brothers became ill. She had mentioned earlier in our conversation that, at that time during the

1960s, mental illness was simply "not acceptable", and that as a result was rarely discussed. She believed the impact of that culture negatively impacted her family's ability to unite in managing the illness.

3. Social support

Social support is defined as the extent to which an individual's social needs (i.e., confidence, encouragement, affection, friendship, and respect) are met through relationships with other people (Hatfield & Lefley, 1993). At least one member from each family with whom I spoke mentioned the importance of receiving emotional support from friends. One sister described her relief at being able to speak honestly and realistically about her feelings of intermittent hopelessness:

> SN: There's a couple of friends, one in particular, she'll say, how are things going? ... I just said, you know what? I really appreciate you asking, but I have to admit that I don't want to talk about it right now because I feel it's really hopeless and, that's the first time I said that. But I was getting kind of tired trying to put a positive spin on everything. And I knew this friend would understand...

A woman expressed concern over her husband's initial inability to share his feelings with friends:

> ST: Anyway, John wouldn't talk to anyone. He wouldn't tell anybody, and his best buddy, they had been friends for thirty-five years... I said, John is having a lot of trouble and he really needs you to understand... I don't know how the two of them ever worked it out so they could talk, but eventually they did. But John needed somebody because he felt, as most men of that generation do, that his job was to protect me... I know that he felt tremendous responsibility to help ME get through this.

A mother who has both a son and a daughter with schizophrenia described how her social life was somewhat precarious, and how she ended up compartmentalizing her friends:

> VL: And so it disrupts relationships that you might have outside the family if you would have included them (her ill children). Now I have many friends outside, but I haven't included my family with them. Partly because the children don't want to be involved... I don't want to expose my kids to the outside world.
> EM: Why is that?
> VL: Because of the stigma that is there. You become very protective. There are some friends that I can talk to about this, but some friends I would say NOTHING to. They quite likely know that my children have schizophrenia, but even if they inquired I wouldn't tell them. I wouldn't say anything. I would just think that you're not REALLY interested the way I want you to be interested, therefore it's none of your business.

Several other individuals mirrored the caution that was exhibited by this mother. It was the perceived potential for stigmatization that led to individuals to be wary of to whom they spoke in an open and honest manner.

4. Mental health professionals

Some family members seek emotional support, specifically, respect and empathy, for their concerns. Sadly, save for a few instances recounted whereby professionals helped families, I heard mostly of how family members felt that they were misunderstood, and they were disappointed by the lack of support they received from this group as a whole. I heard many stories whereby the support was not only non-existent, but also that the behaviour and attitude of the professionals was perceived as callous and uncaring. An excerpt from a mother illustrates:

> VL: My daughter did threaten to move and go and live with the bikers... One of the times when she went into the hospital I wanted the nurse to tell the doctor that she had said she was going to go and live with the bikers. And the nurse said to me, WELL, HOW OLD IS SHE? She can go and live with the bikers if she wants...I was so ANGRY. Because that nurse couldn't understand what I was trying to say.

Family members commented on the need for, and the perceived lack of, support provided by psychiatrists. A father of a son with schizophrenia commented on the frequency, duration, and content of his son's visits with his psychiatrist:

> BT: Just as aside, when Sam meets with his psychiatrist, it's maybe once a month. It sounds like the meetings are short, and he goes home. But I don't think they spend a lot of time pursuing the emotional aspects of his life, and to me that's really where it's at. The emotional side. Because once you're taking your meds, what else is there but the emotional side? It may be an oversight, because if the emotional side is not taken care of, either by the family or the psychiatrist, then where would it get taken care of?

One sister believed her brother would benefit from counseling, perhaps as a way of broadening his perspective:

> DK: … sometimes I wonder if it wouldn't be better for him to have a therapist to talk to. That's my bias. I'm not really fond of psychiatrists, because they don't come from the same school… The psychologists have a very different approach. They deal with the world in a much broader sense. He talks to me and he talks to some of his friends, but I just don't know if that's adequate.

Some family members perceived both the amount and nature of counselling received by PWS as insufficient. Moreover, some family members expressed seeking empathy and validation of their concerns from mental health professionals, and being disappointed and angry at the response received.

C. SYSTEM ISSUES

System issues include mention of how the mental health system impacted a family member's experience of schizophrenia. I defined, for the purposes of this research, the mental health system as the services provided to PWS and their families in and around the hospital. The five main sub-themes involved mental health personnel, certification, education, respite, and treatment planning.

1. Mental Health Personnel

Several family members commented on the perceived lack of compassion exhibited by mental health personnel, particularly mental health nurses and psychiatrists. There was also mention of behaviour that would indicate that professionalism was below expected standards.

1.a. Mental Health Nurses

Shives (1998) recommended that mental health nurses attempt to establish a trusting relationship, aid in the alleviation of anxiety, and foster clear, consistent, and open communication with ill individuals.

1.a.i. Professionalism below expected standards

Some family members described instances of mental health nurses displaying a lack of compassion. In the following illustration, a mother described a situation where the professionalism displayed by a mental health nurse was less than was to be expected. In anticipation of her son being transferred to a new hospital with new medical staff, a mother had organized her thoughts on paper to secure his optimal treatment.

> AN: I listed the symptomatology, um, the difficulties he was having with the Day Programs, and then, what does help him. At the top I had, DO NOT TOUCH in big letters... He cannot stand to be touched. I never touch my son. He finally told me, just before he went to see the doctor that time, he doesn't like it because he thinks when people touch him their skin comes off on his and he can't get rid of it... This one woman, she came up, and said, SO, YOU DON'T LIKE TO BE TOUCHED. She kept poking at him with her finger on his shoulder... Now Robbie is just about ready to explode. You know what would have happened? He would have exploded, they would have sedated him and put him in isolation and she would have walked away from the whole thing.

Another mother commented on service received, on several different occasions, when she visited her son on the psychiatric unit at the hospital:

> ST: But I have had a nurse when I, um, was standing waiting to speak to my son, reading a newspaper, put the paper down like this (gestures with hands), look at me, and put the paper right back up. Knowing I was there to see my son. They had to let me in. It was a locked unit... Um, I had a nurse one time when I went to see Grant, and I didn't know what room he was in ... So I asked where he was. Ah, oh! Down there (points with finger). I mean it was just a wave of the hand. So I went down and he wasn't in his room. I went back and said, he doesn't seem to be in his room and she said, well, he's gotta be around here somewhere. In other words, go look. I said, I can't see him, do you have any idea where he might be? Well, maybe he's in the food room. And where would that be? Over there. I'd go, and I'd look and he's not there. Now, he was under certificate and so I went back.
> EM: Can I ask for clarification? Under certificate means?
> ST: He was certified. He was committed against his will, so he's under certificate, under THEIR protection. So I went and I said, OK, I have looked for him three times. You'd better god-damned know where he is. He's under certificate. He's under YOUR protection...

The above quote illustrates that during times of crisis intervention family members are in a highly anxious and sensitive state. The quality of care and attention they receive from mental health professionals is of critical importance, particularly during this period.

One sister expressed concern about the lack of services offered to mental health patients, and the general receptivity of the system to mental health patients:

> DK: I guess some of the concerns I have about schizophrenia are leveled at the health care system, WELL before these cuts occurred. What's available for people who are emotionally unstable? Do we have emergency treatment for people who are physically injured? There's no question about THAT. But if somebody's going through emergency emotional situation, we seem to have very little staff capable of dealing with that in a humane manner... But there is a [certain] expectation that the people be able to TREAT the patients with some compassion.

The above quote illustrates that some family members perceive that mental health patients receive a lesser quality of care than other acute care patients.

1.a.ii. Positive experiences

On a reassuring note, several family members described mental health nurses "going out of their way" to help their ill relative. One mother described how her son, after a suicide attempt, had been taken to the Hospital A even though he was an outpatient at the Hospital B. She described the action taken by two of his nurses at that time.

> AN: ... One (suicide attempt) was particularly bad...Even though he was a patient at Hospital B he was so bad that they wanted to do it the quickest and thus got him into Hospital A. On the Thursday two of his nurses from Hospital B, who LOVED him as a person, got in a car and drove over and got him and drove him back. They told the staff at Hospital A, if he is going to die, it will be in our care, where he is loved. And ah, those two women have been such mainstays for he and I, to this day (pause). The one, Laura, helped him to accept the reality of his illness... I wasn't getting that from anybody else... I have to say, the psych nurses have been our lifeline ... They've literally saved my son's life.

The same mother spoke accolades about how specific community mental health workers knew the importance of fostering her son's self-esteem. She described a day when she and her son returned to the Volunteer Centre, and that even though he felt the work done there was "beneath" him, his treatment team believed it would be beneficial:

> AN: So he had worked before 1986 a little bit at the Volunteer Centre of Calgary. So when he came home in '86 they felt he should try again. Took him down there, and his nurse went with him. They're waiting in the lobby and another staff, an older woman, walked through. She and Robbie always got along well. She saw him and said, well Robbie, what are YOU doing here? And his head is down to his knees, and he said, well, they want me to try volunteer work again. Am I ever glad to hear that, she said. WE NEED YOU. Could you start today? ... One year they presented him with this beautiful medal... and he and I were sitting there in tears. But, he said, I didn't know people thought of me as a person.

Interestingly, two family members mentioned instances when the nurses "bent the rules" to accommodate their ill relative. A father speaks:

> RT: When he phones and if he hasn't been on his medication, or if he's a few days late getting it, then right away we're phoning Fred, his nurse. He's really, really a nice fellow, and ah, very caring.... So, we'll phone Fred and say, well, what are you going to do? He'll say, well, I'll go see if I can get a hold of him. And he would go and drive up to him. Now I'm not sure if he should be doing that...

A mother described her daughter's bizarre spending habits:

> VL: She was spending her money haphazardly. K-Mart was closing down. She was buying all kinds of things... She threw all her furniture away, she threw a good sewing machine away, she threw a good t.v. away. Beautiful furniture. She had seven pup tents in her apartment; she had four big sleeping bags, twenty bed throws, seven serapies, and all kinds of other things that she purchased at K-Mart... So someone, a wonderful worker, who was not supposed to be in touch with me said, let's see if we can have you become custodian of her AISH... Finally I was given custody of her AISH money...

Each of the above illustrations described simple acts of kindness that family members clearly appreciated.

1.b. Psychiatrist Consultation

Some family members commented on the manner in which psychiatrists communicated with families and ill relatives. Anger and frustration often stemmed from both the content of the consultations and the tone of delivery. A sister described one incident:

> DK: But HIS (her ill brother's) reaction to all this, to both times he ended up being hospitalized, was that he was extremely angry with one of the psychiatrists, who I won't mention. But that individual basically threatened him with, you know, you're going to Ponoka. I thought, really, that's stupid. Here you are a psychiatrist, and you've got someone who's obviously in a highly flared-up paranoid position. It's like, you're afraid of swimming? Well, I'm going to drown you.

This was perceived as someone in a position of power and authority issuing a threat. The sister believed that a collaborative relationship between doctor and patient would have been more helpful.

A mother described a psychiatrist's portrayal of her family member's future:

> AN: And I can remember a doctor saying to me, no, just forget it. He'll never be the same. He's not the same person at all. He'll never do this, he'll never do that, he'll never do the other. And, of course, it was all my fault. And that just made me angry.

Another mother explained a similar exchange, and described her frustration at her input not being considered in the treatment plan:

> GH: I think they [the professionals] need to learn how to state what the possibilities are. Not to dwell on the 'never this and never that'. Most of them don't get married, blah, blah, blah. Oh wonderful, you've just told me he's not going to have a life (laughs). Give me hope. So that was really an ordeal for me, and I think they just don't want you to have high expectations, and I think that I could read into what they were saying… There was one point where we spoke about Jonathon wanting to work. And she said, now you're pushing him. And I said, no, wait a minute, this is Jonathon. And that's what really upset me is that she presumed I was a pushy mother, and I thought, well, how do you even KNOW this? I have just arrived in your office… She even said to Jonathon, we'll talk more about your family when your parents leave.

