INFORMATION TO USERS

This manuscript has been reproduced from the microfilm master. UMI films the text directly from the original or copy submitted. Thus, some thesis and dissertation copies are in typewriter face, while others may be from any type of computer printer.

The quality of this reproduction is dependent upon the quality of the copy submitted. Broken or indistinct print, colored or poor quality illustrations and photographs, print bleedthrough, substandard margins, and improper alignment can adversely affect reproduction.

In the unlikely event that the author did not send UMI a complete manuscript and there are missing pages, these will be noted. Also, if unauthorized copyright material had to be removed, a note will indicate the deletion.

Oversize materials (e.g., maps, drawings, charts) are reproduced by sectioning the original, beginning at the upper left-hand corner and continuing from left to right in equal sections with small overlaps. Each original is also photographed in one exposure and is included in reduced form at the back of the book.

Photographs included in the original manuscript have been reproduced xerographically in this copy. Higher quality 6" x 9" black and white photographic prints are available for any photographs or illustrations appearing in this copy for an additional charge. Contact UMI directly to order.

UMI

A Bell & Howell Information Company
300 North Zeeb Road, Ann Arbor MI 48106-1346 USA
313/761-4700 800/521-0600

University of Alberta

REDEFINING PARENTAL IDENTITY: A GROUNDED THEORY OF CAREGIVING AND SCHIZOPHRENIA

by

Patricia Jane Milliken ©

A thesis submitted to the Faculty of Graduate Studies and Research in partial fulfillment of the requirements for the degree of Doctor of Philosophy

Department of Sociology

Edmonton, Alberta

Spring 1998

0-612-29081-6

University of Alberta

Faculty of Graduate Studies and Research

The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled Redefining Parental Identity: A Grounded Theory of Caregiving and Schizophrenia submitted by Patricia Jane Milliken in partial fulfillment of the requirements for the degree of Doctor of Philosophy.

Herbert C. Northcott, Ph.D.

Stephen A. Kent

Stephen A. Kent, Ph.D.

Wayne W. McVey, Ph.D.

Brenda C. Munro

Brenda Munro, Ph.D.

Roger C. Bland, M.B., Ch.B.

Phyllis N. Stern, D.N.S., R.N.

7 April 1998

Dedication

This dissertation is dedicated to the memory of my parents, both of whom graduated from this university. From them, I first learned about parental caregiving. From their deaths, I learned about grief.

Cauldwell Gardner Craig, M.D.
1913 - 1991

Margaret Carmichael Craig, B.A. M.D.
1917 - 1997

Abstract

In recent decades, the majority of people diagnosed with schizophrenia have lived and received treatment in the community, with periodic hospital admissions. In many cases, caring for them has become the responsibility of their families. This study examines the experience of parents who are caring for an adult child with schizophrenia.

The basic social problem (BSP) identified in this study for these parents is that, although parents typically assume responsibility for their ill child, neither the legal system, mental health practitioners, nor often the ill adult-child recognizes their right to do so. Consequently, parents come to regard themselves as disenfranchised. A grounded theory of Redefining Parental Identity traces changes in a parent's identity during the lengthy and erratic course of a child's mental illness, describing the ways in which parental identity impacts upon, and is impacted by, caregiving and grief. Stages in this process include becoming marginalized, the disenfranchised parent, embracing the collective, parental suffrage, and evaluating my life. This substantive theory is an empirical example of the formal grounded theory of "status passage" (Glaser & Strauss, 1971).

Participants were a convenience, snowball sample of 29 parent caregivers from 19 families in British Columbia, with a total of 20 adult-children with schizophrenia. Transcripts from informal interviews were analyzed by the constant comparative method of grounded theory, using the NUD*IST computer program. Information from this study will be helpful to parents of people with schizophrenia, professional practitioners, and those persons involved in mental health care reform.

Acknowledgments

As I finish my doctoral research, I am grateful to many people who encouraged me and challenged me, thus helping me to probe ever deeper into my participants' stories. No research project, even when single-authored, is accomplished alone. My very sincere thanks go to my dissertation supervisor, Dr. Herb Northcott for his patient guidance and inspiration throughout both my masters and doctoral programs. As well, I am fortunate to have had support from a very talented and perceptive committee. To Dr. Stephen Kent, Dr. Roger Bland, and Dr. Brenda Munro, I extend my heartfelt thanks. In addition, I am grateful to Dr. Wayne McVey who replaced Dr. George Jarvis, when Dr. Jarvis was out of the country during the final months leading up to the dissertation defense. I also wish to thank Dr. Phyllis Noerager Stern from the University of Indiana School of Nursing who served as my external examiner and suggested that the study is worthy of being published. Each has helped me in numerous ways to increase my scholarship and confidence.

The Department of Sociology at the University of Alberta provides a remarkable setting within which to pursue graduate studies. I am beholden to many of my professors for fostering my learning. Two people deserve special mention: Dr. Judith Golec, the Associate Chair of Graduate Studies, for her patience, encouragement, and for teaching me what I know about qualitative methods and Lynn Van Reede, Graduate Student Coordinator. Lynn takes care of all the details regarding a student's program but, more importantly, she cares for every one of us.

Part way through my doctoral program, I moved to Victoria and needed to establish contacts within the "mental health community" there. Many people helped me to do so. In particular, I want to thank Gail Simpson of the Capital Mental Health Association; Anne Bowles, Manager of Consumer, Family, and Psychosocial Rehabilitation for the Capital

Health Region; Jane Duval from the British Columbia Schizophrenia Society; and numerous helpful people from the Victoria Branch of the BCSS. As well, my research was helped considerably by permission to place requests for participants in the newsletters of the B.C. Schizophrenia Society, the Victoria Branch of the B.C. Schizophrenia Society, and the Caregivers' Association of B.C. I also thank Dr. Richard Williams who read and checked the accuracy of my descriptions of schizophrenia and its treatment.

Since moving to Victoria, I have had the privilege of being associated with the School of Nursing at the University of Victoria. The support of my colleagues there has kept me going through many long months of interviewing, analyzing data and writing the dissertation. I want to thank Dr. Anita Molzhan, former Director of the School of Nursing and now Dean of the Faculty of Human and Social Development, who hired me to teach, and also Dr. Janet Storch, the present Director. Special thanks go to Dr. Rita Schreiber who has been my grounded theory mentor for two years and to her husband, Steve Goring of Dogwood Printing and Design for help with the graphics. Rita was instrumental in organizing the Grounded Theory Club at UVic. Every two weeks, we hash out the challenges of each others' research projects and work towards learning more about grounded theory and human interaction, in general. I also thank other members of the Grounded Theory Club, including Tina Jennisen, Marjorie MacDonald, Carolyne Martin, Susan Noakes, and Valerie Watanabe.

I also want to acknowledge several of my classmates for their support and encouragement. I am especially grateful for the friendship of Barb Heather and Karen Martin in Edmonton. Karen's model of the Pathways Through Grief enabled me to understand the grief process in the context of parents of people with schizophrenia and I appreciate the permission of Baywood Publishing Company, Inc. to include that model in my dissertation. Lynn Hickey, my "partner in crime" through the Masters program, has kept me laughing during my doctoral program with her frequent emailed jokes. Thanks Lynn. I also include Marjorie MacDonald as a valued classmate. She is a doctoral student at UBC and a faculty colleague at UVic. We have worked side by side, encouraging one another and commiserating together for the past couple of years.

My family has always been my main source of encouragement, pride, and loving support. I owe a lot to my children, Derek, Megan, Bryce, and Nick, who say that they can hardly remember when Mum was not a student. To Don, my husband, I can never express enough love and appreciation for his ongoing affection and indulgence (and occasional ironing).

Finally, I must thank all the parents of people with schizophrenia who agreed to participate in this study. They have shared so much of their pain, their wisdom, and their strength with me in hopes that I will be able to make their experience more visible and better understood. I pledge to continue my efforts on their behalf.

Table of Contents

CHAPTER ONE

CHAPTER TWO

CHAPTER THREE

CHAPTER FOUR

CHAPTER FIVE

CHAPTER SIX

CHAPTER SEVEN

CHAPTER EIGHT

CHAPTER NINE

List of Tables

List of Figures

CHAPTER ONE

INTRODUCTION

> ...as time goes on, the families experience a persistent feeling of perpetual mourning caused by the loss of a beloved child who remains strangely altered–an adult child–in their midst. It is as though nature has played some cruel prank. The family cannot help but love this stranger who reminds them of another. But, often, this stranger child is hard to love (Backlar, 1994, p. 18).

Schizophrenia is a severe mental illness. For the majority of sufferers schizophrenia follows a course characterized by acute episodes involving a psychotic break with reality interspersed with variable amounts of recovery lasting for variable amounts of time. A chronic mental illness such as this is distinguished by three criteria: diagnosis, duration, and disability. Of these three criteria, disability probably has the greatest impact upon the sufferer (Bachrach, 1986b, 1988). Schizophrenia is thus a major mental disorder causing disability in the form of impaired social functioning that lasts for a protracted period, frequently for the remainder of the ill person's life.

"Functionally impaired adults with periodic needs for crisis stabilization and hospitalization and with ongoing needs for outpatient care and long-term rehabilitation" (Lefley, 1996, p. 4) are in need of caregiving. When schizophrenia is the cause of functional impairment, the family of the sufferer often assumes a caregiving role. Thus, Thorton and Seeman (1991) have called the family "the patient's safety net" (p. 38). Because schizophrenia typically strikes young individuals during adolescence or their twenties, few people with schizophrenia have married or had children before becoming ill. In subsequent years, the symptoms and social disadvantages associated with this illness ensure that very few ever find lifetime partners. As a result, the role of family caregiver is almost invariably fulfilled by the sufferer's parents.

During recent decades, attitudes toward caring for a family member with a severe mental illness have changed. Most people old enough to be parents today can remember when the mental illness of a family member was a hushed topic and people who suffered from schizophrenia spent much of their lives in the mental hospital. To understand the current position of parents caring for offspring who have schizophrenia, requires a basic knowledge of the historical background to this contemporary role of caring for mentally ill persons in the community.

The Historical Context of Caregiving in Schizophrenia

In the Western world over the past four decades, shifts have occurred in both the philosophical orientation of health care providers toward the mentally ill and the preferred mode of treatment. The result has been a progressive transition from hospital-based treatment to community care. This change was initiated by a combination of four main factors: (1) humanitarian concern for the civil rights of mentally ill persons who were detained in crowded, understaffed, and poorly funded mental hospitals; (2) criticism of the "medical model" of treatment; (3) advances in antipsychotic drugs making care outside of the hospital possible for many patients; and (4) various economic factors, including the desire to contain health care costs, the availability of disability pensions and other financial assistance for discharged patients, and a concentrated effort to shift costs among government departments and toward the private sector and voluntary social agencies.[1]

---

[1] The literature on the historical changes in the treatment of the mentally ill and, particularly, deinstitutionalization is extensive. Joan Busfield (1986) provides a

According to Scull (1976), the economic motive to control the escalating costs of large mental institutions was the primary political incentive.

In British Columbia, Riverview, the only provincial psychiatric hospital, has been reduced from 4,306 to 850 patients between 1956 and 1994. By the year 2,000 the projection is 550 tertiary care beds throughout the province, 300 of them at Riverview[2] (Ombudsman, Province of British Columbia, 1994). Bachrach (1986a) cautions against the often made but simplistic conclusion of estimating the patient population now in need of community services as the difference (4,306 - 550 = 3,446). Many additional factors must be considered, including the overall increase in population, the number of patients who are now completely cared for outside the mental hospital, and the fact that many of those discharged since 1956 have now died.

Community based care for the chronically mentally ill has proven effective where there is appropriate discharge planning in hospital, coordinated case-management in the

---

comprehensive review. Slovenko and Luby (1974), Issac & Armat (1990), and Torrey (1996) discuss deinstitutionalization and its negative consequences. Chapter 13 in Cockerham (1996) is devoted to "Community Care and Public Policy." Canadian literature, however, is more limited. Dickinson (1989) documents changes in the way psychiatry has been organized in Saskatchewan from 1905 to 1984. See also Dickinson (1994) and Regan (1987) for discussions of conflict among the various stake-holders as community programs for the mentally ill were developed in this country.

[2] In Massachusetts, Gudeman and Shore found that at least 15 persons in each 100,000 population are chronically mentally ill and not suitable for community programs. Half of these are diagnosed with schizophrenia. A further 5 of the 15 are not "dangerous to themselves or others but exhibit behavior that makes them vulnerable to exploitation and is unacceptable even in enlightened communities" (1984, p. 834). These people require asylum. The remaining 2.5 of the 15 are dangerous and need to have a secure treatment setting. Applying the 15/100,000 ratio to the B.C. population of 3,724,500 in the 1996 Census of Canada (Statistics Canada, 1997) would predict a need for 560 tertiary care beds, provided that 280 are for schizophrenic patients.

community and both formal and informal social support for both patients and their families.[3] Unfortunately, reports of the health care system abandoning the mentally ill and of the unintended consequences of deinstitutionalization are as visible in the literature as reports about successful community care. Problems of the discharged mentally ill include increased homelessness (Isaac and Armat, 1990; Torrey, 1988), inadequate housing (Mechanic & Rochefort, 1990), poverty (Lurigio & Lewis, 1989), victimization (French, 1987; Lehman & Linn, 1984), criminalization[4] (Isaac & Armat, 1990; Kramp, 1995; Sundram, 1986; Torrey, 1988), and the "transinstitutionalization" of patients being shunted from psychiatric hospitals into general hospitals or other facilities that lack appropriately trained personnel and treatment programs, such as nursing homes, board and care homes, and the jail system. Many patients seesaw back and forth from hospital admission to the community and back into the hospital via the emergency department. This cyclic admission-discharge-readmission pattern of care, referred to as the "revolving door," has meant that during their lifetime "some individuals are admitted more than 100 times" (Geller, 1992, p.1532).

---

[3] An example is the comprehensive community mental health center program in Dane County, Wisconsin (Stein & Test, 1980, Reynolds and Hoult, 1984), touted as a model for reform by both the Alberta and British Columbia health care commissions as less expensive and more effective than the state psychiatric hospital (Premier's Commission on Future Health Care for Albertans, 1989; British Columbia Royal Commission on Health Care and Costs, 1991). Programs that follow Stein and Test's PACT model (Program for Assertive Community Treatment) have been found to help families as well as patients. Chapter 14 in Isaac and Armat (1990) reviews a number of community treatment projects in the United States. Some are successful and have been reproduced in other centers; others were pilot projects without continuing government sponsorship for which ongoing funding has been a problem. Some have since folded.

[4] As the population in mental hospitals has decreased, the number of seriously mentally ill in the prison population has increased. How is it better to have these people incarcerated in prison than in a mental hospital, when appropriate psychiatric treatment programs are seldom provided in jail and psychotic prisoners are easy prey for sexual and violent abuse by other prisoners?

Statistics like these emphasize the need of some patients for asylum (Rosenblatt, 1984), in the way that mental hospitals were historically conceptualized as places of refuge and recuperation (Bachrach, 1984; Cook, 1988; Geller, 1992; Wing, 1990).

An important element, available in the asylum but often overlooked, is the patients' need for community, not just a community system of care. New levels of care are necessary (Gudeman & Shore, 1984), perhaps developed along the Fountain House[5] (Beard, Propst & Malamud, 1982; Torrey, 1997) or PACT model[6] (Isaac & Armat, 1990; Stein & Test, 1980) that give the mentally ill an opportunity to interact with others (Slovenko & Luby, 1974).[7] To date, this type of facility is scarce and "deinsititutionalization remains an unfulfilled promise" (Mechanic & Rochefort, 1990, p. 324). In the community, people who have schizophrenia are not finding much opportunity for friendship or for refuge and recuperation. Instead, they are multiply disadvantaged by poverty, inadequate housing, unemployment, disability, and pervasive social stigma.

A major consequence of deinstitutionalization has been to transfer responsibility for the care of the mentally ill from professionals to inadequately prepared lay people—in

---

[5] Fountain House is a club house model of psychosocial rehabilitation open every day of the year, developed in 1948 in New York. Members are individuals who have been disabled by mental illness. The model includes day, evening, and weekend programs that provide pre-employment skills training and transitional employment in addition to social support and relaxation. Usually an apartment complex is attached. All programs and functions of the club are organized and administered jointly by members and staff.

[6] PACT stands for Program in Assertive Community Treatment and is sometimes referred to as the Dane County model (see footnote 3). Continuous treatment teams of mental health professionals take full responsibility for the clinical, housing, and rehabilitation needs of their clients. For the most part this support occurs in the client's home or place of work, rather than the mental health professional's office.

