FAMILIES AND SCHIZOPHRENIA: THE CHALLENGES OF COPING

BY

ANDREA KLYMASZ

A Thesis submitted to
the Faculty of Graduate Studies
In Partial Fulfillment of the Requirements for the Degree of

MASTER OF SCIENCE

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University of Manitoba
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Abstract

This qualitative thesis describes how some families, who belonged to the Manitoba Schizophrenia Society in the 1990's, coped with a relative with schizophrenia. Schizophrenia is a devastating mental illness for those who suffer with it and for the many families who are coping with its effects.

Thirty parents and siblings of people with schizophrenia were interviewed between 1995 and 1996. The interviews were open-ended yet focused on how schizophrenia affected families' daily lives. Families dealt with the process of diagnosis, and issues of heredity, treatment and stigma. Parents and siblings also dealt with advocacy and support issues, as well as the mental health system. Each of these thematic areas is described using the family members' own words.

The interviews showed differences between parents and siblings, and between those families who had been dealing with schizophrenia for many years versus those whose relatives were newly diagnosed. Many family members dealt with shame and guilt when their family member was diagnosed and most had to deal with ongoing stigma. Because of these aspects of schizophrenia, it is not easy to advocate on behalf of people with the illness.

Schizophrenia is clearly a mental illness with many components. Not only does it affect the individual, but families, society and eventually culture. Families' descriptions of living with schizophrenia illustrate the challenges and stresses that they endure and add to the social knowledge of coping with schizophrenia.

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For the many years that I was able to work toward finishing this thesis, I owe deep appreciation to my father for donating a kidney to me in July 2000. This allowed me to be free of dialysis and finally finish my degree. I am forever grateful.

I am also thankful to my husband Bradley Swartz, and son Aaron for their continued patience and encouragement to complete this thesis. Lastly, I dedicate this thesis to Lara and to all the people I know with schizophrenia. Their strength and fortitude is greatly admired. Thank you all.

Please note that this thesis was originally intended to be a PhD, however, due to my kidney disease, I changed it to a MSc.

Table of Contents

Abstract	i
Acknowledgments	ii
List of Appendices and Figures	v
Chapter I: Introduction	**1**
Chapter II Literature Review: The Nature and History of Schizophrenia	**9**
Aspects of Stigma	12
Families and Schizophrenia	14
Community Care	16
Service System Reform	17
Chapter III: The Research Design	**23**
Participant Observation	23
Policy Analysis: Newsletter	24
Policy Analysis: Government Documents	24
Interviewing the Families	25
Ethics	27
Chapter IV: The Mental Health System	**28**
The Historical Processes of Deinstitutionalization	28
Canadian Mental Health Policy and Services	30
Manitoba Mental Health Policy and Services	32
The Imagery of Schizophrenia: Symbolism and Media	36
Chapter V: The Family and Schizophrenia	**41**
Transformation; the Onset of Schizophrenia	42
Family Explanations of Strange Behaviour	45
Genetics, Heredity and Blame	47
Chapter VI: Family Responsibility	**50**
Advocacy and Support	50
Coping with Violence	53
Sibling Relationships	55
Family Relationships	59
Chapter VII: Dealing with the Mental Health System	**61**
Advocacy and External Relations	61
Advocacy and Treatment	63

Gaps in the System 65
Self-Help 67

Chapter VIII: Summary and Conclusions **69**

References Cited **79**

Appendices 95 - 100

Figures 101-106

List of Appendices

A-1	The Interviews	95
	Legend for Appendix A-1	96
A-2	Interview Discussion Areas	97
B-1	Ethics Approval	98
B-2	Manitoba Schizophrenia Society Approval	99-100

List of Figures

1.	Misspelling Campaign	101-102
2.	Barbed- wire head, Janssen-Ortho Inc.	103
3.	Comic Strip	104
4.	Risk of Developing Schizophrenia	105
5.	Antipsychotic Medications	106

Chapter I

Introduction

> *The study of persons with schizophrenic illnesses is thus a window through which one can look into and clarify basic properties of self-functioning...In creating reality distortions, schizophrenia will revel basic assumptions required for normal self-functioning, specifically, and for the production of organized cultural behaviour, more generally* (Fabrega 1989:286).

Mental illnesses affect all Canadians. Approximately 20% of individuals will experience a mental illness during their lifetime, and the remaining 80% will be affected by a mental illness in family members (Health Canada 2002). Mental illnesses can have personal and long lasting health effects that are as severe as many physical illnesses, including limitations in daily functioning and poor quality of life (see Wells and Sherbourne 1999 and Hays et al. 1995). This thesis describes and analyzes the process by which some families come to understand the meaning of schizophrenia and cope with a relative with the illness.

People with schizophrenia and their families have often endured extreme feelings of guilt and self-blame for this mental disorder due to the historical belief that schizophrenia was caused by inappropriate parenting and family interaction processes (see Health and Welfare Canada 1991:11-12). It was not until recently that families of people with schizophrenia had substantial scientific evidence to back up their claims that they were not at fault for their relative's (often children's) schizophrenia (see Kotrla and Weinberger 1994).

Schizophrenia is a devastating mental illness for those who suffer with it and for the many families who are coping with its effects. Families have to deal with the fact that many of the expectations they had for their children will not happen and that stigma will be a large part of their lives. According to Fabrega, "Through its impact on the self, schizophrenia alters, in a tangible way, life career pathways in the interpersonal world as well as personal estimates of worth and accomplishment" (1989:278). The Western self,

that underpins biomedical notions about health and illness is assumed to be autonomous and in control. Schizophrenia, in contrast, by eroding the symbolic orientation of the self, alters the sense of wholeness, integration and cultural boundaries, that give it coherence (Ibid:281) According to Fabrega, this is the cultural model of the self and of schizophrenia that is taken for granted in much of Western psychiatry (Ibid).

Both internal (biological) and external (social) factors alter the self and social identity of the person with schizophrenia. Neither the biological nor the social approach has been able to demonstrate empirically the relative influence of these various forces (Estroff 1989:193). Obviously, individuals with the disorder experience schizophrenia differently. People with schizophrenia change over time as they experience daily life, take medications and respond to symptoms and to other people (Ibid:194). They try to make sense of their own lives. The following is a vivid description by a person with schizophrenia describing what it is like to be ill:

> I know I have become some deviant in society, and I don't know how to get well It is as if someone put me under anaesthetic too long and I suddenly am unable to accept myself as a healthy, well-adjusted human being. Why can't I choose whether I will be good or bad? I am frightened of being so self-introverted and mutilated that I will never amount to much. Suddenly my brain went all wrong to me and I know I am not functioning as well as I was a while ago. I don't know how to get well and fear becoming a vegetable. I am devastated by this, very hurt. Somehow I want to jump out of my cage. Find room for an ego. It seems I'm just reaching out trying to get well - put myself in order. I will continue writing until I have completed my will to reform myself properly. To free myself from these terrorizing thoughts of neglect and mismanagement. I have tried my best to remove myself from this mess. I just want to be normal and think normal thoughts. Not be totally disabled. One day you are going to see the proper way to meet me again (A person with schizophrenia, 1991).

This statement illustrates how schizophrenia affects the whole person and concepts of self. The last line of the statement alludes to a disturbing revelation by Estroff:

> Ironically, the loss and disorder of a person so characteristic of our conceptions of schizophrenia may be at least partly our own invention, and one of the many ways in which we desert the person who has schizophrenia. We may both compound and create the isolation of inner and social self by failing to investigate and acknowledge the persistence of the person (1989:194).

What accounts for inhumane treatment of mentally ill in a civilized society? In one word, money (Warner 1985:176). At one time, far from sheltering the disturbed and helping to restore them to sanity, the mental hospital performed a disabling, custodial function (Scull 1989:308). The role, though, of psychiatric hospitalization in the care of chronic patients has changed dramatically over the past thirty years. In general, inpatient care for chronic patients has moved in the direction of short term, highly specific problem oriented interventions. Shorter lengths of stay may minimize the decreased role of functioning and lowered self-esteem which frequently accompanies hospitalization (Olfson et al. 1990:143). Despite the trend toward shorter hospital stays, there is little systematic investigation of the applicability of crisis oriented treatment to acutely ill hospitalized patients with schizophrenia. Because of the belief that schizophrenic episodes are related to stress combined with an underlying vulnerability, there is at least a basis for the belief that a rapid resolution of the destabilizing stress will accelerate recovery (Ibid:150). But, when deinstitutionalization was implemented there was little or no prior consideration of such basic issues as where the patients who were released would end up; who would provide the services they needed; and who would pay for those services (Scull 1989:315). Aftercare and outreach programs have received mixed results. One study found that patients who were discharged from a U.S. state hospital to aftercare programs that had high patient expectations had a better outcome than those discharged to programs with lower expectations. Another study found that for patients with schizophrenia, day treatment centers which had more staff provided group therapy and had a philosophy of high patient turnover were associated with poor results (Olfson et al. 1990:151-152). At present, very little research exists to guide clinical decisions concerning the selection of optimal treatments (Ibid:152). Most people who run mental health centers prefer treating "good patients" rather than chronic schizophrenics, alcoholics or senile psychotics (Scull 1989:317). Therefore, there are more of these

people on the streets. Although many of the problems of the severely mentally ill are closely related to the welfare system, there remains a distinct tendency to interpret their condition in strictly medical terms.

Medicalization is socially convenient and fits well with major ideological assumptions of individualism and a free market economy (Aviram 1990:79-80). The medical model fits within this framework and the dominant perspective suggests that the problem is individual rather than social. Therefore, issues are not looked at on a system-wide basis (Ibid:80). Housing, community care and rehabilitation of the mentally ill require well organized and coordinated efforts of different components of the health and welfare system. Yet, agencies often pull programs in different directions and their objectives clash. Mental health organizations are often rewarded for maintaining a stable clientele and therefore do not encourage their clients to move toward independent living and employment in the community (Ibid:81). This also works on an individual level as well. Social Security policies present a threat and a disincentive to mentally ill individuals seeking employment (see Estroff 1981:168-173).

Any plans for the improvement of care and treatment programs for the mentally ill require basic organizational changes: centralized agency control; enhancement of advocacy groups speaking for disabled clientele; and a substantial increase in resources to provide medical and social welfare services for this group. Such changes would offer at least the possibility of improving the current condition of the mentally ill (Aviram 1990:84). But, on a social level things are more pessimistic. The status afforded the mentally ill is usually the lowest. Usually indigent and unemployed, the person labeled with a "chronic" mental illness has no valued social role (Warner 1985:180). This is a problem that involves widespread change in people's views of the mentally ill.

Family Life

Many investigations have emphasized the roles of community acceptance, living arrangements, social relationships and occupational and economic states in influencing how well a person with schizophrenia will do over time (Prudo and Blum 1987:346). There is no single predictor variable and no combination of key predictor variables is capable of explaining a majority of the variance in the outcome of schizophrenia (Ibid:352). In fact, one researcher has shown how individual psychiatrists have their own "models of mental illness" which affect their diagnoses and the possible outcomes of patients with schizophrenia (Gaines 1979). Patients who are discharged from hospitals must face many diverse factors which affect them and that should be accounted for: the quality of the home environment, the impact of intervening life events, and the role of symptoms and medication (Prudo and Blum 1987:353). A variety of social factors such as inadequate housing or social isolation may also serve as chronic life stressors and play a role similar to that of life events in provoking further episodes of schizophrenia (Ibid). Warner, also believes that the guilt and shame that families are forced to bear due to the public misconception that mental illness is a product of faulty upbringing, causes censoring and isolation (1985:188). Therefore, "it is scarcely surprising that the families of schizophrenics in Western society are sometimes found to exhibit harmful over-involvement with their sick relatives" (Ibid). There is generally no support from neighbours, friends or treatment agencies and therefore, schizophrenics are encouraged to move away from home and minimize their contact with relatives. This is a complete social disintegration process. Developing countries on the other hand, sometimes offer reintegration, with maintenance or social status, and provision of a valued social role for people with psychoses. Western society maintains schizophrenics in poverty and creates for them social disintegration with pariah status and a disabled role (Ibid).

Families of schizophrenics are in need of support, information and follow-up.

There is a need for both the person with schizophrenia and the family to obtain information about diagnosis and treatment that is personally and culturally relevant. Since many schizophrenics live at home instead of a hospital, one would think that there is a lot of research on the problems experienced by relatives, but this is not the case (Scull 1989:318). According to Scull, most of the distress and misery of family members has remained hidden due to their reticence about complaining, a natural reaction, but one that has helped to sustain a false optimism about the effects of the shifts to community treatment (1989:318). This could also produce more psychological and social disturbance as well as burden on caregivers, families and individuals.

In recent years, the development of community services and self-help groups have partially alleviated this family burden. For example, in Winnipeg, Manitoba, many families were able to access the Manitoba Schizophrenia Society (MSS) for information and support and as time progressed, more services, including a Clubhouse, were established which empowered consumers to function independently in the community.

However, it is still true that little research has occurred to explain the process through which families negotiate both the meaning if the illness and the stresses and challenges that they face in coping with an ill family member.

This thesis is a description of families, both parents and siblings, coping with a relative with schizophrenia. It is based on qualitative data from document reviews, a review of the literature, and interviews. The objectives of the study are:

1. To describe the mental health service environment in Manitoba that impacts on families who have relatives with schizophrenia
2. To describe how families construct the meanings attached to the diagnosis and management of schizophrenia
3. To describe the experiences of families in their efforts to advocate for their relatives with schizophrenia, and
4. To describe how families manage their relationships with other care providers and community services.

The design of this descriptive study was qualitative.Qualitative research is best when emphasizing the depth, richness and quality in peoples' lives. For one to understand what it is like to live with schizophrenia, a qualitative study is important. The complexities and processes that emerge from the interview data are best interpreted through qualitative study. "One cannot understand human behaviour without understanding the framework within which subjects interpret their thoughts, feelings and actions" (Marshall and Rossman 1989:49). How people interpret, manage, and come to understand schizophrenia is an in depth process. The interview is a way to get people to talk about what they know and experience, and from this to build an understanding of this aspect of their lives.

I specifically decided to interview people who were members of the Manitoba Schizophrenia Society. People who belong to this provincial self-help organization primarily do so because they have a relative with schizophrenia and I expected they would be more willing to talk openly about their lives.

Initially, I conducted 24 interviews with 30 people: 15 mothers, 9 fathers and 6 siblings. These interviews express a range of views and I used direct quotes which contained the most relevant and valuable information for the study. Interviews took place from 1995 to 1996 and were generally open-ended conversations. Open-ended interviews were preferred since people naturally spoke for long periods of time allowing very rich and detailed narratives. People were relaxed in their home atmosphere and were very willing to discuss their lives.

This thesis includes the following chapters and contents:

> **Chapter II: Literature Review** - summarizes and discusses literature dealing with historical issues and schizophrenia, as well as aspects of stigma, families, community care, treatment and services
>
> **Chapter III: The Research Design** - presents the study design, methods and implementation
>
> **Chapter IV: The Mental Health System** - discusses the processes involved in mental health reform, as well as describing mental health

policies and services. It finishes with a discussion of the symbolism of schizophrenia and the media.

Chapter V: The Family and Schizophrenia - uses the interview data to describes families' responses to diagnosis, strange behaviours, heredity, blame, and treatment

Chapter VI: Family Responsibility - again uses interview data to illustrate family advocacy, support, coping with violence and sibling relationships

Chapter VII: Dealing with the Mental Health System- uses the interview data to illustrate families' coping with the mental health system, advocacy and external relationships, and to identify gaps in the system and with services

Chapter VIII: Summary and Conclusions - summaries the findings of the study and discusses the policy and practice implications for the future

Chapter II Literature Review

The Nature and History of Schizophrenia

"It is easy to appreciate that historically the insane have been likened to young children, the intoxicated, and wild beasts; for absent the assumption of rationality, the mentally ill are, as Bleuler said of his schizophrenic patients, stranger to us than the birds in our gardens" (Moore 1997:41)

This chapter sets the stage for the study by reviewing the relevant literature. It begins with a discussion of the history and nature of the disorder, and then goes on to discuss the concept of stigma and how it is applied to people diagnosed with schizophrenia. Next, it discusses changing views of the role of the family in the etiology and management of schizophrenia and describes the components of community care. A final section discusses service system reform.

Schizophrenia was first clinically described in both England and France in 1809 (Gottesman 1991:5). John Haslam (1764-1844), who was a superindendent of the Bethlem Hospital in London, described what we term today as schizophrenia in Observations on Madness and Melancholy. Also in 1809, Philippe Pinel (1745-1826), a French physician, characterized cases of schizophrenia (Ibid:5-6). During the next 50 years there were many similar descriptions of schizophrenia with almost all of them giving the disease different names (Ibid:6-7). Emil Kraepelin (1856-1926), a German clinical psychiatrist, became the definitive categorizer and organizer of the abnormal language and behaviour that makes up the substance of contemporary psychopathology. Kraepelin's clinical analyses of schizophrenics, is for the most part, the description used today. He unified formerly distinct categories of the disease and termed it "dementia praecox" (Ibid:7).

Throughout the twentieth century, however, psychopathologists have taken issue with the term "dementia praecox". It implied deterioration when physicians observed some severely debilitated patients who got partially or fully well, and it also implied

adolescent onset when adults in their 40's, 50's and 60's where seen to become ill for the first time (Ibid:8).