It would appear that family members want both the presentation of the diagnosis, and associated information regarding the illness, to be a compassionate exchange and reflective of an alliance between the psychiatrist and family. They desire psychiatrists to display sensitivity, and, furthermore, recognize the impact of the delivery of such a life-transforming diagnosis. While family members do not want to be given false hope, the above two quotes illustrate the importance of instilling at least a modicum of hope in a future of living with schizophrenia. As one father stated, "What is there if you don't have hope?"

2. Impact of Certification

The Alberta Mental Health Act states that individuals must be a proven threat to themselves, or to others, in order to be committed against their will for mental health assessment and treatment. Several family members mentioned the restrictions the Act places on what they can provide for their ill relative. One mother spoke of what she may resort to, depending on how desperate she is to get her daughter into care:

> VL: But when Allison would become ill, before she was on her medication, I used to have to go to court... I have been there probably five or six times, and you swear that they're a danger to themselves, or to you. Occasionally you tell lies.

A father described the "ludicrous" system:

> RT: This, this just drives me nuts when you CAN'T get the help that you need when you need it. You sit and watch someone getting really sick, daily getting worse, and there isn't anything you can do. Until such time as they become a danger to themselves, or a danger to someone else. And it's so ridiculous! I mean, if he had the flu I could take him to hospital, and he'd get some treatment... Your hands are tied.

Both of these individuals mentioned, unsolicited, the degree of dissatisfaction that many family members have with this Act. Moreover, they described the lobbying to change the law.

Some family members view the issue of certification differently. For instance, a sister expressed relief at not having to force her brother into care:

> DK: And fortunately he was calmed down enough that we were able to get him the psychiatric help. The situation for Michael has never been as grave as it has for some other families. Because had he NOT been co-operative we would have had to have him arrested and go through that whole thing. And you're thinking, well, he's going to remember that and he's going to be extremely resentful of the family.

A mother had similar concern and hesitation over forcing her ill son into care:

> AN: ... A mental health warrant was an option to force him into at least seeing a doctor. And that was terrible. That was an awful experience to go, in front of a judge, and deliberately sign a paper forcing someone into the mental health system. It was just devastating. It took me years before I told Robbie I did that. He never knew at the time.

The aforementioned comments regarding certification, so different in nature, exemplify the complex nature of emotions that family members juggle when living with the illness. The anxiety of having to wait for one's ill relative to prove to be a danger to him/herself or to others is juxtaposed with the guilt of being responsible for getting that person forcibly into care.

3. Impact of Diagnosis and Education

The family members with whom I spoke described the process of receiving a diagnosis of schizophrenia as a frightening, shocking, and overwhelming experience. One father likened it to having an anvil dropped on his shoulders. Undoubtedly as a result of the nature of the illness, prognoses are seldom given, but when one is delivered it is rarely perceived to be in a compassionate manner. As a result, family members may feel hopeless. Yet, at the same time, knowledge is an empowering tool. Information needs to be provided in an ongoing manner, not just at the time of initial diagnosis.

Prior to using quotes to illustrate the lack of information offered to family members, I will describe how the Schizophrenia Society has recently focussed on education being a two-way street. There is a program that the Schizophrenia Society of Calgary has developed, entitled the Partnership Program. PWS and family members attend high school and junior high schools within Alberta to make informative presentations to teachers and students about the illness. This year they have performed a play entitled, "Starry, Starry Night". One sister described the aim of the play, and described how it was adapted for presentation to a mental health professional audience.

> SN: In the Partnership Program they put on this play, "Starry, Starry, Night". They actually devised this because they were trying to show the psychiatrists what it was like because they thought that they weren't aware of what their patients went through. So what they do is have four people stand in the corners of the room and read off of these cue cards. Alternately they say really nasty things, really threatening things, really mean things. And the person in the middle of the room is the person hearing all this and they had to answer questions like, 'What's your name? Where do you live?'
> EM: While all this is going on?
> SN: Exactly. And the psychiatrist had to put on headphones, and they were like, whoa! We can't hear the questions. Wait. This is confusing. Turn it down. Pretty telling, hey?

Family members need ongoing information regarding the illness. Furthermore, society, including mental health professionals need to be educated. A sister expressed a common misconception about schizophrenia, that it is often confused with multiple personality disorder:

> BH: When he first became sick I had no idea what he was going through. I still thought it was multiple personalities... He would sleep for about 14 or 15 hours every single day, with a nap in the afternoon. That really bugged me. Like, you lazy little (laughs). I didn't realize it was because of his medication and he was really heavily sedated.

The above excerpt illustrates the need for the provision of education about the illness, its symptoms, and medication side effects, not merely to society in general, but to family members who live with schizophrenia.

3.a. Lack of information

Many families mentioned the time immediately surrounding their ill relative's initial diagnosis, and their "flailing", as a result of their simply not knowing what was happening. A mother speaks:

> ST: John and I were very nervous and very, very concerned. As it came closer to his diagnosis we were almost in a state of being paralyzed because we didn't know where to go, we didn't know who to talk to, we didn't know what to do... Um, I'm quite surprised that we made it together through that part because nobody knew what the hell was going on.

Another mother received advice from her doctor:

> GH: I called the family doctor and said, what should we do? He really needs help, he's got a mental illness of SOME kind. He was VERY compassionate ... and he said, take him to the hospital right away and start the process. So that's what we did and that was all I needed was just one line. Take him to the hospital. OK, fine, I know what to do now. I know where to go with this!

I wondered if the 'paralyzed' state that the first mother referred to, and the second mother being at a total loss about who to take her son to, resulted from fear and panic having replaced common sense.

Another mother commented:

> MS: Well, as I say, we had no knowledge of the illness up to that point in time, and um, this was a very frightening, devastating thing to deal with. The first thing my husband and I did was run around and try and find what this illness was all about, and what could be done.

This mother received her son's diagnosis over 25 years ago, so I wondered aloud if mental health professionals were better versed today, in the dispensing of information regarding the illness. The responses I received were fairly succinct, and dwelled on the negative. Most agreed that time had made little difference in the quality of information that was given to families.

Another mother whose son was diagnosed over 25 years ago described the lack of information available at that time:

> AN: ... I was spoken to as if I was completely stupid. And all this time I've got this boy who is so ill, and who is struggling so hard to make sense about what is going on. No one would tell me what I could do to help him,

> or how to cope, or what the illness was about. What prognosis we could look at either. I, ah, barely got a diagnosis. So, ah, poor Robbie. It was seat of the pants learning for his mother.

Interestingly, she described recent incidents whereby she received little advice or information from professionals, and stated that her "seat of the pants learning" continued to this day.

A father described his frustration with the perceived "laziness" of his son prior to his diagnosis, when in reality it was the manifestation of negative symptoms:

> BT: He was living with us at that time. Um, but during that time we were quite frustrated because we knew that something was wrong, but we didn't know WHAT was wrong. We felt that he couldn't concentrate, he lacked motivation, he lounged around all the time, he didn't want to look for work. And up 'til then, he was, we felt that he just lacked motivation. We just really didn't know what to think.
>
> Another father made a similar comment:
>
> RT: I think when Grant first got sick I didn't understand, well of course, Fran didn't understand either. I would say things, like when he would be sleeping – that is the way it started – he just started not going to school as much. He started spending a lot of time in his room. He started sleeping a lot, and I used to get real cross because he was just LAZY. You know, if he'd just get his ASS in gear he'd be OK...

Lethargy and avolition are two common negative symptoms in schizophrenia. As is evident by the aforementioned quotes, they can cause intense frustration in family members when not understood as an integral part of schizophrenia, rather than merely a "personality defect" of the individual. Families want and need information regarding all symptoms.

4. Respite

Respite is a well-documented requirement, but unfortunately not often provided for the mentally ill or their relatives. Access to it is unpredictable, despite its preventative effects and likely cost-effectiveness. Planned respite is likely to prevent a later crisis, which is disruptive for the ill relative and the family, not to mention expensive in terms of days in hospital (Kuipers, 1998).

> RT: The other thing that's kind of tough with Grant having schizophrenia is the way it affects Sarah and I. Um, we don't take holidays. We don't go away for an extended period of time. We may go away for a week somewhere, but Grant is always in the back of our mind, you know, ah, should we be there? Is something going to happen and he's gonna need us? So it affects the life of the family because we don't take the holidays.

One sister described her family's unique situation in that her brother goes to an out-of-town care centre for extended periods for treatment. This provides relief for her and her family, particularly for her mother:

> EM: When he goes [there], is that something that they offer?
> DS: Well, yes, the last few years. Well, he's actually ended up there because he's been so sick ... There have been periods when he's been away for months and months and months, because he's been so ill... But now not so much because of the bed shortage. Like recently Mom would have taken him to the hospital and he would have, um, he WOULD have been admitted, because he was suicidal, but now it's too hard to get him in.

One father spoke of being a "parent for life", and the constant presence his ill son has in his life:

> JL: I guess we're parents anyhow, but our other son lives in Toronto now. He is your kid but he's got his own life. Randall does not have his own life. We are his life. We are his friends. We're his companions. When we go someplace, invariably he comes along. And sometimes you just want to be alone, you know. There should be a break there, somewhere along the line.

Parents are most often the primary caregivers, and thus the ones most in need of relief. They are often older, which is even more of a reason for relief to be an option. Seven of the twenty individuals I interviewed were over sixty years of age.

5. Treatment Planning

5a. Familial Involvement

Several individuals expressed frustration at their exclusion from the treatment planning for their ill relative, and that they were rarely asked for their input. One brother made the following statement:

> SH: …The frustration that surrounded dealing with that psychiatrist and not knowing what was going on. That was really annoying, and I don't think really helpful… You know, we KNOW Jonathon. This is the part that frustrated me the most. Like I KNOW when he does something when it's even SLIGHTLY off. Even then, there was Jonathon and then there were these schizophrenia peripherals that sort of came with Jonathon all of a sudden. And we knew exactly when he was one or when he was the other. There was no question. But when he goes into the psychiatrists, and then he starts relating to me what he's been telling the psychiatrists, I'm thinking, that's not right at all! This isn't what's going on. You know, they're not talking to us. They can't get the whole picture…

Jonathon's mother expressed her frustration at not being included in her son's assessment:

> GH: They talked to Jonathon and I both, and then just Jonathon, and they decided he had clinical depression and gave him the anti-depressants. Well, over the next few weeks it made him worse I think. He started spending more and more time in his state of fantasy, or delusions, or whatever you want to call it. And I started getting more and more worried. Other people weren't seeing it. I was the one that was here, and I was the one that was seeing him…

One sister expressed concern that her ill brother, Peter, was not part of his own treatment plans, and wondered aloud how the treatment would be successful without his active participation:

> CP: And then we went through the whole episode of, you know, what's best for him, and exercise and all of this kind of stuff. And you know, I'd be over at Hospital D and we'd all be talking about it and I'd say, you know, do you think that this is getting anywhere? There's Peter, over there, sleeping on a bench. He's not part of this (laughs). So we're

> making all these decisions for him, that he has no plan on carrying through on at all. I think we need to ask him what he wants to do. Everybody eventually realized that Peter was going to do what Peter wanted to do...

A brother commented on giving his brother the "right to choose" which medication he takes, rather than have it be a decision that lies in the hands of his mother:

> LM: I believe Bob needs to get off that stuff (Haldol) ... He needs to sit in front of his psychiatrist, and get ALL the information, and HE is making the choice... I will celebrate the day when he sits in the hospital with the doctor and discusses it.