[7] Bachrach (1984) cautions that service planners must consider the cultural relevance of programs to specific communities. Successful programs developed in one community may require some modifications before they will prove successful in another community.

particular, the families of the mentally ill. Although the public cost of keeping thousands of seriously mentally ill persons in government-run psychiatric hospitals has decreased with deinstitutionalization, the private costs to the families of those with serious psychiatric illness have grown, both in financial terms and, perhaps more importantly, in personal and social terms.[6] These personal and social costs are often aggregated under the term, "caregiver burden."

Developing A Study of Caregiving and Schizophrenia

This research began with an interest in exploring the concept of burden and how it affects caregiving by parents for their sons and daughters who suffer from schizophrenia. In particular, because a previous study (Reinhard, 1991) identified grief as one of only two[7] statistically significant dimensions in a composite index of subjective caregiver burden, I became interested in learning more about the grief felt by these mothers and fathers and its effect on their caregiving. In essence, I wanted to know more about reciprocal influences

---

[6] Franks (1990) estimated that family members spend an average of 81 hours per month, when their relative is severely mentally ill. A 1996 study of 44 members of the Schizophrenia Society of Victoria found that caregivers spend an average of $131 and 13.5 hours in one week to care for an ill relative. Whether or not the schizophrenic person lived with the family had no statistically significant effect on either the amount of money or time spent. As family income increased so did the amount of money and time invested in caregiving, but only up to the $35,000 income level. An interesting result of this study is that those patients who used drugs and were hostile to others, including the caregiver, were also more likely to live in the caregiver's home (Domic, 1996). An American study (Clark, 1994; Clark & Drake, 1994) estimated the financial cost to families of looking after a mentally ill member who also has a substance disorder (i.e., a dual diagnosis) and who lives in the family home to be $335.28 (U.S.) per month. For patients who live apart from the family, caregiving expenses were not much less: $307.15. The number of hours spent on caregiving over a 2 week period was 38.75 if the person lives at home and 16.72 if the relative lives elsewhere.

[7] The other significant factor was worry over who would care for the mentally ill relative when the present caregiver died or was no longer able to provide care.

between caregiving and grief. Does caring for a child with schizophrenia influence caregivers' grieving and does their grief impact upon their caregiving, and, if so, how?

Theorists have proposed various models of grief, portrayed as a series of emotional stages through which grieving persons progress. My hypothesis was that grieving for someone who is not dead, but who because of a serious psychiatric illness has changed significantly and not for the better, is unlikely to follow the same course as accepted theoretical models describe.

Purpose of this Study

The goal of this study was to arrive at a comprehensive understanding of how schizophrenia influences grieving and how grief impacts upon both caregiving and the subjective perception of burden, in the experience of parents who are caring for a relative with schizophrenia. To fully explore personal experience requires an interpretive research methodology, the intent being to avoid applying a preconceived system of classification and, therefore, imposing predetermined ideas about the phenomenon of interest upon the data. I chose the perspective of grounded theory and the use of its constant comparative method, which were initially conceptualized by Glaser and Strauss (1967). This is a systematic approach to developing inductive theory to explain complex social processes. Data collection was accomplished by interviewing parents who identified themselves as caregivers for their schizophrenic children[10] who were living in the community.

---

[10] The person with schizophrenia is referred to as a child to denote the kinship relationship to the caregiver. In fact, these persons are most likely to be adults or young adults.

The Research Question

The primary question for this study was:

What is the extent of grief and its impact upon caregiving, for parents of persons with a diagnosis of schizophrenia?

The above question subsumes sensitizing concepts (Strauss & Corbin, 1990) that generated the following supplementary questions that helped to formulate the semi-structured interview schedule (Appendix 1):

- What are the positive and negative consequences of caring for a child who is diagnosed with schizophrenia? How are these consequences related to caregiver burden?
- How do parents of people with schizophrenia describe and cope with the ways in which their child has changed?
- How do parents describe and cope with the ways in which their own lifestyle has changed?
- Do parents of people with schizophrenia experience grief and, if so, how do they describe it?
- Who cares for the caregivers of people with schizophrenia?
- Do family caregivers of schizophrenics mourn and, if so, how do they understand and communicate their mourning?

Significance of the Study

A more thorough understanding of caregiving for people with serious mental illnesses is urgently needed as health care professionals, policy-makers, and administrators must deal with the largely unforeseen but often tragic consequences of deinstitutionalization for both patients and their families. Knowledge of how caregiving changes the lives of families of patients with mental illness is essential in planning for better psychosocial rehabilitation programs and services. To this end, the Canadian Alliance for Research on Schizophrenia has called for psychosocial research "to evaluate the concrete and complex interactions of specific families in order to identify positive attributes which could, in turn, predict improved outcome" (1994, p. 14). This study's findings will help families learn about the intricacies of living with schizophrenia.

The outcomes of this study will inform researchers whose interests include grief, caregiver burden, and quality of life issues. Grief theorists are beginning to look at the experience of grief not only as a reaction to death but also to various other types of loss. Until now, no theoretical models address the loss of a child who is still alive but who has become an essentially different person as the result of a mental illness. Caregiver burden (as it applies to the mentally ill) has not yet been defined in any generally accepted way, nor have researchers agreed upon a standard way to measure the concept. By analyzing the stories of parent caregivers, I expect to discover conditions that contribute to their subjective experience of burden and ultimately to expand our understanding of the constituent factors of caregiver burden. Finally, this study investigates the relationship between the quality of life of parents of schizophrenic adult-children and their caregiving experience.

CHAPTER TWO

LITERATURE REVIEW

Grounded theory is an inductive process of discovery (Glaser & Strauss, 1967). Therefore, the literature search is conducted after the majority of data collection and analysis are completed to avoid forcing the analysis to conform with preconceived concepts (Glaser, 1978; Strauss, 1987). The purpose of the literature review is not to formulate hypotheses for testing but, rather, to support the emerging theory (Hutchinson, 1986).

In recent years, however, Glaser and Strauss developed divergent opinions in this regard. Glaser continued to insist that "there is a need not to review any of the literature in the substantive area under study" (Glaser, 1992, p. 31), although researchers should read literature from other academic disciplines to sensitize themselves to ideas. Strauss recognized, however, that no researcher enters the field without some prior knowledge of the literature. Therefore, his approach to "sensitizing concepts" (Blumer, 1969, p. 147, 148) was different. Although initially, an extensive initial review is not done, researchers do bring to the field significant concepts and relationships from related studies to help them identify what to look for in their own data. Strauss and Corbin (1990) emphasized that the data must be critically examined during analysis for actual evidence of these sensitizing concepts. Despite these divergent views, both Glaser and Strauss have advised that a major literature review in the substantive research area should be undertaken after the core concept has been discovered, to integrate the literature with the emergent theory (Glaser, 1992).

Following Strauss's approach, some background understanding of schizophrenia, caregiver burden, and grief was gained before embarking on this study. Then, during the process of analysis and writing, further reading in these and related subject areas was undertaken to expand my understanding.

Schizophrenia

A general definition of schizophrenia is just that—very general:

> ...any one of a large group of psychotic disorders characterized by gross distortion of reality, disturbances of language and communication, withdrawal from social interaction, and the disorganization and fragmentation of thought, perception, and emotional reaction (Anderson, Anderson & Glanze, 1994, p. 4000).

To fill out this definition, a review of the literature examining the epidemiology, symptoms, etiology, treatment, and outcome of schizophrenia was undertaken.

Epidemiology

Schizophrenia is a common disorder affecting one percent of the population at some time during people's lives (Cockerham, 1996; Jeffries, Plummer, Seeman & Thornton, 1990; Walsh, 1985). In 1992, the president of the Canadian Psychiatric Association estimated the Canadian prevalence at 250,000 persons (Gosselin, 1992). Torrey (1995) suggests a lifetime prevalence[1] of 1.5%. Because statistics are generally collected from hospital populations, the true lifetime prevalence may be even higher, up to 3% (Thornton & Seeman, 1991). Epidemiological Catchment Area[2] lifetime prevalence estimates for schizophrenia are 0.72% in the United States (Torrey, 1995) and 0.6% in Edmonton (Bland, Orn & Newman, 1988).

---

[1] Different authors appear to define lifetime prevalence differently. Bland (1988b) defines lifetime prevalence as a cumulative measure of the proportion of the population who have ever been diagnosed with a disorder. This is the measure used by the Epidemiological Catchment Area studies. The figure of 1/100 probably is what Bland defines as morbid risk or expectancy: the chance of a person developing a disorder during his or her lifetime.

[2] The Epidemiological Catchment Area Study was a survey of mental health and illness in 5 university cities and their surrounding counties in the United States: New Haven

The mortality rate for schizophrenics is twice that of the general population (Geller, 1994; Newman & Bland, 1991) and life expectancy is 20% shorter (Newman & Bland, 1991). Suicide for Albertans with schizophrenia is 20 times the expected rate, higher for men than women (Newman & Bland, 1991), and attempted by 30% of those with chronic schizophrenia (Geller, 1994). A review of suicide risk research found that for people with schizophrenia the risk of suicide ranges from 15 to 75 times that of the general population (Health Canada, 1994). Thus, for a substantial proportion of patients, schizophrenia is a terminal illness.

World wide and racially, the overall prevalence is similar,[3] but geographic pockets exist of higher and lower prevalence (Thornton & Seeman, 1991). Opinions differ as to why these pockets occur. The appearance of higher prevalence in urban areas and among the lower social classes is explained as an artifact of the downward economic drift of schizophrenics and their movement into inner city areas. Few people with schizophrenia are fully employable[4] and family finances are strained by the long term course of the illness. The disease affects both sexes in equal numbers, although usually males are diagnosed earlier in

---

(Yale), Baltimore (Johns Hopkins), St. Louis (Washington), Durham, NC (Duke) and Los Angeles (UCLA) (Cockerham, 1996). This study was a cooperative effort, conducted from 1980 to 1985 and funded by the National Institute of Mental Health (NIMH). The Edmonton study, using the same instrument, the Diagnostic Interview Schedule, surveyed 3,258 residents within the city limits between January, 1983 and May, 1986.

[3] Cross cultural statistics show lower prevalence rates in developing countries, which has lead some investigators to imply a causal relationship between developed (Western) cultures and schizophrenia. Sartorius and de Girolamo (1991) refute this conclusion, predicting that as infant and child mortality decreases with economic development, more individuals will survive into adolescence and young adulthood, the age of greatest risk of schizophrenia.

[4] One study found that people with schizophrenia were 3.8 times as likely to be unemployed as they were to be employed (Bland, Stebelsky, Orn, & Newman, 1988).

their late teens, as compared to the mid-twenties for women. Males also tend to display more severe symptoms, more negative symptoms[5], and be less responsive to pharmacological treatment, thus suffering a poorer outcome. Females, in contrast, are more likely to have a family history of schizophrenia. These gender differences may reflect differences in brain abnormalities (Pearlson & Pulver, 1994).

Symptoms of Schizophrenia

According to the conventional classification (Jones, 1992; DSM-IV), symptoms are categorized as either positive or negative. Positive symptoms generally describe an exaggeration or distortion of normal functions, whereas the negative symptoms describe reduced function. The positive symptoms can be subdivided further into psychotic and disorganized dimensions. Psychotic symptoms include hallucinations (distorted perceptions involving any of the five senses) and delusions (unrealistic and unfounded beliefs). Auditory hallucinations, in which the voices that patients hear are usually threatening or disapproving, are particularly prevalent. Common delusions are of grandeur, of being persecuted, of being controlled, or of having one's mind read. Consequently, patients with schizophrenia will, from time to time, have a markedly different view of reality from that of the people around them and their behaviour will reflect these often frightening perceptions.

Disorganized symptoms include bizarre appearance or behavior, hostility and aggression, and incoherent, illogical and/or disconnected thoughts and speech. Cognitive disturbances, i.e., problems in processing information, may include an inability to

---

Rutman (1997) estimates that between 85% to 90% of identified former mental patients are unemployed.

[5] Various categories of the symptoms of schizophrenia are outlined in the next section of this thesis.

concentrate. People who have schizophrenia may be bombarded with ideas at such a rapid rate that it becomes impossible to focus on anything or sort out what is relevant from what is not. Memory and abstract thinking, i.e., logic, can be affected. Speech tends to reflect the sufferer's disturbed thoughts and may be rapid, jumping from one topic to another (National Institute of Mental Health, 1986).

The negative symptoms of schizophrenia include inappropriate affect (the display of emotions that are inconsistent with the occasion), flattened affect (diminished emotions or emotional reactions), alogia (lack of or inadequate communication), poor attention (inattentiveness and impaired concentration), anhedonia (inability to experience pleasure from activities or social relationships), and apathy and avolition (physical inertia and an inability to persist with activities). This last symptom includes impaired grooming and hygiene. Until recently, drug therapy improved the positive symptoms only. New medications, clozapine being the first, offer the promise of reducing negative symptoms as well.

Not all patients suffer from all of the symptoms. Liddle (1996) identifies a number of sub-types of schizophrenia with characteristic symptom groupings. Not all patients, however, conform to these subtypes. As well, many of the symptoms also indicate other mental illnesses and no one symptom is both necessary and sufficient for a definitive diagnosis. In addition, for the majority of the time, most patients are at least partially in touch with everyday reality and thus may behave normally or hide their symptoms from others. For these reasons, diagnosing schizophrenia is complex.

For a diagnosis of schizophrenia, the following three criteria must be met (DSM-IV, 1994):

Criterion A: At least two of the five symptom classifications must be experienced concurrently for at least one month. These are delusions, hallucinations, disorganized speech, grossly disorganized behavior, and negative symptoms.

Criterion B: Marked social or occupational dysfunction, affecting interpersonal relations, work or education, or self-care.

Criterion C: Persistence of recognizable symptoms for at least six months.

Etiology

If the combinations and permutations of symptoms make schizophrenia difficult to identify, the causal explanations, both medical and social, are equally complex. No single cause of schizophrenia has been identified. Schizophrenia appears to result from the interplay of many factors, both physiological and environmental.

Physiological Explanations

Andreasen (1996) reviewed various research initiatives. There is controversy about whether schizophrenia is a single disease, a group of disorders, or a syndrome with dimensions reflecting different pathophysiological processes (Liddle, 1996). Researchers have discovered a number of abnormalities in brain development, in the neural pathways, in neurochemistry, and in genetics. For example, at the time of diagnosis, people with schizophrenia have larger cerebral ventricles, a smaller brain size and weight, and a variety of other structural abnormalities. As the disease progresses, however, further degeneration of the brain is no greater than that which would be explained by normal aging. For this reason, some researchers have hypothesized that schizophrenia is a developmental abnormality[6] which is possibly triggered by sex hormones or some other process at or around the time of puberty. Abnormalities in the pre-frontal cortex and its associated connections to other parts of the brain have also been found in some cases of schizophrenia. These are associated with reductions in some of the higher cognitive functions and, presumably, with the negative symptoms of schizophrenia. Neurochemical transmitters, in particular dopamine and serotonin, are implicated because of the mechanisms and effectiveness of various drug treatments. Finally, there can be no question after decades of twin studies[7] that there is a genetic influence in schizophrenia, although the possibility of locating the tendency to develop schizophrenia on a single chromosome is slim (Andreasen, 1996). Given the large amount of evidence, it is difficult to argue against a physiological explanation for schizophrenia, although the ultimate cause or causes of these abnormalities remain largely speculative.[8]

---

[6] Torrey (1995) cites five types of research pointing to the origin of brain abnormalities in schizophrenics before birth or very shortly afterward. Studies have found an excess incidence of schizophrenia among persons born following a complicated pregnancy or delivery, people with minor physical abnormalities, mainly of the hands and feet, particular fingerprint patterns, and neurological evidence of questionable brain development. A popular theory is that schizophrenics are proportionately more likely to be born during the winter but an Alberta study (Bland, 1988a) found no risk associated with the season of birth.

[7] Torrey, Bowler, Taylor & Gottesman (1996) report an extensive six year study of mental illness in 66 pairs of twins. The study ended in 1992. Their book also reviews the history of twin studies on mental illness.

[8] Even dietary influences have been proposed, particularly in regard to the high prevalence of schizophrenia in Ireland. Several hypotheses place the blame on (1) toxic insecticides, (2) solanine, an alkaloid produced when potatoes are exposed to sunlight and which can produce psychotic symptoms, or (3) dopachrome, related to dopamine, which increases as potatoes age (Walsh, 1985).