In 1908, Eugene Bleuler (1857-1939) introduced the term "schizophrenia", literally meaning, splitting of the mind. By renaming the disease to focus on the splitting of usually integrated psychic functions and mental associations, Bleuler called attention to the frequent recovery that Kraepelin had downplayed (Ibid). Bleuler's conceptualization contributed to the scientific understanding of schizophrenia "as a disruption of the thought processes and feelings of persons who, in most other ways, are like ourselves" (Ibid). An unintended effect of this term is that many people believe that those with schizophrenia display multiple or split personalities and they do not. "Schizophrenia can - for a time, for many times, or forever - change its victim from a rational, intellent human being into an irrational, totally deranged person, but it does not create a new person" (Ibid).

The value most often accepted as the lifetime risk of schizophrenia in the general population is 1.0 percent. This means that 1 out of every 100 people born today and surviving to at least age 55, will develop what is termed and diagnosed as schizophrenia (Gottesman 1991:75). In Canada, approximately 270,000 people will suffer from schizophrenia at some point in their lives, and since this disease usually occurs within the 16 to 30 year age group, it takes a large economic and social toll on the country (Health and Welfare Canada 1991:10).

According to the DSM-IV, the essential characteristics of schizophrenia are a mixture of both positive and negative signs and symptoms that are present for a significant portion of time during a one month period (or a shorter time if successfully treated), and with some signs of the disorder persisting for at least 6 months (American Psychiatric Association 1994:274). Schizophrenia has diverse manifestations and different subtypes including: paranoid, disorganized, catatonic and undifferentiated

(Ibid:275-279 and Castillo 1997:242). Case identifications usually begin with the observation of psychotic symptoms and bizarre behaviour, however, "bizarreness" may be difficult to judge, especially across different cultures (Ibid:275). The World Health Organization conducted two international comparisons of persons with psychoses and found important cross-cultural differences in symptomaptology (WHO:1973 and 1979). The differences are most likely due to "cognitive structuring of cultural schemas, which produce different cultural experiences of self, illness, and the environment" (Castillo 1997:243).

Many people with schizophrenia also exhibit low levels of emotion and social drive. These so-called negative symptoms can be the most debilitating aspects of the long-standing impairment observed in some people with schizophrenia (see Carpenter and Buchanan 1994). Negative symptoms, however, are difficult to evaluate because they occur on a continuum with normality, are nonspecific, and may be due to a variety of other factors such as medication side effects or environmental understimulation (DSM-IV:277). However, these negative symptoms are often the first sign to families that something is wrong. "Family members may ultimately report that they experienced the individual as "gradually slipping away" (Ibid:278).

Many scientists from diverse disciplines have studied schizophrenia for nearly 200 years. Different therapies have been tried to alleviate schizophrenia, including bloodletting and insulin/coma induction to no avail. It was not until the early 1950's that antipsychotic medications came to be used to alleviate some of schizophrenia's symptoms - the delusions, hallucinations, and disordered thinking (Gottesman 1991:15). To this day there is no clear concensus among experts on the cause or causes of schizophrenia, and there is still no cure.

Although stigma was not something tailored soley for mental illness, the side effects of being labelled "schizophrenic" are unjust (See Capponi 2003:153-155).

Aspects of Stigma

Schizophrenia is a mental illness that literally changes the self of a person. It is an "I am" illness that includes not only the experience of complete emotional and cognitive change but a transformation of the inner self and of the outward personality or identity known by others (Estroff 1989:189).

Schizophrenia has for centuries been the subject of myth, punishment, isolation and neglect. It is a disease so stigmatizing that those with it have been described as the "lepers of the twentieth century" (O'Brien 1998:39). In addition to the individual's and family's personal stigma, society's reaction is often negative. Warner points out the guilt, shame and stigma that not only the person with schizophrenia feels, but also their families, which leads to further isolation (1985:187). As Capponi states, "We are more than whatever mental illness affects us, but sometimes we forget that, and the system we're in forgets that, and the government forgets that" (2003:220). "Difference does not equate with disease" (Ibid:215).

The initiative of people with physical disabilities and their caregivers to acquire strong lobby groups for their needs, has set an example for people with schizophrenia and their families and caregivers. Despite the fact that disability itself is not inevitably stigmatizing, research reveals that it often undermines the taken-for-granted aspects of ordinary encounters between disabled and non-disabled people. Disability often discomforts "normals" as well as disabled participants in encounters (Susman 1994:17). This is also true of schizophrenia. But, there are differences between how the physically disabled are treated in Western society compared to how the mentally ill are treated (Page and Day 1990). According to Scull, "the public still resists the straightforward equation of mental and physical illness" (1989:328). Prejudice against mental illness has been directly associated with the fear of it (Lyketsos and Panatakopoulos 1970). As Foucault suggests, madness is beyond the bounds of normality (1973).

Mental illnesses have been shown to provoke some very diverse reactions of people (Crocetti 1973; Page and Day 1990). As Goffman pointed out, "what psychiatrists see as mental illness, the lay public usually sees as offensive behaviour - behaviour worthy of scorn, hostility and other negative social sanctions" (1967:137). The reasons why mentally ill people are rejected by society are diverse - due to poverty, dependency and behaviour (Katz 1981). Mental stigmas are also disruptive of social relationships. Many mentally ill people do not conform to so-called socially acceptable rules or norms of conversation (Ibid:137-148). Results from two studies, Novak and Lerner (1968) and Lehtinen and Vaisanen (1978) suggest that reactions to people with mental illness are not solely the result of a dislike of the unfamiliar, but may be related to a sense of personal threat. Mental stigmas, like some physicals stigmas, can provoke anxiety and fear.

To account for the negative and prejudicial side of most people's reactions to those who are different, social scientists have proposed many causal factors, some specific to minority groups and others more general in their application (Katz 1981:1-2). Goffman (1963) stated that the word stigma originated with ancient Greeks, who used it to refer to bodily marks or brands that were used to disgrace criminals or slaves. Stigma is widely used in something like the original sense, but it is applied more to the disgrace itself then to the bodily evidence of it (Katz 1981:2). Also, social context can be crucial to stigma, since an attribute may be discrediting in one situation but not in another (Ibid).

Advocacy, for specific services to meet the needs of individuals and families of people with schizophrenia, may be hindered by the stigmatization of the mentally ill in general (Page and Day 1990). Stigma is an important influence on the capacity of a family to meet the needs of and advocate for a relative with schizophrenia (see Allison-Bolger 2001).

Families and Schizophrenia

During the past 25 years, there has been a radical shift in the understanding and approach to the families of people with schizophrenia. Before the development of antipsychotic medications resulting in the deinstitutionalization movement of the 1960s, family members were often seen as the major cause of schizophrenia (see Torrey 1988:161-165). Psychoanalytic theories of schizophrenia were replaced by family interaction theories which asserted that family processes and the "schizophrenogenic mother" caused schizophrenia (Bellack and Mueser 1993:324). The major problem with family interaction theories is that they fail to distinguish family interactions which cause schizophrenia from those *caused* by schizophrenia (Torrey 1988:164). Psychogenic models of schizophrenia were gradually replaced by the biologically based "stress-vulnerability" models and sociogenic models, both based on the notion of biological and environmental causes (Bellack and Mueser 1993:324).

Three factors were important in promoting the shift toward viewing family members as an important resource in the management and social rehabilitation of people with schizophrenia: research documenting that some expression of negative affect by a family member is predictive of symptom relapses (Brown et al. 1972; Vaughn and Leff 1976); recognition of the heavy burden on family members of caring for an ill relative (Kuipers and Bebbington 1985); and the dissatisfaction expressed by many family members over how they are treated by professionals (Appleton 1974; Terkelson 1983).

The Camberwell High Contact Survey has amassed a large amount of information on the care of people with long-term mental illness in a British community. MacCarthy et al.'s study (a part of the Camberwell Survey) is based on structured interviews with 45 "supporters" of chronically disabled patients in the community (1989). The focus of the study is a group of relatives who were living with patients chronically disabled by psychiatric illnesses, yet still maintaining long-term regular contact with day-care

services. The supporters reported having to cope with high levels of disturbed behaviour (slowness, apathy and lack of social skills) together with rather low levels of functioning (e.g. lack of management of household affairs and little participation in leisure activities). It was also common for supporters to feel that they were unable to socialize outside the home and they tended to spend a considerable proportion of their time in direct face-to-face contact with the mentally ill person. Usually, they did not want their relative to move out for fear that he or she would not receive adequate care somewhere else. This study recognized a considerable degree of burden that some relatives of people with schizophrenia have.

New programs were developed which focused not only on improving patient outcome, but also on enhancing the coping skills of family members (Birchwood and Cochrane 1990; McFarlane 1991). These programs were based on the assumption that families need to be educated, not "treated", on how to live with a person with schizophrenia (see Berkowitz et al. 1990; Cozolino et al. 1988; Kuipers et al. 1989; Levene et al. 1989; Smith and Birchwood 1990; and Zastowny et al. 1992). Families most frequently cite the need for education and support in helping them to cope with their relative's illness (Dixon 1999:4).

Increasing cumulative evidence shows that family-based psychoeducational programs which focus on communication, support, and problem solving training help in the management of schizophrenia (Zastowny et al. 1992). Lam critically reviews some family education studies and finds common components of effective approaches including a focus on improving stress and coping in the "here and now" rather than dwelling on the past (1991). Family coping strategies involve more than the utilization of fiscal and structural resources and include emotional and intellectual reasoning. The best known example of a family education program is the National Alliance for the Mentally Ill Family to Family Education program, formerly called the Journey of Hope (Dixon

1999:5). This 12 week program, developed in the United States, has been and continues to be used by the Manitoba Schizophrenia Society. Currently, however, self-help and consumer/survivor initiatives are changing the traditional service model of educational programs.

Community Care

There has been a recent movement to change the kind of care offered to de-institutionalized mental patients, from overcrowded boarding houses to something that is more like real life (Capponi 2003:xiv). As well, psychiatric survivors became eager to challenge the profitable "non-profit" mental health industry such as hospitals, unions, charitable foundations, agencies and pharmaceutical companies that had been purported to care and speak for them (Ibid:xv). The needs of members of the psychiatric community are not different from anyone else's needs - a home, a job, a friend (Ibid).

Governments, however, want a less costly method of care for mentally ill people, but not one synonymous with lower quality of care. Measurements of social support and adjustment are important to any community-based program for the care of the mentally ill. The broad construct of quality of life which includes, social functioning, activities of daily living and physical health, is increasingly viewed as an important indicator of functioning for people with schizophrenia (Huppert et al. 2001:172)

Another study, which examines the applicability of specific psychotherapy methodology to indicate why a family intervention program is beneficial, found that the impacts of emotional support, backup, and reassurance were more commonly reported as helpful to relatives then were the more specific impacts concerning behaviour change and skills acquisition (Budd and Hughes 1997:344). Even though this family intervention program contained a large and explicit skills training program, the relatives involved reported finding emotional support and reassurance to be at least, if not, more helpful

than the more specific therapeutic factors. The most frequently cited positive impact was an increase in relatives' knowledge or understanding of schizophrenia (Ibid). Relatives of people with schizophrenia often feel empowered and more able to deal with their relatives when they have information and an understanding of schizophrenia. They are also more apt to cope with the stigma that surrounds schizophrenia.

In an effort to keep people with schizophrenia as functioning and autonomous as possible in the community, various programs have been implemented to help people find and maintain jobs (see Bustillo et al 2001). Vocational rehabilitation which traditionally included transitional and sheltered employment, now encompasses supported employment as well as permanent competitive employment. With the majority of people with schizophrenia living in the community and hospital stays becoming progressively shorter, a comprehensive system of services based on aspects of assertive community treatment principles will be necessary.

Service System Reform

The focus of care for people with schizophrenia has shifted from long-term institutions to other facilities such as residential shelters and group homes, the family and the community (Carpenter and Buchanan 1994). Economic pressures on the health care system have created a new urgency for mental health service reform through the 1990s and into the 21st century. The basic challenge for mental health reform, according to the Manitoba government, is to identify the most appropriate combination of in-patient, hospital psychiatric services and community-based services to respond to the needs of individuals (Manitoba Health 1992).

It is often family members who must fight for proper treatment, medications, services and legislation for those with schizophrenia. Currently, mental health acts differ for each province in Canada. In Manitoba, involuntary admission to a hospital can occur

only when a person suffering from a mental disorder is considered, by a psychiatrist, likely to cause serious harm to another person; or likely to suffer substantial mental or physical deterioration if not detained in a psychiatric facility. Of course, it is of the physician's opinion what is "serious harm" and "substantial mental or physical deterioration". As well, any psychiatric patient may apply to a review board to review aspects of admission and treatment including: to review an opinion that a person is or is not mentally competent to consent or refuse treatment; or to review an opinion that a person is or is not capable of managing his or her affairs. Some patients, who have the right to a review board hearing, have been discharged from hospitals and they still need hospital care. There are also people with schizophrenia who are in need of hospital care but cannot get admitted in the first place. Many families of people with schizophrenia are battling with legislation that may not be in line with the treatment they would want for their relatives.

Changes in the Manitoba service industry have produced some new and innovative services for people with mental illnesses, such as crisis stabilization units and mobile crisis teams. However, these services are primarily accessible in the City of Winnipeg, and the coordination and referral to these services is often a problem. Manitoba government agencies have recognized the need for "clubhouses" (see Beard, Propst and Malamud 1982 for a description of the clubhouse model pioneered by Fountain House in New York) and drop-in centres for people with mental illnesses and the "coalition for mental health services" has stated the need for collaboration among community agencies.

Family organizations have grown to fill urgent unmet needs in services provided for people with serious mental illnesses such as schizophrenia, bipolar disorder and major affective disorders (Johnson 1994). National organizations of families of people with schizophrenia have been formed in countries throughout the world. In the United States,

the National Alliance for the Mentally Ill (NAMI) is well-known for its advocacy activities, as well, in Canada, the Schizophrenia Society of Canada (SSC) has about 100 affiliated groups or chapters (Ibid). These types of self-help groups, for relatives of people with schizophrenia, have become vital organizations for thousands of people. Long-term activity in self-help groups obviously depends on personal attitudes. One study has found that relatives, active in self-help organizations, are more self-confident and problem-conscious than is the case among many other relatives of the mentally ill (Monking 1994).

The Manitoba Schizophrenia Society, Inc. (MSS), a chapter of the SSC, now has 8 offices throughout Manitoba. This organization was founded in 1979 by parents of people with schizophrenia as a self-help group. Their misson statement, "to alleviate the suffering caused by schizophrenia", includes providing emotional support and help to families and friends and support to people with schizophrenia.

"The biopsychosocial nature of mental disorders underscores the need for psychiatry to work with organizations with which the profession previously has had relatively little contact (Pankratz and Bebchuk 1996:150). This includes family support groups and consumer organizations. The Canadian Psychiatric Association (CPA) has forged strong ties with the Schizophrenia Society of Canada (SSC) primarily through the SSC's research affiliate, the Canadian Alliance for Research on Schizophrenia (CAROS) (Ibid:152) Both of these organizations believe that fundamental changes are needed in societal attitudes and in the way the health care system facilitates the "reintegration" of persons with schizophrenia (see Redefining Schizophrenia and Its Treatment: A Multidisciplinary Approach 1992).

The history of mental health policy reflects changing perceptions of treatment opportunities and altered willingness to invest public resources (Mechanic 1991:1). In the United States, the Reagan Administration of the 1980s tried to reduce the role of the

federal government in mental health expenditure by returning mental health policy initiatives to the states (Ibid:3). This effort along with cuts to welfare programs seriously affected the mentally ill. Those who were hospitalized were now in the community without adequate social supports, subsistence or an adequate infrastructure of essential community mental health services (Ibid:4).

In Canada, it is estimated that schizophrenia costs taxpayers over $4 billion a year, but that the amount spent on research is disproportionately low, about $4 million a year (CAROS 1993:1). Despite the high costs, those who suffer from schizophrenia often have difficulty obtaining the health services they require. Approximately, 80% of all funds are allocated to institutional and medical services, with only 20% going to community programs (Health and Welfare 1990). The average proportion of the mental health budget spent by the provinces on community mental health support services is 13% - ranging from Manitoba at 3.1% to Saskatchewan at 22.8% (Macnaughton 1991).

Currently, in Canada, self-help and consumer/survivor initiatives are changing the traditional service model. Assessments, done in the United States, of the behaviour of long-term psychiatric patients living in communities and utilizing day treatment programs have shown reductions in crisis contacts and hospital admissions (Brewin et al. 1990; Linn et al. 1977 and 1979; Stein and Test 1985: and Weissman et al. 1978 and 1981).

Mental health policy in Canada is increasingly focused on community care. Numerous reports have called for systems which provide a range of supports in life areas such as employment, housing, and income as well as medical-therapeutic treatment (Lurie and Trainor 1992:11). Families' responses and experiences to the many issues surrounding schizophrenia are varied, but most families have genuine concern for the well-being of their relatives with schizophrenia and are dealing with historical, societal and legislative issues and obstacles. The effect that mental health reform in Manitoba has on the families of those with schizophrenia is important to a thorough understanding of

the reconstruction of schizophrenia for advocacy.

How do families deal with stigma and advocate for their relatives with schizophrenia? McLean's study of how families in the United States, along with the National Alliance for the Mentally Ill (NAMI), have changed the "blame-the-family" ideology of schizophrenia to viewing schizophrenia as a brain disease is one example of reducing stigma (1990). However, McLean argues that by doing this the NAMI and families have accepted the reductionist biomedical model, and by focusing on the body as separate from the mind, have reduced the patient and family to objects (1990:977). She criticizes this philosophical move on the part of the NAMI and families, but the view that schizophrenia is a brain disease is widely accepted and the evidence for its neurobiological basis is accumulating (Serper and Harvey 1994; Ancill et al. 1994). In fact, in 1997 the NAMI labeled what used to be termed "mental illnesses" as neurobiological diseases.