5b. Individualize Treatment

Several family members were adamant mental health professionals recognize the importance of individualizing treatment. One mother described a phase of rehabilitation in which her son participated:

> AN: ... One time he was living in a group home and I took him out to EPC, Employment Preparation Centre... He's really an intelligent kid. They had him cleaning the earplugs for the headsets they use on airplanes. And he didn't want to go and do it anymore. And his group home supervisor and I happened to be in a meeting and she was complaining about him not complying.... I just looked at her and said, ah, would YOU like to clean those earphones all day? ... My son's intelligent and why should he have to do something like that? That's not constructive work.

She continued to describe how each individual must be considered as such and treatment plans, including rehabilitation, ought to reflect this individualism.

A father described the consultation at the time of his sons' diagnosis:

> RH: We had a bad experience with a psychiatrist... We were told that because he was going to be diagnosed with schizophrenia, he would never be able to work, he would not be able to do a number of things. And that was very depressing to me, and it was horrifying for my wife. I actually don't think she's gotten over that yet.

This quote illustrates the lasting impact that a lack of compassion and perceived thoughtlessness may have on family members at times of acute stress and shock.

One sister described the lengths her family went to in order to receive attentive health care for her ill brother:

> SL: Robbie ended up switching doctors because he felt that no one really listened to him anymore. And I think he'd been stabilized for so long that he was taken for granted and no one listened with fresh eyes. He's gotten that by switching to Hospital D.

D. RESPONSES

There are six sub-themes within this theme, responses to living with schizophrenia. In addition to expressing affective dimensions, they described: a process of seeking understanding, accepting the illness and adjusting expectations; coping and managing; gratifications; lifelong learning; and advocating.

1. Affective dimensions

Family members face a variety of emotional reactions from despair and anger, to anxiety and frustration. Kuipers (1998) suggested that as part of family therapy it be stressed that such emotional states are to be expected, and specific problems that arise be negotiated.

1a. Frustration

Family members reported a great degree of frustration. Most notably this surrounded their contact with mental health staff, specifically psychiatrists and the lack of information they received regarding their ill relative. The treatment planning sub-theme in the section entitled, 'System Issues', explored this.

In addition, several relatives described being frustrated by certain symptoms that their ill relative exhibited. Specifically, negative symptoms including lack of motivation, memory and concentration difficulties were frequently mentioned. Despite this being a well-documented phenomenon, I was struck by its severity and pervasiveness. Often the frustration stemmed from household disruptions. One father described it as follows:

> JL: I think one of the frustrating things about living with Randall and having the illness, is that he doesn't think. He'll take the milk out to put in his coffee and he'll leave it out all night. Or he'll take the mayonnaise out to make a sandwich, and leave it out all night. And ah, he goes out to the garage to smoke because he's not allowed to smoke in the house. He leaves all the ashes all over the place so I want him to wear his shoes. Well, he doesn't. He'll step in the ashes and walk back in the house and get ashes all over. It's frustrating. He'll say, oh, I forgot. And he DID, but it's still frustrating.

Yet another father spoke of his son's lack of motivation:

> BT: Well, through that time, before we really recognized that this was schizophrenia, Sam was very, very frustrating to live with. Especially for me, because I don't have the patience. I'm very much an achiever kind of person, and Sam didn't seem to have goals, or be achieving anything. I couldn't motivate him. Nothing seemed to motivate him.

A mother made a similar comment:

> GH: I've often found that if I suggest something to Jonathon he'd say, that's a great idea, I'm going to do it. But if he was on his own he couldn't think of a thing to do.

Two sisters described the frustration that surrounded their perceived helplessness:

> SN: So, it's hard to figure out what they want to do, because they can't always say what they want, or maybe they don't know themselves. So, I guess there's that frustration.

> SL: It was so difficult seeing him go into the hospital. You know, you hope you're doing the right thing, and you hope you're helping. It's so frustrating because you feel like there's not a whole lot you can do.

Interestingly, this sense of helplessness was expressed solely by siblings.

1b. Anxiety

Anxiety was a pervasive emotion. Many family members described the difficulty involved with the unpredictability of the symptomatology, and the frustration of not knowing what to do, or being afraid of doing something wrong when their ill relative was experiencing suicidal ideation.

> AN: Sometimes at night I'd be lying in bed thinking, I could kill this kid by doing the wrong thing. I'd try not be overly cautious either, because then he would pick up on my feelings. And we all say that it's like walking a tightrope ALL the time when they're so very ill. And you don't really relax from it. It's just that sometimes you can get a bit of distance from it, where you take a bit of a breather ...It's such a way of life.

Another mother described her anxiety during the time immediately prior to her son's attempted suicide:

> ST: So, eventually he did overdose on his pills, but five days and five nights he was awake prior. Didn't close his eyes. John and I took shifts sleeping (pause). He called me one night (pauses – wipes eyes). He called me at 3 o'clock in the morning and said, Mom, I have to talk to you. It is one thing to be called in the middle of the night by one of your youngsters that, you know, are in trouble. To be called by a person that has schizophrenia you can be – the level of anxiety is so high that it is palpable. You can FEEL it. Um, your hands are clenched. Every muscle in your body.

A mother described her state of anxiety that was due to the unpredictability of her ill son and daughter when they were off their medication:

> VL: The most difficult part was when they would be off their medication, because then EVERYTHING would be erratic. You're not sure what their movements are going to be. How they're going to react towards me or themselves.

Another mother, who had lived with her son's illness for over 25 years, spoke of watching her son getting progressively more ill, and worrying over obtaining access to a hospital bed:

> MS: Because Andrew's illness is severe he continues to relapse at times, and ah, I can see the signs of relapse coming. When I see that I'm in a high state of anxiety, because I know it's just a matter of time until he'll have to be hospitalized. Due to the current situation, the bed shortage, the shortage of psychiatrists, and mere thought that this is happening... I'll

> probably have to, in the very near future, get him over to Emergency, try to have him admitted into hospital for the kind of acute care he needs, knowing full well that right now my chances are only 50/50 of him being admitted. People are being told, well, sorry, there are no beds. You'll have to take this person home. That terrifies me!

1.b.1 Worry over future

Siblings, in particular, expressed a great deal of worry over the future of their ill relative. One sister's specific concern was her mother's failing health that provided the impetus for her increased involvement in her brother's life:

> SL: I worry, I mean, when she dies what will happen to my brother? That's why this last go round (her brother's recent relapse) I thought I really need to get in there and get some experience with -- and try and deal with this, while she's still here and stuff... It is very hard, and I don't know what he's going to do without her. I think it will be very hard on him.

Another sister commented on the bond that her brother and mother share, and her worry about after her mother dies:

> DS: She's got the patience of a saint. It's unbelievable. She just loves him SO much, and she'd do anything for him to make him more comfortable... I think he and my mom are really bonded.... It's amazing that he's still alive. That he hasn't killed himself. It really is, and I think it's because of Mom's love. She's kept him going, for sure. Or he wouldn't have been able to handle the torture [of his hallucinations and nightmares]. What will he do when she is gone?

1c. Despair

Extreme sadness was a commonly expressed emotion. It had number of sources, including one sister being particularly struck by a scene of a woman on the same floor as her brother at the hospital:

> SL: ... She was in isolation beside him and she was not allowed out. I came out of his room once to get something and I looked over and she was looking at this mirror... She was just sitting there looking at herself, with tears rolling down her face. No sound. You know, you can just imagine what it was, probably some lucid moment that she had... I didn't even

> know her and it broke my heart. Those poor lonely people that are there, nobody to care for them, and nobody that cares about them. It's a family destroyer. Not just the life of the one with schizophrenia, but it destroys the life of the family, because not everybody can cope with it. Or there's not enough resources to help them deal with it.

Quite often despair stemmed from the sense of loss that family members experienced. One father was moved to tears when he described the dashed hopes of his son:

> RT: Well, to me the most difficult part is to look at him and see that he's not going to have a normal, a normal life like my two other kids. One time Grant was sitting on the chesterfield and he was in tears. And he said, what's the point, Dad? What's the point of me even being here? He said, I'm not going to get married, I'm not going to have any kids, I'm not going to have a job, I'm not going to have any money, I'm not going to have a house. I'm not going to have anything! There's no reason for me to be here at all.

He continued:

> RT: In my opinion, this is the worst thing that can happen to anyone. I'd take cancer ahead of this... if someone said to me, you have to have a disease, the very last one I would choose would be schizophrenia. The reason for that is that you're still living and functioning to a certain extent, but you don't have anything that you really would have had if you hadn't had the disease. And that's why they commit suicide (teary eyed). It's a difficult thing to talk about (tears).

When asked what schizophrenia meant to him another father made a similar comment:

> BT: ... You're trapped with this illness. You still have the same mental horsepower that other people have, so you are intelligent enough to know that things aren't working right. And, you can see into the future to see that nothing's going to change.... And I think, hence, the high suicide rate, because the people with schizophrenia recognize their future.... And they look around and they see other people getting married, and having relationships, they have families, they have jobs... And all the things that most people who are around you – you can't participate in any of that stuff.... You don't have enough money for anything other than an old, old car that sometimes runs, sometimes doesn't. You can't seem to develop

> relationships with people. So I think of schizophrenia as – not stopping you from recognizing where you can be, but it stops you from getting there and you know that.

I found it intriguing that it was most often fathers whom expressed despair stemming from material loss and relationship losses.

Interestingly, and perhaps this woman's brother is not as ill as some, a sister disagreed with focussing on loss:

> DK: … I feel for him, but I don't focus on that (the disappointment)… It's not too healthy. I mean, that's fine, and it's good for people to recognize that that can be a problem, but I don't think it's a good idea to over-focus on that… I heard my brother say, ah, it's too bad for Michael. He'll never be able to have a wife or kids of a regular family life. And I said, NO, it's not too bad. And I don't think that's the correct way to look at him. I don't think that's the correct way for him to look at himself.
> EM: Do you think it's a dead end?
> DK: Yah. Why say that? Why if we all did that to ourselves? OK, so I'm a high school teacher and I'm head of the Modern Language department. So – what if I had been a diplomat? And I said, what if, what if, what if?… The right approach is to take Michael where he is, and say, yah, he has this emotional disorder, and how is he handling it? And how are we handling it?

It was interesting that this woman consistently referred to her brother's illness as an "emotional disorder", rather than as schizophrenia. When I made this observation aloud, she stated that she loathed the "baggage" that was attached to such a label, and thus chose not to use it.

1d. Anger

Anger was a pervasive emotion. One young sister manifested a great deal of anger, which she coupled with frustration, when talking about her relationship with her brother.

> BH: Ah, I basically felt like I lost my brother because he turned into a completely different person and I am very angry because we used to be

> really, really close, and now he's totally changed... My parents really focussed on him, and I resented that too. Every time I would get a letter or a phone call it was about Jonathon, and I resented that too. The bottom line is anger. I was angry at Jonathon. It wasn't anybody else, it was him. It's weird, because he's the one that's sick.

This particular sister recognized the futility in being angry with her brother, and mentioned to me that if I asked her a few months from now how she felt she was entirely likely to be feeling differently. I speculated, and she agreed, that it was because of her young age, and that her brother had not lived with the illness for long, thus she was still "digesting" the associated issues.

One brother displayed intense anger, which seemed to specifically be targeted towards his mother, and stemmed from their different approaches to his ill brother's psychotropic treatment:

> LM: But I need to get him off that Haldol. I need to get him on Risperidol. I believe that the drugs are more to tranquilize Mom's fears than they are for his... My mom is the quintessential little army general. It's her way or the highway. She'll die that way. She started to be a mother at age ten because her mother died and she had siblings to take care of. She had no one to tell her how to be, which is no wonder she's so [f---] horrible at it. She's maybe one of the worst communicators. And probably the reason is that she never got the opportunity to communicate with her mom.