Environmental Explanations

A number of social explanations for schizophrenia have been offered over the years. For example, some sociologists have subscribed to labeling theory, while other explanations are more psychological in origin, assuming a psychodynamic perspective and attributing schizophrenia to environmental stress arising out of family dynamics. Psychoanalytic theory emphasizes that early experience shapes behavior and, although Freud recognized an organic source of schizophrenia (Isaac & Armat, 1990), his followers have blamed child rearing and family interaction. A review of the important environmental etiological concepts of schizophrenia must therefore include labeling theory, the schizophrenogenic mother, marital schism and skew, the double-bind hypothesis and expressed emotion.

Labeling Theory and the Anti-Psychiatry Perspective

In 1951, Lemert postulated that when a person's misbehavior (primary deviance) is negatively labeled by others, people respond to the deviant person in terms of that label. Internalized as part of the individual's self-concept, the label then determines his or her subsequent behavior (secondary deviance). When labeling theory is applied to mental illness, misbehavior becomes defined as "crazy" when "residual rules" (social conventions that are deemed to be natural or a part of human nature) are broken (Scheff, 1966/1984). Thomas Scheff explains that people learn a stereotype of mental illness during childhood. Scheff contends that although a tendency exists to normalize aberrant behavior among intimates, the stereotype is applied and hospitalization is sought if the misbehavior becomes public. Particularly when the label of insanity is applied by someone in authority, it becomes an accepted "master status" (Hughes, 1945; Becker, 1963) and the person is "launched on a career of 'chronic mental illness'" (Scheff, 1975, p. 10, cited in Cockerham, 1996, p. 20) and becomes permanently stigmatized (Goffman, 1961, 1963) as a psychiatric patient. Gove reviews a number of studies of the mentally ill and criticizes this view, stating that, in the short run "a person's behavior determines the expectations of others to a much greater degree than the reverse" (1970, p. 71). He recognizes, however, the influence of labeling in determining the need for rehospitalization, although he contends that labeling theorists have overemphasized the importance of secondary deviance.

Labeling theory rests upon rejection of the medical model of psychiatric illness. Important to this view are assertions from two influential renegade psychiatrists, R. D. Laing and Thomas Szasz. In particular, Szasz (1974) claimed that because there is no physical evidence of disease, mental illness cannot even be called an illness. Instead, he asserted that psychiatric symptoms result from "problems in living." They are subjectively defined as illness by psychiatrists because the symptoms of mental illness conflict with dominant social values. Therefore, according to Szasz, a psychiatric diagnosis is a social judgment used for the social control of culturally inappropriate behavior. Laing (1969) agrees that mental disorders do not constitute disease. According to Laing, social, political, and economic circumstances are so intolerable that some people dissociate themselves from their environment. The medical profession then defines their reaction as a mental illness. His statement that "schizophrenia is a sane response to an insane world" (Cockerham, 1996:86) has been widely quoted and was germane to the development of the anti-psychiatry perspective in sociology and other social sciences.

Studies that support this opposition to psychiatry have highlighted the ambiguity of psychiatric symptoms and the inconsistent application of psychiatric diagnoses. The most frequently cited study is that of Rosenhan (1973a), a psychologist, whose associates were admitted to psychiatric hospitals on the strength of hearing voices. Once admitted, they ceased reporting any symptoms but their behaviour continued to be viewed as symptomatic.

An average of nineteen days elapsed before they were discharged, not as cured but as "in remission." Publication of Rosenhan's study produced a flurry of critical response (Blair, 1973; Burr, 1973; Fleischman, 1973; Hanley, 1973; Hoaken, 1973; Hunter, 1973; Israel, 1973; Lieberman, 1973; Ostow, 1973; Pattison, 1973; Pinsker, 1973; Reich, 1973; Thaler, 1973; Weideman, 1973; Zucker, 1973) citing his flawed method, ethical dishonesty, placing of his subjects at risk, inconsistent and contradictory conclusions, and his lack of knowledge about schizophrenia — in particular, the fact that people with schizophrenia are not floridly psychotic all the time and often settle down once admitted to the hospital. Rosenhan's (1973b) rebuttal fails to address most of these concerns, concentrating instead on the difficulties of diagnosing an illness without biochemical laboratory tests.

Another classic and often quoted example is Ash's (1949) study which revealed that psychiatric practitioners agreed with one another's diagnoses only 45.7% of the time. Another study by Kendall et al. (1971) compared British and American psychiatric diagnoses. Both groups observed the same videotaped behaviour but, while 62% of the American psychiatrists diagnosed schizophrenia, only 2% of the British psychiatrists did. According to Matarazzo (1983) developments within psychiatry, such as standardized interview schedules for taking psychiatric histories and diagnostic criteria for the various disorders (DSM II and then DSM III), have markedly improved the inter-rater reliability of psychiatric diagnosis. The DSM-III field trials yielded an inter-rater reliability of 82% for schizophrenic disorders.

The Schizophrenogenic Mother

Fromm-Reichmann (1948) contributed the theory of the schizophrenogenic mother, that is, that mothers who were cold and distant appeared to reject their children. These children allegedly grew up lacking the affection necessary to develop social and psychological skills. The theory was influential, although never empirically supported, but Hatfield (1987) states that its influence has weakened over time.

Marital Schism and Skew

Lidz and his associates (Lidz, Fleck & Cornelison, 1965, Hatfield, 1987) proposed the theory of marital schism and skew that blamed both parents for creating families characterized by emotional upheaval. Schism is a state of chronic upset, while skew refers to one parent continually giving in to the other to achieve an appearance of harmony. Although he did not have a control group, his twelve year investigation of only seventeen families (Walsh, 1985) continues to influence the approach of some professionals to treatment (Hatfield, 1987).

The Double Bind Hypothesis

The double bind hypothesis (Bateson et al., 1956, Cockerham, 1996) centered on communication in families. Children who are continually faced with having to choose between two or more ambiguous messages, usually between two "no-win" situations both of which are liable to result in punishment (Walsh, 1985), will "eventually behave as if they have lost the ability to discriminate" (Hatfield, 1987). Torrey (1995) notes that Bateson's theory was never statistically tested. He concludes that, in addition to having no scientific basis, family interaction theories are tautological. They "fail to distinguish family interactions which cause schizophrenia from those *caused by* schizophrenia" (p. 170).

Expressed Emotion

A final theoretical perspective within the environmental paradigm notes that a high level of expressed emotion, referred to as EE, is observed in the families of schizophrenics (Brown, Birley & Wing, 1972; Cole & Kazarian, 1993; Vaughn & Leff, 1981). Originally conceived as measuring warmth,[9] hostility, criticism, and emotional overinvolvement of family members towards the mentally ill person, expressed emotion usually was assessed during an interview when the ill person was being admitted to hospital. High levels of expressed emotion were found to predict more frequent relapse, although subsequent studies have found EE to affect relapse in males more often than in females (Goldstein, 1987; Hogarty, 1985). Consequently, considerable research has focused on developing family treatment interventions, especially education programs, to reduce EE in families of the mentally ill (Brooker, 1990a, 1990b; Falloon & Pederson, 1985; McCann & Clancy, 1996). Such courses have proven effective in lowering the relapse rate.

The relationship between EE and relapse and rehospitalization is more complicated than early studies would indicate. The causal direction may be reversed or bi-directional (Rosenfarb, Goldstein, Mintz, & Nuechterlein, 1995), i.e., living with someone who is severely mentally ill increases the emotion level of family members. Alternatively, the correlation may result spuriously from other factors, such as medication non-compliance (Charlesworth, Sacks, Templer, & Thackrey, 1993; Goldstein, 1987)). Clinically, lowering expressed emotion in some families may have a detrimental effect, inadvertently increasing the ill person's negative symptoms when parents become less stimulating and afraid to set firm rules for behaviour (Gottschalk & Keatinge, 1993; Hatfield, Spaniol, & Zipple, 1987).

Hatfield and her colleagues (1987) remind us that EE blames families for their ill child's outcome and that researchers should investigate other environmental predictors as well. For example, Hunter and Storat (1994) have identified three major stressors implicated in precipitating relapse: a change in the patient's living arrangement, a physical illness that

---

[9] Later, warmth was removed from the expressed emotion scale because of its inconsistent correlation with relapse (Gottschalk & Keatinge, 1993).

changes the physiological response to medication, and a lack of understanding on the part of both professional and lay caregivers of the meaning behind the patient's bizarre behaviour.

Given the number of theories that blame families for either causing or exacerbating the illness of people diagnosed with schizophrenia, it is remarkable that a number of studies show lower rehospitalization rates for those mentally ill people who have more frequent contact with their relatives (Avison & Speechley, 1987). Nevertheless, the professional interest in expressed emotion has led to an increased focus on developing family interventions and education programs.

Treatment of Schizophrenia

The treatment program for schizophrenia generally consists of a combination of medication and psychosocial approaches. Where families are involved, a three-pronged program combining (1) medication, (2) psychosocial rehabilitation for the patient, plus (3) a psychoeducational treatment program for family members has proven most effective (Schooner, 1995).

Medications

For forty years, antipsychotic medications, also called neuroleptics, have been the "cornerstone of treatment" (Remington, 1995) for schizophrenia. Neuroleptics control the positive symptoms by reducing the transmission of dopamine in the nerve pathways in the brain. They are less effective, however, for the negative symptoms and may increase these in some people. Generally antipsychotics produce sedation, sometimes memory problems, and a number of other uncomfortable side effects. One of the most uncomfortable is akathisia, which incorporates (objectively) restlessness and jitters and (subjectively) anxiety. Others include having a dry mouth, blurred vision, various movement disorders,[10] and symptoms mimicking Parkinson's Disease, such as muscle tremors and rigidity, shuffling gait, stiffness of arm movements and drooling. These are frightening to patients, although they can usually be controlled with medication. Unfortunately, people respond differently to the neuroleptics, thus dosages must be individually calibrated and then frequently readjusted. Establishing the correct dosage "that keeps target symptoms under control without undue side effects is an art as well as a science" (Thornton & Seeman, 1991).

Many patients find the side effects, particularly akathisia (Remington, 1996) too difficult to endure. Consequently, non-compliance, that is, patients refusing to take their medications, is a problem. Studies estimate the rate of noncompliance at between 15% and 30% for patients in the hospital and from 20% to 65% after discharge (Remington & Adams, 1995). For this reason, many people are maintained on long-acting injectable medications, called depot neuroleptics, rather than oral medications. Depending on the drug used, patients receive their injections at intervals ranging from one to four weeks (Remington & Adams, 1995), provided they attend their appointments.

Recent neurochemical research has shown that dopamine blockage is only the beginning of effective treatment for schizophrenic psychosis. Consequently new drugs have been developed that block serotonin (also called 5-HT) preferentially to dopamine. In addition to controlling positive symptoms, these atypical or novel neuroleptics appear to control negative symptoms significantly and with fewer side effects. To highlight the complexity of medication management, new research shows, firstly, that there may be

---

[10] Long-term treatment on some antipsychotics may cause tardive dyskinesia, characterized by involuntary movements of the lips and tongue, such as sucking and lip smacking, as well as difficulty swallowing and a stiff neck.

numerous neurotransmitters involved in the limbic system[11] of the brain and, secondly, that blocking dopamine transmission, while reducing positive symptoms, may also accentuate the negative symptoms originating in the prefrontal cortex (Remington, 1997).

Psychosocial Rehabilitation

Psychosocial care consists of long term support and training aimed at increasing the patients' independence, enhancing their self-esteem, and improving their social functioning. The goal "should be to help each patient attain the best possible adaptation to his or her illness over the course of a lifetime" (Minkoff, 1987). Traditional and/or non-traditional psychotherapy to discuss thoughts, feelings, relationships, and problems comprise the psychological part of the patient's treatment. By assisting him or her to "sort out the real from the unreal and distorted" (National Institute of Mental Health, 1986), psychiatrists and psychologists may help the individual come to terms with having a psychotic illness.

Learning to live with the illness comprises the social rehabilitation aspect of care. Usually a team of mental health professionals offers a variety of programs to improve social skills, provide assistance with daily living, and give vocational training and counseling, leading to various levels of sheltered employment. As well, housing, financial support, and social or recreational programs are essential components (Thornton & Seeman, 1991). Available treatment programs vary geographically and may be provided by the mental health system or community agencies.

---

[11] The limbic system is associated with emotions, such as, anger, fear, sexual arousal, pleasure, and sadness. It is composed of a number of structures, including the amygdala, the cingulate gyrus, the isthmus, the hippocampal gyrus, and the uncus. Poor regulation of the limbic system by other structures in the brain can, in some individuals, cause periodic episodes of uncontrollable rage (Anderson, et al., 1994).

Seven basic principles underlying psychosocial rehabilitation as reviewed by Rutman (1997) are:

1. Normalizing of roles and responsibilities, with the recognition that people who have mental illnesses are persons (as opposed to patients),
2. Empowerment, which encompasses a recognition of the person's potential for growth,
3. A pragmatic focus on the here and now by concentrating on day-by-day challenges and needs,
4. Experiential learning by working through and living through real situations, in contrast to talking about them,
5. An egalitarian relationship between the client and staff person,
6. Blurred professional roles, thus a team approach, and a
7. Non-clinical environment, consequently, rehabilitation takes place primarily in community settings.

These basic principles are supplemented by four emerging trends that:

1. Expand empowerment to include the family as well as the person with mental illness,
2. Recognize multicultural differences,
3. Include the evaluation of rehabilitation outcomes,
4. Emphasize recovery rather than a cure, thus encouraging a sense of hope and a sense of control.

This last parameter prepares the individual for the inevitable ups and down in the illness course but engenders an expectation of overall, long-term accomplishment (Rutman, 1997).

Psychoeducation for Family Members

Family therapy brings the patient, therapist, and family members together to learn about schizophrenia and discuss the program of treatment. Ideally, it gives each person the opportunity to understand each other's concerns and views and offers support to the family. In preparing for discharge, families may help devise the treatment plan, as well as learn about available community and family services and ways to help their family member avoid relapse (National Institute of Mental Health, 1986).

The research on expressed emotion has established the value of educational programs for family members in reducing the rate of psychotic relapse (Brooker, 1990a, 1990b; Falloon & Pederson, 1985; McCann & Clancy, 1996). Falloon and Pederson (1985) also examine the consequences of reducing stress for the family members, showing a reduction in stress-related physical and mental health problems. This health-enhancing outcome was more pronounced for mothers than fathers, reflecting the gender differential in which the mother is more likely to assume the major responsibility for caregiving in two-parent families.

One extensive review of the literature on the needs of families who are caring for a chronically mentally ill member (Bartol, Moon & Linton, 1994) identified four categories of requirements, namely skills training, information, personal support, and participation in planning their loved one's care. Skills that families require include strategies for managing disturbing behaviour, monitoring medications and handling emergencies. Families also need information about the diagnosis, medications, treatment plan, and prognosis. They want to communicate regularly with professionals and be part of the treatment team. Finally, support for families should include access to support groups, therapy for themselves in overcoming the stigma and guilt they experience, respite care, and occasional assistance provided in the home.

A program that addressed the above needs was evaluated qualitatively from a phenomenological perspective (Van Hammond & Deans, 1995). Four families who had attended an eleven week psychoeducational support group led by two registered psychiatric nurses and a physician were interviewed. Analysis of the data revealed that families replaced their perception of guilt with "feelings of hope, universality, acceptance and adaptation, and the empowerment of knowledge and understanding" (p. 12). By universality, the authors refer to group members feeling understood and less alone, through the realization that "others have experienced similar thoughts, feelings, and actions" (p. 9). Adaptation and acceptance entails understanding the diagnosis, learning to discuss it openly, and accepting the reality of its limitations. Finally, by participating in this psychoeducational support group, families felt they were respected as members of the caregiving team.

The Outcome of Schizophrenia

Although schizophrenia's onset may be abrupt or (more frequently) gradual and although generally it is considered to be a chronic condition, opinions as to its outcome are varied. The DSM-IV states that complete remission is unusual. For some, the course will be relatively stable; "others show a progressive worsening associated with severe disability" (1994, p. 282). Manfred Bleuler estimated that one quarter will recover completely, one half will fluctuate between remission and exacerbation, and the remaining quarter will have persistent symptoms, although just 10% will remain chronically psychotic (Bleuler, 1978; Walsh, 1985; Wing, 1988). Thornton and Seeman (1991) in reviewing five longitudinal studies are more optimistic, suggesting that 60% of patients will recover or show significant improvement over the long term. For most sufferers, the symptoms tend to be most acute in the earlier years and "stabilize at a mild to moderate level of cognitive impairment, although they may deteriorate socially as a secondary phenomenon" (Andreasen, 1996, p. 10). Wing (1988) asserts that the discrepancy among studies results from different ways in which schizophrenia is diagnosed and different criteria for defining outcome, coupled with methodological differences in defining samples. Although one must remember that 10%[12] will die from suicide (Health Canada, 1994), a general rule of thumb that is often cited is that approximately "one third of schizophrenics recover, one third are sick off and on, and one third stay chronically ill" (Walsh, 1985, p. .23).