The family (and society, if ever possible) must support and encourage the person with mental illness as if he or she were physically ill so that the person is not ostracized. Otherwise, as Estroff points out, the individuals cease to have jobs, friends and valued social roles, and become chronically "schizophrenic" (1989:195). This profoundly cultural and transcendent category carries implicit verification that the person is not who or how we may have thought he or she was before. "Instead of becoming part of the inventory of person, the category of schizophrenic engulfs or pervades the person" (Ibid). Preserving valued roles and retaining a positive personhood contributes to positive outcome and a lessening of the suffering and despair that the individuals feel. How families frame their definition of schizophrenia is explored in this thesis.

The literature clearly notes an increasingly occupied and acknowledged role for families in caring for and advocating for their immediate relatives diagnosed with schizophrenia. This relates to both an increased pattern of community care and increasing

evidence of the effective roles that families can and do play. Families must support their affected relatives, not only in coping with positive and negative symptoms, but also in managing stigma and a sometimes poorly organized service system. Families have played an important role in service system reform, including developing supportive services for family caregivers.

Chapter III

The Research Design

The implications for a family of having a member with schizophrenia are multi-dimensional and multi-layered. Based on this premise, this study was designed with the assumption that the analysis of the issues faced by these families must also occur at several different levels. The first and the primary level is the family itself; the second level is the Manitoba Schizophrenia Society (MSS), which acts as an intermediary between the family and government; and the third level is the Manitoba Government whose mental health policies often impact directly on individuals with schizophrenia and their families. A different research method has been used for each level. Participant observation was used to study the MSS; documentary analysis formed the basis for the research on government policies; and the experience of families was explored through in depth interviews with members of the MSS who were closely related as either a parent or a sibling to someone with schizophrenia. This chapter briefly describes each method, its advantages and disadvantages and its ethical implications.

Participant Observation

As described in the previous chapter, the MSS is a non-profit charitable organization which provides individuals and families with information and support, but also acts as an advocate for its members in relationship to government policies and funding. I was an active member of the Society before becoming a researcher and I combined the two roles to become a participant observer (participant observation is a traditional and widely practiced method in anthropological research). This change was made with the permission of the MSS. The Society allowed me to attend meetings and events organized by the MSS and to sit in on board meetings. Thus, I was able to observe the workings of the Society and its relationships with government policy makers and with

its own membership.

There are many advantages to being a participant observer. Listening at meetings or taking part in discussions on the impact of government mental health and social welfare policies provided me with critical insights into these policies when seen from the perspective of the MSS and its members. The disadvantage was not knowing individuals with schizophrenia and their families who may not have seen issues in the same way. As always, with participant observation, there was also the inherent risk of losing objectivity, so at the same time I gained immeasurably from being a participant observer, I also had to guard against losing the proper balance between being an insider and an observer.

Policy Analysis: Newsletter

In addition to taking part in the activities of the MSS, I also received the newsletter that they send out to their membership. These newsletters were a very valuable source of information. The MSS issues a monthly (except for the July-August issue which is combined into one) newsletter called "Caring" which was changed to "Sharing" when a new executive director was hired in 1996. This newsletter contains articles written by people with schizophrenia (usually referred to as consumers) as well as by some family members and supporters. It also contains updates on programs available at the Society, such as the group support meetings, and reprints of journal articles and other articles pertaining to schizophrenia.

Policy Analysis: Government Documents

In addition to the historical, medical and social science literature on mental illness in general and on schizophrenia in particular, I also collected Provincial and Federal governmental and non-governmental reports on the same topics. These documents served several purposes. They provided materials on the background to mental health policy in

Manitoba. This background filled in an important piece of the context which lead to the formation of the MSS and its adoption of its advocacy role. Finally, knowing this context helped me to understand what families had to say about the ways in which the action (or inaction) of the Manitoba Government have affected the ability of a family to care for an individual member with schizophrenia. The analysis of these different materials form the basis for Chapter IV.

Interviewing the Families

The MSS gave me access to its membership list and permission to contact families to ask if they would take part in the study. This meant that I could randomly sample families for the interview part of the study (this is often not possible in small scale, qualitative studies of this type). One problem was not knowing whether members of the MSS were representative of other families who were not members of the organization, but had a relative with schizophrenia.

At the time the study began, the MSS had a membership of approximately 300 people. Selecting every fifth member resulted in a list of sixty members. Each member on the list was sent a letter describing the purpose of the study and setting out the criteria to be used in selecting potential participants. To be included in the study, an individual had either to be providing care to an individual in their family who had been diagnosed with schizophrenia, or had to have done so in the past. Examples of care included cleaning his or her apartment or house, preparing food, or contributing money for rent.

The final sample of those who were eligible and who agreed to an interview included fifteen mothers, nine fathers and six siblings. The thirty individuals were interviewed, but six of these interviews included both parents, giving a final total of twenty-four interviews (Appendix A-1).

Some families had more than one member with schizophrenia; two-thirds were

male and their ages ranged from twenty to fifty-two years of age. In some of these families, the diagnosis of schizophrenia for a relative was relatively recent, but in others the diagnosis had been made many years earlier and the individual had now reached middle age. Only six were living with a family member at the time of the interview; two were in hospital and two were living in a group home. Twenty individuals were receiving social assistance or had so in the past; two were receiving the Canada Pension Plan; two were working and five worked and received social assistance at the same time.

Interviewing started in January 1995 and took place through the following year. The interviews were arranged to suit the convenience of the individual and were usually in their own homes. Most people gave permission for the interview to be tape recorded and detailed notes were made of the others. The interviews followed an open and relatively unstructured format in which participants were encouraged to talk freely about what it meant to them and to their family to care for a family members with schizophrenia. A loosely structured interview guide ensured that the same key topics were covered in all the interviews. See Appendix A-2 for a list of topical areas. The interview process was open but focused on the topic of how schizophrenia affects people's day to day lives. The interviews were for family members to be able to address their concerns and frustrations, as well as their satisfactions - to talk about what it means to care for someone with schizophrenia.

Interviews were transcribed and entered into computer files. The next step in the process was to read and re-read all the interviews, looking for common themes and sub-themes. These were then coded for subsequent analysis. Examples of common themes include the search through family histories for other relatives who had or might have had schizophrenia. These and other themes form the basis for Chapters V to VII.

Ethics

Ethical issues involved in this study include maintenance of confidentiality and discussing potentially difficult subject matter with family members. When the individuals were asked to participate, they signed a consent form agreeing to participate, knowing that they could stop at any time or withdraw from the study.

I had an awareness of the potential for bias in the course of the interviews, related to my involvement in the Manitoba Schizophrenia Society, however, I found it advantageous to be a member of the same organization that the interviewees belonged to because the family members were very comfortable with me and spoke very candidly about their situations.

The research proposal was submitted to the University of Manitoba Ethics Committee and was approved in 1994 (Appendix B-1).Research permission was also obtained from the executive director of the Manitoba Schizophrenia Society (Appendix B-2). Before any participation in the study, the research was fully explained to each individual and written consent was sought. The most strict confidentiality has been adhered to and pseudonyms have been used throughout the thesis. The study was voluntary and at any time a person did not want to participate, he or she could withdraw from the study. All information acquired from interviews was and is considered confidential and for use by the researcher only. All transcribed interviews were shredded after their use.

Every effort has been made to protect the identity of people involved, therefore, times, dates and places (situations) have been altered to protect all participants. The focus is on the commonality of experience, and therefore, many families with mentally ill relatives may see similarities to their own situations. It was impressed upon everyone involved that this is a study to show the need for appropriate support services for the mentally ill and for those actively caring for them.

Chapter IV

The Mental Health System

This chapter reports on the findings from documentary reviews, observation and family interviews related to the changes in the mental health system in Manitoba, which occurred in the final decade of the last century. It begins by placing these changes in the historical context of deinstitutionalization, referring to international, national and provincial developments. The mental health system "reform" of the 1990's in Manitoba is then explicitly discussed. The chapter ends with a discussion of the role of the media in defining the meaning of schizophrenia.

The Historical Process of Deinstitutionalization

The mental health reforms of both the nineteenth and twentieth centuries were initially stimulated by therapeutic innovation but were ultimately accelerated by political-economic considerations (see Morrissey et al. 1985:70-80). During the 1960s and 1970s, the community mental health movement, which began in the United States, emerged in Canada (Johnson 1990). The movement was marked by a belief that it was preferable to care for people with mental illnesses in their community rather than in a psychiatric hospital; optimism about the effectiveness of new psychotropic medications; and an interest in preventive measures to reduce the incidence of mental disorders (Ibid).

With the emphasis on community-based mental health care, persons who had been treated in psychiatric hospitals were moved back into the community- a process that came to be termed "deinstitutionalization". But, while it was consistent with principles of the community mental health movement, deinstitutionalization revealed numerous shortfalls in the mental health care system (CMHA 1984).

In the 1980s, two major criticisms were raised. First, fiscal and human resources were not reallocated when individuals were discharged from hospitals to communities

and many people were found to be mearly "subsisting" in the community (Toews and Barnes 1986:2). Although they were in a less-restrictive environment, they were receiving fewer services and less care (Krauss 1989).

A second criticism was that community mental health centres and general hospital units developed services for people often labeled as "worried well" and ignored the population of "mentally ill" who were traditionally served by provincial hospitals. This created a two-tiered system which serviced two different groups of consumers which rarely overlapped (Richman et al.1984).

During the mid 1980s provinces pursued various courses of action to improve the lives of people with severe mental illnesses - a group which represents approximately 2% of the population but has been poorly served by past policy initiatives and as a result, has consumed a disproportionate share of expensive inpatient and treatment services, with little benefit to themselves and their families (Advisory Network on Mental Health 1997:1).

As the 1980s ended, those in need of mental health services seemed to place an increasing demand on the health care system, and there was growing concern about governments' ability to pay for needed services. This was the impetus for many governments to reorganize their mental health care services along with their general health care services. The restructuring of the mental health care system became a priority for Canadians in the 1990s (Canadian Nurses Association 1991:3).

Fiscal conservatism joined the ideals of community mental health advocates and civil libertarian reformers (e.g., Szasz 1968), but with little documentation of the cost-benefit virtues of deinstitutionalization and no analysis of the social costs of "dumping" patients (Ibid). As organizational and institutional perspectives on mental health care changed, professionalism and economic concerns defeated many fine ideas. And despite the many changes within the mental health system, the overall framework remained very

much the same. As Mechanic has stated,

> The history of mental health care attests to how endorsement of organic viewpoints and the professionalization of psychiatry, when it had little specific to offer in any immediate terms, undermined constructive and humane efforts for patient management and rehabilitation (1991:5).

Mental health policy and services are linked with political, economic, professional and institutional factors (Brown 1985:6). Many of the disabilities associated with long-term mental illnesses can be contained by good community management (Mechanic 1991:7). Kiesler and Sibulkin reviewed 14 studies comparing hospital treatment and community care and found the alternatives to hospitalization to be more effective (1987). The Training in Community Living model was developed at the clinical research unit of Mendota Mental Health Institute in Madison, Wisconsin in the early 1970's (see Stein and Test 1985). This model was used in other counties in Wisconsin and has increased knowledge about the treatment of severe mental disorders in public mental health settings throughout North America (Ibid; see Mosher and Burti 1989).

The most optimal and cost-effective community programs are likely to depend on the array of community resources already in place, the mix of patients, and the complexity of the community (Mechanic 1991:7). Many of the newly developed community care programs have been pragmatic and oriented to patients' basic needs for medical and psychiatric care, subsistence and housing, basic living skills and social support (Ibid). Financing provides the framework for community care, but its success also depends on professional leadership, interagency communication and cooperation, and a supportive community environment (Ibid:8).

Canadian Mental Health Policy and Services

In Canada, researchers have estimated that 20% of the general population has some type of mental health problem at any given time, and that 3% of the population is affected by a serious mental illness (Goering et al. 1996). Mental health policies and

practices in Canada have been affected by aspects of mental health care in Europe and the United States. Schizophrenia, since it first occurs primarily in the 16 to 30 year age group, has a devastating impact on the Canadian economy and family life. Canadian mental health policy has essentially moved through 5 stages: a policy of neglect during the years prior to the mid-1800s; a policy of confinement of the mentally ill in asylums up to World War II; a rapid growth of the mental health system due to government social and economic policies resulting in a shift from care in asylums to general hospitals and to communities by the 1960s; a period of activism from the 1960s to the 1980s due to attitude and legal changes toward the mentally ill; and a period from the late 1980s to the present of reevaluation and reform.

The move towards deinstitutionalization in Canada began in Saskatchewan in the 1950s. This move to community care was driven by financial concerns, aided by new anti-psychotic medications, and in most provinces, poorly planned (Lurie 1984; Simmons 1990). In practice, the central problem was seen to be the delivery of medical-therapeutic services in the community, and little attention was paid to other important areas of life such as housing, income and work (Bachrach 1979; Lurie 1984). The range of functions carried out by old mental hospitals was underestimated, and the failure to plan for these functions in the community led to a crisis situation by 1980 (Lurie and Trainor 1992). Many people with serious mental illnesses ended up in substandard housing and with few social supports (see Trainor and Ballantyne 1980; Toews and Barnes 1982). Repeatedly, national and provincial studies identified serious deficiencies in the mental health system.

In 1984, the Canadian Mental Health Association (CMHA) launched a research initiative to assess how people with serious mental illnesses could best be supported. Consultations with consumer groups, families and professionals lead to a set of guiding principles and concepts (see Trainor and Church 1984). The goal of the CMHA's Framework for Support Project was to ensure that people with severe mental illnesses

lived rich and fulfilling lives in the community. In order to reach this goal, there were two basic requirements: 1. that individuals with mental health problems be empowered to control their own lives and make choices about which supports to utilize; and 2. that the community be mobilized to use all its capacity to support people with mental health problems (see Trainor et al. 1992).

Initial attempts at policy development saw the major problem to be the service system itself. This focus neglected to see the limitations of formal services and the potential benefits of non-service approaches (Trainor et al. 1992:26). The CMHA believed that by strengthening overall support in society, rather than limiting its efforts to the narrower perspective of formal service provision, there would be potential in the community process paradigm (Ibid:28). This principle has continued to the present, however, discrepancies often exist between stated policy goals and actual practice.

There are problems with service coordination, resource allocation, and priority setting within every province (see Health and Welfare 1990; Macnaughton 1992; and Corin 1992). If Canadian policy is to promote community-based services, then these services must be adequately funded. Community-based services should also be culturally relevant (see White 1982; and Scheper-Hughes 1987).

Since community-based services are currently being promoted in Canada, it is important to study how this mental health reform effects families of the mentally ill.

Manitoba Mental Health Policy and Services

During the 1970s the need for enhanced community based services in Manitoba was met by largely established service providers such as community mental health workers (Manitoba Health 1992:10). Throughout the decade new additions to the community mental health service system included: The Selkirk Mental Health Centre's Independent Group Living program, Sara Riel and others (Ibid). These developments

paralleled the emergence of a national shift in community mental health programming from an emphasis on psychotherapeutic interventions to a combined treatment/rehabilitation orientation, and from a medical approach to a social welfare strategy (Carling and Broskowski 1986).

During the 1980s, the national trend gave increased consideration to housing, employment, community outreach, advocacy and consumer rights in mental health program design and delivery. Several community interest groups were established including the Canadian Mental Health Association throughout Manitoba, Manitoba Friends of Schizophrenics (now the Manitoba Schizophrenia Society, MSS), the Society for Depression and Manic Depression, and the Society for Self Help (Manitoba Health 1992:10). By the mid 1980s, there was a continuation of this trend with the development of more self-help groups, such as the Anxiety Disorder Association of Manitoba (ADAM), and the growth of residential services (see Manitoba Health 1992:11). Many programs started to incorporate vocational, and outreach and advocacy components, with increased recognition of consumer rights (Ibid).

Manitoba's mental health reform policy continues to focus on the "needs of individuals and communities across Manitoba" (Manitoba Health 1992). Hopefully, policy turns into practice. Mechanic has pointed out, the release of patients to the community is always less expensive in direct care costs than other alternatives, but if this is all that is done, required welfare expenditures and indirect social costs to the patients, their families and the community measured by patient deterioration, disruption of family life, and social control problems may be large (1980). In 1987-88, 95,000 Manitobans received mental health services at a cost of $200 million; yet many who suffered from these problems had difficulty obtaining needed mental health services (Health and Welfare 1990:80). Again, this shows how past policy initiatives were of little benefit and that there was a need for a better interface between primary care and mental health

specialty sectors (Canadian Psychiatric Association 1996).

One of the obstacles for people receiving proper treatment is that most mental health institutions are based in Winnipeg and resist regionalization (Pape and Church 1987). In 1993, the provincial government announced a $1 million expansion of mental health services for northern communities - the Pas, Flin Flon and surrounding areas. This was a long awaited and needed establishment of community-based resources in the region.

Manitoba Health made mental health reform a priority through the 1990's. And for mental health reform to be effective, it must encompass proven models of community care. The clubhouse model of psychosocial rehabilitation is one such model. The worldwide clubhouse community is a proven, effective organization of successful services for people with psychiatric disabilities (see "Fountain House" by Flannery and Glickman 1996). Clubhouses have proved time and time again to benefit each city they are in because they are cost effective through keeping hospital admission rates down, and by providing necessary work and paid employment for people with mental illnesses. Manitoba Health and the Winnipeg Regional Health Authority made a commitment to the clubhouse movement by opening the Clubhouse of Winnipeg, Inc in September 1999. It is hoped that this program has a long and prosperous future in Winnipeg.