The same brother was angered by the perceived lack of control his ill brother had over his treatment:

> LM: The problem is, they are told, here's this medication. And they're having it given to them and being told that this is what's good for them, or whatever. They never, ever say, yes, I understand this is the medication that is going to make me healthy. I commit that this is going to make me well. For my own health I will take this. But because they don't make the commitment around it, they're living their life on somebody else's terms. Maybe a doctor's. And meanwhile, the schizophrenia, in the back of his mind is saying, [f---] you, doctor. And as soon as they get on their own, the [f---] you comes out and they get off the medication.

A mother described her hurt at one of her well son's reactions to her ill son's diagnosis:

> ST: You know, he couldn't handle Grant getting sick… he just ran away… I was furious with him. I was hurt and I was angry and I was talking to my mom and she said, you just leave Bob alone. Very smart woman. So I didn't say – EVER say anything. He still doesn't know how upset I was.

She described her behaviour at the first Schizophrenia Society meeting she attended:

> ST: I don't know how they stood me. I cussed, I swore. The support group meetings were held in Rosedale United Church in the upstairs. I kicked their chairs, I threw chairs, I swore at every doctor that ever walked the face of the earth. I was awful. I can't begin to explain how hurt I was. How did God dare do this to me? I swore at God… So I felt, I spent the first year, the first probably five to six years, very, very angry. But that anger I really did put to work.

Other family members described being fuelled by intense emotion and channeling this energy into useful ways, such as volunteering at the Schizophrenia Society.

2. Seeking understanding, accepting the illness and adjusting expectations

Almost all of the conversations I had with relatives began "at the beginning". They spoke of having to actively seek out answers and information related to their ill relatives' unusual behaviour, both prior to and after diagnosis. Several spoke of searching for years, attending countless meetings with school counselors and psychologists. Moreover, they spoke of seeking to understand their relative. One father, who teaches at a local high school described his family's search:

> JL: I think that if we went back historically, I think Randall has always been, he's always had problems right from a very young age. Um, you wonder what the problem is. Why he's not doing well in school. Why he's acting kind of strangely.
> EM: Do you mean as far back as elementary?
> JL: Even as far back as elementary school. I mean, going to parent teacher interviews was not a very pleasant experience. And he was never diagnosed with schizophrenia until he was 27… I don't know how many psychologists we went through. School psychologists, private psychologists, etc., trying to develop, trying to come up with some sort of strategies so that we could work with him. To help him, and even work with ourselves, you know.

Another father described his search for answers to his son's behaviour:

> BT: Probably in his late teens is when we started to get some help through counselors. So we ended up speaking to the family counselors with Sam… Um, we didn't make a heck of a lot of progress with that counseling. And then there was a person in our church who had his own family counseling business. He was a psychologist so we went to him and had some sessions with him. He came back saying that he thought Sam had schizophrenia.

A mother described what her family knew about schizophrenia, and the state of information about the illness when her son was first diagnosed twenty-five years ago:

> MS: We knew nothing AT ALL about the illness of schizophrenia. We didn't know what the early symptoms were and so we didn't recognize it as such. And we went through several months of very difficult times for all of us, um, trying to understand what was happening to him.

A father, whose son was diagnosed less than five years ago, commented on his struggle to understand the complexity of the biochemical components in schizophrenia:

> RH: And I remember I had to start into the whole research of what is the illness, and what causes it and what is this thing called serotonin in the brain, and what are the blockages? … I couldn't figure it out. It was as if somebody came into our house in the middle of the night when we were sleeping and they went to the electrical panel and they re-wired our whole house so I turned on the bathroom light and the garage door went up. And that's where I found this thing totally, totally off the wall.

One sister chose to describe her search to understand her brother's needs and desires with the following analogy:

> SN: It's very hard to know what to do for him, what he wants to do, because perhaps he does want to just sit and relax. Um, I sort of think it's like a cat actually. People think that cats just sit for very long periods of time, looking out the window at nothing. But actually they are probably seeing many things we would not, and actually having many experiences that we would not sitting in the same position. I sometimes think that that is what it's like for someone with schizophrenia, because there are so many things going on in their mind that we can't imagine – pleasant or unpleasant.

She further commented on her search to gain a deeper understanding of her brother's desires:

> SN: And again, it's this feeling that you want to include your sibling all the time, like they're being left out. You WANT them to have something to do. They may or may not want to be included, and that's, I guess, what's hard to get to know. So, it's hard to figure out what they want to do, because they can't always say what they want, or maybe they don't know themselves.

The guilt she felt in enjoying life and leaving her brother behind was hinted at in the above quote. I perceived this particular sister to be intensely involved and committed to maximizing the quality of her brother's life. Throughout the conversation she explained many instances of considering his needs prior to hers, and displayed a deep, pervasive loyalty.

A mother compared her journey into acceptance with her husbands' coping. At one point during the conversation, she wondered aloud whether her husband's demise was hastened as a result of his inability to accept their son's illness:

> MS: It (the diagnosis) particularly hurt his father. His dad was, I think, never really willing to accept what was happening.... He always wrestled with it. Agonized over it. It took me a VERY long time to accept what was happening too. And until I did it was the most difficult time of my life.

> Once that feeling of acceptance comes, you realize you have to just live with your expectations very much lower than perhaps they were. And that you have continuing care of your son, with all of the problems involved in that. Until you sit down and accept that that's just the way it's going to be, then it's hard. But once that happens it becomes a lot easier.

Another mother is blunt in her assessment of her feelings, and her perception of what concerned persons offer:

> AN: Our only escape is when we die or our -- person dies. THAT is our escape. And that is one thing about having to cope with mental illness, is that you face reality or you go under. And facing reality can be very hard on other people, because they immediately want to console and comfort, and there, there. And it takes them a long time to understand that you are NOT looking for sympathy. You're just taking exactly what is there and coming to terms with it and just getting on with life. Because if you don't, you're in a mess and the person you're trying to help is devastated, and it's just a waste of time and energy.
>
> One mother concisely summed up her adjusted expectations for her son's life:
>
> GH: On another note, you have to be realistic. I have to come to terms with the fact that Jonathon is not going to be a violinist, or a teacher, and he's not married anymore, and he may not have a career. All of my children were very bright, so you just expect them to have all these great things in their lives and they just may not get to. You just have to let go of that...

A sister described her struggle to cope with altered expectations for her brother's life:

> SN: How do you cope with the expectations that you have for your siblings' life? You have so many hopes, you know, at one point I was hoping that he'd just be able to live independently and have a certain quality of life. I feel like that's been really shot down. I don't think he could live independently, and I don't know what his quality of life is, quite frankly.

The warmth of a sister shone through when she described offering comforting words to her brother:

> SL: He says, you know, I really wanted to accomplish something in life and I don't think I'm ever going to do that. So I said, well Robbie, maybe you just have to change your views to something a little more attainable. Appreciate the smaller things, you know. I said, look at the joy you bring in OUR lives because of the type of person you are.

One mother described the importance of adjusting her expectations:

> AN: But we, as caregivers, have to have a shift of attitudes ourselves. And gratification in those early years (of the illness) can be, he got up and stayed up today for half an hour. He got up and had a shower. He got up today and he went to Clinic. He had a meal today. He is alive today.
> EM: Your expectations drastically change.
> AN: They change and they become very basic. Even though you are dealing with such dreadful complexities caused by this illness, nothing is simple except, in my mind, that I can change my attitude and my way of looking at things, and I can change my view of what is important in life.

The above quotes illustrate the incredible strength and tenacity family members exhibit in the face of a potentially devastating illness, at the same time as recognizing the importance of being realistic.

3. Coping and managing

Family members described coping with issues and challenges that arise day-to-day, and managing on a broader basis, such as juggling different roles in their lives. One sister, who has two brothers with schizophrenia, also has two grown children of her own. She described her role as a mother and a sister to her ill brothers:

> CP: ... Having my own children and being very fearful. I think my children missed out on a lot. I was trying to do so many things and so my emotional, um, strings being pulled so many ways. I don't know that they would think of it that way, but that would be my view, that there was all this responsibility.

A mother described the guilt she felt at wanting to distance herself from her ill son when she returned home from work:

> GH: I started to feel a little bit overwhelmed, like I needed a bit of space. When Jonathon was living here at home we did lots of talking together, and I liked that to a point. But my job's very tiring, and some days I just wasn't up to it, and Jonathon didn't always understand that. We work 12-hour shifts, and I work with small children and we work with very troubled moms. We just have very, very busy days. So at night, you know, I just – my husband often has the bath ready for me and I just hop in. Then I'd go to bed. Jonathon is very talkative and outgoing. I just sometimes couldn't take it… Although I was so interested in his thoughts and how he was feeling, um, there was just a limit to how much, the quantity of time I could take.

A sister described her hectic days, and commented on the difficulty she had visiting the psychiatric ward:

> SL: So, um, I was going up to the hospital – I was working full-time – but I was going to the hospital twice a day. I had four little kids and they have very busy social lives and stuff like that. But I went up on my lunch hour, and would come back, and would go back before I came home to make supper.
> EM: So it's true (laughs). Your family doesn't sleep (her mother had mentioned this to me).
> SL: (laughs) Sometimes it was great, and I was so happy I was there for him, because it's a tough situation. The ward is a tough place to be.

A mother described resorting to active management of her daughter's finances:

> VL: It became so bad, that in the end I went over there every day with 16 dollars. That's how much money, breaking it down, that she had left and I would take it over every day and put it under the door. So that she would have enough for her food and I would give her fifty dollars for her bus pass… Now, at first when I thought about this I thought, NO, I can't do this to an adult person. But I spoke to two or three people who said, exactly, I'd cut her off. Well, I can't cut her off. She's my daughter!

It is apparent that family members do not take such decisions lightly. This mother's anguish associated with assuming the management role is clear.

4. Expression of gratification

Although schizophrenia was often perceived as a daunting, inexplicable and devastating illness, family members articulated specific gratifications they associated with living with the illness.

4.a. Teaching tolerance

Two women with brothers who have schizophrenia commented on the effect of the illness on their own children:

> DS: I think it's been a really good learning experience for my children to be around someone so – different. To learn about mental illness so that they accept other people better. To know that he's a gentle person, a kind person, and all that despite that he makes no sense (laughs), and is weird, and does all these strange things… Absolutely non-judgmental. They couldn't have been around anybody more extreme than him, so it just makes them that much more patient and understanding of other people. And I've already seen that through my girls, how they accept other people and their odd behaviour as not being anything to make fun of or be scared of.

Another woman described the understanding her children had of their two ill uncles:

> CP: They grew up with two schizophrenics their whole lives. And Peter (one of her ill brothers) was like my son and like their older brother. He was absolutely a part of their life and they adored him, and they protected him, and they just knew that there was something different. They were very, very good to him, so when you think about good things, it has made them absolutely non-judgmental… I guess for my kids they really understand human behaviour.

This tolerance of "different" people was described as a welcome "by-product" of living with schizophrenia. I found it surprising that it was described as being displayed by children so young.

4.b. Family Coherence

Several family members described how living with the illness had united their family. One sister explained that her brother was born with cerebral palsy, and that challenge prepared them for what lay ahead when living with schizophrenia:

> SN: … I think they (her parents) are like, OK, here's another challenge and we're going to deal with it. Although it's COMPLETELY different in its nature, they coped really well. I think that it has a lot to do with them thinking of Dennis, and not themselves… It brings our family closer for sure. Um, I probably spend more time with him because of it, and take more time with him… It makes you a much more compassionate person… It just hasn't happened in our family that it's broken us apart at all. Um, there's little things that my parents argue about, like when to give him an Ativan (laughs) to calm down. They'll argue over that, but there hasn't been a lot of stresses because the purpose we have is to make his life really good and there's no point is us arguing or getting upset because that doesn't make his life better.