Harding (1988) is more hopeful. She and her colleagues (Harding, Brooks, Ashikaga, Strauss, & Breier, 1987a, 1987b) conducted a thirty-two year panel study of 269 patients from the back wards of the Vermont State Hospital who were deinstitutionalized in the mid-1950s. Prior to and following discharge, this cohort of patients participated in a comprehensive rehabilitation program. Ten years later, 30% were back in hospital. Many of the remaining 70% had been in and out of hospital and were socially isolated. Harding maintains that in the longer term (between 20 and 25 years after discharge) half to two-thirds recovered or showed significant improvement. She contends that programs and clinicians must treat all sufferers more optimistically, assuming that they will recover eventually:

> The irony is that just as the illness begins to lift after several years, and patients begin to regroup their energies toward development of work and relationships, the system, families, and often the patients themselves become discouraged and resigned to permanent chronicity (Harding, Zubin, & Strauss, 1987, p. 483).

Statistically, a number of predictors of better functional outcome have been identified (Henry & Coster, 1985). The tendency is for people to do poorly long-term if

---

[12] Given the difficulties in proving suicide, this ratio could be higher. Dr. Richard Williams, the head of the schizophrenia service in Victoria and a noted researcher has suggested 10-15% (private communication, November, 1997).

onset was early, symptoms developed insidiously, and negative symptoms were more pronounced. Such people tend to have less opportunity to develop social competency, coping skills, and occupational skills prior to becoming psychotically ill. Consequently, it follows that women, in whom the onset is later and illness course less severe, will tend to recover more completely. These are, however, statistical tendencies, not necessarily causal relationships. Clinicians and families must bear in mind that research shows considerable heterogeneity in the long-term outcome (Harding, Zubin, & Strauss, 1987).

Increasingly, evidence shows that early diagnosis combined with early intervention using antipsychotic medications is associated with better outcome (Liddle, 1997; McGlashan, 1996). That is, the sooner the patient begins pharmacological treatment, the more quickly he or she will respond to treatment (McGlashan, 1996), the lower the dosage required to produce an improvement (Liddle, 1997), and the greater the probability of being one of the 25% who recover after the first psychotic episode (Williams, 1997). The corollary, unfortunately, is that poorer outcome is associated with delays in recognizing symptoms and the tendency to normalize them, coupled with a waiting period averaging three months for an appointment with a specialist before treatment commences (Williams, 1997). Delay in initiating treatment is also due to the reluctance of psychiatrists to label people until absolutely certain of the diagnosis, a strategy that is aimed at avoiding unnecessary medication and the "stigmatization of false-positive cases" (McGlashan, 1996). Consequently, recent research is focusing on better identification of at-risk groups and of the prodromal symptoms, in order to facilitate early detection and treatment of schizophrenia.

Family Caregiving for People with Schizophrenia

Estimates of the proportion of deinstitutionalized patients living with their families vary widely, with one research review reporting the range as between 25% and 66% (Spaniole, Jung, Zipple & Fitzgerald, 1987). Goldman (1982) cites Minkoff's (1978) estimate of 65% of deinstitutionalized patients living with their families and states that one quarter of these are chronically mentally ill. In another review, Biegel, Sales and Schulz (1991) found a mean for studies in the '60s and '70s of 72%, whereas in the early '90s, the proportion of patients returning to their family of origin was 25%. While it is possible for many patients now to live in some type of supported housing, the sicker ones have fewer options. As Lamb & Goertzel (1977) and Goldman (1982) discovered, 50% of severely disabled persons lived with their families. Lefley (1987, 1996) estimated that 35% to 40% of the those who are persistently and severely mentally ill live with their families. However, Estroff (1981b) disagreed, stating that few deinstitutionalized patients live with their families. This disparity in the estimates of the number of mentally ill people who live with their family likely springs from differing definitions of both mental illness and family, variability in the availability of suitable housing for ex-patients, and the now common but fairly recent occurrence of a large subgroup of young patients who have never been hospitalized. Whatever the true figure is, the fact remains that a significant number of patients do live with their families and, contrary to expectations, family caregivers experience similar levels of distress whether their schizophrenic relative lives at home or not (Carpentier, Lesage, Goulet, Lalonde & Renaud, 1992; Reinhard, 1991).

Whether or not the mentally ill person lives with the family, Backlar (1994) agrees with Hatfield's assertion that family caregiving encompasses four spheres:

- monitoring support services,
- acting as a resource to professionals,
- advocating for patients politically and in everyday affairs, and
- providing social support, often to the point of virtually completing the patient's social network.

Hatfield and Lefley state:

> ...professionals must know mental illness from the perspective of the family....It is distressing to see how willing the mental health profession is to assign responsibilities for care to families with little apparent concern for what happens to these families in the process (1987, p. viii).

Stress and Family Caregiving

Terkelson calls the presence of mental illness in the family a "disaster in which all are victims of the event and its sequelae" (1987, p. 128). The problems facing family caregivers dominate their lives (Chafetz & Barnes, 1989) and seem endless. Managing the behavior of the ill person can lead to ongoing tension (Lefley, 1989) which is life-long (Howard, 1994). Further conflicts arise when different family members disagree on the best way to deal with socially distressing behavior (Terkelson, 1987). The ill person's supersensitivity to criticism and the unpredictability of schizophrenia lead to a home atmosphere resembling "walking on eggshells" (Terkelson, 1987, p. 138). Caregivers are burdened with deciding when the illness has reached a crisis requiring hospitalization and then having to withstand the patient's accusation of betrayal[13] (Splane, Monahan, Prestholt & Friedlander, 1982; Lamb, Hoffman, Hoffman & Oliphant, 1986). In addition to the intrafamilial problems, numerous authors (e.g. Francell, Conn & Gray, 1988; Hatfield & Lefley, 1987; Lefley, 1989) have written about the isolation of caregivers from friends and extended family relatives, the experience of what Birenbaum (1970) calls a "courtesy stigma," and the difficulties families face in dealing with professionals and inadequate support services.[14] Feelings of anger, guilt, depression and frustration are normal responses under such trying circumstances (Creer & Wing, 1975).

A study of families with schizophrenic members (Hatfield, 1978) looked at the behavior and symptoms that family members find upsetting. Negative symptoms, such as lack of motivation, money mismanagement, refusal to take medications, poor grooming, and forgetfulness were very disturbing to over 25% of families, as were suicide attempts and unusual eating and sleeping habits. Hatfield noticed that families are under constant tension and beset by grief:

> ...parents of schizophrenic patients grieve over the loss of their once promising child who now seems to be a different person and all but a stranger in the family. Working through disappointment and grief is made more difficult for them by the often cyclic nature of the illness: a family's hopes are raised as their patient improves, only to be dashed as his or her illness resumes its course (Hatfield, 1978, p. 358).

---

[13] Goffman describes a "betrayal funnel" in which a series of trusted agents strip the prepatient of his or her rights and liberties, reducing the patient's status from an adult to a patient on a psychiatric ward. The first and primary agent in this process is his "next of relation", who inherits the patient's rights and becomes his or her guardian (1961, p. 136-144).

[14] Hatfield & Lefley (1987) propose that researchers concentrate, instead, on a conceptualization of family caregivers within the stress paradigm. Their own research has concentrated on coping and adaptation strategies and developing educational programs for caregivers.

Mothers are the Primary Caregivers

Mothers are the primary caregivers in the home. Research shows that, when caring involves a mentally ill family member, middle-aged and elderly women are the major caregivers (Beley, 1991; Chafetz & Barnes, 1989; Lefley, 1996; Reinhard, 1991; Scheyette, 1990; Terkelson, 1987; Wright, 1994) while their male offspring are the main care recipients (McElroy, 1987)[15]. Even where caregiving is shared by other family members, "a woman caregiver will be expected to bear more of the burden" (Wright, 1994, p. 31).

Feminist authors assert that caring is the obligation of women in a patriarchal society and a source of their oppression (Gilligan, 1993; Sheyette, 1990). Sheyette (1990) maintains that women see caring as being caring for others; caring for themselves is equated with being selfish. According to Gilligan (1993), women view morality in terms of relationship, while men equate morality with justice, fairness, and rights. The very basis of women's experience is interconnectedness, thus women have "a moral ideal of self-sacrifice" (p. 165) and caring for others is their means of maintaining connection in the social world. Males, on the other hand, view themselves less in terms of relationship than in terms of individuality and achievement. Gilligan's view of social structure places women at the center of a web of connection with men striving to reach the top of a hierarchy. On the other hand, in a patriarchal culture in which men tend to make more money than women, the traditional division of labor in the home may be merely a practical solution.

---

[15] With their later onset, less severe symptoms, and better outcome (on average), daughters who have schizophrenia tend to have achieved some independence prior to being diagnosed and may continue to be able to live more independently (Walsh, 1985).

Violence in Family Caregiving

Violence is a concern of many family caregivers. Within the family, mothers, as the primary caregivers of mentally ill children, are also the most common targets of their violent acts (Estroff, Zimmer, Lachicotte, & Benoit, 1994). Overall, violence on the part of seriously mentally ill persons is more often directed at family members than at strangers (Asnis, Kaplan, van Praag, & Sanderson, 1994; Herman, 1985; Torrey, 1994). Unfortunately, reports suggest that violent acts by the mentally ill are increasing ("Careless Britain," 1996). Many caregivers are afraid of their ill family member. Some of their fear is justified but not all is, as some of it is based on their exposure, along with the general public, to the widespread stereotype of dangerousness projected by newspapers, television and the movies[16] (Torrey, 1994, 1997).

Among those with serious mental illnesses, however, people with schizophrenia are over-represented in studies of violence compared to other diagnoses. Asnis et al. (1994), in a study of homicidal behaviour of psychiatric outpatients, found that 20% of people with schizophrenia had homicidal thoughts and 11% had attempted homicide. Only those with substance abuse had a higher proportion of homicidal thoughts, but fewer, 3%, had acted on them. Neither homicidal ideation nor homicide attempts were differentiated by gender, in contrast to studies that find males in general to be more violent (Herman, 1986). Torrey (1994) differentiates between threatening to harm someone (males are twice as prominent) and carrying it out (no difference by gender).

---

[16] Magazine articles appear to be more balanced than other media. One review of 137 articles over a period of 28 years found that aggression as a symptom of schizophrenia was included in only 10.2% of the articles. In addition, the reporting of aggression in these articles decreased over time. Although from 1964-1970 aggression was noted in 18% of the articles, from 1988-1992 it appeared in only 3% (Wahl, Borostovik, & Rieppi, 1995).

The seriously mentally ill are statistically no more violent than the general public, provided they are undergoing treatment and are compliant with that treatment (Kramp, 1995; Torrey, 1994). Several predictors of violence among schizophrenics have been identified. Torrey (1994) cites three: a history of violent behaviour, concurrent substance abuse,[17] and noncompliance with medication. Asnis et al. (1994) state: "hostile and aggressive feelings in conjunction with a paranoid view of the social environment appear to be an important combination of symptoms in differentiating patients with past homicidal acts from those without such a history" (p. 131). Threat and the perceived need to defend oneself was also important in Estroff, et al.'s (1994) study, which also implicated such social variables as low socioeconomic status, social isolation, poor self-esteem, and past patterns of violent behaviour within the family. An important finding in this study is that having a trusted mental health professional as part of the ill person's social network is a buffer against violent behaviour. Therefore, the study concluded that:

> ...our findings support assigning intensive case managers trained to detect and prevent violence to individuals with a diagnosis of schizophrenia who are isolated and fearful and who live with relatives, particularly with their mothers (p. 677).

Parents' Caring Practices

Although there are a number of "how-to" books to help parents learn about caring for a child with schizophrenia (Dearth, Labenski, Mott, & Pellegrini, 1986; Jeffries, Plummer, Seeman, & Thornton, 1990; Mueser & Gingerich, 1994; Thornton & Seeman, 1991; Torrey, 1995; Walsh, 1985), Chesla's (1991) work on parents' caring practices is the

---

[17] In contrast to many studies, Estroff et al. (1994) found no relation between substance abuse and violence among her sample. Her sample, however, is composed of a mixture of diagnoses representing serious mental illness and fails to distinguish those with schizophrenia.

only recent one that uses a participant action methodology to investigate how parents carry out their caregiving. In this study, twenty-five hours were spent in each of the homes of seven families, chosen from the 14 families that were interviewed. Chesla developed a typology of four different ways in which parents care for their loved ones who have schizophrenia: engaged care, conflicted care, managed care, and distanced care. Those who were fully engaged were totally devoted to their ill child, providing unconditional financial, social, and practical support. They were more concerned with improving their child's self esteem than social functioning and thus had difficulty setting limits or changing disruptive behaviour. As a result, "their lives were disrupted by the symptoms to a greater extent than were those of other families" (p. 457). In the conflicted care scenario, parents were angry at the disruption in their lives and unable to balance their own needs with those of their child. Sometimes blaming their child's misbehavior on manipulation, these parents were the most emotionally distressed group. The managed care parents had clear objectives for care based on the latest scientific information they found. They thought of themselves in a therapist role, in contrast to the "parent" role of engaged parents. The children of managed care parents overcame their disabilities to a greater extent than children in the other categories. Finally, the distanced care group was composed of fathers, only, who were concerned about their loved one but seldom took part in the hands-on care. Chesla concluded that conventional research into caregiver burden misses the distinctions among these groups:

> For example, parents who practiced conflicted care and managed care would probably rate themselves as significantly burdened on most subjective burden scales. However, the nature of the burden in the two groups was quite distinct (p. 463).

Contributions of Patients to their Families

Most authors concentrate their research on the negative consequences of caring for a severely mentally ill relative, ignoring the possibility of any positive outcomes. Horowitz, Reinhard, & Howell-White (1996) approached their study from an exchange perspective. The norm of reciprocity would suggest that people with a serious mental illness are unlikely to receive much social support because of their inability to reciprocate. Although equivalency in the short term is not always possible, over time the support between parties should balance out. Essential to the understanding of reciprocity among kin, however, is the perception that each member is doing their best to reciprocate, given their abilities. In Horowitz et al.'s regression model, the best predictor of parental support was support (or help) received from the ill person, regardless of the level of the patient's symptoms. Thus the norm of reciprocity is upheld, which may serve to buffer the perception of burden within families.

Greenberg and his colleagues (1994) identified a number of areas in which people with severe mental illnesses and considerable chronic disability contribute to their family. Although their sample included other mental illnesses, 65% had diagnoses of schizophrenia and schizoaffective[18] disorder. When the mentally ill family members lived with their parents, companionship was their major contribution, as was noted by 80% of the parents. Other positive contributions named by over 50% of families were helping with meal preparations and other household chores (74%), providing news about family and friends (66%), helping with shopping (60%), and listening to problems and providing advice (50%). The authors conclude that "these positive contributions have previously received little recognition" (p. 479).

---

[18] Schizoaffective disorder combines the symptoms of schizophrenia with mood disorders, either mania or depression. The prognosis for schizoaffective disorder tends to be better than for schizophrenia, but worse than the long-term prognosis for mood disorders (Townsend, 1993).

Although there may be positive consequences to looking after a mentally ill relative, what families generally report is usually not positive. Backlar's qualitative interviews with 24 family members revealed four common threads: initial confusion, perpetual mourning, inescapable tumult, and conflict between the family and the community (1994, p. 17). Such negative consequences have been called "family burden" and "caregiver burden" by many authors.

Caregiver Burden

Caregiver burden has spurred a diverse body of theory and research. Reviewing the studies chronologically reveals how their conceptualizations and understandings developed.

In 1960 Grad and Sainsbury (1968) began comparing the families of mentally ill patients (with mixed diagnoses) in a conventional hospital psychiatric service with those in community care. In this study, family burden was measured as a disruption in family routine and in social and leisure life, reduced income and employment, emotional upset and neurotic symptoms, physical illness of family members, and effects on the patient's children. Severe burden was associated with five of the patient's symptoms: aggression, delusions, hallucinations, confusion, and the inability to perform self care. Grad and Sainsbury concluded that the community service families experienced more burden. Their higher family burden may have been a cumulative effect, as the patients involved were young, mainly psychoneurotic patients who had never been a severe burden, but whose problems continued for over two years. In contrast, a subgroup of the sample, the 20% of the families identified as most burdened at the time the patient was admitted to treatment, were helped equally in both hospital and community programs.