During the 1990's, a number of programs and services were developed including: a crisis stabilization unit, a safe house called "Seneca House", and a phone line called "Warm Line". Supportive employment programs managed by agencies such as Sara Riel, the Canadian Mental Health Association (CMHA),and Self-Starting Creative Opportunities For People in Employment (SSCOPE) also continued to be funded.

Another model of psychiatric care that started to be developed for Winnipeg was the PACT model - Programs for Assertive Community Treatment (see a description of the model in CMHA Network 6(1), May 2001). The PACT model is based on a Wisconsin

model of an assertive approach to providing care and support for clients with serious mental illness in the community (SSC Bulletin 9(1), January 2000). It was approved in Winnipeg in the year 2000. PACT case managers provide services through outreach, treatment, rehabilitation and support. The maximum caseload size recommended for this type of model is 1 worker to 10 clients (see Mental Health Working Group 2000, Appendix E).

In 1999, research showed that early and rapid intervention lessens the chances that symptoms of schizophrenia will lead to full-blown schizophrenia (Clinical Psychiatry News 27(9) 1999 as quoted in Sharing 10(5) Sept-Nov. 1999 p. 6). Currently, early intervention programs are being developed in conjunction with adolescent psychiatry in Winnipeg. For a detailed description of the mental health services available in Winnipeg see Appendix E of the "Analysis & Discussion Paper on the Adult Mental Health System in Winnipeg" (WRHA Mental Health Working Group December 2000).

Another perspective revolved around the concept of "recovery" from mental illness. A recovery mental health system requires shifts in traditional thinking about mental health and services. First of all, people with mental illness are not just seen as "patients", but as "consumers", and families are viewed as partners in support and recovery (Carling 1995 and CMHA Network 1(2), Oct. 1998).With the concepts of recovery and remission used when treating schizophrenia, the outlook in mental health services is more optimistic and hopeful.

More research is needed to study the specific implications of mental health reform and community-based services for those with schizophrenia as well as their families. During the time of mental health reform in the 1990's, there was a simultaneous surge of "schizophrenia" used in the media - primarily in high profile drug company campaigns, schizophrenia was portrayed as an illness that commanded attention.

The Imagery of Schizophrenia: Symbolism and Media

The media's portrayal of schizophrenia has always been a contentious issue with many mental health organizations. An organization called, "Focus on Mental Health" thinks that mentally ill people get a raw deal from the press with words such as "manic", "schizo" and "psycho" (Ferriman 2000:522). The main complaint from mental health organizations is that the media often presents mentally ill people as dangerous time bombs waiting to explode, when the reality is quite different. Most homicides are committed by people with no history of mental illness and mentally ill people are far more likely to harm themselves than others (Ibid). According to many newspaper and media representatives "it is always easier to reinforce your readers' views than challenge them" (Ibid). Because of this type of media reporting, there is a reinforcing effect on the stereotype of mental illness (Angermeyer and Matschinger 1996).

Other discussions of media and its impact on mental health have shown that using words like "users", "sufferers" and "survivors" portray mentally ill people as victims, whereas, the term "consumer" implies having a say in the product of mental health care (Sheringham 2000). The media, however, is not the only perpetrator of stigmatizing attitudes. Government press releases regarding mental health often focus on "public safety" rather then "service users' needs" (Ibid). Media coverage, whether good or bad can serve a purpose in making mental health issues a focus of public and political agendas.

Throughout the 1990's, developments and changes in mental health policy and services had implications for all families and people with mental illness. As well, the way schizophrenia was symbolized and discussed in the media profoundly affected public awareness and advocacy. There was a greater awareness of what schizophrenia is - a split from reality versus what it is popularly thought of as a split mind or multiple personality. Public awareness campaigns also helped with the never ending fight against stigma and

mental illness. According to recent research, opinions about violent behaviour are influenced more by dramatic reports of violence in the media than by personal contacts. If this is correct, campaigns against stigma have to pay attention to media reporting as well as to providing information to the public (Crisp et al. 2000:6). The most negative opinion - that people with mental disorders are dangerous - was held most often about those with schizophrenia, alcoholism and drug dependence (Ibid).

During the 1990's, debates arose as to whether schizophrenia should be called a biochemical brain disorder, a biopsychosocial illness, or a neurological disease. The Schizophrenia Society of Canada (SSC) started a discussion of whether schizophrenia should or should not be called a mental illness but rather a neurological disease like Parkinson's or Alzheimer's (The Bulletin, February 1997). It was stated that abandoning the mental illness label might remove schizophrenia from less serious illnesses that have a low priority in the health system with both provincial and federal governments. The other thought was that the stigma associated with schizophrenia might be lessened if it was viewed as a disease like Alzheimer's. These ideas were discussed and debated at public education meetings held by the MSS, but nothing specific ever came about after them. In other words, schizophrenia remains a mental illness.

Also, during this time, the slogan, "If You Think Spelling It's Hard, Imagine Living With It" part of the SSC campaign of "hope" that started in 1994 (Figure 1). Pamphlets, book marks, and ads in newspapers with this slogan as well as other information, were mass produced for this public awareness campaign. The essential message included a number of misspellings of schizophrenia, the slogan and a 1-800 number for more information. The pamphlet also included a short description of schizophrenia, a discussion of research on schizophrenia and how families could be supported, a list of what schizophrenia "is" and "is not", and the affiliated provincial associations listed on the back. This campaign was very successful in drawing attention to

schizophrenia by focussing on the spelling and then on the meaning and where one could get further information or help. The SSC stated, "We are committed to ensuring a greater understanding of the illness. Understanding and acceptance from all Canadians will allow people with schizophrenia to achieve a better quality of life". This is ultimately their major goal through increasing public awareness with this campaign.

In 1995, the pharmaceutical company Janssen-Ortho released an information brochure about schizophrenia with an image using barbed wire in the shape of a head (Figure 2). This was part of their direct-to-consumer (DTC) advertising in conjunction with marketing their medication - Risperdal (risperidone). The barbed wire head on dark blue background changes to a smooth wire head on dark green background, with the discussion of new treatments for schizophrenia, alluding to risperidol, since DTC advertising is illegal in Canada. One person with schizophrenia, who worked at the MSS at the time, said she really identified with the Janssen barbed wire head because she viewed her illness as mechanical and not organic. She thought it was similar to holocaust/barbed wire showing that schizophrenia was imprisoning the mind and thought that some people may not have liked it for that reason. She said, though, that most consumers really liked the image. I believe that the image does convey the idea of pain in the brain and the mental torment of schizophrenia. Janssen-Ortho launched their ad campaign with a 1-800 number to "invite caregivers to ask for information" (Canadian Market Research Ltd. 1996:1). To all callers an information booklet called "Schizophrenia, Understanding the Disease", a summary card with symptoms of schizophrenia, and a pamphlet from the SSC was mailed. It was hoped that caregivers would take the initiative to speak to a psychiatrist directly or with the patient about the importance of negative symptoms (Ibid). According to the research conducted to track the impact of the Janssen campaign upon caregivers, many people (51% of 2000) did not call the 1-800 number because they did not need further information or they received

information elsewhere (Ibid:5). The company states that if they are to achieve even a higher response, they will need to "challenge the complacency or belief by some caregivers that they already know it all" (Ibid). As I noted, most of the family members I interviewed did have a vast knowledge of schizophrenia and medications. The Janssen-Ortho advertising continued through 1997 with their "Risperdal Partners in Care" program (see The Medical Post June 17, 1997), and the barbed wire image is still used on their risperdal and schizophrenia pamphlets and booklets.

Also in 1995, the MSS started distributing a comic strip/one page information sheet (Figure 3) about schizophrenia that the same person mentioned above did not like because she felt it trivialized schizophrenia. "It is too cutsie media and the psychiatrist would never say 'there is hope'. It is difficult to get across to the unknowing public the truth about suffering with schizophrenia".

In 1994 a magazine called "Schizophrenia Digest" was first published by a consumer named Bill MacPhee and continues to be published four times a year. The first publication highlighted Dr. Michael Smith's Nobel Prize in Chemistry which he donated to schizophrenia research. This was a very important time for research on schizophrenia in Canada.

Through the past decade there have been numerous popular magazine features on mental illness and schizophrenia including Time (1996, 1992), Newsweek (2002) and MacLean's (1995). In 1991, Chatelaine published "My son, the Schizophrenic" by a mother of a 27 year old with schizophrenia. She states "I can't live with him. Having him hanging about would drive me crazy too" (McCabe 1991:47). In 1999, Chatelaine published another story called "A Way Out" about consumer/survivor run businesses in Toronto. For people diagnosed with a mental illness, "getting a job of any kind is more often an unrealizable fantasy than part of getting well" (Hannon 1999:94). According to this article, how society handles mental illness has implications for all. These two articles in Chatelaine, almost 10 years apart, show the influence of the consumer empowerment

movement and the switch from discussing the "schizophrenic" from the mother's perspective to actually talking and interviewing consumers themselves. Selective reporting of mental illness does have an impact on the attitudes of the public which has important implications for public policy issues (Angermeyer and Matschinger 1996).

The next section of this thesis includes family members' discussions about living with schizophrenia. How they deal with treatment and services, as well as self-help groups is described. Aspects of stigma, and their own explanatory models of schizophrenia permeate their descriptions of living and caring for someone with schizophrenia.

The decade of the 1990's was characterized by a major effort to identify and correct significant anomalies in Manitoba's mental health service system. Many of the problems resulted from or were exacerbated by poorly planned efforts at decentralization in the past. The extent to which these changes are reflected in the narratives of the families described in the next chapter will vary, depending on when contact with the system occurred.

Chapter V

The Family and Schizophrenia

The open ended format of the in-depth interviews allowed people to talk freely about their experiences as part of a family in which another member had developed schizophrenia. Everyone had a different story to tell and accounts varied depending on their relationship to that individual (mother, father or sibling), the severity of the condition, when schizophrenia was first diagnosed, the nature of the treatment at the time, the availability of support, and such personal issues as the impact on the dynamics of their relationships with other members in their family.

Nevertheless, when analyzing the transcripts of these interviews, four themes emerged as relatively common. The first was a profound and ongoing sense of responsibility for the family members with schizophrenia. The second was a continuation on this theme, but focused on the importance of acting as an advocate for this individual in relation to the external world. This world was sometimes represented by social workers, the police, or other government agencies, but people talked most often about the medical profession, particularly psychiatrists. This latter relationship was often marked by extreme ambivalence and sometimes resentment with a sense of having been excluded from care decisions.

The third and fourth themes were quite different. Both focused on the past and were preoccupied with the search for an explanation of what had happened to their family, why it had happened and what, if anything, was responsible. Several interviews included discussions of family's history in which they listed and described particular individuals who might have had schizophrenia. This third theme may have been a response to the new genetics and the promise that science would eventually find a "schizophrenia gene", or it may have been an expression of much older ideas about

heredity. The fourth theme emerged out of discussions of the events that had preceded the diagnosis of schizophrenia and the initial realization that something was wrong. The details of these stories varied from family to family, but each one was an attempt to deal with the puzzle of how and why the transformation had occurred and rejected the idea that family dynamics are a root cause of schizophrenia.

Although finding an explanation for the presence of schizophrenia in their family was very important, most interviews centred on relationships within family and more particularly on the relationship with the family member with schizophrenia. People talked about the social, economic and emotional implications for themselves and other family members. Parents talked about their other children and siblings discussed the impact on their parents.

Chapter VII focuses on what people had to say about the external rather than the internal relationship. The interviews revealed that people deal with health professionals, social workers, employers, landlords and police. Some of these relationships were supportive, some contentious, and many required that they advocate for their relative, particularly in situations in which they could not advocate for themselves.

The biopsychosocial model of mental illness was used to frame the data in Chapters V to VII (see Engel 1977). Biological, psychological and social components were recognized as important aspects of schizophrenia. The concept that families are a valued resource and collaborators in the treatment process of schizophrenia also guided the research (see Walsh 1996).

Transformation: The Onset of Schizophrenia

The symptoms of schizophrenia may include hearing voices, when no one else is there, having other people's thoughts put inside your head, seeing or receiving messages, and having experiences of telepathy or mind reading. People with schizophrenia can have

bizarre or impossible beliefs about the world or their place in it. They may have trouble thinking straight or getting themselves motivated to do things, and they may say or do odd things (see the latest *Diagnostic and Statistical Manual of Mental Disorders*).

The families I interviewed had noticed behavioural changes in their relatives sometimes years before they were formally diagnosed with schizophrenia. Parents tried to discern what was normal adolescent behaviour from what was mental illness and schizophrenia. Several parents reported that their children developed symptoms of schizophrenia between the ages of 16 and 20 years coinciding with the last year of high school and beginning years of university, college or a job. These stressors were seen as contributing to the onset of schizophrenia. Family members would acknowledge the behaviour of their relative and would see this behaviour as the sign of schizophrenia. As one woman describes her sister:

> Lisa was always sort of an odd ball. From the time she was 16 or 17 she became very socially inward, not a lot of friends. I don't know that she ever heard voices, but she became paranoid. I've had too much mental illness in my background...you knew something was wrong. I mean it's like an instinct, it's like an alcoholic (14).

Parents often described the time when their son or daughter became ill as a stressful period in his or her life. One mother discussed the time her son became ill:

> I think it started when he was in highschool but we didn't recognize what it was. He was having trouble but we didn't know why. I thought it was something in my imagination because it's something you feel but you can't quite put your finger on (2).

Both siblings and parents would describe what they thought were the initial signs and symptoms of schizophrenia in their relative. One brother stated:

> It was a gradual transformation. My brother was really reserved and very shy. He had problems adjusting. When he was about 14 he started really exhibiting more strong behaviour. He stopped talking to me for 2 years and he broke off all communication with me and we shared a bedroom. It was very stressful on the whole household.

Some family members saw a gradual change in their relative's behaviour while others saw a sudden definite change or incident that started the illness. One mother talked about

when her son became ill, "It could have started when he was 16 and then he went to his teacher at school and said he was going to commit suicide" (5). Another mother said, "he developed schizophrenia when he was 16 or 17. He laughed and talked loudly to himself"(15). Both of these mothers described a time period and incident when their sons were obviously ill to them. One sister described the behaviours of her ill sister:

> It got to the point where she was locking all the windows...in general conversation she was so bad you could not have a conversation with her at all and you even had to watch her particularly in the kitchen cause she'd turn the stove on and not turn it off (3).

Other parents were not aware that what they had seen were the symptoms of schizophrenia until their son or daughter was hospitalized. "We were so naive, we didn't know anything about psychotic thoughts"(17).

Most of the people that I interviewed were dealing with schizophrenia during the time when hospitalization was the norm. Many of them welcomed the diagnosis of schizophrenia since their son or daughter had been sick and they didn't know what was wrong. One mother states, "I was not devastated by the diagnosis because I saw the deterioration in Ray over the years and didn't know how to handle it" (11). Other parents did not know that their child had schizophrenia until they were taken to a hospital, diagnosed and labelled. Even though they knew something was wrong with their son or daughter, the diagnosis shocked them.

According to some parents, their adult children with schizophrenia lacked insight into their illness and did not comprehend their disease. A father of one man stated:

> He didn't start referring to himself with this disease until about 2 or 3 years ago. When he had an episode he wouldn't talk about it. He thought that there wasn't anything wrong with him. When he was not at that stage, he just wanted to be considered normal. We're talking about at least 20 years of suffering with this and he wouldn't want to be labeled (13).

Many people with schizophrenia did not want to be labeled with the disease or tell people that they had the disease due to discrimination. This shows how some parents and adult children would disagree about the application and implications of the diagnosis of

schizophrenia. The mother of the same man states:

> I'm not sure that he understood that he was seriously ill. In spite of a label or no label he was able to rationalize a lot of his problems. I think it was more, almost a normal frustration with himself that he couldn't handle and not necessarily an episode. Because, here he was 41 and he wasn't really doing anything, he was doing well, but he looked around at his brother and sister and they have kids and they have relationships and that's terribly frustrating. He just didn't have the ability to know how to deal with it. That's the way I see it. It's horrible and awful (13).

The parents of this man were able to articulate what they thought was the frustration in their son due to his illness and the fact that he could not attain the same type of jobs or relationships his siblings had. The son with schizophrenia wanted to be like his brother and sister and free of the label of schizophrenia.

Family Explanations of Strange Behaviour

Although all family members interviewed had a diagnosis of schizophrenia for their relative, they still looked back at certain times and circumstances and tried to explain their relative's behaviour in their own terms. Many families members searched for an explanation for the psychotic behaviour of their relative. One mother described when her son first became ill:

> He deteriorated in university, he was 24 or 25, driving a cab for money and living on his own. He had been drinking too much coffee. I'm not saying the coffee caused schizophrenia, but maybe his brain was programmed to develop schizophrenia and the coffee sent him over the edge (11).

Her belief was that the amount of coffee he was drinking affected his already vulnerable brain to develop schizophrenia. This suggests this mother felt that schizophrenia had both a developmental component coupled with external stressors such as excess coffee as causal elements. Another mother thought that her daughter had a spiritual problem:

> One time she came to the house, and she lived downtown so it wasn't that easy for her to come, and about two minutes later she said I have to go, she said I feel so evil, like there is evil in the house. And that really was scary. I thought I don't know whether she saw some strange movies or what happened. I did not really know what went wrong with her. And I was thinking about witch craft and that kind of stuff cause I really didn't know what else to think. I started to wonder what was causing her to be like that...I thought it was a spiritual problem. That she

> some how got involved with the occult (8).