4.c. Gaining perspective

There was a clear theme expressed in several families that living with schizophrenia clarified what was important in life. It seemed to paint a positive light on any seemingly insurmountable challenges. One mother stated:

> ST: When you face a disorder like this and it shakes you to your very core, your priorities get in order… Schizophrenia straightens you right out. It either – either you get straightened right out or it affects you the other way. Um, it destroys you and certainly I have seen that happen too, where people are totally destroyed. Family members included… Ah, tremendous pain will also bring tremendous joy.

She commented on the importance of recognizing special moments:

> ST: Sometimes you go through your life not realizing how special moments can be. That's another thing that schizophrenia teaches you. It teaches you that special moments need to be marked. Um, seeking to find the beauty and joy in life and mark those things to be remembered, to be special.
> EM: Not overlooking. I suppose, taking time to reflect?

> ST: Taking time to reflect and making sure that those around you understand the beauty of this moment. That's a very important thing in family history, and that kind of, ah, recognition of love and joy and all of those mushy things will keep a family together through tough times.

She further described her personal growth:

> ST: Sometimes it takes this impact for people to grow up and find out who you are, and schizophrenia makes you do that. You either find out who you are and you move forward or you never look at who you are and so are crushed. There isn't any in between with this. I'm very grateful that I have been MADE to look at myself.

Yet another mother extended this sub-theme:

> AN: It's selfish. I have grown and developed so much as a person, and that would NEVER had happened if it weren't for having to cope and learn. And life has become a real learning experience for me in many aspects, not just caregiving or in mental illness... It's made me work at my relationships with my children. And we've been through some rocky times and we've had to rebuild, but we are stronger and better than ever...

She added:

> AN: Another blessing is ... that I have had to learn to observe, deduce and implement what my conclusion has become... And I have to say, it isn't just thinking. I've had to use intuition, and I know this is always an argument. Female intuition. I believe in it. My sister-in-law had intuition, and it was like a gaping hole when she died, but um, so a blessing is serendipity, something that just happens. And it takes you a while to realize it HAS happened, and then you're down on your knees and thankful it did happen. That you were able to recognize it and build on it. So, learning to learn has been a real bonus.

The two mothers quoted above, who are also grandmothers, mentioned that they enjoy and cherish their grandchildren, and specifically say that they 'bring perspective' and joy to their lives.

After struggling with her family members over the logistics of care for her two brothers with schizophrenia, one woman described her personal liberation:

> CP: … I got a little older – and I became a freer spirit and sort of had a lot less to do with my family. I felt that I wanted to have a life. A life away from, actually, not Richard and Peter (her two ill brothers), but away from the rest of my family that would not support me… I started doing my own thing… I thought, I've had enough of this confusing behaviour, this unpredictable behaviour that my other siblings and my mother are displaying. I have got to start to control my own life, and my own children's life away from all that family. So I quit smoking and I thought, if I can quit smoking I can do anything. So I did. Actually I quit for a year and left my marriage too.

5. Lifelong learning

Some family members described the ongoing learning process that accompanied living with schizophrenia. The unpredictable course of the illness required adaptability, flexibility and patience. One mother's comment illustrated an instance of her learning:

> AN: And, I had to learn that, ah, his time sense was out of warp… I remember one day I asked him to take out the garbage. He looked at me with a very puzzled look on his face, and he sort of tipped his head and said, pardon? So I repeated it and I thought, what's the matter with you? I'm exhausted here. It was so stressful, my life (laughs). Finally I just pointed to the garbage and I said, take it out. Oh, you want me to take out the garbage? And I said, yes. OK, he said, I'm just going to lie down for five minutes first. Two hours later he came up to take out the garbage and he was SURE it was only five minutes... I discovered some months later he and I were talking that this happens to them. This was AFTER he was into care and was stabilized, and I happened to mention that day. I said, I just couldn't get you to understand, and he said, Mom, I thought you were really sick. I couldn't understand a word you said. It was all garbled. And he said, I thought you were having a stroke… He was hallucinating, so when he looked at me my face would twitch and change. So, ah, families have to learn these things and HOPE that we twig into them when they occur.

The same mother described another instance of, what she had previously called "seat of the pants" learning:

> AN: And I had to learn when my antenna was saying, there's something REALLY wrong here. I had to open my mouth and say, do you feel suicidal and do you want to go to the hospital? Would it help for us to just have a cup of tea? You know, going through ALL this, the moment-to-

> moment, um, actions and thoughts. And learning when to shut-up and when to at least be up and around, not necessarily in the same room because that can be very aggravating... So, I had to learn how to be a support for the suicidal feelings and everything, and again (sighs), nobody would talk to me about it or tell me what to do.

One mother described how living with her son's illness forced her to acquire and display emotional stability:

> PJ: ... This is a difficulty that became a plus because, I've always been very – quick. I would go up quick and come down quick. And now I have to be careful. I have to think before I jump, in other words, if it was you I'd say, what the hell did you do that for? So, I have to think about how I'm handling him, what I'm asking him to do. Not to feel he is taken for granted, the things he does for me. Um, I have to remember to praise him... So, in a way I'm saying they're difficulties, but it's how you cope with them. In other words, you have to keep a little calmer, don't be too demanding. Be a little more understanding.

It was interesting to note that this woman's daughter had also mentioned that living with schizophrenia had tempered her mother's emotional swings, and that this was a blessing to their entire family.

6. Advocating

Several family members described having adopted an advocacy role, for both their ill relative and for other individuals with the illness. The two types of advocacy described were personal/altruistic, and systems levels activism.

6.a. Personal/altruistic advocating

Family members often advocated on behalf of their ill relative or individuals they perceived needed representation. One sister described her involvement in the Schizophrenia Society's Sibling Support Group:

> SN: I've talked to siblings at support group meetings, so I know what goes on with the parents... There was this family that brought in an eight and ten year old. They had a sister with schizophrenia and were being

> bullied at school. Strangely enough, the group they were given was the psychiatrists with their parents AND them. They had to say what they were feeling IN FRONT OF THEIR PARENTS, and they didn't feel comfortable doing that at all. So they wouldn't say anything.... I know there are problems in the system, but that is one thing that I would like to say. When it happens to young children they should be dealt with on their own ... They should have some confidentiality and some trust there.... I think the psychiatrists should just take the initiative and say, you know, we'd like to see the children alone and see how things are going.
> EM: Do you think it's an issue of time?
> SN: Maybe, but I think they should make the effort when it's children of that age. Because when you're older maybe you can find other support services when you're a sibling. But if you're a young child I don't think they have the ability to.

A mother described her son's sense of responsibility, but also recognized its limits:

> AN: You know, I tried very hard to keep him from getting a victim mentality because I think that's just crippling. So, he takes responsibility on his shoulders, that if there's something wrong it must be his fault. It's something he didn't or did do. And he finally NOW knows that if he is not being responded to the way he needs to be, then he will ask me to intercede and to advocate for him. We have both tried through the years to have him regain and maintain his self-reliance and independence.

One father stated his involvement with the Schizophrenia Society had resulted in an advocacy role:

> JL: I've [volunteered] for the organization for the last four or five years, and I've had some successes ... Instead of just sitting back watching it happen at least I've gone out and lobbied for him and for other people in the organization with the illness. And that I've tried to make sure the organization functions well for the people.

A mother described her struggle to get her son admitted to hospital. In the process she made reference to another mother affiliated with the Schizophrenia Society and the lengths she had gone to get care for her son:

> ST: If I had known what I know now, I mean, he would have been in the hospital. There wouldn't have been a doctor in the world that would DARE not admit him. I mean, I would have been like Mary. Fine, I'm goin' down. I am leaving him here and I'm going down to the media. I've

> got a lot of friends. What was your name again, doctor? The things you learn you have to do to get your people care, but you don't know these things until you go through it.

6.b. Political activism

Some family members described trying to effect change at the systems level. One mother, in particular, explained the Schizophrenia Society's ongoing endeavor to increase its membership and disseminate its goals:

> MS: ... In this city we probably have 8,000 people with schizophrenia. One in 100 people. And in our Chapter there are just a little over 300, so I ask myself, where are all those other people? If we even got 10% of those people to join, not only would it help them, but think what we could do... We could double, triple and quadruple services to help people with the illness... To see people with the illness who come and work with us in the Partnership Program and all of our other activities and see how they bloom where they are in an atmosphere with people who understand their illness. We know what to do to make them feel comfortable, feel loved... I see partners who have never been able to speak well in a small group in a hospital situation. Now they're going out there, standing up in front of 50, 60 people and it all comes out. And why? Because they have the right kind of support. And this is what we are trying to get across to the people in our mental health system in our province. That with the right kind of support, a lot of people, although they may not be able to work full-time or do many things we'd like them to do, they could function a lot better then they are.

The same woman's hope and optimism is evident in the following excerpt in which she described her representation on an accreditation team:

> MS: I'm the family representative on the accreditation team that's in operation right now... there are people from CRHA, CMHAB, the hospitals, and we also have, I hate this term, consumers. This means someone with the illness. And the very fact that we're on the team is a sign of the major progress made in the last ten years. That they are now understanding and realizing that this illness is too big for any one person, for any one group... The family members are now being accepted as part of the medical team in a sense...

Her political activism is illustrated below in her comments about funding:

> MS: People in the mental health system, a lot of people are certainly aware or are becoming aware of the kinds of support, the kind of housing for instance, that we need. And ah, we have been trying to develop these things in our city, but are constantly hampered... They just don't get the money that they need to do it. And until somehow we manage to convince governments, at all levels, that it's in the best interests of everyone in this country, particularly the taxpayers, to give every kind of support, the right kinds of support, AT THE RIGHT TIME, then, you know, we'll continue to pay a very high price for not doing this... Every single time you prevent someone from being hospitalized, you're saving thousands of dollars... Schizophrenia is the lowest funded of all the major illnesses, despite the fact that it's one of the highest in costs to society. I think it's over $4 billion a year we spend on hospitalizing, institutionalizing them...

The same mother described the goals of the Schizophrenia Society's Partnership Program, and its micro-level goal of targeting young minds and attitudes:

> MS: Our Chapter, as you probably know, developed the Partnership Program... What I really enjoy is reaching people at that age, when their minds are still open. And after giving a presentation you can almost SEE the change in attitude as they're listening while one of my partners that has the illness and I try to dispel the myths about the illness... and you KNOW that when you leave the classroom, you've changed their minds about mental illness and schizophrenia... I'm afraid my generation is probably a lost cause, as far as changing attitudes drastically, though.

Another mother explained a situation in which she perceived her son was not receiving sufficient community support, and her determination to effect change:

> AN: It started out well, but then he was given a roommate and the roommate also had schizophrenia. But he was an alcoholic and on drugs, too. It got to the point where Robbie was terrified to be alone in the apartment. And they had a supervisor who was 21 years old who was supervising that bunch of people who were in such dire need. She didn't have experience. She didn't have an education... I went to see her because Robbie was so scared he would come home on weekends to get some relief from this. And he was becoming more and more despondent. When something's wrong with Robbie, he clams up... Finally he told me what was going on. So I did what I thought was proper procedure. I made an appointment and went in to talk to this little supervisor. And ah, she sat there with this bored look on her face, let me finish, and then said, Oh, I'm sure he'll be alright... So, I said, I take it you aren't going to do anything about it. He's fine? He just has to learn how to cope? No

> way!… I had her fired…. I determined very early on that if I was going to try and affect change it couldn't just be for Robbie, because there were so many that had NO ONE to give a damn about them. I was trying to keep a broader focus and affect the system.

These family members all chose to maintain highly active roles in their ill relatives' lives. Hearing their stories made me wonder what happens to those who are estranged from their families.

III. SUMMARY

Participants described issues regarding stresses, support, the mental health system, and how they have responded to living with schizophrenia. Some appeared to have reached a certain level of "closure" with the issues, while others continue to struggle. All family members recounted painful memories, and most displayed accompanying tears. There was a common language in the expression of family members' experiences. I began to sense that the emotional responses to the illness were critical aspects of each individual's adjustment.