Hoenig and Hamilton (1966, 1967, Wright, 1994) were the first to separate the subjective and objective dimensions of burden. Objective burden was composed of "adverse effects upon the household" (1966:167, cited in Wright, 1994) and the amount of the patient's abnormal behavior, while subjective burden was composed of the emotional reaction of the family member and the extent of perceived burden. The two types of burden were not necessarily correlated in any particular family. Noh and Avison (1988) note that this discrepancy suggests other influences upon subjective burden in addition to the effects of objective burden.

The unpredictability of behavior, uncertainty as to how to deal with inactivity, and elderly caregivers' worries about the patient's long term future caused burden in Creer and Wing's (1975) study of 80 relatives of patients with schizophrenia. The difficulty in obtaining help at the beginning of the illness and the failure of professionals to recognize families as major primary care providers were also important. Burden was evident in the relatives experiencing guilt, depression, disappointment and frustration or anger at "the insoluble nature of the problem"(p. 79). In this study depression was related to feelings of failure as a parent and to grief:

> As one mother put it: 'You just can't understand it. Here's someone you've known all these years and always got on well with, and suddenly he can't even stand being in the same room with you.' Such feelings of grief could be sharpened if the patient occasionally 'became his old self again' for a short while. This reminded his family vividly of what he was like before his illness (pp. 78-79).

Doll (1976) studied 125 families to identify which characteristics of discharged patients are burdensome to their families. Although this study did not use a scale of caregiver burden, the results have been used subsequently by other researchers to construct their measurement scales. Doll noted that many families have ambivalent feelings toward the ill person. Although concerned and caring, they were also bitter, resentful, and felt trapped. Finances and disruption of the normal family routine were not a problem and, apart from those whose relatives continued to display severely disturbed behavior, these families did not experience shame or stigma. The severity of the patient's condition was found to influence whether the family wanted to take the patient home at the time of discharge from the hospital. Variables such as social class, education, age or sex of the caregiving family member or the closeness of relationship to the patient were not related to subjective burden.

In India, Pai and Kapur (1982) divided objective burden into six categories: effects on finances, family routine, leisure, family interaction, physical health and mental health. Subjective burden was assessed with one global question asking about the amount of suffering the family member experienced as a result of the patient's condition. This global question was scored on a three point scale. The study was longitudinal with eight assessments over a six month period and showed that home treatment reduced family burden more than hospital treatment did. Significant correlations were observed between family burden and measures of the patient's social dysfunction and clinical psychopathology.

In the Social Behavior Assessment Scale, SBAS (Platt, 1985), objective burden was composed of the informants' estimation of changes in their physical and emotional health, social life, leisure time, disposable income, work performance, time off work and disruption of life. Subjective burden was the self-report of distress caused by the patient's behavior, limited social performance, or by the influence of the objective burden dimensions. The previously mentioned work of Carpentier et al. (1992), comparing caregiver burden when the patient lives with the family and when the patient lives elsewhere, utilized this same burden scale.

In Canada, Noh and Turner (1987) measured the effect of several variables upon the psychological distress of family members, defined in this study as significant others, not parents. Their objective burden scale was a shortened version of the Personal Adjustment and Role Skill Scale, PARS (Ellsworth, 1975, Noh and Turner, 1987). Subjective burden was measured with an abbreviated Patient as a Problem scale (Pasamanick et al., 1967; Noh and Turner, 1987). None of nine items in this scale refers to grief or mourning. Instead, each item asked whether different patient's behaviors caused a problem or anxiety, often or sometimes. In the stepwise regression analysis, subjective burden was significantly correlated with psychological distress in the caregiver but objective burden was not. The authors' explanation is that "difficulties associated with the presence and behavior of patients seems to be relevant to psychological well-being only to the extent that they are perceived as sources of strain" (p. 268). In the final regression, the only independent variables significantly related to distress in the families of schizophrenics were the length of time since the patient was discharged and the family member's perception of mastery, defined as "an intrapsychic resource that influences, and is influenced by, one's ability to competently manage life's challenges" (p. 264)[19]. When mastery entered the equation, the effect of subjective burden became insignificant, although the authors could not determine whether "perceived mastery conditions the experience of subjective burden or subjective burden influences the perception of mastery, or both" (p. 268). Noh and Turner concluded that family burden only appears to influence the distress of those caregivers who are relatively low in mastery.

In a follow-up study using the above nine item subjective burden scale as the dependent variable, Noh & Avison (1988) compared the burden felt by spouses of the mentally ill. Here, mastery was only important to the burden felt by the wives. The

---

[19] The authors contend that mastery is similar to (but not exactly the same as) the concept, locus of control (Rotter, 1966). Seeman & Seeman (1983) review a number of other measures of personal control over environmental events.

perception of burden for patients' wives increased with age and the presence of young children in the family and decreased with the wives' perception of mastery. For husbands of patients (42% of whom had the diagnosis of schizophrenia) the only significant predictors were the patient's symptoms, length of time since discharge and stressful life events.

Reinhard (1991) developed her burden scale from several previous studies. Nine items measured four dimensions of objective burden: financial problems, household disruptions, personal activity limitations on work/leisure activities, and difficulties with social interactions with family, neighbors and friends. Nine items investigated five areas of subjective burden: shame/stigma, guilt, resentment, grief, and worry. A final item asked to what extent the caregiver experienced physical strain from caregiving. According to Reinhard, one important question was, "To what extent in the past six months have you been upset about your relative's change from his/her former self?" There were four response categories. Hardly conveying the complex nature of the experience of grieving, this question was Reinhard's only measurement of grief as a contributor to caregiver burden. Nevertheless, in her analysis, the only items reported by more than half of the respondents were grief (54%) and worry about the future (87%). Unfortunately, in her regression analysis, burden is treated as one global (summed) measure or else is divided into subjective and objective burden. Consequently, the contributions of the various dimensions of subjective burden cannot be determined.

In another study, an extensive 27 item burden scale was analyzed by its four dimensions: family disruption, client dependency, stigma, and caregiver strain.[20] Biegel, Song and Chakravarthy (1994) constructed this scale to measure the "feelings that caregivers have

---

[20] Although the full scale is not published, none of the dimensions would appear to incorporate grief.

about their psychological well-being and social life as well as their feelings about their family member with mental illness" (p. 195). In their final regression model, which explains 46% of the variance in caregiver burden (as conceived in this study) the frequency of the patient's disturbing behavior was the best predictor of all four types of burden. The only other significant variable was the health of the caregiver, which influenced family disruption and stigma.

The above review highlights the multi-dimensional character of family burden and the confusion as to what constitutes the concept. Comparing these studies is difficult when almost every researcher has defined and measured burden differently. Further, Hoenig and Hamilton (1966, 1967) and Noh and Turner (1987) included disruptive patient behaviors as part of their burden scales; the rest conceptualized them as predicting burden levels. Since Hoenig and Hamilton's work, the separation of objective and subjective dimensions of burden tends to be recognized. However, objective burden is seen to affect subjective burden by Noh and Turner (1987), while other studies utilize only the subjective dimensions (Noh and Avison, 1988; Biegel, et al., 1994). The relationship between burden and perceived stress is difficult to unravel, considering that Noh and Turner (1987) conceived of burden as causing psychological distress, Reinhard (1991) used burden to predict depression, but Biegel et al. (1994) included caregiver strain as a dimension of subjective burden. Grief was only recognized as contributing to burden in three studies (Creer & Wing, 1975; Hatfield, 1978; Reinhard, 1991). Before we can attempt comparative statistical studies of caregiver burden, researchers will need to come to some consensus about what it is and how it can be measured.

Several criticisms pertain to all of the studies. Global burden scales fail to distinguish the differential contribution of individual items in the scale to the overall perception of burden. The majority of studies employ summative measures of burden, and only a few of the researchers attempted to separate out some of the dimensions. Biegel et al. (1994) is the only study that attempted to explain causes for these different dimensions. As well, only one study (Pai & Kapur, 1982) attempted any longitudinal measurement of burden, and they did so for only six months.

Reinhard's (1991) suggestions for further research include the need to more fully understand each of the components of caregiver burden. Because grief was a significant variable in her analysis, in spite of being inadequately measured, it is an important component for health care professionals to understand. Lefley (1989) has noted that parent caregivers grieve for the promised adult their child did not become and for their own expectations of freedom and a more relaxed lifestyle as they age. As well, they are required to help their schizophrenic child deal with his or her own significant losses. Because of the importance of grief in the experience of these parents, we need to understand more fully the relationships among grief, burden, and caregiving, as experienced by relatives of those with schizophrenia.

Grief

In order to begin to sort out these relationships, it is important to have some background knowledge of the literature on grief and, in particular, to distinguish between three concepts: bereavement, grief and mourning. Kastenbaum (1977) defines bereavement as the fact of the loss and the change in status that results, while grief is the response to bereavement, encompassing physical and mental symptoms of suffering and distress. "Mourning refers to the culturally patterned expressions of the bereaved person's thoughts and feelings....[The expectation is that][21] the bereaved person will experience grief and that the grieving person will mourn" (Kastenbaum, 1977, pp. 243, 244). This distinction is not always made by those who study death and dying, with the confusing result that the terms are often used interchangeably.

For this study, I shall endeavor to adhere to Kastenbaum's differentiation. As such, grief is conceptualized as a personal and psychological process. Mourning, I would suggest, is a more social process involving the demonstration and communication of grief. Although the accepted theoretical models of the grief process assume a psychological outlook, the symbolic interaction perspective[22] can serve better for describing and understanding the contextual influences upon grief and the process of mourning. For parents who lose a child to mental illness, our culture may recognize that the parents have experienced a loss and there may be a partial understanding of their grief. Nevertheless, it seems that we do not expect them to demonstrate and communicate mourning. Lacking a set of cultural prescriptions for mourning in the absence of death, parents of schizophrenic children have no socially accepted rituals to follow and others find it difficult to empathize with their anguish.

Most theoretical models of grief describe stages in a process beginning with the death (or knowledge of impending death) of a loved one and working toward some sort of resolution. For early authors, there was an expected duration of one or two years (Horacek, 1995), and grief that was unresolved within that time limit was considered pathological. The

---

[21] Where square brackets appear in quotations throughout this thesis, the enclosed words were inserted by this author.

[22] Symbolic interactionism is the theoretical perspective employed in this study. It is explained in Chapter 3.

best recognized model is Kubler-Ross's (1969) theory of five stages: denial and isolation, anger, bargaining, depression and finally acceptance. A major contribution of her approach was her entreaty to caregivers and family to openly talk about the grief process and to reassure the grieving (and in her research, this was usually the dying person) that their reactions were normal. Each stage served a purpose in helping the individual toward acceptance. However, Kubler-Ross acknowledged that different contingencies would affect the progression from one stage to the next and, therefore, no time-table was prescribed. Her work became the foundation for further studies of grief.

Pathological grief, also called exceptional grief, may be due to many factors. Stephenson (1992) describes several manifestations of unresolved grief, stating that a common reaction is denial, in which the person represses feelings of grief. Emotional numbness in Kubler-Ross's model allows the individual to get over the initial shock of the loss, however, some people are unable to allow themselves to begin to feel any emotion. As this is an essential element of the grief work that allows progression into the stage of anger, these people become stalled at the denial stage. The inability to resolve grief may also stem from ambivalent feelings toward the person who died. Guilt is a part of this reaction. Another unusual grief reaction is mummification in which the survivor is unable to dispose of the deceased's belongings or change any of his or her surroundings, in effect, preserving a shrine to the deceased.

Theorists began to recognize that, for various "high-grief deaths," there was no actual end point to grief (Fulton, 1978, Horacek, 1995). A death that occurs out of the normal life sequence is particularly devastating. The death of a child, particularly for the child's family, is probably the most difficult to accept. In fact, it may be that the death of a young adult child, in whom the parents have invested two decades of their life and love and who has already begun to achieve some goals, is the hardest of all (Rubin, 1990). Parents invest their hopes and dreams and a certain notion of their own immortality in the future of their children. Rubin states that even after adjusting to their loss, they continue to grieve.

Horacek (1995) describes three sets of reactions to high-grief deaths. The first two are included in traditional models of grief: acute grieving and adapting to the loss. Acute grieving consists of physical reactions (shortness of breath, tightness in the chest and throat, sleep difficulties, crying, an empty feeling in the stomach, etc.), emotional reactions (numbness, shock, guilt, pining and longing, anger, despair, depression, ambivalence and relief) and cognitive responses (disbelief, confusion, lack of interest and motivation, impaired concentration and preoccupation with the dead person). Adapting to the loss involves a conscious working through of the emotions, along with a life review of the deceased which is done in order to identify the values, wishes and aspirations of the deceased. This serves as a way of keeping one's relationship with the loved one alive. Horacek goes on to describe a third reaction, continuing grieving. This involves integrating aspects of pain and loss into the grieving person's life, even after the mourner returns to normal functioning. He explains that chronic or pathological mourning is exhibited by those whose grief persists at the intensity of acute grieving. Continued grieving, on the other hand, is not pathological but is expected following high-grief deaths. Horacek describes it as "low-grade shadow grief that reflects the continuing sense of loss but does not significantly inhibit everyday functioning" (Horacek, 1995, p. 28).

Other authors have recognized that grief can occur when the loss is not a death, but due to a traumatic experience, disease or disability. Stephenson and Murphy (1986) described "existential grief" as the struggle of the chronically ill and disabled to achieve a meaningful life in the face of a disability. It involves the person separating from his or her former self and overcoming stigma to create a new self-image, congruent with his or her new status. Trolley (1994) compares and contrasts grief following a usual type of death with grief after a death that is extremely traumatic (involving suicide or violence) and grief after other traumatic experiences, such as disasters, alcoholism, abuse, disability, divorce and infertility. She concludes that because the common experience in all these events is loss, therapists need a universal model of loss that applies to all eventualities, in order to help victims become "survivors."

A body of literature is accumulating around a conceptualization of grief termed "chronic sorrow" (Copely & Bodensteiner, 1987; Davis, 1987; Olshansky, 1962). Mainly applied to parental grief reactions following the birth of a mentally defective child and in response to a child's chronic physical disability, it describes "a course of recurrent, cyclic sadness...periodic as opposed to continuous" (Davis, 1987, pp. 353-354). Chronic sorrow occurs when the source of the grief does not disappear but remains ever present. Consequently, the grieving person's life has to change to accommodate endless caregiving as well as the caregiver's need to mourn. Public attitudes toward the caregiver as "heroic" and the social expectation that mourning should lessen over time complicate the process.

Finally, Rando (1992) discusses how "complicated mourning" differs from a customary model of grief. She describes six "R" processes of involved in accommodating to any loss. The mourner needs to: (1) recognize the loss, (2) react to the separation, (3) recollect and re-experience the deceased and the relationship, (4) relinquish the old attachments to the deceased and the old assumptive world, (5) readjust to move adaptively into the new world without forgetting the old, and (6) reinvest (p. 45). The first three stages, according to the definitions I am using, refer to grief, while, stages four, five, and six describe mourning. In "complicated mourning," however, mourners are unable to give up the lost person or to allow themselves a complete reaction to the separation. When a death is sudden, particularly violent, traumatic or lingering, when it involves a child, or is perceived as preventable, mourners are at risk of complicated mourning. The presence of mental health problems or excessive stress at the time of the loss, ambivalent or poor relationships with the deceased when alive, or a perceived lack of social support during their grief are also risk factors. Rando states that these conditions are prevalent in modern society and, consequently, complicated mourning is fairly common.[23]

How well can these theoretical models help to explain the grief experienced by family members caring for people with schizophrenia? One self-help guide for those with mental illness and their caregivers utilizes a traditional model of stages to help people work towards acceptance[24] (Lafonde, 1994). Such an approach, however, is overly simplified because of the uncertainty of schizophrenia. Atkinson speculated that "the characteristic course of exacerbations and remissions may play a unique role in shaping the family's reaction to the patient's illness" (1994, p. 139). The expectation is that, as sufferers recover, parents hope that this will be the last psychotic episode but, with each psychotic break, parents are flung back to Kubler-Ross's initial stage of shock. As John Hinckley's mother[25]

---

[23] Rando's theoretical explanation covers so many risk factors and conditions that it would seem complicated mourning is very common.

[24] Lafonde's stages are acknowledging loss, denial, sadness, anger, taming fear and acceptance. Her view is that if people understand the process, grieving mental illness can be positive and progress to renewed hope and recovery. She does acknowledge that during the acceptance stage, people are prone to return to other stages in the process but she maintains that eventual recovery will occur.

[25] In 1981, John Hinckley attempted to assassinate U.S. President Ronald Reagan. He thought that by killing the president, he could impress movie actress, Jodie Foster, with whom he was infatuated.

recalls:

> ...each time I came up against his unrealistic thinking the emotional shock was fresh. Surely this was the hardest thing for families of the mentally ill. John wasn't bed bound or physically handicapped: his illness came out in abnormal and unreasonable behavior that made him hardest to love when he needed it most (Hinckley & Hinckley, 1985, pp. 268-269).