Another mother who had two sons with schizophrenia described in detail the life of her oldest son:

> He had been doing drugs and drinking a lot. He told me what it was like to have this black veil come over his face and he frightened me, cause even the look in this eyes frightened me...I thought it was the drugs, because when he would describe what was going on he, even when he was off the drugs, I guess maybe if he had LSD maybe he was having flashbacks. So I thought it was the drugs (4).

She believed that the schizophrenia in both her sons was exacerbated by drug and alcohol use. She firmly believed, however, that she did not make her kids schizophrenics and felt that it wasn't bad parenting or her fault, it was just the way things were and "what is the shame of it?". This mother had incorporated her understanding of the onset of schizophrenia in her sons with their drug and alcohol use. She also described a time when one of her sons had been walking around Calgary aimlessly:

> he found an abandoned house that had curtains and everything and there was furniture in there too but it was sort of ...and he set fire to it because he was getting rid of the devil, he had a thing with the devil (4).

Some people with schizophrenia are known to have hallucinations and delusions dealing with religious beliefs. When evaluating delusions it is important to remember that their content is culture-bound (Torrey 1988:45-46 and Warner 1985). This same mother describes a final episode with her son:

> When he went to Calgary one time he went to his sister-in -law's place and she let him stay there. And she said she woke up in the middle of the night with this terrible screaming, she didn't know whether they were animal screams, they were such inhuman cries and he was stark naked and he was after the devil and she had a black cat and he was chasing the black cat he thought it was the devil. And she finally got him calmed down, but these were the outbursts and I believe that they were exacerbated the use of illegal drugs also. I think that if he had stayed on straight, you know, legal medication he would have been ok, but he got hooked on this stuff (4).

These family members are identifying a variety of external agents such as caffeine, alcohol and other drugs as precipitating factors in the onset of schizophrenia.

Genetics, Heredity and Blame

Many family members believed that their son, daughter or sibling had schizophrenia since their grandparent, uncle, aunt or cousin also had the illness (the average risk for developing schizophrenia is shown in Figure 4.) One couple with three daughters with schizophrenia had relatives with the illness from both sides of the family. The mother's mother and the husband's aunt both had schizophrenia. At the time that these relatives were ill no one really spoke about schizophrenia and "there was lots we didn't know" (1). The issue of inheriting the illness affects further generations, the mother stated, "my daughter is frightened cause she has 5 children, and it's on both sides [of the family]" (1). One father whose son has schizophrenia said he knew his son was ill since his sister has the illness:

> I knew because I have a sister with the illness, she is 67...my brothers and sister, they can't talk about it, they don't understand, they think it's their fault. With my own mother I didn't feel that she was to blame (for my sister), I couldn't believe that...I feel that there are varying degrees of schizophrenia like there are varying degrees of depression (16).

This man had read psychology books, and with these readings and his personal experience he felt that there was no one to blame for his sister's or son's schizophrenia. He also realized that there are varying degrees of schizophrenia and that some people are worse off than others.

One woman whose sister has schizophrenia started looking at her family tree:

> There is a pattern. When I started researching this I started looking at the family tree and there is something there - on my mother's side. Unfortunately I don't know if the word schizophrenia comes up, but my mother has a nephew who at age 16 "flipped out" and he spent about 6 months in a psychiatric ward. But his pattern since then is very close to schizophrenia, he got into drinking and all of that type of thing. And then there was another sister of my mother's who had a niece in her 20's who had some coping difficulties. So, it makes you wonder, when you see these things in the family, if there isn't some kind of clinical find here. That's what I mean - genetic, that there is a genetic thing here (3).

This woman believed that the schizophrenia her sister had was inherited from her mother's side of the family although she says, "I don't really have any hard facts to

substantiate it". As she discusses her family she also states:

> When I look at my grandmother...I think she was tuning out because she too did like my sister does now, she'd sit there on her chair and just smoke one cigarette after another and be starring off into space. Nobody [in her family] realizes the reality of the situation that first of all you know that there is a very good chance that your children - this could be transmitted to, that's one reason that I have no children...because of this genetic pattern (3).

This woman described her grandmother's odd behaviour as possible schizophrenia that she thought may be an inherited illness transferred through her family and even visible in relatives' traits. Because of this link, she has decided not to have children and she believes, "an individual like that requires special...there are special needs".

Some instances of finding relatives with symptoms of schizophrenia leads to blaming in some families. One woman whose older brother has schizophrenia described how her father's side of the family had the disease: "See, it is on my dad's side of the family, my cousin had schizophrenia. Oh, my mom has even blamed him. She'll say it's your fault, it's on your side of the family" (9).

Some family members would blame each other for having the schizophrenia or mental illness on their side of the family. One woman states:

> My sister has a son who has had a problem and we've wondered all these years what was wrong with him. It could be schizophrenia. So, you begin to pick up on some of these things (problems in other people/relatives). So I'm not sure it's not in the family somewhere (5).

As this woman discusses her son with schizophrenia and more about her family she also states:

> My husband's sister's family has 2 manic depressives and there's my brother's family who has a daughter who seems to exhibit some signs that she is either manic depressive or has schizophrenia or just clinical depression, cause there is something going on that is not right (5).

This woman was also looking back at her family tree and recognizing that schizophrenia may be related to other mental illnesses. Other people who could find no one else in their families with schizophrenia would simply state that their relative must be the 1 in 100 with the illness. This is the number that many had heard from the MSS and other mental health organizations as the prevalence of schizophrenia. Studies of schizophrenia have

shown that approximately one out of 100 people worldwide will be diagnosed with schizophrenia during his or her lifetime (Torrey 1988:3 and Gottesman 1991:75).

Chapter VI

Family Responsibility

Families of people with schizophrenia are the single most important primary care providers (Torrey 1988:9). Approximately, 482,000 people with schizophrenia out of a total of 1.2 million (in the US) lived with family in 1980 (Ibid). Family members generally receive little information on what they can expect and they may not know the importance of medication compliance, etc. Some become victims of violence and cannot believe that their son or daughter would be capable of such an act (Isaac and Armat 1990). And although families are usually the main caregivers at the beginning of the illness, they often find their experience very frustrating and relationships suffer.

Advocacy and Support

Some parents felt burdened by being the sole advocate for their son or daughter. For example, one mother stated:

> You know, at one point I thought it would be good for Marlene to have a...I feel like I am the only care...support person she has - like advocacy. It seems like to me that I am the advocate person for her and sometimes I can only do so much because I am her mother - it puts me at a disadvantage, at a real disadvantage. Because she doesn't hear me the same way and many times she doesn't want to hear me and she rebels against what I say. So, it is very difficult and I thought it would be good if she had somebody, like a professional, that she could see regularly and that she would be more attentive to or that she could test her ideas, say about moving or whatever, with this other person, rather than me having to deal with it (8).

This mother expressed her frustration with dealing with her daughter on a daily basis and wished that she had someone else to advocate for her and talk with her, so that she could have a perspective that was not just from a parent. This mother expresses feelings of a regular mother-daughter relationship that is compounded due to schizophrenia. It shows the negotiating of meaning surrounding this type of relationship.

Family members often monitored medication, noticed signs of relapse, telephoned

community mental health workers and dealt with the daily necessities of their sons and daughters. One mother described her son's medication:

> The injection works when he gets it. He responds very well to it. It works for 2 to 3 weeks and then it starts going down. His energy level goes down and he doesn't talk as much. But he won't stay on it. He claims it's the medication that causes him to be the way he is, so to feel better, to take care of his health, he goes off of it then he starts to hear voices again (5).

Parents had genuine concern for their children and often wanted them to take medication hoping that it would get rid of psychotic thoughts, delusions and voices. The children on the other hand had to contend with side effects that included drooling, lethargy and involuntary movements.

Parents described some of the ways they managed with their son's and daughter's illness. One mother described how scared she was of her son:

> When he did live here for some time, I remember getting up with my husband very early in the morning and going to work with him cause I was afraid to stay home with Chris. Because of the look on his face, the look in his eyes was very, very terrifying, but then again he wasn't on his medication (4).

Another mother described how she coped:

> I got a job, I was away for about 2 years, 6 hours a day. To get away from him. The other thing I felt I really needed was go out and be around normal people and I would sometimes go out and just sit in parking lots and watch. Cause back then things were so abnormal here that I would need to hear just normal conversation (2).

Both of these women express a need to "escape" their daily routine of dealing with their sons' behaviour. A sense of normalcy was important to many families who dealt with years of struggling with symptoms of schizophrenia. Some parents realized that when the person took their medication his or her behaviour was better. One of the mothers just quoted above explained:

> I just take it in, think well, this is it, this is what I've got and you have to deal with it and I'm dealing with him as though he were a rational person cause he's on medication and I know that they have certain things that really they don't control but you mustn't let that override the fact that they have to try, I mean you have to practice. Like his impatience. I said patience son, patience...you have to learn this. Now he's learning about budgeting and he's doing really well now (4).

A sense of responsibility was very important for this mother to instill in her son whom she

thought was able to learn new things when he was taking his medication. Parents realized that it was difficult to do things for their adult children as well as give them a sense of their own responsibility. One mother describes her relationship with her daughter:

> It got to the point where...I can't even give you an example of what she would say that would upset me, but it got to the point where I just let her talk and I really didn't react, I didn't say will you, should you, or shouldn't, or anything like that. I would totally be a passive listener like I was listening to the radio and I let her go on and on. Because, I think that sometimes she would just say things to get a reaction and that would just take too much out of me, like energy wise (8).

This mother goes on to talk about her daughter's money situation and how she would spend money on things she didn't need and that when she ran out of money, "we helped her just a little bit, but we tried not to be too helpful so it wouldn't encourage her to that reckless [behaviour], so that she would be more responsible. So only if it was absolutely desperate, that we could see she was in a desperate situation, but we made it clear that it was a one time thing and that she would have to look after herself better". This is another example of the struggle for parents to deal with adult children whom they know should be responsible and living on their own, but due to schizophrenia they often have to care for them in ways that contradicts independence. Parents were often trying to find a balance in response to the crisis of an illness - schizophrenia, but not to the degree that would completely remove responsibility. Some parents felt that other parents were definitely doing everything for their children. One mother describes what she sees other parents doing:

> I find that some parents literally bend over backwards, I mean they have to learn to stand on their own two feet. I find that they baby their children so much - "we don't do this because it might upset him". But you know, this is real life, you have to learn how to deal with things everyday, whether you have a mental illness or not, you can't be shielded because they are not going to be around forever and brothers and sisters can move to Timbuckto (4).

Another mother describes her son, "he's matured now to the point where he realizes he's got to stay and he makes his own food and he's supposed to keep his own house tidy, but he lives like a bachelor. I have trouble knowing where the illness ends and where the actual personality of the person begins" (2). This statement is an example of the struggle of

disentangling personality from disease and lifestyle issues.

Coping with Violence

Many families described the tension and violence that they endured. The following quotation describes the tension in one home:

> She lived with us for a year before. It was really hard on the three of us cause her younger sister was still living with us and still going to school and my husband wasn't feeling well at the time, and we were just barely getting by with our own problems. It was difficult at the time and she added to the tension and difficulties in the household because of her behaviour and the whole family had to give a lot and they had their own problems. Simone (sister) was just a teenager and her self image was very fragile, with her friends and that, so she was kind of embarrassed about her sister, she was (8).

This family had their own problems to deal with and could not cope with their daughter's behaviour. One sibling with a brother with schizophrenia described some her family situations:

> He's very disruptive in the home and he can also get very verbally abusive and very angry. He went through a period where he was destroying family pictures and he was rearranging things and that type of thing (9).

Because of the aggressive behaviour of this person, he had to move out of the family home and is now on social assistance.

Some parents had to call police to take their son or daughter to the hospital or dealt with violent situations where they had to phone the police. One mother and father stated, "In 1994 we went to the police and pleaded with them to take him to the hospital" (17). Another mother described her son's behaviour:

> When he was 17 they put him in the youth centre because he threw stuff at us and smashed up things in the house. He threw air conditioners and things like that at my husband and me and wrecked the furniture and everything and when the police came they asked us, was he on medication and we said no, which I should have done something about it then maybe he would have gotten help sooner than he did (5).

This mother goes on to describe another time when the police were called:

> Last Christmas he hit his brother in his apartment and his brother had him brought up on charges for that and they gave him 2 years probation for it, but he was sick then, we didn't know he was sick, and all them times the doctor says he must've been

> really sick. So he smashed his apartment and I phoned the police and he said mame we can't do anything about it unless you place him under arrest (5).

Some parents were placed in the position of calling police and getting their children arrested just to get treatment. One family situation was as follows:

> On day Cliff was over and they had bought some new furniture and asked him if he liked it and he went into a rage and smashed his plate, smashed the kitchen aid off the kitchen counter and almost hit his mother's leg. They were afraid of him and wanted their keys to their house back. He punched his father in the face and asked him if he was going to call the cops and father said I don't have to answer that and he said ok, I am going to kill myself and rode away on his bike. They went to the cop station and were told to go to the magistrate. The warrant was signed and they picked Cliff up at 3:00 am and took him to HSC. Doctor in emergency phoned at 4:15 am and said he doesn't want to stay so therefore he had to release him (17).

Many of the families were not used to the violent episodes that led them to call police for assistance. One father describes a situation with his daughter:

> All of a sudden on that particular day, a fight developed between my wife, my middle son and Eva. It ended up Eva falling down the basement stairs and getting her head split open. And that was the last day she was ever in the house. So, I picked her up...put her in the car and drove her to Seven Oaks (hospital). She called the police, she was going to lay charges against her brother and mother. So, there two constables arrived and a sargent, well it was obvious to them, it was obvious to the people on duty at the hospital that Eva should be hospitalized. Not because of the cut, but because she was ill (18).

In this situation the person with schizophrenia ended up calling the police herself and they realized that she needed treatment for mental illness. One sibling described her family's dealings with the police:

> My parents were away and my brother was staying in the house and he just went crazy and chopped the fence down and chopped our tree down and the neighbours called the police and they took him to the hospital, the Health Sciences. And he'd been getting really, really bad like he beat up my parents and stuff. And they took him to the hospital - he's been several times (to the hospital). This is like ongoing all the time (9).

Many families dealt with a revolving door syndrome when it came to violent outbursts with their relative - hospitalization and then release. This scenario repeated itself many times. In fact, one sibling stated, "Like I say, if someone like my brother who's been through the system for years, he knows what questions they are going to ask him and he can say whatever he wants. And like I say, he just gets mad" (9). Her brother had been in and out of hospitals

many times and her parents had lived on "eggshells" for years. The situation was volatile all the time.

Even though the majority of families never experience the trauma of assault from a family member, the day-to-day managing of stressful events can take its toll on family caregivers. Since there is no adequate substitute for the family as a support system, families need support to prevent burn-out (Hatfield 1996:63).

Sibling Relationships

Parents often discussed the differences in their children and the effects that the sibling with schizophrenia had on the others. Many parents would state that "the siblings can't cope", and "some more than others". The relationships of siblings, when one has schizophrenia, is profoundly affected (see "My Sister's Keeper" Margaret Moorman 1992).

Depending on the age of a sibling and the circumstances of their life, most siblings did not physically and financially care for their brother or sister with schizophrenia until their parents were either elderly or dead. In other words, most parents looked after their children with schizophrenia until they were no longer able to do so.

Many sibling described at length their dealings with their sister or brother. One detailed example of a sibling relationship is as follows - the sister stated:

> She's younger than me. She's had it [schizophrenia] 10 years at least cause she had it before she had the child and I'm not sure if he's 9 or 10. When it developed she did stay with the family and the it was discovered she was pregnant and as a result of that my family couldn't cope with that situation so she went to Villa Rosa, had the child and kept the child...It got to the point where she was locking all the windows and she actually brought the child here one day and just left him with me. In order to get her to respond, I took the child to my parents because my mother and her have such a relationship that my mother has a fair amount of control over her (3).

This sibling described how her family and mother specifically could keep her sister's behaviour in check as well as making sure she stayed on her medication. She goes on to say:

> She stayed there for a number of months and got back on her medication which was supervised of course by my family, so she again got better to the point where she could cope reasonably well without becoming delusional...as a result of her going

> home at that point my parents, or my mother, was made legal guardian to that child (3).

This sister also talks about the difficulty for her parents of caring for their adult daughter and letting go or giving her responsibility over her own life.

> I don't know if you can say my mother is helping her because it's a fact that this is her child and her responsibility although the child is now an adult and she [mother], I think in my estimation, was doing it only because there was an infant involved, had it been just my sister alone I doubt very much that my mother would have been involved to the degree she was (3).

The sister continues to explain:

> I think my family wanted to displace the whole thing (embarrassment because her sister is an unwed mother) and unfortunately no one knows who the father is, but it would appear that the father is aboriginal which again is another source of embarrassment to the family. So, it became a whole out of sight out of mind concept. I assume my mother still has a fair amount of contact with her. It's not a subject we discuss simply because I felt she (sister) should have been handled differently, so it's actually caused a rift between me and my family (3).