CHAPTER 4 - DISCUSSION

I. KEY FINDINGS

Stresses, support and system issues were the main themes articulated by family members of persons with schizophrenia (PWS). As conversations were rarely dispassionate I will link emotional responses with my discussion of the key findings. Some participants appeared to be grieving and therefore this will be examined, together with the related concepts of suffering and hope. I will also discuss associated implications for education, research and/or practice.

A. STRESSES

The sub-themes entitled symptoms, familial dissonance, household disruptions, and stigma were cited as stresses associated with living with schizophrenia.

Most family members cited both positive (e.g., hallucinations and delusions) and negative (e.g., affective flattening and amotivation) symptoms of schizophrenia as sources of stress. Interestingly, fathers were the individuals who most often mentioned negative symptoms as stressful. They expressed varying amounts of frustration regarding their relative's lack of motivation or "laziness". This concurs with the past findings of several researchers (Chafetz & Barnes, 1989; Goldstein, 1996; and Solomon & Draine, 1995b) who stated the withdrawn behaviours could appear volitional. However, that mainly fathers expressed this frustration is an intriguing new finding. Perhaps this gender-specific expression is related to males being the traditional "achievers". It is important to note, however, that all but one of the PWS in the families with whom I spoke were sons. An area for future research would be the exploration of fathers' reactions to daughters who exhibited amotivational symptoms.

Familial dissonance was clearly articulated by several participants in my research; it would appear that in some families individuals are pitted against one another on certain issues. Unity in decision-making was rarely described. Friction, with an undercurrent of anger and frustration, was clearly evident.

This sub-theme is similar to the objective dimension in caregiving burden as defined by Reinhard (1994). She defined objective burden as encompassing "friction with other family members". An implication for practice is that mental health professionals could help by assisting families to develop skills in problem solving and communication to aid in the resolution of conflict (Marsh & Johnson, 1993).

Family members described upheaval to the routine running of a household caused by the symptomatic behaviour of their relative. Actions taken by PWS to escape hallucinations and delusions were described as particularly difficult to live with. One sister described her brother's attempt to "drown" his auditory hallucinations by playing loud music at 3 o'clock in the morning, and others described food left cooking on the stove all night. These disruptions were the source of reactions that ranged in nature from mild annoyance to frustration and outright fear for both the safety of the family and of the PWS.

Again, this theme could be viewed as a facet of objective burden as conceptualized by Reinhard (1994). She stated that objective burden had a "household disruption" component. As the unpredictable and often volatile nature of positive symptoms can prove highly disruptive, an implication for practice would be that mental health professionals could provide family members with creative suggestions for managing illness behaviours. Furthermore, as there is wisdom in experience, families could share suggestions.

Intense emotion was evoked as family members described perceived stigma and a general lack of respect for the PWS' and/or family member's experience. Some family members perceived insensitive actions towards their ill relative whilst in a hospital setting.

Societal views of mental illness appeared as an important issue for family members. Several participants commented on different sources of perceived stigmatization. One father described his shock and disappointment at being "shunned" by his fellow church members who had previously been "good friends". A sister described her family's choice to keep her brother's diagnosis a secret in order to protect her family from hurtful comments. A mother explained that although she had many friends, she made a concerted effort to "protect" her ill son and daughter by excluding them from her social life.

One mother stated that the targeting of young adults provides the "best chance" at fighting the stigma, as this is when their "minds are still open". She added that she felt persons of her generation were a "lost cause", as they were fundamentally "set in their views and ways". Here lie clear implications for education. These findings provide support for the continuation of educational programs such as the aforementioned Partnership Program of the Schizophrenia Society. General practitioners, mental health professionals, and junior and high school students are groups specifically targeted for sensitization to the realities of schizophrenia and thus to the impact of the illness on family members.

Subjective burden has been broadly defined as involving family members' feelings about the objective burden and the extent to which they perceive themselves as being burdened (Solomon & Draine, 1995a). It includes such affective dimensions as worry, grief, and stigma. The pervasiveness of emotional responses of the participants in this present research corroborates family members' experience of subjective burden.

B. SUPPORT

Family members expressed appreciation for the different sources of support that enabled them to better manage the illness. Support groups and the lack of support received from mental health professionals were two sub-themes of particular importance to the participants in this research.

As mentioned earlier, it is perhaps not surprising that the majority of participants embraced the support gleaned from membership in the Schizophrenia Society, since 80% were affiliated with it. The Society appears to function at the practical, personal, and political and advocacy levels. On the practical level, it provides informational and emotional benefits, the opportunity to share coping mechanisms, advice on the management of symptoms, and an opportunity for informal networking. These findings corroborate those of Heller, Roccoforte, Hsieh, Cook, & Pickett (1997) who stressed the informational benefits of such organizations. Furthermore, several mothers cited personal benefits, such as providing a sense of worth by being given something constructive to do. Finally, the Society encourages advocacy, as several individuals described working towards affecting governmental policy, expanded research, and improved services for PWS.

Given the high regard for such support groups, it is suggested that practitioners might provide information about local groups to family members as a matter of course, when individuals are first diagnosed. Marsh & Johnson (1997) have suggested that family members be referred to this resource, provided with an explanation of benefits of participation, and then encouraged to join. However, it is my impression that some families may find receiving a diagnosis of schizophrenia overwhelming and need time to reflect upon the diagnosis prior to receiving referral information. Family members may feel pressured if they are encouraged to join at that particular time.

It is recommended that mental health professionals learn about such organizations and support them by speaking at their monthly meetings. This would promote a collaborative relationship among families and professionals. Professionals could disseminate recent research findings, and the meetings would also provide a venue for them to gain knowledge about the experiences and needs of family members. If this could be done on paid time rather than in a volunteer capacity, quality could be governed.

Family members expected to receive respect, empathy and understanding from mental health personnel. Yet they spoke of being met with indifference, and in some cases insensitivity, to their despair. Their disappointment resulted in expressions of anger and frustration. This finding corroborates recent research that described family members' views on shortcomings of mental health personnel (Hell, 1997; Howe, 1995; Kuipers, 1993; Rose, 1996; Thorne, 1993).

C. SYSTEM ISSUES

Issues involving a lack of compassion exhibited by mental health personnel, the need for education and information regarding the illness, and exclusion from treatment planning were identified by participants as inadequacies in the system.

Family members cited a perceived lack of compassion and instances of professionalism being below expected standards. There were reports of the unsatisfactory handling of crises and emergencies. Those most commonly referred to involved situations of crisis care, when the PWS was receiving either emergency room care or was undergoing assessment and treatment as an inpatient. This finding is corroborated by the findings in many studies (Bloch, Szmukler & Herrman, Benson, & Colussa, 1995; Carpentier, Lesage, Goulet, Lalonde, & Renaud, 1992; Hatfield & Lefley, 1993; Marsh, 1992; Rose, 1998). These were described as acutely stressful and anxious times for family members, since it was not unusual for the PWS to be experiencing suicidal ideation. As mentioned earlier, it is an inherent assumption that mental health nurses, specifically emergency nurses as they are they first contact with the system, strive to alleviate anxiety, and foster clear and open communication (Shives, 1998). It would be helpful for family members to be met with a calming presence, rather than for them to perceive an impending confrontation. Indeed, this has become increasing difficult as recent stresses have manifested in the work context. The reduction in numbers of psychiatric beds, staff shortages, long hours, uncertainty in organization, and the casualization of the work force have all contributed to strain in the workplace. Nevertheless, a practical recommendation is that mental health professionals, specifically Emergency Room personnel, attend ongoing workshops on communication and sensitivity issues specifically designed to maintain positive interactions with family members at this entry point into the system.

Participants also spoke of unsavory and insufficient communication with their ill relatives' psychiatrist at the time of initial diagnosis. They often perceived the manner in which the diagnosis was delivered as curt, and the delivery of prognosis comments as callous. As one mother stated, professionals "need to learn how to state what the possibilities are. Not to dwell on the 'never this and never that'." This corroborates the findings of other recent studies that exposed dissatisfaction with the communications at the time of initial diagnosis (Rose, 1998; Tuck, du Mont, Evans, & Shupe, 1997).

Participants expressed the desire that psychiatrists be aware that they are responsible for delivering a life-altering diagnosis that undoubtedly carries repercussions for every family member. They suggested that it is the psychiatrist's responsibility to develop a heightened awareness of the impact of delivering such a diagnosis.

It was promising and reassuring to hear accounts of positive experiences with mental health personnel. Several family members praised certain community-based caseworkers that are nurses, most of whom have had long-term involvement with their ill relative. An area for future research would be to determine what facilitates this healthy rapport and mutual friendship among professionals, ill individuals, and family members. Aside from the length of relationship, what other factors are involved in building trust and a collaborative relationship?

Family members spoke of the need for information regarding the illness, both at the time of initial diagnosis and throughout the course of the illness. This finding corroborates earlier research that asserts families desire information during all stages of the illness (Chafetz & Barnes, 1989; Falloon & Coverdale, 1994; and Kane, 1992). Several parents described their extensive and lengthy search for answers regarding their relatives' difficult and perplexing behaviour prior to diagnosis. Given the accounts from the majority of the research participants about the time lag between the appearance of symptoms and the time of diagnosis, it is of critical importance to continue research about the onset of schizophrenia and the efficacy of early intervention.

Most participants described their search for answers and attempts at gathering information regarding the illness. This finding suggests the need for comprehensive information dissemination, and for some family members it may be helpful to be referred to self-help groups at the time of diagnosis. As mentioned previously, some may find referral at this stage too early, and for those it is recommended that a helpful list of current sourcebooks and medical books for information regarding symptoms and prognosis be provided. In their research into information sharing about schizophrenia with family members, Main, Gerace, & Camilleri (1993) concluded that the desire, receptivity or ability of family members to digest information regarding schizophrenia varied. It is also my sense that individuals vary in their readiness to absorb the realities of schizophrenia.

Several family members expressed frustration at their exclusion from the treatment planning process. In fact, two individuals cited this as the most difficult aspect of living with schizophrenia. They perceived that mental health professionals had little respect for their insights into their relative and their illness, and that their thoughts and opinions were often dismissed. This is of critical importance because it is their experience, and as such, family members should be viewed as experts. Collaborative partnerships designed to build upon the strengths and expertise of *all* involved parties should provide the groundwork to current modes of service delivery (Marsh, 1994). Participants expressed the desire for mental health professionals to work towards the acknowledgement and respect for the needs, desires, concerns, and priorities of family members.

D. GRIEVING, SUFFERING and HOPE

Most participants expressed varying degrees of despair during our conversations. They mourned the relative they knew before the diagnosis, they spoke of the loss of human potential, and occasionally they referred to their own losses. This reaction to loss can be viewed as a grieving process and, for some, appeared to be the essence of the experience of living with a relative with schizophrenia. In On Death and Dying, Kubler-Ross (1969) described a phase model of grieving, with five categories of reaction: denial; sadness; anger; fear; and acceptance. However, acceptance in the context of grieving mental illness is defined differently, as the losses associated with mental illness are complicated as they lack finality and are recurring (Ryan, 1993). In the context of the grieving process, Lafond (1994) defines acceptance as facing the realities brought about by schizophrenia, and then building and practising coping skills so that recovery can be achieved and maintained. It has also been suggested that, in addition to involving these specific strategies and styles to manage stress and solve problems, coping relates to making sense of the illness experience, and with an internal working out of deep emotions (Stern, Doolan, Staples, Szmukler, & Eisler, 1999; Thorne, 1993).