Traditional models of grief may have explained the experience of parents with schizophrenic children in the days of life-long internment in an asylum, but they do not apply to the modern experience.

While on the surface, the experience of parents of schizophrenics may have parallels with that of parents whose children die or are physically or mentally disabled, there are also important differences. A study comparing grief among parents whose adult child had died or who sustained a head injury leading to organic brain disorder, or who had schizophrenia showed that initial grief was highest for those whose child died, particularly when the child died suddenly (no opportunity for anticipatory grief) and lowest for parents with a schizophrenic child. However, for parents of schizophrenics, grief increased significantly over time (measured 1 to 5 years following diagnosis), whereas initial grief decreased over time for the other two groups. The explanation given for the low initial levels of grief was that the majority of parents were not told of their child's diagnosis immediately, learning it and the child's prognosis over a period of years, "piecemeal from their child, the hospital staff, and other parents" (Atkinson, 1994).

Chronic sorrow and Rando's complicated mourning may describe some aspects of these parents' experience. There is, however, a final model which incorporates both internal grief and interactional mourning and may help to account for the contribution of grief to these caregivers' burden.

"Pathways through grief" (Martin & Elder, 1988) depicts grieving as two opposing and connected circles in the pattern of a figure 8 (Appendix 2). This is not a stage model; no particular direction or order to the movement is implied; and no end-point is shown. The lower circle is the person's inward or self-journey through detachment, protest and despair. To detach involves an unconscious avoidance of feelings; to protest involves denial that a loss has occurred.[26] Despair denotes the pain and depths of grief. The upper circle represents moving outward and forming attachments to others and includes exploration, investment and hope. To invest (the opposite of detach) implies beginning to experience joy in living; to explore (the opposite of protest) represents examining the loss and the importance of the former relationship; to hope(the opposite of despair) gives a person's life a sense of direction and purpose, with a focus on the future. Joining the two circles is the meaning that individuals give to their loss and, depending upon whether they define their experience as positive or negative, the meaning given to their loss determines whether their journey proceeds outwardly or inwardly. Whenever the meaning is redefined, the grieving individual is propelled into the other circle. Another strength of the model is its depiction of social interaction. The model is superimposed upon a wavelike image representing connections among the people-figures in the "Circle of Influence" that surrounds the model.

The foregoing review of research and theoretical literature related to caregiving and schizophrenia reveals the complex nature of this experience. How individuals carry out their family and caring responsibilities depends on their personal interpretations of the meaning of family and caregiving. This is the basic premise underlying symbolic interactionism, i.e. that

---

[26] Protest seems to me to be a misnomer for this phase. How can one protest against something that they are either unable or unwilling to believe has occurred? Kubler-Ross named the initial phase in her model denial.

human beings act in response to the meanings they give to their situation. Symbolic interactionism, the theoretical perspective underlying this study, is the subject of the next chapter.

CHAPTER THREE

THEORETICAL PERSPECTIVE

Qualitative researchers must examine, from the outset, their own "conceptual baggage" (Kirby & McKenna, 1989), that is, their thoughts, values and assumptions about the research topic. Recognizing these requires the researcher to make explicit the theoretical paradigm which underpins the study although, up to now, studies of caregiving have been largely descriptive and atheoretical (Ravies, Siegel & Sudit, 1988). My approach to mental illness is grounded primarily in symbolic interactionism and a pathophysiological understanding of schizophrenia as a disease of the brain.

This study conceives of caregiving and grief that occurs in response to a child's suffering from schizophrenia as being social processes, influenced by the parents' changing definitions of their identity and role. This chapter addresses, in turn, the evolution and basic premises of symbolic interactionism, followed by the symbolic interactionists' understandings of identity, roles, and mental illness.

Symbolic Interactionism

Scholars have traced the philosophical origins of symbolic interactionism to the eighteenth century Scottish moral philosophers who posited a reciprocal relationship between human beings and society mediated through communication and interaction (Stryker and Statham, 1985) and to the nineteenth century German social theorists, Simmel and Weber (Wallace & Wolf, 1986). Simmel's contribution was an understanding of society as composed of multiple individual-level social processes in a web of interaction, while

Weber's was the importance of understanding the subjective meaning, *verstehen*, that actors assign to their behaviour. These ideas informed American Pragmatists in the early twentieth century and their assertion that individuals interpret the social world and modify it to suit their needs. Thus, people continually create social structures, a perspective which contrasts with the macro-social perspective of individuals being constituted and controlled by them (Ritzer, 1988). Arising from these historical insights and as a response to the dominance of structural functionalism in sociology in the early twentieth century, symbolic interactionism as originally formulated by George Herbert Mead (1934/1962) and practiced at the University of Chicago became the primary impetus to the expansion of micro-sociology.

Social life is a process, a sequence of events, and therefore the theory of symbolic interactionism explains behaviour "in terms of process or sequences of interconnected processes" (Lindesmith, Strauss, & Denzin, 1975). Symbolic interactionists assume that most human behavior is consciously motivated, and not an automatic response to a stimulus. Consequently, individuals act and interact on the basis of the meaning that a particular event or object holds for them. Meaning, itself, is socially constructed. Thus, understanding the meaning of a situation and responding to it is predicated on the interpretation given by the involved individuals to significant symbols, language and gestures. Significant symbols are interpretations that are shared by and produce the same response in all those involved in an interaction. Mead (1934/1962) described the meaning of a symbol as being the response it evokes. Miller (1981) explains that, when Mead speaks of the same response, he is referring not to the overt act of responding but, instead, to an unobservable mental response, experienced by both parties in an interaction. "The meaning of a symbol can therefore be experienced in the form of a disposition or a readiness to act in a certain way, prior to actually acting that way" (Miller, 1981, p. 168).

Mead described how the mind interprets and controls human interaction. Before a person actively responds to an event, its meaning is constructed in the mind of the individual. He or she then considers the relative advantages and disadvantages of possible courses of action and decides among them. Therefore, human behaviour is distinguished from animal behaviour by the interjection of the thinking process of the human mind, through which reactions to stimuli are temporarily delayed (Ritzer, 1988). The critical elements in this process are the person's empathic ability to assume the attitude of the other person in regard to him or herself and to mentally forecast the other person's reaction to the response. Mead calls this "taking the role of the other,"[1] a concept derived from Cooley's (1902/1964) "looking glass self."[2] Mead's description of interaction is characterized by Shibutani (1991) as a cybernetic process, made up of a "series of self-correcting adjustments to a developing situation, as it is successively redefined by the actor" (1991, p. 61). Thus, the evaluation of each successive act, stored in memory, influences subsequent interaction.

Through socialization and communication individuals learn common meanings and values for symbols. Shared meanings, synonymous to culture, make interaction predictable much of the time and allow individuals to plan and evaluate their own behaviour in terms of the anticipated response of others (Rose, 1962). According to Blumer, such patterned

---

[1] This concept is often designated by the shorter term, "role-taking."

[2] Three elements comprise the "looking-glass self:" (1) the way a person regards himself or herself, (2) the way a person imagines he or she appears to others, and (3) the person's own emotional reaction to him or herself, e.g., pride or shame (Cooley, 1902/1964; Wallace & Wolf, 1986).

behaviour, which he termed "joint action" (1969/1986, pp. 70-71), gives a measure of structure to social interaction, while historical contingencies and differences in individual experience introduce uncertainty. Not every situation has a precedent, however, and any individual event may be interrupted or transformed when individuals who interact define the situation differently. Consequently, new meanings and actions will emerge in the process. As a result, social structures may "set the conditions and set limitations on human action, but they do not determine it" (Ritzer, 1988, p. 194). As Blumer stated, "It is the social process in group life that creates and upholds the rules, not the rules that create and uphold group life" (1969/1986, p. 19).

Two Schools of Thought

Over time, two divergent schools of thought have emerged within symbolic interactionism: the Chicago School identified with Blumer, and the Iowa School led by Manfred Kuhn (1964). Blumer's extension and interpretation of symbolic interactionism is truer to Mead's original thought than Kuhn's (1964) variation. The Iowa School criticizes the ambiguity and vagueness of Mead's conceptualizations, arguing that sociology cannot ignore the impact of social structure and macro-organization upon behaviour. Therefore, Kuhn's version emphasizes the structure of social roles and their associated attitudes, rather than "the dynamic and processual character of self and society and the negotiated character of social arrangements" (LaRossa & Reitzes, 1993). In Stryker and Statham's (1985) view, this social structural version of symbolic interactionism incorporates a dual focus: "an emphasis on the constructed character of that social life and an emphasis on culture and social structure as constraints on what, in fact, occurs in social interaction" (p. 361). While the Chicago School views human behaviour as unpredictable and innovative and relies on qualitative and interpretive methods, the Iowa School primarily investigates the ways in which roles and attitudes determine behaviour, by using quantitative methods to test hypotheses. Hence, their observations on individual identity and roles also vary.

Symbolic Interactionism and Identity

People think of themselves as specific human beings with individual sets of "traits, distinctive ways of thinking and acting, [and] established relationships with significant others" (Shibutani, 1991. p. 63). In the symbolic interactionist frame of reference, a person's identity involves social relations because the identity is created in social situations by two processes that simultaneously define the individual as part of the group in the interaction but, at the same time, as a separate being (Lindesmith, Strauss, & Denzin, 1988). The meaning one has of oneself derives, like all meaning, from taking the viewpoint of the others in the interaction and objectively evaluating oneself. This process is called reflexivity, "the ability to respond to oneself as one does to others" (Ritzer, 1988, p. 179). The resulting meaning through which an individual characterizes him or herself necessarily influences how he or she behaves (Blumer, 1969/1986; Shibutani, 1962, 1991; Stryker, 1980).

The Contingent Nature of Identity

In Mead's theory the self is composed of two phases, the "I" and the "Me." The "I" is the self as subject and the "Me" is the self as object (Wallace & Wolf, 1986). "I" is the part of the self that responds freely, creatively, and spontaneously. Shibutani (1991) describes "I" as "the impulse of an individual with a distinct personality" (p. 61). In contrast, "Me" is the organized and internalized set of attitudes and perspectives about the self that have been learned from others and the only part of the self of which the actor is aware. As a result, "Me" is the socialized part of the self that exercises self control and conformity (Ritzer, 1988), having learned the expectations of society from both particular others in interaction, as well as from the "generalized other" in the form of culture. Consequently, an actor's identity is associated with "Me." The self is not just the "I" and "Me" added together; it is the relationship or interaction between the two, conceptualized by some authors as an internal conversation between the "I" and the "Me."

Typically, those who subscribe to the Chicago School describe the self as quite flexible in response to environmental factors. For example, the self "is a behavioral response to our own gestures as we direct these gestures toward others in interaction. In this respect, self emerges in the on-going process of interpersonal interaction" (Rigney & Smith, 1991, p. 72) and "the self changes as its social relationships and social worlds undergo transformation" (Lindesmith, Strauss, & Denzin, 1988, p. 249). In contrast, Kuhn's followers envision a developing self which, while evolving reflexively, always retains what it learned about itself in the past. In summary, Stryker and Statham (1985) state, "The self is a social structure, emergent from social interaction" (1985, p. 317).

A More Structured Notion of Identity

The Iowa School, therefore, views the self as more stable, usually referring to a self concept rather than to the self. The self concept is the self as object, in essence the same as "Me" in Mead's self (Ritzer, 1988). The self concept is an abstract object that develops slowly through the acquisition of language. Shibutani's description conveys its relative stability when he says that the self concept:

> ...is an abstract object. An abstraction is a general idea, something that exists apart from concrete realities, actual instance, and specific experiences. It is an item that is referred to and thought about repeatedly as if it were the same thing; a self-concept is a unit that transcends particular situations (1991, p. 63).

For those who adhere to the Iowa School, the self-concept is not the same as identity, however. Identity is related to roles and a person has as many identities as role relationships. These multiple identities comprise the self-concept or self (Stryker, 1980). Identities are the meaning a person attributes to the self "as an object in a social situation or social role" (Stryker, 1980, p. 131) but identities are able to direct action only indirectly through the self image[3] that an individual constructs in a specific situation. Thus while self-images may be modified to suit each situation, they act as a buffer between the interaction and the self-concept to protect the integrity of the person's identity. Within the self-concept, identities are organized into a hierarchy according to their salience — those that are most important to the individual receive more support from others, are more closely related to the individual's self-esteem, and will motivate his or her behaviour more strongly (LaRossa & Reitzes, 1993; Stryker, 1980, Stryker & Statham, 1985).

Two final concepts are important to understand in regard to identity: reference groups and commitment. A reference group is "any group with which people psychologically identify themselves, or in relation to which they think of themselves" (Lindesmith, et al., 1988, p. 288). The source of a person's values is known as a normative reference group. Shibutani (1962) observes that reference groups exert social control because behaviour within the group is always directed toward people whose judgment is valued and whose approval is sought by the actor. As a result, the culture of the group becomes incorporated into the actor's identity and guides his or her behaviour in any new

---

[3] Self image is similar to Goffman's notion of impression management. Erving Goffman (1959) developed the analogy of drama to compare every day interaction to a stage performance, in which actors perform their roles to audiences.

situations that s/he encounters. A person's commitment to a particular group is a function of the salience of the person's identity as a member of that group. If membership in a group is a highly salient identity for a person, then he or she will display greater commitment to that group than to those groups associated with lower identity salience.

In summary, symbolic interactionists of different persuasions conceptualize identity slightly differently, although identity is always related to the more stable and conscious part of the self that Mead referred to as "Me." In a dialectical interaction between the "I" and the "Me," a person's conception of self (identity) is constructed. Rose (1962) has said that "...because the conception of self is the most important meaning for man's behavior, a conception of self once learned affects an individual's behavior throughout his life" (p. 18). Besides the self-concept, a second major influence on behavior is role, that is, the manner in which people execute their identity.

Symbolic Interactionism and Roles

Within structural-functionalist sociology, a role is generally understood as the set of culturally defined expectations for behaviour associated with a particular social position or status. Roles are essentially prescriptions for behaviour. Thus, people who take on a role tend to behave in accordance with it. Symbolic interactionists view roles as more fluid and flexible than traditional role theorists do. In their opinion, roles arise from interaction among individuals and groups, instead of determining the way in which the interaction proceeds. Rose (1962) offers these definitions of role and social structure. A role is "a cluster of related meanings and values that guide and direct an individual's behaviour in a given social setting" (p. 10). A social structure is "a cluster of related meaning and values that govern a given social setting, including the relationships of all the individual roles that are expected parts of it" (p. 10). Thus, father, mother, son, daughter, brother, and sister are the usual roles within the nuclear family structure. Sociologists maintain that the only way to fully understand a role is within a relationship. That is, for every role there is at least one counter-role or other-role and therefore, within families, the role of a parent is incomprehensible without taking into account the parent's relationship with his or her child (or children) and the patterns of behaviour that the child (or children) displays.

Once again, there is a discrepancy in the explanation of roles between the two schools of thought. While roles were not central to either Mead's or Blumer's analysis (Wallace & Wolf, 1986), Ralph Turner (1962) analyzed roles in terms of role-making, in keeping with the Chicago School perspective. In contrast, Sheldon Stryker (1980, Stryker & Statham, 1985) represents a more structural perspective. Although Stryker views himself as an independent contemporary symbolic interactionist (1980, p. 5), his work is more consistent with the Iowa School.

The Inconsistent Nature of Roles

In Turner's view, roles are contingent and inconsistent. Role-making allows an actor to create and modify a role in keeping with his or her definition of the situation even though, Turner points out, people tend to behave as if roles were more concrete and constraining. As a result, human behaviour is constrained "more or less [into] explicit collections of interacting roles" (Turner, 1962, p. 22). He observes that, apart from institutions like the military and bureaucracies in which role boundaries are rigidly assigned and enforced, most social situations allow individuals to modify their roles and their relationships to complementary roles. The outcome is that, "the self- and other-role perspective in any situation may occasionally shift" (p. 22).

When one role changes, any complementary or other-roles also change or they are perceived to change. In the "tentative process" (p. 23) of interaction, actors constantly test their conceptions of the role of others. When another person's response to the first actor's chosen behaviour disconfirms the original conception, the first actor will modify his or her role to fit with his or her assessment of the other's response. This modification follows the principle of role reciprocity.