This sibling describes how the relationship between her parents and her sister has caused a rift between her and them. She disagrees with the way they treat her and expect "normal" behaviour from her. For example, she says her parents believe that her sister will get better especially if she gets a job whereas, she says "that's a crock...and of course it would cause a conflict between me and them". Part of the "rift" between this sister and her parents is due to what she sees as denial on their part to acknowledge that there is mental illness throughout the family, and that "nobody realizes the reality of the situation that there is a very good chance that your children, this could be transmitted to [them]". This has caused less contact between this sister and her parents and she does not even attend family gatherings at holidays. She has "minimal contact" with her family. In fact, she says that it has become progressively worse and a "confrontational type of thing" because she brings up the issue that they don't want to hear. She feels it's a sort of mutual choice that she doesn't see them because if she is not around then they are not reminded of the situation. She sums up her feelings:

> Denial removes responsibility, that's the key issue. Because I've thought about this

> long and hard and I think that's part of the factor. I'm not saying that's the total thing, the total issue here. I mean just responsibility because as I said, these individuals require more maintenance, they're high maintenance people, you know they require supervision and there is a certain dependency that exists there. And I don't think my family, first of all, wants to take responsibility for that nor can they handle, accept the responsibility, that there could be this genetic connection (3).

Her relationship with her sister seems to be the same as it has since her sister first became ill. She feels a sense of responsibility since she is older, as well she has concern for her nephew's future. But she does have some difficulty discerning the personality of her sister from the illness, for example:

> My sister's the type when she gets into her schizophrenic pattern she just...I call it "cops out". She'll sit there and smoke one cigarette after another and she's in another world. There is no...and reality become quite questionable, you have to be very careful like for example you don't ever want to watch the news too much because she tends to extrapolate things from the news, that type of thing (3).

This sister has concern for her sister's well being, however, she does not expect "normal adult behaviours" from her and believes she needs help and more maintenance. She explains:

> My sister and I were never close, but because when she does get like this I tell her, you know you're delusional, have you taken your medication? So, she doesn't want to hear that so she hangs up, because I'm the policeman (3).

It is quite clear the symptoms of schizophrenia have affected this relationship.

> One sibling described her brothers' lack of involvement with their sister:
>
> My brothers have nothing to do with her. I mean my brother will say "hi" to her but he won't go to her place. I suppose he thinks she's lazy, he doesn't understand mental illness, and I think it's a lack of compassion. Like give her some of your time, you can't make her into what you would want her to be cause she is not that way. My view is if you have a lack of understanding of it (schizophrenia), you have a lack of understanding of lots of things in life (14).

This sister could not believe that her brother did not have acceptance of his own sister. She also makes this excuse for her sister who is a social worker, "because she has children - everybody is too busy in their lives". But goes on to say "she (sister with schizophrenia) may not have a friend in the world which is too bad, but she is at least connected with the family" (14).

Siblings had varying relationships with their ill sister or brother depending on their age, sex and place in the family, as well as their profession. The siblings I interviewed, who were involved with their ill sister or brother more than other siblings, were counselors, nurses, court reporters, etc. They also tended to be proactive and have a positive outlook. They had some post-secondary education and an interest in mental health issues. These factors lead to differences in the responses of siblings to ill relatives. Parents also described how their children related to each other.

One mother described her family's relationship and feelings about her daughter with schizophrenia:

> There is one in particular, she had a sister, they used to be very close when they were growing up, she just doesn't relate to her at all, she totally feels that her sister does not exist. And that hurts Marlene because they were close and she tries just to be in touch and she knows that she is not accepted...it is very hard as a parent to see this, although we have come to accept it as much as we can. And I feel badly for Marlene, cause it must really hurt to be totally rejected by your own sister who you were close to (8).

This mother described how her daughter reacted with anger when she tried to explain her sister's illness and give her a pamphlet on schizophrenia. "She just really blew up, just literally blew up. She didn't want no part of it". Many parents described strained relations between their child with schizophrenia and other family members. Some siblings react with anger because this has happened in their family and they see the stress their parents have to endure, others feel sorry for themselves and fearful that they or their children may get schizophrenia. Anger seems to be a common reaction by some siblings. This anger stems from some siblings witnessing the financial burden of their ill sibling on their parents and the tensions this causes. They resent the position their family is in and blame the ill sibling for any family problems.

Family Relationships

Families had to deal with issues of maturation and independence of their adult children. It was difficult to encourage some of the people to go on social assistance. "We had a hard time convincing her to go on Social Assistance, she didn't want to have any part of it. And I said how are you going to live? You've got to have some sort of income, so then finally she did" (1). Social assistance and welfare are very stigmatizing, as one sibling stated:

> The messages that the family gives the schizophrenic are important and I don't want to minimize that. But the messages that they get from society often counteracts the family so the whole question about being on welfare we know what 80% of the people think about being on welfare no matter what one says, we know what 80% of the population thinks about work and the value of work to the person, we know that these are two huge areas where schizophrenics are not in the main stream, so that's what I am getting at in terms of their own self image and what they have missed (13).

One mother talked about how she felt with her son on welfare:

> I felt ill at ease that a son of mine should have to be on welfare. I could have covered his expenses and so forth out of my own resources, but he wanted to live independently much of the time...and Ray didn't want to receive money from me either and he was against that because he had a right to receive welfare if the need arose...I can supplement the benefits that he received from welfare cause welfare itself is very minimal existence so that over the years I have bought groceries, about every two weeks I would buy him $50 of groceries...I felt he is my son and he is still my responsibility (11).

This mother felt that because she came to Canada as an immigrant and was received with open arms, that for her to bring a son who ends up becoming a financial burden to society is very unfortunate.

One sister of a person with schizophrenia described her problem with the health care system:

> What I don't care for really is the way the health care system is that they want these people to live out in society, but there's not enough support systems in that area of society and they expect the family to deal with it and like I say my family, they don't know how to cope with it, and it's only because I've had lots of therapy myself and I've gone through lots of things that I know how to cope with some things and do different things. But most families I don't think have that, no skills whatsoever. So they just throw those people out on the street (9).

This sister went on to discuss living conditions for people with mental illness and she felt that the Light House Mission and the core area of downtown Winnipeg were not appropriate

places for people with schizophrenia. Some of the families had used the services of CMHA and their housing program, others had relatives who had been in group homes. Dealing with trying to get some self-supportiveness instilled in their children was difficult for many of the families and they often turned to mental health organizations.

Chapter VII

Dealing with the Mental Health System

Family educations and support has been shown to improve outcomes and family knowledge of practical solutions is an important factor in relapse prevention (Torrey 1988:273). Without education and good relapse prevention, families often burn out. It is not a reflection of the family so much as a lack of adequate treatment and support. Families need help in the day-to-day care of a relative and with interactions with the mental health system (Szathmary 1999:86-87). Parents are often the only resource an ill adult child has. As one mother said, "If it weren't for us he would be on the street" (17).

Advocacy and External Relations

Some families welcomed a diagnosis so that they knew what treatment and medication was necessary, others dreaded a mental illness label and the stigma that followed. To attain a diagnosis of schizophrenia, many families had to take their children to hospital repeatedly or have the crisis unit and/or police involved. Some people were sent home with medication and not told much else only to find their son or daughter deteriorate or have symptoms worsen and then a crisis would cause them to be hospitalized again. This revolving-door syndrome was seemingly never ending for some families. The diagnosis of schizophrenia for some families became the start of years of dealing with the symptoms and behaviours of their relative with the illness. One sister talked about her brother:

> We didn't know what the hell was wrong with him and we were trying to get the crisis unit to go and see him and I phoned the crisis unit myself and I said look, this is the situation can somebody please go and assess him and when they went to assess him, he'd say "what's the problem?". He's very manipulative and very bright. He knows the system, he's been in it long enough now that he knows it completely (9).

Her brother had been involved for years with the mental health system and knew how to

(according to her) manipulate the system to his advantage.

Some families had to deal with very violent outbursts from their relative with schizophrenia leading to a diagnosis as opposed to having the process of diagnosis occur through several years of dealing with fairly minor symptoms and behaviours. For example, one woman discussed her sister:

> I committed her 2 or 3 years ago. I went to the Canadian Mental Health Association and then I went to the mobile crisis unit. We all (the mobile crisis unit) went to her apartment and she would not let them in. So they told me what my options were and that they would call me. They called me the next day and I just signed her in on a mental health warrant (14).

Another sister describes the circumstances that led to her sister's hospitalization:

> She was so paranoid about the mafia...she was screaming, swearing and hurting herself. She called the police and said that her parents were hurting her. She was riding a bike and smashed (into a parked car) and hurt herself. The police took her to the hospital and this was her first time in the hospital. The psychiatrist said, "we have reason to believe that she may be schizophrenic" (12).

A mother discussed how her son was hospitalized:

> I phoned the police and he said they couldn't do anything about it (smashing his apartment) unless you place him under arrest. So, I phoned my sister that night and told her the situation he was in and she said phone the crisis (unit) line, so I did and they went to see him. He had glass all smashed up on the floor, he was walking in it, all of his clothes were on the floor, there was tons of water in the bathroom, there was food on the floor and the dishes I gave him were in the garbage - he didn't want to wash them. Well we left him like that for a couple of days and then we went back and when we did he opened the door to let us in, me and the crisis team. He had kicked in the walls and there were holes all over. The crisis people took one look at everything and said just a minute we're going to call the police, he needs to go to the hospital. And that's how we got him to the hospital (5).

The diagnosis of schizophrenia by a physician, for most of the families, came after years of dealing with behaviours and symptoms of the illness. In general, mental health patients learn to trust professionals, and families want a label assigned to the odd behaviours and are sure that the doctors must know what's best (Capponi 2003:30).

After a diagnosis, some families wanted specific disability labels for their relatives for income tax purposes. One father, whose son and sister both had

schizophrenia, described some of the problems with his sister's psychiatrist:

> I have a sister with the illness, she is 67 now and up until 9 years ago her psychiatrist would not give her disability pension because...no, the income tax deduction, she wouldn't even sign that. Because the psychiatrist said that she didn't want my sister to feel disabled. Meanwhile she had the illness for over 35 years, hadn't worked, didn't have a lot of money, etc (16).

Many of the families felt their relative was entitled to money from disability pensions and income tax deductions when they found out about these resources. One family discussed their daughter:

> We wanted Brenda to get help from say a social worker, to help her out, because when she was being eased out of her job she had to go into some sort of financial support and I figured a social worker would be the best one to advise her cause I couldn't. I found out that she would qualify for a pension from Canada pension. But then he [the doctor] was putting her off. He told her, well don't worry about that, go on UI first - go on UI sick benefits and then go on UI and then go on CP later. But there is a waiting period, this is what I am afraid of, she is going to be waiting 6 months after UI runs out, she's going to be 6 months without any money (1).

Some psychiatrists and physicians thought that if the person with schizophrenia was not labelled disabled then they wouldn't be as stigmatized, however, these families had been dealing with years of stigma and problems such as lack of employment and, therefore felt entitled to any money owed them and their relatives. The families were willing to label their relative "disabled" as long as the person received money or services to help and support them.

Other peoples' children had held jobs and were therefore entitled to CPP benefits. One father stated "he is on CPP cause he worked for the railway for 10 years" (16). Family members had to negotiate with physicians to receive payments and benefits that they needed.

Advocacy and Treatment

Dealing with physicians of course included the treatment their son, daughter or sibling was receiving. Many complained that the physician they were dealing with would

not want the family present with their son or daughter during an appointment to discuss the illness. As one mother stated, "this is what I don't understand...cause we really wanted to talk to the doctor about (explain) something that happened, and find out what we can do to help her, but they just won't let you do that" (1). Sometimes families felt helpless and exacerbated with the medical profession:

> I don't think the medical profession knows what's going on in the family at all. We had been to doctors in Winnipeg and we checked him into a hospital once and he was never diagnosed. They gave him sleeping pills and sent him home. Another time in Portage, they said he had schizophrenia and didn't explain anything. There was no counselling, there was no getting together with the medical profession or other families, so I thought Bill [husband] and I should go to the library and get some books of schizophrenia" (2).

One family was so desperate for answers they sent their daughter to a neurologist. As the sister described:

> Of course the denial thing kicked in, you know it's got to be something neurological, my parents said this and it got to the point that they coerced the family doctor in making an appointment with a neurologist to...I think maybe they were hoping to find something, but even after that when he said no, there was nothing neurologically wrong with her...I did bring her here to see the psychiatrist at one time and we discussed the prognosis (3).

Because schizophrenia is something one cannot visibly see, it is difficult for families, especially parents, to accept that their son or daughter is in fact ill when he or she may look just the same as they did before they became sick. It is difficult for many families to accept the "mental" illness in their children.

Some of the families I interviewed dealt with physicians who said that their son or daughter would not accomplish much, if anything in life. One psychiatrist stated:

> your son has schizophrenia and he will never get better. He will be like a bird with a broken wing who will survive and find shelter somewhere and he'll survive with some medication (16).

Another doctor told a family that their daughter would be incapable of working, that she would be in an institution the rest of her life. Both the mother and father did not believe this. "She was able to perform certain things, she was able to work, she was working at Salisbury House. The idea was to get them (daughters) in and get them working"(1).

Physicians tended to have a hopeless attitude whereas the families view was optimistic. The assessments by physicians did not coincide with the reality of families' lives. Many of the children who developed schizophrenia have gone on to complete school and have some type of job. The job may not be what the person might have attained had he or she not been ill, but they are functioning at a socially respectable position. Some of them have jobs through SSCOPE and Skills Unlimited, and Sara Riel - agencies for people with mental illness. One woman's son works at a hotel as a housekeeper. She stated that "he is probably the most educated (grade 12 and some university) person working at his type of job in the city"(11).

Other children who developed schizophrenia have not been able to complete school or hold a job and are on CPP or social assistance. One family's story is as follows:

> Cliff got himself admitted to hospital in Edmonton. A couple of years later we pleaded with the police to take him to hospital, he was a mess and so was his apartment. When he stopped talking his medication he became paranoid and convinced we were out to get him. The crisis stabilization unit says that we can't use his messiness as a reason to admit him to hospital. When Cliff is sick, getting him to wash a dish is like climbing Mount Everest. The police and social worker did nothing (17).

The parents wanted their son to receive medical attention. They felt that psychiatrists should have the authority to give or force medications on people with schizophrenia. Once a relative had been diagnosed with schizophrenia, families had to deal with physicians and the mental health system for many years.

Gaps in the System

Families have to deal with many challenges including anger and tolerance of their relative's behaviour, perceptions of the illness symptoms, and dealing with relapses.

Once families had a diagnosis of schizophrenia for their ill relative, they often needed supports and services to cope with the ongoing illness. At one time, there was an extreme lack of information given to parents by the medical profession. One father stated:

> At that time the information wasn't there...eventually the psychiatrist said your son has schizophrenia and he will never get better, he will be like a bird with a broken wing who will survive and find shelter somewhere and he'll survive, with some medication. He himself didn't know...he didn't direct us to the organization (MSS) and at the time the organization wasn't strong. They would send material to the hospitals, written material and the hospital would keep it on file and maybe a doctor would bring it out and say, oh, here's some information if you want (16).

Many parents had to use their own resources to get the information and help they needed.

One mother described the situation with her son who had been hospitalized for a week:

> And nobody explained anything to me. I wrote to the Society and I got a newsletter, but at that time it wasn't well organized. I got lots of information on symptoms, but not much else, nothing on how to cope. And for a long time that's all I got. Then I finally went to a society in the US and got a book list and I got some books and then I went to the one in Manitoba, this must have been 1985 or 1986, so we finally got some information (2).

Some families had to struggle to get adequate help for their son or daughter:

> So, here I am sitting in a hospital waiting room with my daughter, there's no place to go - I couldn't bring her home, they wouldn't admit her to the hospital...And they referred me to several agencies, gave me phone numbers, every place I called- nothing, there was nothing. So, there I am, no place to go...so I put her in the Y, at the Y downtown (18).

One sibling described how difficult it was for her family:

> It's just awful because as parents and family we don't have a lot of access to even his care or treatment and he had a mental health worker who was excellent and left his office and he was transferred to somebody else...so then he had nobody and we didn't know that and we kept phoning and phoning (10).

Families dealt with a variety of agencies and services including the Crisis Stabilization Unit, the Canadian Mental Health Association and employment agencies such as SSCOPE. One mother described her daughter's situation at length:

> Marlene couldn't hold a full time job. I don't know what happened to her, I don't know whether she has deteriorated because of the illness or because of her lifestyle. She's very isolated, now she's living alone and she seems cut off from the world sort of thing, except for her own errands and whatever little things she does for herself...but now she works for SSCOPE, she works a couple of hours a week or so, but it is limited (8).

This mother talked about how her daughter had worked at Skills Unlimited and through Sara Riel. She had been involved with many programs, however, "there doesn't seem to be any continuity to whatever help there is available and that is my biggest regret, or that's

what I feel is lacking so desperately" (8). People with schizophrenia need appropriate programs that are fulfilling and have continuity. "If people are treated as capable, then they often surprise everyone and live up to expectations" (Steele and Berman 2001:103).

Some family members found it hard to ask for more information from health professionals:

> I didn't want to "rock the boat" myself because I didn't know where to turn to, I didn't know what to do. One of my daughters, the second oldest, works at the Crisis Centre and she told us that you should be able to do something. You could do this, you could do that. She is trying to help in her way, she said there are certain places that you could turn to, but she didn't know exactly where. She couldn't tell me exactly what to do (1).

Self-help

Self-help groups are normally aimed at improving one's own situation, however, schizophrenia self-help groups are usually focussed toward the families of people with the illness (Monking 1994:149).