Grieving has been stated to be a normal and adaptive response for parents of a child with schizophrenia (Davis & Schultz, 1998). It may also be a prolonged process affected by ongoing reminders of loss, since it is chronic loss that is being mourned (Davis & Schultz, 1998; Lafond, 1998; Schene, Tessler, & Gamache, 1996). In order to provide satisfactory support an implication for education is that practitioners be instructed regarding the nature of the grieving process in this specific population.

One can conceptualize suffering as part of a grief reaction. Suffering appeared to be a significant phenomenon experienced by family members. For the purposes of my research I will adopt Rodgers & Cowles (1997) definition of suffering: an individualized, subjective and complex experience that involves the assignment of negative meaning to an event. However, some of my findings corroborate Cassell's (1982) conclusion that suffering can be associated with positive outcomes such as personal growth, strength, and altered life perspectives. This is consistent with Frankl's (1963) assertion, as cited in Hinds (1992), that the highest level of suffering is to find meaning. I will elaborate on this when discussing mothers' adaptation to suffering.

1. Adaptation to suffering

Pollock and Sands (1997) employed the use of an adaptation to suffering model with subjects with multiple sclerosis. It was composed of hierarchically arranged categories with the base category entitled shock and denial, then depression and despair, then fear and anger, then coping and reappraisal, then acceptance and understanding, and finally, "finding meaning" was at the apex. The long-term goal was movement up the hierarchy. I believe this to be an intriguing framework with a certain degree of applicability to my finding that individuals appeared to have had progressed to differing levels of adaptation of living with a relative with schizophrenia.

Hinds (1992) studied the phenomenon of suffering in family caregivers of non-institutionalized patients with cancer. She cited Battenfield's (1984) categories in the operational scheme of suffering, one of which was "finding meaning". This can be observed in such responses as an expansion of self-awareness, the development or strengthening of interpersonal relationships, a reappraisal and strengthening of values, and finding joy in suffering.

The content of my conversations with several fathers would seem to suggest that perhaps they had not yet found meaning in their experience with schizophrenia. It is possible, however, that they had indeed reached that level, yet had not articulated it to me.

I noted that both their physical responses in our conversations and their body language portrayed their suffering. There were often tears, much pacing, and many pregnant pauses in our conversations. I noted that one father seemed trance-like during the entire time he recounted his experience with his son's illness. He spoke in a monotonous voice and sat slumped and virtually motionless in his chair. This mode of delivery changed drastically after our conversation about his son's illness ended and we spoke of other topics. He became gregarious, animated and positively charismatic.

This finding that fathers were expressive with their emotions repudiates research mentioned in Davis and Schultz' (1998) article on grief, parenting and schizophrenia. They referenced Cook's (1988) criticism of contemporary research that concluded males were assumed to be less affected in the grief reaction because they expressed less emotional distress than females.

In response to the question, "What does schizophrenia mean to you?" one father stated bluntly, "sacrifice and lifelong parenting". He said that he hoped it was going to get better, but he doubted it would, as it "didn't look that positive". Another commented that it meant, "the loss of most of the things you would have had if you didn't have the disease". Yet another father alluded to this notion of loss when he concluded, "You are trapped with this illness... There's nothing you can do...". Another commented on the guilt he felt because the illness forced him to spend less time with his other children. These are words of men who are despairing and suffering. It is important to note that Morse and Penrod (1999) describe despair as "a state of suffering in which hope theoretically does not exist".

Wintersteen & Rasmussen (1997) used ethnographic methods to explore the coping capacity and service needs of twenty-five fathers of persons with mental illness. A structured interview was administered separately to husbands and wives, and focussed on their thoughts on how the father had been involved with the family before and after the diagnosis, and an exploration of what the father experienced during this process. The authors concluded that the fathers exhibited indicators of emotional stress that were unrecognized and unacknowledged. Moreover, in the area of patterns of healing, they concluded that it takes fathers "longer to come to terms with the realities of illness than their wives (if, indeed, they ever do)." I found this a hasty conclusion, and believe that the fathers in my study may indeed be in the midst of "coming to terms with", but simply engage in a longer or different process.

Howard (1998) explored the experience of fathers of adult children with schizophrenia and assessed the extent to which they engaged in caregiving. Twelve fathers were interviewed using the method of naturalistic inquiry. During the interviews they were asked to describe their perspective of the events related to the onset and course of their child's illness, and also to describe their involvement in care. Based on both verbal responses and observations made during the interviews, the author concluded that fathers exhibited four categories of unresolved issues related to caregiving. These issues encompassed future care, financial concerns, quality of time with other children and description of family life. This is indeed an intriguing finding and warrants further research, as some findings in my study also suggest the presence of unresolved issues.

Most mothers articulated that they had found meaning in living with a relative with schizophrenia. My findings suggested that some mothers viewed life with a new perspective and were also more appreciative of joy. This finding corroborates the conclusion of Morse & Carter (1996) in their research into the concepts of enduring and suffering in illness experiences. The authors proposed that once those who suffer were able to accept the altered reality they "gained new insight and an appreciation for life as a reformulated self". Their suffering did not eliminate adversities in their lives, but rather it empowered them to find meaning in those experiences and take control of their lives (Morse & Carter, 1996).

One mother succinctly illustrated the concept of adaptability in her statement, "nothing is simple except, in my mind, that I can change my attitude and my way of looking at things, and I can change my view of what is important in life". This corroborates a finding of Doornbos' (1996) research into the strengths of families living with serious mental illness (SMI). The author showed support for the notion of adaptability, which was defined as the family's ability to adjust to stressors presented by SMI. Family members exhibited flexibility and the ability to change in response to various situational and developmental stressors.

I suggest that an area of future research is examination of the relationship between the length of the suffering experience and the process of adaptation and acceptance. Each woman that described gaining perspective and appreciation of the "smaller things" in life had lived with schizophrenia for more than 15 years. Furthermore, as acceptance was described as pivotal, I suggest that there be an examination of what facilitates the process of acceptance.

Benner (1984) studied problem solving in the novice to expert in the applied practice of nursing. She asserted that the process differed between the two, and that this was attributable to the "know-how" that was acquired through experience. She stated that the expert nurse perceived the situation in its entirety, used past situations as paradigms, and moved to the "accurate region of the problems without wasteful consideration of a large number of irrelevant options" (Benner, 1984, p. 3). On the other hand, in a new situation the novice nurse relies upon purposeful and analytic problem solving of a rudimentary nature. Given the apparent relationship between number of years living with a relative with schizophrenia and the attained level of adaptation and acceptance, an interesting area for future research would be to explore the applicability of Benner's process of knowledge accrual in a discipline to research into family members living with schizophrenia.

There are several implications for practice based on the suffering experienced by family members. To begin with, they should be taught that their feelings are to be expected. They are not pathological reactions. In addition, Lafond (1998) asserts that the act of acknowledging wherever the person is at emotionally, including those points when the person is "acting out" the feelings of grief, provides "fertile ground" for effective grief expression. Some family members may need professional help, as well as seek social support, as a means of working towards emotional resolution. For successful mourning to occur individuals need to be assisted in the examination of the loss and its associated feelings (Lively, Friedrich, & Buckwalter, 1995).

Rodgers & Cowles (1997) suggested that compassion is the most important manner of interacting with persons who are suffering. It is indeed unfortunate that this was seldom mentioned as a manner in which mental health professionals communicated with the participants in the present research. Gadow (1989), as cited in Gunby's (1996) research into the lived experience of nurses in caring for suffering individuals, stated that it took courage and devotion for nurses to make the "conscious choice to be fully present and energetically open in a compassionate way" with suffering persons. As a result they may take a somewhat detached stance to avoid wholly feeling the suffering.

2. Hope

Despite evidence that family members experience tremendous suffering, there is expression of a definitive positive theme in my research. This was not of a cursory nature, for instance, of looking on the bright side, but rather something much more substantial and rich. It seemed to be a matter of transcendence. Some individuals thrived and maintained hope despite the trials associated with the illness. Accepting reality was the process of accepting the limits of what could be expected and what could be done concerning their relatives' illness. It appeared to be a critical step in individuals' adjustment to the illness.

Morse & Doberneck (1995) employed qualitative methods to delineate the components of hope. The components encompassed having a realistic assessment of the threat, envisioning alternatives and setting goals, preparing for negative outcomes, continuously reevaluating choices made, and fostering a determination to endure.

In an article that linked the concepts of enduring, uncertainty, suffering and hope, Morse and Penrod (1999) stated that "the acceptance achieved through suffering initiates the process of developing hope because it begins the realistic assessment of the threat or predicament". In the present research, several mothers who had lived with schizophrenia for many years spoke of the integral role hope played in their lives, and of the preceding necessity of acceptance of the illness. This finding corroborates one by Howard (1994) who researched the stages of lifelong maternal caregiving in schizophrenia. This author elucidated that the final stage was described as a time of acceptance, hope and determination.

The pervasive expressions of despair indicate that family members mourned the loss of what might have been. Yet Landeen et al. (1996) suggested that a sense of what is possible is important to the process of recovery. Hope is an important component in helping families work towards some reconciliation with schizophrenia (Hatfield & Lefley, 1993; Lafond, 1994; Landeen et al., 1996). As one father stated in my research, "What is there without hope?" I believe it worthy to note that the monthly newsletter of the Calgary Chapter of the Schizophrenia Society is entitled, "Hope".

The present research gives support to the existence of strengths, resources, and competencies of family members who live with schizophrenia. A primary goal of nursing practice for families who live with schizophrenia is to empower the families by recognizing these "assets". Saunders (1999) proposed that nurses assist families to work with their strengths and inner resources in managing the illness. An implication for practice, particularly nursing, is that professionals assist individuals to engage inner strengths for the amelioration of suffering, and to aid in instilling a sense of hope.

An implication for education would be to consider adopting the concepts underlying an American-based endeavor entitled, “Journey of Hope: A Family to Family Self-Help Education Program”. It is a comprehensive family education program presented by trained family members, based on an empowerment model that stresses the strengths of families (Burland, 1995). As of 1995 it had been adopted in two provinces in Canada.

The finding that family members of PWS gained a sense of cohesiveness repudiates Doornbos' (1996) conclusion that families of the mentally ill feel connected less to one another and less bonded as a unit. Moreover, that some family members in the present research gained perspective and expressed a sense of cohesiveness also repudiates Gerace, Camilleri, and Ayres' (1993) assertion in their research into sibling perspectives on schizophrenia and the family. The authors stated that in illnesses other than schizophrenia individuals often mention some good that has come from the illness situation, such as uniting the family, reordering and enriching their values, or simply valuing one another more. Based on the reports of their subjects, they concluded that it was "difficult to portray schizophrenia as a cloud with a silver lining of any kind". I believe this may have something to do with the participants being siblings of PWS, and of a comparatively young age (i.e., 28-45, with the mean being 35 years). Future research could examine the possibility that wisdom and hopefulness are related to increasing age.

Furthermore, phenomenological research could involve the examination of what enables some individuals to derive not merely satisfaction, but a deep meaning from caregiving. What enables one to reframe the challenges associated with caregiving as opportunities for personal growth?

II. LIMITATIONS OF MY RESEARCH

My study has a number of methodological limitations that need to be addressed. As with all research of a qualitative nature, there is no expectation of the generalizability of the results. As described, this was a non-random sample. The families that participated are likely to be different from a randomly selected group of families in terms of their involvement with the family member, as well as their desire and ability to discuss their feelings concerning their relative's illness.

The composition of the sample is a limitation since participants were drawn largely from families affiliated with the Schizophrenia Society. As such, they were individuals who chose to join a self-help organization, and who had been exposed to the principles and philosophies of that organization. The experiences described herein undoubtedly reflect the Society's philosophy, advocacy and social action mandates. Future research should endeavor to glean a more inclusive perspective by recruiting participants not associated with the Schizophrenia Society.