People understand roles as patterns of behaviour that a certain type of actor is expected to display. Turner distinguishes between formal roles as prescribed in organizations and the actual or informal roles that are remade by actors. Thus, roles are structured in the sense that they follow a pattern, but Turner states that the pattern is "merely a skeleton consisting of rules which are intended to invoke the appropriate informal roles" (p. 28). Within that general pattern, however, individuals create their own role in relation to the counter-roles that are present in an interaction. Thus, like other aspects of interaction, roles are improvised in concert with the ongoing dialectic conversation between "I" and "Me" but the characteristic nature of the role, itself, remains recognizable. This ability of actors to role-make clarifies how it is possible for "different people to play the same role" (p. 25), for the same person to "adopt even conflicting roles on occasion" (p. 24), and for the same behaviour to be displayed in different roles, depending on the occasion (p. 28).

A More Structured View of Roles

Stryker does not reject the notion of role making, recognizing that improvisation in interaction makes social change possible and ultimately has the potential to change larger social structures (Ritzer, 1988, p. 200). By combining role theory from structural functionalism with symbolic interactionism, Stryker emphasizes the variation in roles, some inhibiting innovation more than others. Criticizing theorists like Strauss (Strauss, Schatzman, Ehrlich, Bucher, & Sabshin, 1963) who underscore the fluidity of negotiation in establishing roles within human encounters and organizations, Stryker and Statham (1985) stress that shared behavioural expectations emerge through interaction and that improvisation has to take account of structural impositions.

Not all social structural constraints on role are imposed from without. People name and classify objects in their social and physical environment. When classifying themselves and others, they do so in terms of the positions people occupy in the social structure. Consequently, in responding to themselves and others in interaction, individuals respond, not just to the person's behaviour at the time of the interaction but to the shared understanding of that person's class or position. In classifying oneself, the "reflexively applied positional designations become part of the self and create internal expectations with regard to [one's] own behaviour" (Stryker and Statham, 1985, p. 344). Consequently, such positional definitions play a part in defining each new situation in which the individual takes part. Although role-making occurs within the situation, it begins from the stand-point of these classifications and larger social structures, thus influencing the degree to which role-making is possible.

Stryker and Statham maintain that their conceptualization allows for routine and habitual interactions better than other versions of symbolic interactionism. Just as one can belong to and be committed to a group, individuals are committed in varying degrees to their social roles (p. 345), thus, in many interactions they may plan their behaviour to conform to the role they wish to be seen by others as fulfilling. In the same way that identities are hierarchically arranged, a person's multiple roles will vary in how important they are to him or her. Where a particular role fits on the hierarchy is dependent on the self-esteem, resources, and gratifications attached to the role, the individual's ability to fulfill the role well, and the amount of support received from others when he or she enacts that role (p. 346). Thus, when a role serves as a source of motivation and is appropriate to a person's definition of the situation, he or she will tend to project that role.

Selected Aspects of Role Theory

Finally, two supplementary aspects of role theory are important for this study: role conflict and role strain. Each helps explain some of the difficulties faced by parents who are caring for a family member who has schizophrenia.

Individuals experience role conflict whenever they are aware of differing expectations attached to a role. Stryker (1980) points out that resolving role conflict depends upon the intensity of the conflict and commitment to the role. Where commitment is high, the role derives from a highly salient identity, and the expectations of others are particularly insistent, the conflict will be severe and difficult to resolve. One possible resolution is to withdraw from the role, but that is not always practical or even possible. Group affiliation may also influence resolution, such that obtaining or retaining membership in a highly valued group may convince a person to compromise principles and role-make in favor of the group's expectations. Role conflict may also be resolved creatively through accommodating various points of view and either performing different roles sequentially or constructing a new role that avoids or diffuses the conflict. Thus, role conflict may have both positive and negative outcomes.

Stryker states, "What is role conflict, from the point of view of the person, is role strain, from the point of view of the larger social structure in which the person is located" (1980, p. 76). Role strain is difficulty experienced in fulfilling role obligations, which Stryker says is normal. People occupy multiple roles and juggling them can pose problems. As well, each role may have a different set of counter-roles, often with conflicting interests. Consequently, a parent with an ill child, trying to satisfy the expectations of the ill child, siblings, spouse, employer, and many others, is likely to suffer role strain. Role strain is thus a problem encountered by both an individual having difficulty acting out a single role satisfactorily and an individual attempting to manage multiple roles.

Symbolic Interactionism and Mental Illness

Most sociological research on mental illness within the symbolic interactionism paradigm has rejected the medical model of mental illness. Symbolic interactionists have historically followed two research traditions: Goffman's (1961) notions of the total institution and its impact on inmates and, secondly, labeling theory which is also referred to as societal reaction theory and was described in chapter two. More recently, Morris Rosenberg has posed a symbolic interactionist theory of mental illness that rejects the labeling perspective.

A major challenge to organized psychiatry was Erving Goffman's participant observation of a large state mental hospital, published in 1961. Goffman described the mental hospital as a "total institution" within which all social life functioned primarily to serve the goals of the staff and administration. Patients were depersonalized and institutionalized to the point of becoming dependent upon the hospital and unable to function outside of it. Goffman's exposé of overcrowded, understaffed and under-financed mental hospitals, and of largely ineffective (by today's standards) psychiatric treatment in the 1960s was a persuasive impetus for political reform and the deinstitutionalization of psychiatric care.

Morris Rosenberg (1984, 1992) explains psychosis from an interactionist frame of reference but without using labeling theory. Recall from chapter two that labeling theory states that when people label an individual's misbehavior as crazy and treat the ill person that way, the ill person eventually identifies him or herself as crazy and will behave accordingly. Although Rosenberg's argument also locates the cause of the attribution of mental illness in society's reaction to aberrant behavior, he uses Mead's basic theory to explain insanity as role-taking failure:

> ...insanity is not a matter of arbitrary social labeling; it is not a matter of impaired functioning or social maladjustment; it is not a matter of subjective distress. It is unequivocally an interactional concept that is distinguished by an observer's inability to take the role of the actor (Rosenberg, 1984, p. 291).

He goes on to show that the actor's behavior, thoughts or emotions do not define insanity because, in a different context, these same behaviors, thoughts and emotions may be judged as sane. In addition, he points out that for long periods of time a schizophrenic person's behavior and thoughts are indistinguishable from those of a normal person. Thus, he concludes, it make no sense to say that a person with mental illness is acting out a social role assigned by an internalized label. Instead, insanity is a judgment made initially by lay persons who are "unable to see matters from the actor's perspective, or to assign cause, motive, purpose, or intention to the act" (1984, p. 292).

There are two qualifications to the above statement. The first occurs when a lay person judges his own "thought-reading failure" (Rosenberg, 1992, p. 51) to be due to his personal limitations in understanding the other's point of view. Some examples of this occur when individuals realize that they lack the knowledge or the ability to understand a foreign language or culture. Similarly, a lay person may recognize that he or she is not familiar with the particular context within which the action occurred or that the other individual has a different cognitive structure, for example, when the other individual is a small child. The second exception occurs when the behavior is presumed to be normal in some recognized but different belief system. In general, the less well and less often the actors' roles are connected, the harder it will be for them to understand one another's perspectives.

My own understanding of symbolic interactionism in relation to mental illness fits with that of Rosenberg. As well, I am comfortable with his attitude toward the medical model of illness. Although he charges that psychiatry views mental illness as a disease with physical causation and tends to ignore the social consequences, he also does not deny the possibility of physical or biochemical abnormalities. Where, he says, the medical perspective falls short is in seeing mental illness as:

> ...simply an intrapersonal phenomenon; it is also an interpersonal process. It takes two to make a psychotic: an actor and an observer. Insanity, then, is a social problem, not an individual one (Rosenberg, 1992, p. 104).

Where labeling theorists and some medical sociologists fall short is in refusing to recognize the intrapersonal (i.e., physiological) phenomenon along with the interpersonal process. Similarly, symbolic interactionists need to recognize that the intrapersonal involves the physical body as well as the mind and the self. This concept of the duality of illness is found in the writings of Emile Durkheim (Doubt, 1996; Wolff, 1979) and Parsons (Gerhardt, 1989). As Cockerham (1989, p. 169) noted, even Becker[4] (1973) stated that

---

[4] Howard Becker is well known for his interactionist approach to both medical sociology and deviance, having stated that, "deviance is not a quality of the act the person

labeling theory "cannot possibly be considered as the sole explanation of what alleged deviants actually do" (Becker, 1973, p. 179). Freidson, a medical sociologist, advised that sociologists must "analyze illness as a form of social deviance which is *thought* to have a biophysical cause and to require biophysical treatment" (1970, p. 212). Dingwall, recognizing that early medical sociologists borrowed their understandings from medicine, challenged sociologists to develop a more social understanding when he stated that "a biology of illness is complementary to a sociology of illness" (1976, p. 25). Therefore, a comprehensive inquiry into any illness ought to include both the biological and social aspects.

Sociologists make a distinction between disease and illness (Eisenberg, 1977). Disease refers to pathology; illness to the subjective experience and the social consequences. Rather than rejecting one understanding in favor of the other, it is important to admit that knowledge of the disease and of the illness complement one another. Acknowledging the two models, Gerhardt says:

> ...when pathology is accepted as belonging to the medical realm where clinical knowledge and expertise are vital and sufficient sources of diagnosis and treatment, a new understanding of what is social in medicine becomes feasible (1989, p. 176).

Sociologists[5] are beginning to acknowledge the excesses of the anti-psychiatry movement and recognize that some mental illnesses have physical origins. Recent advances

---

commits, but rather a consequence of the application by others of rules and sanctions to an 'offender.' The deviant is one to whom that label has successfully been applied; deviant behavior is behavior that people so label" (Becker, 1973, p. 9). Later, Becker softened his stance to recognize that labeling is not the only explanation of deviant behavior.

[5] See, for example, Cook (1988), Isaac & Armat (1990), Doubt (1996), and many articles written by Leona Bachrach, e.g., Bachrach (1988). In contrast, the view of post modern sociology tends still to be very anti-medical, and to revere the psychotic person as the only truly free human being (Doubt, 1996).

in antipsychotic medications and brain imaging techniques leave little doubt as to the brain and neurophysiological abnormalities associated with schizophrenia. My viewpoint can be summarized with the following two quotations:

> ...schizophrenia, as a physical illness, constitutes a serious invasion of the self, which may then be what predisposes the afflicted person to society's labeling and abuse. When the self of someone with schizophrenia is preoccupied with the task of preserving self in the face of grotesque hallucinations and hostile voices, it cannot attend well to the task of interacting with others (Doubt, 1996, p. 7)

> Theoretical argument over the presence of organic disease versus social designation and control has all but ignored the empirical fact that, regardless of what causes and defines negative differentness, persons who experience and display bizarre symptoms do exist in our society, and do live with the culturally conditioned consequences and meanings of these diseases, labels, and experiences (Estroff, 1981a, pp. 39-40).

CHAPTER FOUR

THE CONSTANT COMPARATIVE METHOD OF GROUNDED THEORY

Grounded theory (Glaser & Strauss, 1967; Glaser, 1978; Strauss, 1987; Strauss & Corbin, 1990) is a qualitative research method developed within the symbolic interactionist tradition in sociology. Its purpose is to understand the relationships among concepts "that explain, account for and interpret the variation in behavior in the substantive area under study" (Glaser, 1992, p. 19) and that have been derived from the data. Using this method, researchers aim to discover the basic issue or problem for people in particular circumstances and then explain and describe the process that helps them cope with that issue. The goal is to develop a qualitative theory from the "ground up," i.e., the theory is derived inductively from the data.

One important characteristic that distinguishes qualitative research methods is the evolutionary character of the research design. Because researchers want to understand in depth the meaning that an experience has for the participants, variables or important concepts cannot be identified in advance but emerge during the interviewing process and the coding and categorization of the data. The process must, therefore, be flexible, to allow new insights to guide further data collection and be explored further.[1] Grounded theory meets these requirements. At the same time, it is a rigorous and systematic approach to empirical research (Blumer, 1969/1986).

---

[1] For a summary of the differences between grounded theory and traditional scientific research methods, see Charmaz, (1983). For critiques of the method and its perceived limitations, read Brown (1973) and Layder, (1982).

This chapter addresses the relationship of grounded theory to symbolic interactionism, followed by a description of the constant comparative method. Examples from this study of schizophrenia and parental caregiving illustrate the application of the method.

The Relationship Between Symbolic Interactionism and Grounded Theory

Symbolic interactionism calls for a research methodology that investigates not just the social world but, rather, the processes by which human beings construct their social worlds. Attempting to understand the meanings through which individuals interact requires an emic research perspective, i.e., the researcher enters the everyday world identified by the research topic to learn the experience of those living in it. Mead's proposition that the only way to understand the experience of another is through significant symbols requires that researchers, who begin their endeavor as outsiders (Blumer, 1969/1986, p. 35), assume the perspectives of their respondents in order to learn about the insiders' behaviors and attitudes, finally reaching the point where the researchers' own responses approximate those of their participants (McPhail, 1989).

Because the problems that generate research are located in the natural world, symbolic interactionists investigate their questions in (and draw their interpretations from) the natural world of their participants. Symbolic interactionist research is a two-step process of exploration and inspection (Blumer, 1969/1986). Exploration entails becoming broadly familiar with a new social setting and gradually focusing the inquiry to allow the "data, analytical relations, and interpretations [to] arise out of, and remain grounded in, the empirical life under study" (Blumer, 1969/1986, p. 40). Inspection includes the analysis of the concepts that have emerged in comprehensive written accounts of what has taken place. Blumer's own words, "social action is the primary subject matter of social science, the subject matter from which it starts and to which it must return with its schemes of analysis" (p. 55) summarize both his own position and the assumptions from which Glaser and Strauss (1967) derived grounded theory as a method for exploratory and explanatory research.

Grounded theory is regarded as a suitable method for obtaining reliable knowledge about the self concept (Shibutani, 1991). According to Shibutani, this method can reveal how people regard themselves in distressing situations, as well as the subsequent transformations in their self-concepts. In this study, changes in parental identity were identified as the core concept.

The Constant Comparative Method

Grounded theory relies on insight generated from the data. Unlike traditional research that begins from a preconceived framework of logically deduced hypotheses, grounded theory begins inductively by gathering data and posing hypotheses that are confirmed or disconfirmed during subsequent data collection. Thus, grounded theory employs both inductive and deductive reasoning. Constant comparison refers to the simultaneous collection, analysis, and interpretation of the data. Emerging concepts are continually compared with one another, with new data and with the researcher's observations. Throughout the analysis this process generates new hypotheses about the emerging concepts. Hypotheses are tested with further observations and data collection from both new participants and also previously interviewed participants for validation, refutation, or clarification. Hypotheses are not tested statistically but instead "by constantly comparing hypotheses against [the developing theory and against] reality (the data), making modifications, then testing again. Only that which is repeatedly found to stand up against reality will be built into the theory" (Strauss & Corbin, 1990, p. 187).

As an exploratory method, grounded theory is particularly well-suited for investigating social processes (1) that have attracted little prior research attention, (2) where the previous research is lacking in breadth and/or depth, or (3) where a new point of view on familiar topics appears promising (Schreiber, 1995; Stern, 1980). Earlier studies of family care for persons with serious and chronic mental illnesses have been largely descriptive, identifying the tasks required to provide the technical aspects of care. Where researchers have looked at the subjective or emotional aspects, they have concentrated on quantitative burden scales measuring the risks to the caregivers' health, or expressed emotion measuring the risks of relapse for the sufferer (Chesla, 1991). Explanatory models of caregiving generally apply to caregiving of elders and follow the stress paradigm. No grounded theory study has been published giving a broad description and explanation of the subjective and emotional experience of parental caregiving in schizophrenia.

Theoretical Sampling

Theoretical sampling is achieved by collecting, coding, and analyzing the data simultaneously, rather than sequentially. After the initial interviews, data collection is directed by the emerging theory so that as the analysis proceeds, the researcher seeks information for the portions of the theory that need further development as well as additional data to support and enlarge upon the insights that have been learned from the participants during the interview process. Sampling in grounded theory is a deductive process (Stern, 1980) and, rather than sampling persons, grounded theorists sample "on the basis of concepts that have proven theoretical relevance to the evolving theory" (Strauss & Corbin, 1990, p. 176), as well as to test hypotheses about possibly relevant concepts that emerge during analysis (Glaser, 1992).

Because of theoretical sampling, the sample size cannot be determined before the study commences.[2] Only when grounded theorists are satisfied that no new concepts are emerging and no new information on the important concepts is forthcoming does data collection end. This last point is termed theoretical saturation (Glaser & Strauss, 1967).