Family members spoke about their involvement with the MSS and their beliefs about what the Society should've been doing, "they should be trying to work and foster and be a lobby group for changes in the welfare act and the mental health act and the ability of parents to somehow provide for their ill offspring without fear of that money being caught by the government" (18). But these same people didn't feel that the "self help" aspect of the Society was important to them. One father said, "I'm not the type of individual who gets benefits talking to others. I mean if I need to get relief for my pain and the problems with schizophrenia I don't get it by going and siting and talking in a group of people who have similar problems" (18). Other parents stated that they did not want to hear other people's problems and "oh, woe is me", they wanted to get help for their son and wanted treatment not lamenting over their situation (17). One father stated, "realistically, you've got to get beyond the stage of just "oh woe is me" to become successful and more acceptable as an organization for research money, like alzheimers, to

get as much attention as possible" (16). A few of the families realized that for the MSS to be proactive for people with schizophrenia, it's members had to stop complaining and be more hopeful for the future. Also, some of them did not view support groups as helpful but as a group of people who would commiserate and complain about their situations as opposed to doing something about them.

Mental health services extend across a wide range of human need and as an aspect of comprehensive health care, the services should aim beyond the reduction of psychiatric symptom patterns and be actively concerned with the alleviation of the causes of human disability (Mental Health Services in Canada 1990:7). Mental health services when broadly defined, comprise of health, vocational, recreational, volunteer, occupational and educational services, as well as, income and housing support (Manitoba Health 1991, 1992). Therefore, mental health service structures need to be comprehensive, interrelated and coordinated for individuals to receive the type of support they need. In 2002, the Manitoba Minister of Health announced increased funding for mental health support programs including self-help agencies (Manitoba Government News Release May 07, 2002).

Families can face significant challenges in obtaining support and information from both professional services and self-help organizations. They are in a strategic position to identify gaps in the service system and some families felt that the self-help organization could play a more effective role in policy advocacy.

Chapter VIII

Summary and Conclusions

"Practitioners of psychiatry often speak in strong, confident voices, secure in their knowledge of pathology and their ability to re-trace history. They rarely look, however, at the profession's past mistakes and missteps. Such a collective denial does not recognize the harm that was done "back then" in the name of mental health. Instead, the focus is on the present and on the very promising, very lucrative future" (Capponi 2003:29).

Mental illnesses affect all Canadians. Approximately 20% of individuals will experience a mental illness during their lifetime, and the remaining 80% will be affected by a mental illness in family members (Health Canada 2002). The focus of this thesis was to describe and analyze the process by which some families deal with schizophrenia and cope with a relative with the illness.

Schizophrenia can be a devastating mental illness for those who suffer with it and for the many families who are coping with its effects. In the 1990's in Winnipeg, Manitoba, many families were able to access the Manitoba Schizophrenia Society (MSS) for information and support and as time progressed, more services, including vocational rehabilitation, and supportive housing were established which helped empower consumers to function independently in the community. This thesis is a description of families, both parents and siblings, coping with a relative with schizophrenia. It is based on qualitative data from interviews, document reviews, and a review of relevant literature.

This thesis adopted qualitative research methodology which is best when emphasizing the depth, richness and quality in peoples' lives especially when dealing with schizophrenia. The complexities and processes that emerged from the interviews were

best interpreted through qualitative study. "One cannot understand human behaviour without understanding the framework within which subjects interpret their thoughts, feelings and actions" (Marshall and Rossman 1989:49). How people interpret, manage, and come to understand schizophrenia is an in depth process. Interviews were a way to get people to talk about what they knew and experienced, and from this to build an understanding of this aspect of their lives.

I interviewed 30 people who were members of the Manitoba Schizophrenia Society. I did not want to try and find people via the newspaper or other methods since schizophrenia continues to be stigmatizing. People who belonged to the provincial self-help organization primarily did so because they had a relative with the illness and were willing to talk openly about their lives. Interviews took place from 1995 to 1996 and were generally open-ended conversations. Open-ended interviews were preferred since people naturally spoke for long periods of time allowing for very rich and detailed descriptions. People were relaxed in their home atmosphere and were very willing to discuss their lives.

The materials I gathered showed differences between being the parent of a person with schizophrenia as opposed to being a sibling. Parents often have more feelings of guilt since the person is their child. Siblings struggle with feelings of survivor guilt, stigma, anger and shame. Some siblings face a dilemma, one in which they have to draw the line when their own needs compete with those of their ill brother or sister (Denberg 1996:99). In my study, I found that siblings did truly care for their brother or sister in a similar way that Denberg states that some siblings attempt to rescue their relative (Ibid).

There are varying patterns of response by family members of a person with schizophrenia and these were explored in this thesis. The remainder of this chapter will discuss some of the main issues when families cope with schizophrenia.

Diagnosis

Parents of children with schizophrenia described a number of behavioural changes which they associated with the symptoms of schizophrenia including social withdrawal, bizarre thoughts, and problems concentrating at school. Different signs and symptoms often lead families to physicians who then diagnosed their child with schizophrenia. Parents would often recollect times their child was "different" and look back at these situations as signs that something was wrong, however, it is was difficult to pin point when most people became sick since it was usually a gradual process. Most parents just knew something was wrong but had no idea that it was schizophrenia.

Strange Behaviour and Genetics

Many family members had explanations for the strange behaviours of their children which often coincided with adolescent experimentation of drugs and alcohol. Most parents felt that schizophrenia had both a developmental and a causal component, and their explanations also centered around aspects of genetics and heredity."Imagine having your relatives obliquely avoid talking about the ill family member, unmistakenly implying that your side of the family is guilty of something akin to Original Sin" (Johnson 1988:xi). Many family members dealt with the shame and guilt of possibly

passing down a gene causing schizophrenia in their children (even though no schizophrenia genes have been found yet). Siblings often "studied" relatives in the family and felt that with the genetic links in their families that they were not going to have children because of the risk of schizophrenia.

Treatment

The treatment for schizophrenia has primarily focused on medications prescribed by psychiatrists (Figure 5). Only recently have psychosocial issues been recognized as important for the treatment of schizophrenia. Programs that consist of one-on-one counseling or training, group support, activity programs, and/or daily monitoring and communication with caregivers seem to be the most beneficial (see Schizophrenia Society of Canada 1999:80). Education, family involvement, social skills training, cognitive therapy, and case management positively influence the outcomes of people with schizophrenia.

Coping with violence and issues of advocacy

Many parents and siblings had dealt with violent episodes from their ill relatives. Due to disruptive behaviours parents often had to phone police and get involved with the legal system. Because of these aspects of schizophrenia, it is not easy to advocate on behalf of people with the illness. Media often sensationalize and exaggerate the few violent events where mental illnesses are involved and the public becomes very wary of anyone with schizophrenia. Public perception of mental illness is partly driven by fear:

fear of disease, fear of the unknown, and fear of violence. The devastating reality of the public's incorrect perception is its impact on those with schizophrenia and their families. Stigma has caused many families to shy away from public involvement and without powerful advocates, funds necessary to carry out research have fallen far behind those of other illnesses. Better public education programs can help to correct these misunderstandings.

Siblings

I interviewed 6 siblings. Most of the siblings did not directly care for their sister or brother until their parents were elderly or deceased. But siblings often described a caring type of relationship with their brother or sister where they made sure medications was taken, apartment rent was paid, there was food to eat, etc. Some siblings felt that their ill sibling was coddled by their parents and that their parents were putting up with too much of a burden. Other siblings had nothing to do with their ill sister or brother and this was not understood by the one who did. The siblings who were involved were usually an older sibling, very independent, with a post secondary education and good employment. They saw it as their "duty" to look out for their ill brother or sister. Literature on siblings discusses a "sibling bond" which siblings receive from the degree of access to one another (Bank and Kahn 1982). When one sibling becomes ill, the other may mourn the loss of their normal family and what might have been (Denberg 1996:99).

Mental Health System

Parents can and often do experience a loss when a child is diagnosed with a chronic mental illness such as schizophrenia. Unfortunately, their grief has not been adequately acknowledged or addressed by most clinicians. Families have not been afforded the opportunities to mourn their existing hopes, dreams, and expectations of their child. Instead their dilemmas have been considered only to the extent necessary to meet the needs of the system. Ultimately the goal should be to help families learn to live with the mental illness to the best of their ability (Collins 1996:87). Families of people with schizophrenia need continued support, information and follow-up.

Current mental health policies and practices in Canada have been affected by aspects of mental health care in Europe and the United States. Schizophrenia, perhaps since it occurs primarily in the 16 to 30 year age group, has a devastating impact on the Canadian economy and family life. Families have to deal with many challenges when dealing with the mental health system. On-going supports and services are needed since there is no cure (as of yet) for schizophrenia. People with schizophrenia often do best at part-time, time limited employment called transitional employment which Clubhouses have developed. Research on work and mental illness has shown that work programs, including transitional and supportive employment programs can increase productivity (Bell et al. 1996). People with schizophrenia, who participated in paid work, showed a significantly greater decline in symptom severity from intake to 5-month follow-up than did those with "no-pay" work (Ibid). People with schizophrenia also are entitled to disability benefits and income tax deductions which many people do not know about.

More research is needed on the specific implications of mental health reform and community-based services to those people with schizophrenia as well as their families.

Conclusion

Schizophrenia is clearly a mental illness with many components. Not only does it affect the individual, but families, society and eventually culture. Traditionally, people with schizophrenia had serious difficulties in finding their own place within the social and cultural institutions that are the common fabric of life, and a form of "social deinstitutionalization" pushed them toward psychiatric institutions and hospitals (Corin 1990:165). Schizophrenia was viewed as changing how a person related to the world, and had been described as:

> involving a loss of "natural evidence" that is a pre-conceptual understanding of the world and of oneself, on the basis of which people build more explicit meaning. Such a loss of sense of belonging to a shared universe leaves the patient without any defense before the world pressures (Ibid:159).

The detachment of the person with schizophrenia pervaded every aspect of his or her life, but a complete withdrawal from society was not always the case. Public spaces, such as restaurants and also the home environment are important, "When we asked where they prefer to stay, patients expressed a significant preference for staying at home or for going to a public space" (Ibid:176). Familiar spaces become a symbolic elaboration of the withdrawn position of the person. "It is their way of finding themselves and putting up with the outside world" (Ibid:177). It is now realized that people with schizophrenia want the same things as everyone else a home, a job, and a friend (Capponi 2003).

With the adjustment of people with schizophrenia to their new self and the family's understanding and acceptance of the illness process, a better prognosis and outcome for people with schizophrenia may be attained. The self and the meaning of that self changes for people with schizophrenia. We must adapt to these changes or somehow come to understand them without placing blame on individuals for the well being and care of people with schizophrenia.

The families' descriptions of coping with their relatives with schizophrenia provides valuable information for anyone dealing with mental illness. Families had to cope with symptoms, medications and appointments for their relatives. They dealt with barriers, whether it was finding the right doctor or medication, support services or social assistance. Many of the issues they had to deal with had negative effects on themselves - chronic fatigue, depression and other "caregiving" stress related illnesses. "One reality that makes schizophrenia a family illness rather than an individual one is the increased prevalence of illness in other members of the family" (Milliken 2001). But, families also had coping strengths and resilience as evidenced by acceptance, loyalty, trust, respect and shared values - the "family bond". They also became more knowledgeable about mental illness in general.

Families' descriptions illustrate the challenges and stresses that they endure and add to the social knowledge of coping with schizophrenia. This research may be important for understanding the advocacy role which many families take when supporting their relatives with schizophrenia.

Policy Implications

Family narratives can be used to inform future treatment in the mental health system. While previous research focused on critical and overprotective families, current researchers are starting to look at the positive force of the family. Policy and practice should focus on competency instead of the traditional help-seeking behaviour models. Emphasis would be on the positive qualities of families, and professionals could work collaboratively with families involving them in decision making and developing goals for treatment and recovery. Policymakers and therapists of all professional designations can recognize their responsibility to include the family in both planning and enacting treatment for people with schizophrenia. Mental health services need to be comprehensive, interrelated and coordinated for individuals and families.

Families may be the most important resource for people with schizophrenia and ongoing research on the origins, manifestations, course and treatment for schizophrenia is always needed.

Recovery

The concept of recovery and schizophrenia is not a new concept, but few people realize that it is possible (see Harding 2002). One does not need to be cured of an illness to recover from that illness. With the movie "A Beautiful Mind" in 2001, the public was introduced to a Nobel Peace Prize winner with schizophrenia. Dr. Nash continues to be an inspiration for many people to "come out" with their mental illness and show how they have dealt with their illness and "recovered". Aspects of recovery and schizophrenia are

now talked about and accepted as possible. With this new hope, schizophrenia is not the dreaded disease that it used to be.

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Appendix A-1 The Interviews

Person	Relation	Age	Hospital	Living	SA/Work
sister	y sister	42	2	house	SA
brother	y brother	30	3	family	SA
sister	y brother	36	5	apt.	SA
sister	y sister	43	2	family	SA
sister	o sister	47	3	apt.	CPP
sister	o brother	52*	12	just apt.	SA
* same	+ suicide				
mother and father	3 daughters	47, 45, 36	3, 2, 1	apt.,w sis, house	both
mother and father	son	52*	12	just got apt.	SA
mother and father	son	44+ heart attack	5	condo	work
mother and father	son	27	2	family	work
mother and father	son	30	4	apt.	SA
mother and father	son	22	2	family	SA
father	son	31+	3	family	SA
mother	2 sons	29+, 26	3, 4	group home, apt.	both
mother	son	32	4 cont.	hospital	SA
mother	son	27	4	trailer	both
father	son	38	10	apt.	CPP
father	daughter	33	5	apt.	SA
mother	son	20	2 cont.	hospital	SA
mother	son	45	3	house	both
mother	son	46	10	condo	SA
mother	son	32	5	apt.	both
mother	daughter	35	4	apt.	SA
mother	daughter	26	3	grp. home	SA

Legend for Appendix A-1

Person - the person interviewed

Relation - the person with schizophrenia
y - younger
o - older

Hospital - number of times hospitalized

Living - where the person with schizophrenia was residing

SA/Work - whether the person with schizophrenia was on social assistance or working or both

Appendix A- 2

The unstructured interviews were discussed within the following areas:

1. **The duration of experience with schizophrenia**
   For example, how long a person's son or daughter has had schizophrenia.

2. **The history of service utilization**
   For example, how many times the person has been hospitalized.

3. **Concerns about family well-being**
   Issues involving financial concerns, traveling, and being in public places.

4. **Issues involving the public knowledge of schizophrenia**
   Issues surrounding the stigmatization of the mentally ill was discussed.

5. **Concerns about services changes**
   Concerns involving the closing of psychiatric beds; issues and knowledge of the mobile crisis stabilization unit; and the knowledge of and usage of services which are available as well as concerns about the need for other services.

UNIVERSITY OF MANITOBA

FACULTY COMMITTEE ON THE USE OF HUMAN SUBJECTS IN RESEARCH

NAME: Ms. Andrea Klymasz

OUR REFERENCE: E94:270

DATE: November 30, 1994

YOUR PROJECT ENTITLED:

The Reconstruction of Schizophrenia: The Implications of Mental Health Reform on Families.

HAS BEEN APPROVED BY THE COMMITTEE AT THEIR MEETING OF:

November 28, 1994

COMMITTEE PROVISOS OR LIMITATIONS:

None.

You may be asked at intervals for a status report. Any significant changes of the protocol should be reported to the Chairman for the Committee's consideration, in advance of implementation of such changes.

**THIS IS FOR THE ETHICS OF HUMAN USE ONLY. FOR THE LOGISTICS OF PERFORMING THE STUDY, APPROVAL SHOULD BE SOUGHT FROM THE RELEVANT INSTITUTION, IF REQUIRED.

Sincerely yours,

Gordon R. Grahame, M.D.,
Chairman,
Faculty Committee on the Use of
Human Subjects in Research.

GRG/ll

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November 14, 1994

Dr. Gordon R. Grahame, Chairman
Human Ethics Committee
A115 Chown Building
753 McDermot Avenue
Winnipeg, Manitoba
R3E 0W3

Re: Andrea Klymasz - Ph.D. Thesis on Implications of Mental Health Reform for Families Coping with Schizophrenia

Dear Mr. Grahame:

This letter is in connection with the above mentioned study to be conducted by Andrea Klymasz.

The Society is cognizant of the scope of this thesis and has granted Ms. Klymasz permission to access the Society's membership list with the intent of sending out letters or questionnaires to further this research.

It is understood this membership list will not be used for any other purpose and will not be shared with any organization or individual(s).

It is also the expectation the results of this study will be shared with the Society in as much as it relates to the illness of schizophrenia.

Yours very truly,

Maureen Lennon-Borger
Executive Director
Manitoba Schizophrenia Society, Inc.