The experiences family members articulated were inevitably influenced by the phase of the PWS' illness. They are affected by the course of schizophrenia and given the chronic, unpredictable nature of remissions and exacerbations, the issues that may arise will no doubt change over time. Indeed, several of the participants prefaced our conversation with a statement to the effect that what they believed to be important on the day we spoke may be very different than in the future, whether it be two months or two years hence. It must be stressed that the conversations were the initiation of an exploration into their experiences, and provided intriguing findings. Longitudinal studies would provide an interesting, long-term perspective on how important matters develop over time.

III. STRENGTHS OF MY RESEARCH

There are several strengths of this research that deserve special mention. First, there were clearly articulated questions that were posed to each participant. Second, the qualitative method I chose to employ enabled a relatively straightforward route for a novice researcher such as myself to follow. Third, I was able to link my findings to research that corroborates. Finally, although the sample had the aforementioned limitations, it was comprised of a group of highly articulate and varied participants. There were differences in gender and age, relationship to the PWS, and number of years living with a relative with schizophrenia, all of which enhanced inclusiveness of the exploration of experiences.

IV. RECOMMENDATIONS FOR PRACTICE

Based on the content of the conversations there are two main recommendations for practice. First, given the extent of experiences describing friction with family members, it is suggested that mental health professionals (specifically, social workers and case managers in the community context) assist those families who express the desire to develop or enhance their communication skills. Furthermore, suggestions for the management of illness behaviors could be shared by both family members and professionals. Second, is it recommended that Emergency Room personnel attend workshops on communication and sensitivity issues, as this is the entry point into the system with which participants expressed particular dissatisfaction.

V. RECOMMENDATIONS FOR FUTURE RESEARCH

In summary, there are several suggestions for future research. All ill relatives were male, except one. Future research should strive to incorporate families with ill daughters and sisters. As aforementioned, this would enable research into the exploration of fathers' reactions to daughters who exhibited amotivational symptoms. Second, further research is warranted regarding factors that contribute to healthy, collaborative relationships between mental health professionals, ill individuals and family members. Third, future research involving male participants is appropriate. There is some suggestion that gender differences in certain aspects of experiences exist, and the recruitment of more males would aid in elucidation of these differences. Fourth, further research examining the relationship between the length of the suffering experience and the process of acceptance and adaptation is warranted. Finally, given the extent of family member's involvement in their ill relatives' lives, together with their level of empowerment, participatory action research (PAR) is an appropriate alternative method to examining this same area. Driven by their common need, a group of people search for and create a path of inquiry and movement. One aim of PAR is to produce knowledge and action directly useful to a group of people. The second aim is to empower people at a deeper level through the process of constructing and using their knowledge (Reason, 1994).

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APPENDIX A

FAMILY INFORMATION

FAMILY NAME (Pseudonyms)	PARTICIPANT # - Identifying Initials	RELATIONSHIP TO PWS	AGE	YEARS LIVING WITH ILLNESS
1/ Thompson	1 - ST	Mother of son	50-59	16-20
	2 - JT	Father	50-59	
2/ Johnson	3 - PJ	Mother of son	70-79	20+
	4 - DK	Sister	40-49	
3/ Hall	5 - RH	Father of son	50-59	1-5
	6 - GH	Mother	50-59	
	7 - BH	Brother	30-39	
	8 - SH	Sister	20-29	
4/ Palmer	9 - CP	Sister to brother	50-59	20+
5/ Lowrey	10 - JL	Father of son	60-69	16-20
6/ Smith	11 - MS	Mother of son	60-69	20+
	12 - DS	Sister	40-49	
7/ Newby	13 - SN	Sister to brother	20-29	6-10
8/ Neilson	14 - AN	Mother of son	60-69	20+
	15 - SL	Sister	40-49	
9/ Todd	16 - CT	Mother of son	60-69	6-10
	17 - BT	Father	60-69	
10/ Lundell	18 - VL	Mother of both son and daughter	70-79	11-15
11/ Morrison	19 - LM	Brother to brother	40-49	20+
12/ Landry	20 - SL	Sister to brother	30-39	11-15

APPENDIX B

CONSENT FORM

Research Project Title:	The experience of family members living with a relative diagnosed with schizophrenia
Investigators:	Emily McKenzie (MSc Candidate) Dr. Ardene Vollman (Assistant Professor, Department of Nursing)
Sponsor:	Department of Community Health Sciences, University of Calgary

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

The purpose of this study is to develop an understanding of the experience of family members who have a relative with schizophrenia. The researcher will ask you, for instance, to describe your experience of living with the person who has the illness, and also what schizophrenia means to you. If you agree to participate in this study you will be taking part in a conversation approximately 1-1.5 hours in length. You may also be contacted at a later date for clarification of specific details and to aid in the interpretation of aspects of the conversation. You are under no obligation to answer any questions you would prefer not to. If you choose to take part in the study, the information you provide may help three groups: those responsible for the development of the development of treatment and rehabilitation plans for persons with schizophrenia, professionals who provide services for families, and family members themselves.

There are no apparent risks to your participation in the study. You may find that it is difficult to talk about certain issues, and referral to counselling services is available should you request it.

These conversations will be audio-taped and then transcribed into a type-written copy. Only Emily McKenzie, Dr. Ardene Vollman, and a peer auditor will have access to these tapes and transcriptions. Your descriptions will be kept confidential and you will never be identified, as pseudonyms will be used in the study report. To the degree possible, the interviewee, to ensure that anonymity is not threatened through the use of the quote, will review any quotes used in the report. The audio-tapes and computer disks will be kept in a locked filing cabinet in the investigator's office for five years following the completion of the study. We may wish to further analysis once the original project is completed. However, if further analysis is done, we will continue to protect your privacy. Upon completion of the post-study period, all files related to the study will be erased from the computer, and disks and transcripts destroyed.

In the event that you suffer injury as a result of participating in this research, the University of Calgary will not provide compensation for you. You still have all your legal rights. Nothing said here about treatment or compensation in any way alters your right to recover damages.

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the investigators, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time without jeopardizing your health care. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation. If you have further questions concerning matters related to this research, please contact:

Emily McKenzie at 287-2818, or
Dr. Ardene Vollman at 220-8053

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

______________________________ Participant's Signature	________________ Date
______________________________ Investigator and or/Delegate's Signature	________________ Date
______________________________ Witness' Signature	________________ Date

A copy of this consent form has been given to you to keep for your records and reference.

APPENDIX C

APPENDIX C

Theme	*Free Node/ Sub-theme*	*Number of Documents*	*Text Units (# of lines)*	*Theme Presented with Intensity?*	*Collapsed To Which Theme?*
Gratifications					
	Teaching tolerance*	3	89	Yes	Responses
	Family coherence*	3	141	Yes	Responses
	Gain perspective*	8	185	Yes	Responses
	Companionship	2	17	No	
	Household contributions By PWS	2	28	No	
Progress in societal attitudes		3	22	No	
PWS social naivete		2	28	No	
PWS insight into illness		7	76	No	
PWS social restrictions		2	33	No	
Quality of life		4	76	No	Despair
Responses					
	Advocating*	6	199	Yes	

*** Denotes themes that are discussed in thesis**

APPENDIX C (cont.)

Theme	*Free Node*	*Number of Documents*	*Text Units (# of lines)*	*Theme Presented with Intensity?*	*Collapsed To Which Theme?*
Responses (cont.)					
	Coping	6	137	No	
	Hope	2	17	No	
	Emotional reactions				
	Admiration	3	27	No	
	Anger*	9	183	Yes	
	Anxiety*	8	137	Yes	
	Worry about future*	7	76	Yes	
	Compassion	2	22	No	Tolerance
	Denial	6	67	No	
	Diagnosis denial	2	8	No	
	Detachment	2	17	No	
	Fear*	7	99	Yes	
	Frustration*	10	168	Yes	
	Guilt	6	80	No	
	Irritation	2	83	No	
	Pride	2	67	No	
	Resentment	1	45	No	
	Sadness	3	39	No	
	Depression	4	74	No	
	Despair*	8	177	Yes	
	Learning*	5	139	Yes	
	Lifelong parenting	3	22	No	
	Managing roles	6	100	No	

*** Denotes themes that are discussed in thesis**

APPENDIX C (cont.)

Theme	***Free Node/ (sub-theme)***	***Number of Documents***	***Text Units (# of lines)***	***Theme Presented with Intensity?***	***Collapsed To Which Theme?***
Responses (cont.)	Mastering the system	3	27	No	
	Protecting	6	121	No	
	Searching for answers*	7	128	Yes	
	Seeking understanding, accepting the illness, and adjusting expectations*	8	179	Yes	
Responsibility		3	27	No	Worry about future
Sacrifice		2	19	No	Despair
Stresses	Dissonance*	9	264	Yes	
	Household disruptions*	6	129	Yes	
	Familial overinvolvement	3	26	No	
	Marital stress	1	10	No	
	Compromised sibling attention	1	22	No	
	Medication side effects	8	101	No	
	Medication switch	2	27	No	
	Lifestyle restrictions	2	31	No	
	Stigma*	11	242	Yes	
	Suicide attempt	3	43	Yes	
	Symptoms				
	Initial	12	202	Yes	Positive/Negative symptoms
	Positive*	13	195	Yes	
	Negative*	7	63	Yes	

***Denotes themes that are discussed in thesis**

APPENDIX C (cont.)

Theme	*Free Node/ Sub-theme*	*Number of Documents*	*Text Units (# of lines)*	*Theme Presented with Intensity?*	*Collapsed To Which Theme?*
Stresses (cont.)	Symptoms (cont.)				
	Triggers	2	13	No	
	Unpredictability	2	30	No	
Support	Community	3	63	No	
	Familial*	6	134	Yes	
	Mental health professionals*	4	78	Yes	
	Social support*	9	115	Yes	
	Support groups*	10	120	Yes	
Systemic	Certification*	7	73	Yes	
	Confidentiality	2	40	No	
	Continuity of care	2	31	No	
	Education*				
	Lack of information	5	60	Yes	
	Lack of knowledge	9	132	Yes	
	Emergency visits	5	70	Yes	
	Hospital administration	2	69	Yes	Emergency visits
	Personnel*				
	Mental health nurse*				
	Lack of compassion	4	102	Yes	

***Denotes themes that are discussed in thesis**

APPENDIX C (cont.)

Theme	*Free Node/ Sub-theme*	*Number of Documents*	*Text Units (# of lines)*	*Theme Presented with Intensity?*	*Collapsed To Which Theme?*
Systemic (cont.)					
	Professionalism below expected standards	3	99	Yes	
	Psychiatrist*				
	Consultation*	10	192	Yes	
	Initial diagnosis	4	53	Yes	Consultation
	Lack of compassion	4	85	Yes	
	Positive experiences	3	49	No	
	Rehabilitation	2	38	No	
	Respite*	7	80	Yes	
	Treatment Planning*				
	Familial involvement	5	92	Yes	
	Individualize treatment	6	96	Yes	
	PWS involvement	1	9	No	

***Denotes themes that are discussed in thesis**

APPENDIX D

ATTESTATION OF AUDITOR

The Experience of Family Members Living With a Relative With Schizophrenia: A Qualitative Study, Master's Thesis by Emily McKenzie

An audit was conducted to assess the trustworthiness of this study. Specific attention was paid to the dependability and confirmability of the inquiry and the openness of the investigation to alternative explanations and interpretations of the data.

A modification of the audit procedures suggested by Halpern (1983) and outlined in Lincoln and Guba (1985) was used. An audit trail was established and a randomly selected audio-tape of one conversation, together with the associated raw data, was reviewed by a community health nurse external to the research. The auditor verified that the inferences drawn from the data were logical.

The audio-tape was transcribed accurately. There is a complete record of the transcript and field notes. The list of themes developed and their accompanying definitions was accurate. Categories that were generated were comparable with the data. There was agreement that the inferences that were drawn were fair.

Marlene Lucas

Marlene Lucas
August 30, 1999