Manitoba
Schizophrenia Society, Inc.
3 - 1000 Notre Dame Avenue
Winnipeg, Manitoba R3E 0N3
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February 1997

To Whom It May Concern:

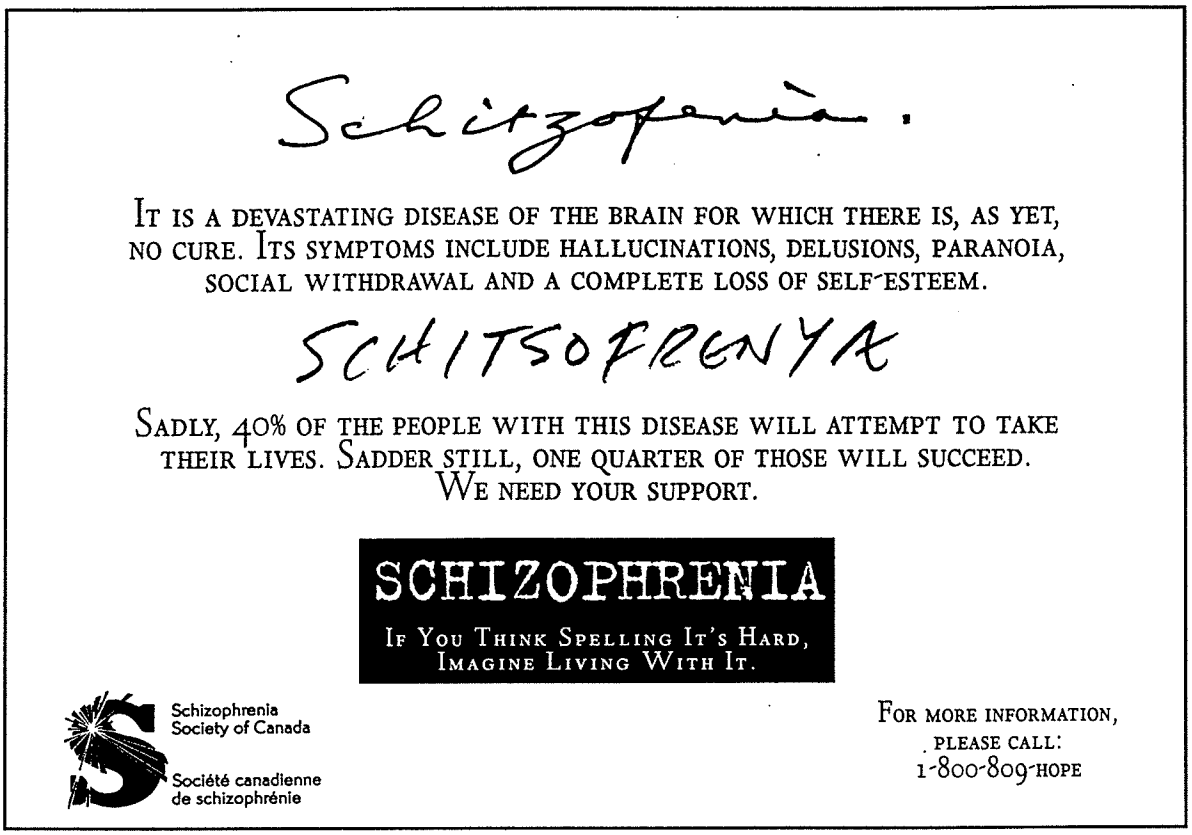
As the current executive director of the Manitoba Schizophrenia Society (MSS), I am aware of Andrea Klymasz's PhD research and I have read her thesis proposal entitled The Reconstruction of Schizophrenia: The Implications of a Self-Help Organization for Families.

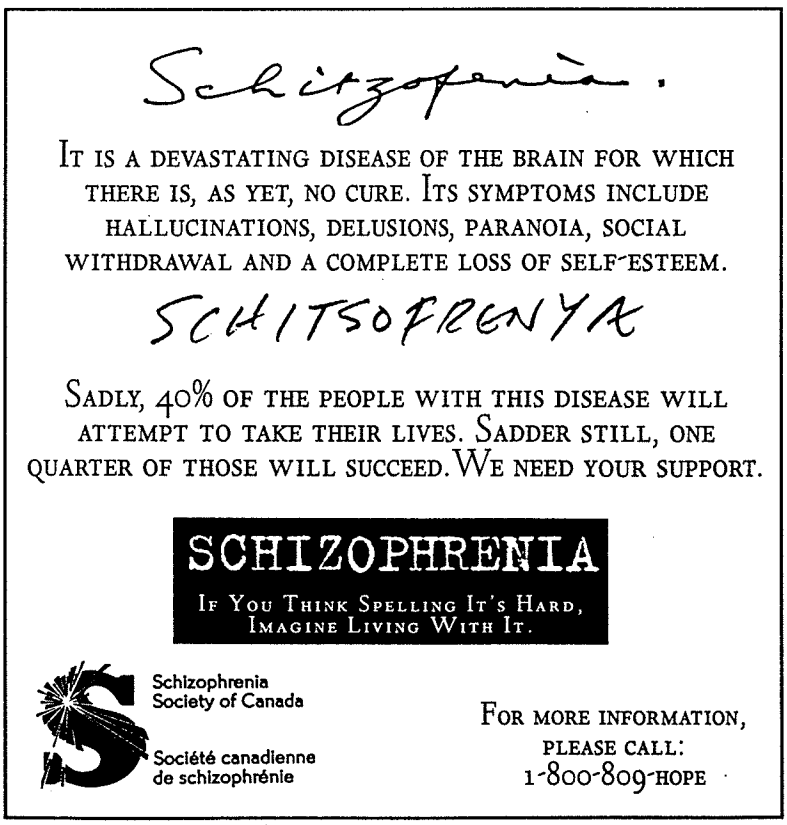
I know that Andrea has completed her interviews of randomly selected members of the MSS and that she continues to attend events and conferences related to schizophrenia.

I trust that Andrea will share her thesis with the Society when it is complete.

Sincerely,

Chris Summerville





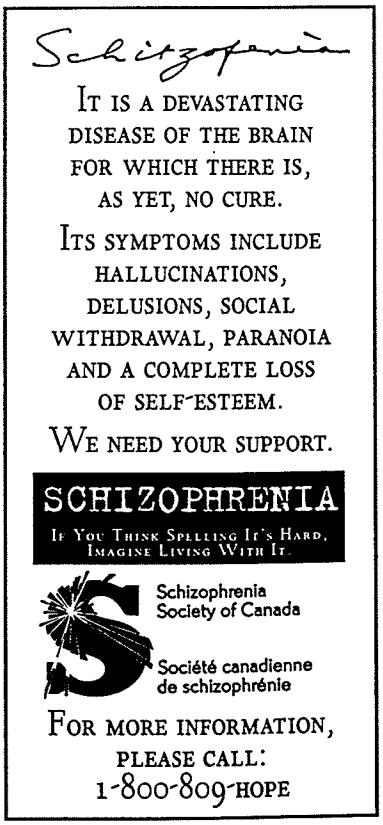


Figure 1.
Misspelling Campaign

Schitzopenia.

IT IS A DEVASTATING DISEASE OF THE BRAIN FOR WHICH THERE IS, AS YET, NO CURE.

Schizofrynea

ITS SYMPTOMS INCLUDE HALLUCINATIONS, DELUSIONS, SOCIAL WITHDRAWAL, PARANOIA AND A COMPLETE LOSS OF SELF-ESTEEM.

scizophrenia

SADLY, 40% OF THE PEOPLE WITH THIS DISEASE WILL ATTEMPT TO TAKE THEIR LIVES.

Scitzofrenia

SADDER STILL, ONE QUARTER OF THOSE WILL SUCCEED. WE NEED YOUR SUPPORT.

SCHIZOPHRENIA

IF YOU THINK SPELLING IT'S HARD, IMAGINE LIVING WITH IT.

Schizophrenia Society of Canada

Société canadienne de schizophrénie

FOR MORE INFORMATION, PLEASE CALL: 1-800-809-HOPE

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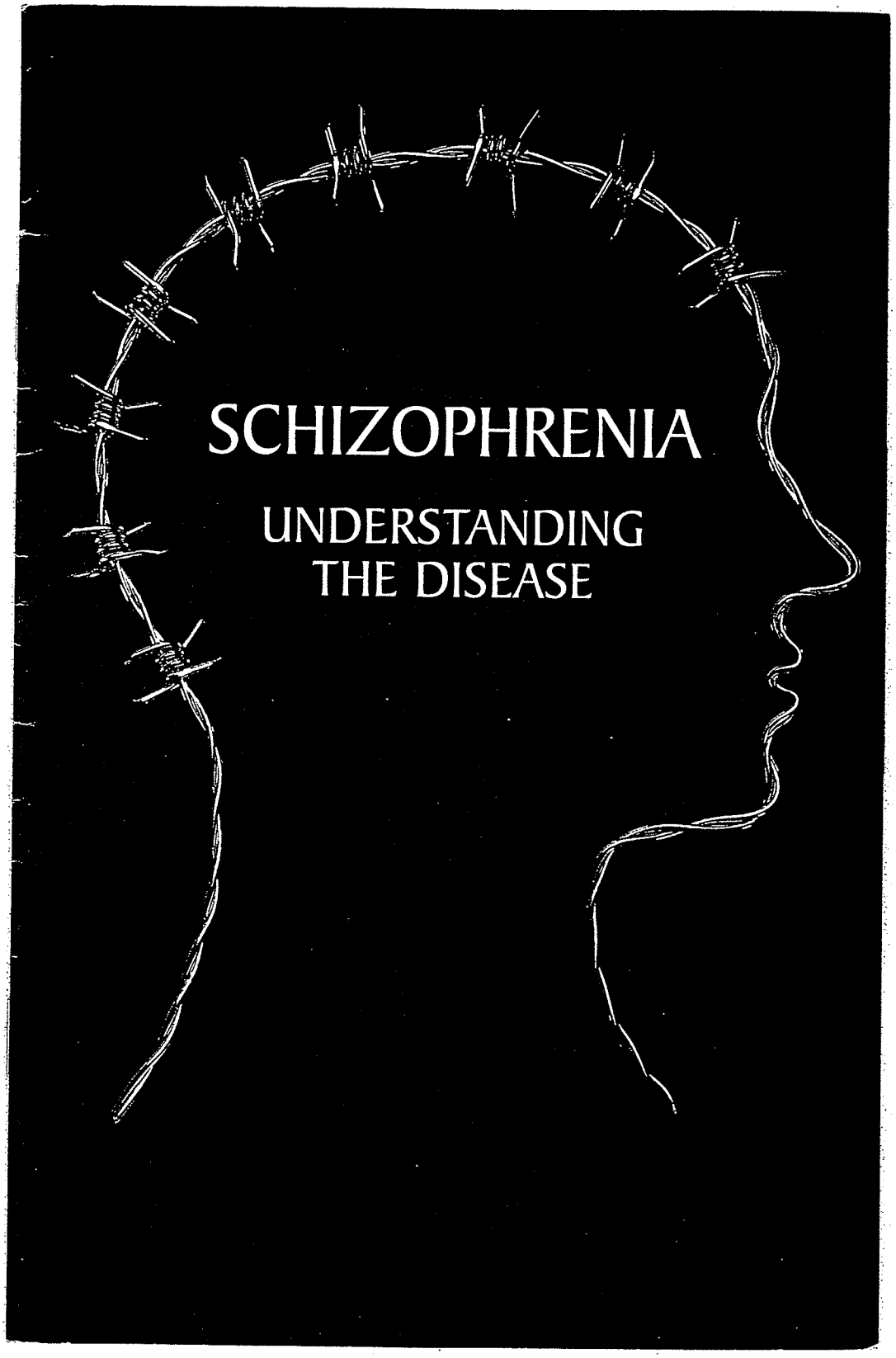

Figure 2.
Janssen-Ortho, Inc.

Figure 3.
Comic Strip

Although you've just read a comic strip, there's nothing "funny" about schizophrenia. But, there is hope for Marla and all Canadians diagnosed with schizophrenia every year.

The Manitoba Schizophrenia Society provides much needed advice and support to people with schizophrenia and their families. We extend understanding, acceptance and information to individuals, and we promote public awareness and understanding of this disease through our public awareness campaigns in the media. Through our support of research we have begun the long journey to a cure.

For information contact any of our offices listed here.

Web Site: www.mss.mb.ca
EMail: info@mss.mb.ca

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- 1000 Notre Dame Avenue
innipeg, Manitoba R3E 0N3
ıone: 1-(204) 786-1616
ıx: 1-(204) 783-4898

terlake Mental Self-Help Group
- 2nd Avenue
mli, Manitoba R0C 1B0
one: 1-(204) 642-4622
x: 1-(204) 462-4134

Brandon, Manitoba R7A 4J2
Phone: 1-(204) 725-8558
Fax: 1-(204) 728-7209

Mental Health Self-Help
320 Fischer Avenue
The Pas, Manitoba R9A 1K5
Phone: 1-(204) 623-7346
Fax: 1-(204) 623-4254

Flin Flon, Manitoba R8A 1J7
Phone: 1-(204) 687-6006
Fax: 1-(204) 687-6015

Eastman Self-Health Service
220 - 449 Main Street
Oak Bank, Manitoba R0E 1J0
Phone: 1-(204) 444-2793
Fax: 1-(204) 444-2732

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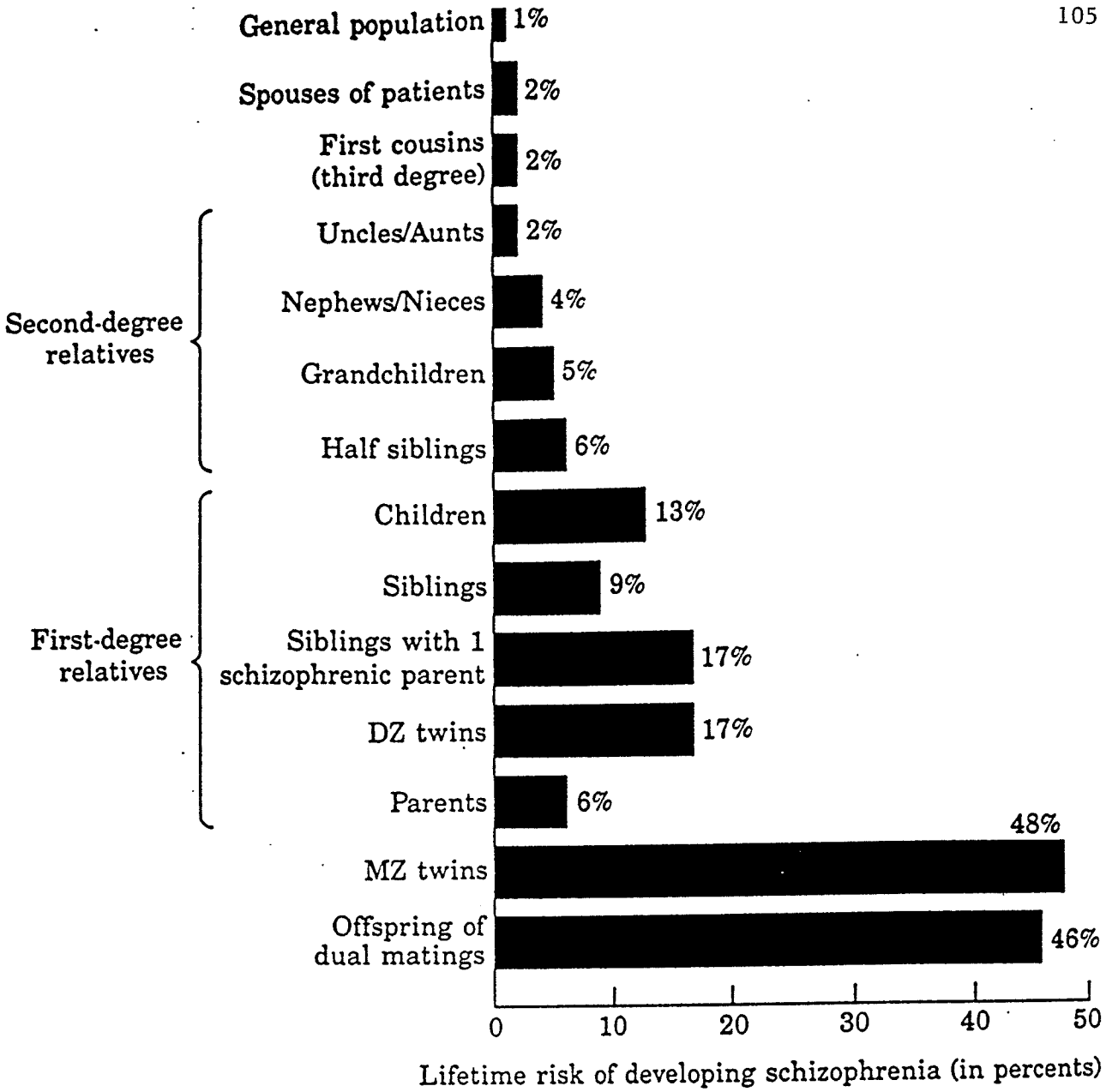

Figure 4.
Risk of Development

Grand average risks for developing schizophrenia compiled from the family and twin studies conducted in European populations between 1920 and 1987; the degree of risk correlates highly with the degree of genetic relatedness. (Gottesman 1991)

ANTIPSYCHOTIC (Neuroleptic) MEDICATIONS

ORAL

High Potency (more movement side-effects, less sedation)
Haldol (haloperidol)
Orap (pimozide)
Moditen (fluphenazine)
Stelazine (trifuoperazine)
Fluanxol (flupenthixol)

Lower Potency (fewer movement side-effects, more sedation and dizziness)
Largactil (chlorpromazine)
Nozinan (methotrimeprazine)
Mellaril (thioridazine)

INJECTABLE (long acting, "depot" neuroleptic)

Modecate (fluphenazine)
Haldol LA (haloperidol)
Fluanxol (depot flupenthixol)
Piportil (pipotiazine)
Clopixol (zuclopenthixol)
Risperdal Consta (risperidone) (2003)

"NEW" (novel) antipsychotics

Clozaril (clozapine)
Risperdal (risperidone)
Zyprexa (Olanzapine)
Seroquel (Quetiapine)
Geodon (Ziprasidone) (coming soon?)
Other in development

Figure 5.
Medications (STEP for Families, HSC 2003)