Identifying this Research Sample

Participants were drawn from parent caregivers of people with schizophrenia in British Columbia, primarily but not exclusively in the Greater Vancouver and Greater Victoria areas. Initially, the participants were volunteers from the British Columbia Schizophrenia Society. To gain access to this group, I met with the Executive Director of the Victoria branch[3] of the B.C. Schizophrenia Society (BCSS) and with the Policy Development and Communication Coordinator for BCSS in Vancouver. Following the acceptance of my research proposal by my candidacy committee and the ethics review committee, I wrote to the president of the Victoria Branch and met personally with the provincial president of BCSS, gaining their support. Notices soliciting participants were placed in their respective newsletters (Appendix 3).

The majority of studies of psychiatric caregivers have drawn their samples from members of self-help and advocacy organizations in primarily urban settings, especially

---

[2] Morse (1994) advises 30 to 50 participants for a grounded theory study, although Stern (1985) suggests that 20 participants should be sufficient to achieve saturation. My best estimate at the time of my research proposal was that between 25 and 35 participants would be necessary to ensure enough variation.

[3] The executive director of the Victoria Branch of BCSS resigned shortly after our meeting. After their reorganization which dispensed with this position, I met with both the office manager and the director of programs.

members of NAMI, the National Alliance for the Mentally Ill in the United States. Presumably, this introduces a self-selection bias into the research, in that participants have generally been white, well-educated, urban residents with an established social support system in the organization. Consequently, studies of caregiving are unlikely to account for negative cases.[4] Therefore, an effort was made to find parents who were not well connected to the Schizophrenic Society. A notice appeared in the newsletter of the Caregivers Association of British Columbia, asking for volunteers on Vancouver Island and on the lower mainland of British Columbia. Snowballing was utilized to contact participants via word of mouth. Although snowballing was not successful in finding participants outside the circle of BCSS, it did broaden the sample to include two families whose sons had died.[5] Finally, with the data collection nearly complete and still lacking any participant without BCSS membership[6], I used CFAX radio station in Victoria on July 11, 1997 to specifically request volunteers who did not belong to a support group. This effort attracted one participant who had only recently become involved with BCSS.

Data Collection

Data for grounded theory studies consists of three types: observation, interview, and written documents, although recent studies have included data from visual media, as well. For this study, data was collected primarily in face-to-face interviews. A small amount of

---

[4] Negative cases are those which do not conform to the grounded theory. Accounting for negative cases will promote fuller understanding of the phenomenon and push the theory to a higher level of abstraction (Schreiber, 1995).

[5] Analysis produced the hypothesis that grief for a child with schizophrenia was different while the child was living than it would be following an ill child's death. These two families helped identify these differences.

[6] One participant, however, is a member of BCSS but does not attended meetings.

written data was supplied by some participants, e.g. photocopies of a suicide note and other self-deprecatory notes found in one son's bedroom, a written document prepared by one father describing his son's medical history, and a written document and letters to me from one father about his family and his advocacy efforts.

The Interviews

In-depth interviews usually lasting one and a half to two hours[7] were conducted in a private setting chosen by the participant. In most cases, this was the participant's own home. Two interviews were held in the researcher's office at the University of Victoria and one in the researcher's home because the participant was intimidated by the parking situation at the university. Each participant was interviewed separately, except for one couple (Philip and Donna) who were interviewed together. Follow-up interviews were conducted with several participants individually and with one couple together, during the later stages of the research project. The purpose of these follow-up interviews was theoretical elaboration, in which unsaturated categories were discussed and the emerging theory was presented to participants for their verification and comments. Interviewing lasted over a ten month period, from October, 1996 through August, 1997. The final tally was 32 interviews with 29 parents, for a total of 52.7 hours.

A preliminary, 90 minute interview in my office with one participant, Clifford, was not recorded nor used as data. This gentleman arrived at a pre-arranged interview with a two-page, type-written list of questions which he used to interview me. His questions inquired about my perspective on schizophrenia, my research ethics, my purposes in

---

[7] The briefest interview lasting 35 minutes was with Tom, although Tom expressed surprise at the end of the interview, stating that he had never talked that long to anyone before. The longest interview, with Clifford, lasted 3 hours and 40 minutes.

conducting the study, and my intentions for dissemination of the research results. Satisfied with my answers, he then invited me to interview him two weeks later in his own home.

The interviews were tape-recorded and transcribed verbatim to preserve the richness of the data. Following each interview, field notes of my observations were tape-recorded as well. There was an exception made for one participant who was intimidated by the tape-recorder. During this interview, written notes were made, in an attempt to produce as complete an account as possible. Immediately following the interview, I tape recorded the notes. Short segments[8] of two other interviews were lost due to mishaps with the tape-recorder. Again, my recollections were recorded immediately following and clarification was sought in follow-up interviews.

Initially, participants were asked broad, open-ended questions to try to elicit both the positive and negative consequences of caring for a family member with schizophrenia (Appendix 1). After the initial interviews, the interview schedule was largely disregarded as I became more familiar with the issues and as theoretical sampling began to drive the questions. As the theory developed, the emerging concepts were validated against the stories of new interviewees and also in follow-up interviews with some respondents.

The words loss, bereavement, grief, and mourning were not introduced into the initial interviews until after the respondent used one of these terms. Instead, participants were asked to describe their son or daughter prior to the illness and presently, and then to describe their own reactions to the changes. This relative lack of explicit direction in the questions was a conscious effort not to bias their responses towards what informants might believe I wanted to hear. Instead, I wanted to allow them to offer their own interpretations

---

[8] These periods lasted 15 minutes with one participant and 30 minutes with the other.

and understandings of what is important in their caregiving experience. After each of the first five participants had spontaneously introduced the subject of grief I felt justified in introducing the topic myself. The question that I used was, "Some people have said that having a child with schizophrenia is similar to your own child dying and being replaced by someone else. Does this idea agree with your experience?"

A research journal contained four categories of notes: field notes, memos about analysis, methodological ideas and arrangements, and personal reactions (Richardson, 1994). These were treated as data and were coded along with the interview transcripts. As the theory developed, the memos were attached directly to the appropriate data codes.

Data Analysis

Analyzing voluminous amounts of textual data is a matter of data reduction, segmenting the data into sections which can be compared and contrasted, then sorted by categories. In the grounded theory method (Hutchinson, 1986), as soon as the first interview has been typed, the transcript is coded line-by-line (sometimes phrase-by-phrase) into substantive codes (level I), generally named by using the participant's own vocabulary. Comparing these coded segments for similarities and differences allows them to be grouped into categories (level II). After each subsequent interview is analyzed to this point, the categories and codes in it are compared with previously discovered codes and categories. Categories may be collapsed into a higher level of category (level III), as patterns, dimensions and relationships[9] among them are noticed.

---

[9] One way to look for these relationships is to examine the codes and categories in terms of their causes, contexts, contingencies, consequences, covariances, and conditions. Glaser (1978) describes 18 families of theoretical codes. The "six C's" are commonly employed, to tease out the meaning of a code or category. Some other examples are dimensions, degrees, types, and temporal ordering. These coding families are meant to

Theoretical constructs[10] are derived by questioning the data. In other words, each new level of code requires the researcher to re-examine the data to ensure that it is congruent with the emerging theory. Unanswered questions guide subsequent interviews, until the researcher is no longer able to find new information pertaining to that construct or code. Thus, the code is "saturated" and further data collection omits this category, concentrating on other issues. Throughout, as linkages are discovered and recorded in memos, the analyst posits hypotheses about how the concepts fit together into an integrated theory. Eventually, a core variable (or basic social process) becomes evident. This is an "umbrella concept" that appears to explain the essence of the problem for participants and how they attempt to solve it. Final interviews focus on developing and testing this core category by trying to discount it. Finally, a literature review is conducted to connect the theory with previous work in the field.

Data analysis utilized the NUD*IST (Non-numerical Unstructured Data: Indexing, Searching, and Theorizing) computer software[11] (NUD*IST, 1997). This qualitative data analysis program allows the analyst to go beyond the usual coding and categorizing to building and testing theories and to constructing matrices, in order to discover patterns in the data. Many grounded theorists believe that NUD*IST is particularly well-suited to the constant comparative method of grounded theory.

---

sensitize the analyst to relationships that may emerge among codes and categories. They are not meant to serve as a checklist for matching with theoretical constructs (Glaser, 1992).

[10] Reading various grounded theory methodologists can be confusing. Hutchinson (1986) calls level III codes theoretical constructs, while Strauss and Corbin (1990) refer to them as axial codes.

[11] For a brief overview of the capabilities of this program, see Richards & Richards (1991).

Considerable controversy has arisen over the use of computer programs for analyzing qualitative data. Purists contend that using a computer program forces the researcher in particular directions, confining the analysis and stifling creativity. Those who support the use of computers recognize their proficiency for managing large amounts of complex data. Even computer program sponsors recognize the danger of using computer programs to analyze the data rather than to expedite only the routine and mechanical tasks of analysis (Richards & Richards, 1994). Prudent qualitative researchers who use computers as tools to facilitate the examination of their data continually examine their use of technology to enhance, rather than replace, recognized analytical methods.

Coding and Categorizing Data

Codes and categories are the building blocks of theory. Open coding begins by examining the data minutely, phrase by phrase and line by line[12] to identify concepts and processes, by asking oneself, "What is this an indication of?" and "What is going on here?" Each phrase does not have to have its own separate code, as frequently several will group together within a concept and often codes will overlap. To illustrate, the following is a quotation from my second interview:

> So, for me, without having a, with the support of the friends that got me through, finally people would be, "Oh, what is the matter with you?' because it would be obvious that I would be falling apart when I would come into the school, even though you try to hide it. Um, so I was lucky because I was not allowed to withdraw. When the diagnosis came in I was devastated

---

[12] In NUD*IST, one must code line by line. Thus there are often a few extraneous words attached to a segment, when the data is separated by code. These can be edited out; more often, the researcher just disregards them.

This whole section was coded, "support from friends." Lines 513-515 were coded, "falling apart," line 515 was coded, "hiding emotions" and line 517 was coded "parent's reaction to diagnosis." At this stage most codes are substantive or "in vivo" codes, named with the participant's vocabulary where possible.

Coding allows the data segments belonging to each code to be sorted together. NUD*IST does this automatically.[13] A two hour interview obviously yields a multitude of codes, although many will be repeated. As the codes are identified, memos are written defining the code. Codes are then compared for similarities and differences, enabling the researcher to combine some and group others together into categories. As this is done, memos are written[14] for each analytical decision. When each new interview is coded, the substantive codes and the data they contain are compared with other codes and categories, and with the coding in previous interviews. In this study, for example, codes such as "friends changing," "street drugs" and "taking off," all clustered under the category, "suspicious behaviour." "Suspicious behaviour" was eventually included with the codes, "personality change," "relations with parents," and "religious beliefs" in a higher level conceptual code called "becoming alarmed." These categories describe the beginnings of aberrant behaviour on the part of the child leading to a crisis and eventually to the schizophrenia diagnosis. Thus, by comparing data segment with data segment, code with code, codes with categories, and individual cases, connections among the data are identified

---

[13] NUD*IST creates a node in the program for each code. At any point, the researcher can retrieve all of the data coded to that node for analysis.

[14] In NUD*IST, memos are written and attached to the appropriate code and a running log of commands records any combinations automatically.

and the number of conceptual codes reduced. As codes fit together,[15] the relationships among them are recorded in memos.

Hypothesizing a Core Category

Gradually, enough linkages were generated from the data that the dimensions and properties of the categories and concepts began to fit together into an integrated theory. At this point of theoretical coding, I became convinced that parents of people with schizophrenia were disenfranchised, that is, that they lacked the rights towards their ill child to which they believed they were entitled. At this point, I determined that "disenfranchisement" was the basic social problem for these parents.

The core category or core variable in a grounded theory is defined as the category that "accounts for most of the variation in a pattern of behavior" (Strauss, 1992). At this point, however, the core category is only tentative, and I began, through further constant comparison, to look for a conceptual framework revealing the organization of the study's theoretical constructs in terms of "disenfranchisement." In doing so, I became aware that the basic problem for these parents is antecedent to being disenfranchised. That is, they have no right to determine their ill child's affairs because society views their ill child as old enough to take that responsibility and parents are therefore prevented from interceding.

The basic social process (BSP)[16] of a grounded theory is a particular type of core category that changes in character over time. Although participants may not recognize the

---

[15] Nudist portrays this as a hierarchical tree. Grounded theorists build the tree by combining codes from the bottom up, rather than the top down. Often codes are later divided by dimensions or properties, and the hierarchical tree can be revised to depict this as well.

[16] Grounded theorists identify a basic social process or BSP as the core variable which appears to link the other categories and concepts together.

BSP, the researcher's goal is to explain the process, making it understandable for them (Schreiber, 1992). Just as the basic social problem is prior to disenfranchisement, the process by which parents encounter it and deal with it extends temporally, before and after disenfranchisement. The core category that explains this is the parents' definition of themselves as parents, that is, their parental identity. As a child becomes ill with schizophrenia and throughout this chronic mental illness, parents redefine their parental identity. Consequently, "redefining parental identity" emerged as the BSP for this study.

Ensuring Rigor

Judging qualitative work by the positivist standards of validity and reliability is inappropriate as these tests are not applicable to the naturalistic paradigm. However, validity and reliability have been redefined into three appropriate standards for ensuring the rigor of qualitative research: credibility, auditability and authenticity.

Credibility

Credibility is somewhat parallel to internal validity in quantitative research. An analysis is credible if there is a match between reality as understood by the participants and the findings produced by the researcher (Guba & Lincoln, 1989). Credibility, or "truth value" (Sandelowski, 1986) is ensured when the participants are able to recognize the interpretations of the researcher as their own. Guba and Lincoln suggest several techniques for ensuring credibility.

First, lengthy observation and engagement with the participants is necessary to identify what is relevant to them and prevent premature closure of the analysis. This was accomplished by following the method of grounded theory in theoretical sampling and achieving theoretical saturation. When I returned to participants for follow-up interviews, near the end of the interviewing period, I reviewed the developing theory for them and asked how well the concepts reflect their experience. The theory was then modified as necessary. Most participants had little to challenge about the theory or to add to it. One participant, however, was helpful in pointing out desirable changes in the wording for a couple of phases of the model. For example, the final stage was originally titled, "appreciating my life." Willow observed that many of her friends felt they had little to appreciate in the sense of "being grateful." I changed the name for this stage to "Evaluating my life." Future plans have been made to present my research at the May, 1998 general meeting of the Victoria branch of BCSS and to chapters of BCSS on the lower mainland. Their responses will be a further test of the study's credibility.

Secondly, peer debriefing, i.e., discussing the developing theory with colleagues and other persons who have no direct connection to the research project, is recommended. Probing questions from people outside the research setting help to refine conceptualizations and keep the research on track methodologically. In the summer of 1997, at the School of Nursing at the University of Victoria, we formed a grounded theory club that meets every two weeks. Members include a faculty member who practices grounded theory research, myself, another Ph.D. candidate (faculty member) and two masters students. Our discussions have provided valuable insights and suggestions during analysis of this data. In addition, I have presented my final model to two people who are working in the mental health field, Jane Duval,[17] the Coordinator of Policy Development and Communication for

---

[17] Jane Duval has a family member with schizophrenia but did not participate in this study.

BCSS in Vancouver, and Anne Bowles[18], the Manager of Consumer, Family, and Psychosocial Rehabilitation for the Capital Health Region in Victoria. Their responses to the model validated the theory. All these measures guarded against my personal biases influencing the research results.

Finally, negative cases were sought and incorporated into the grounded theory. For example, the theory accounts for those parents who do not participate in support organizations. They remain disenfranchised, they have a spouse who is the primary caregiver, or they identify their own needs as primary earlier in the child's illness than most parents do.

Auditability

Auditability , also called dependability (Guba & Lincoln, 1989) is somewhat analogous to reliability in the positivist paradigm. Nevertheless, qualitative researchers recognize that a complete replication of either the method or results of a qualitative study is impossible. Instead, the appropriate judgment is whether another researcher could arrive at the same or comparable results, but not contradictory conclusions, given the data, the researcher's perspective, and a similar situation. Thus, conscientious researchers provide an "audit trail," in both their data and the final report.

In writing my dissertation I believe I have included sufficient description and documentation of the research procedure to enable readers to follow my decisions about how the data were collected and analyzed. Keeping memos of the analysis and data collection process is essential to providing this information. Using NUD*IST to analyze the

---

[18] Anne Bowles was the Chairperson of the BC Task Force of Families of People with Mental Illness (British Columbia Ministry of Health and Ministry Responsible for Seniors, 1993) and, before that, was the Executive Director of the Victoria Branch of BCSS.

data provides a permanent record of changes in the coding and categorization used in building the hierarchical model. If another researcher wished to track the complete process of analysis, including blind alleys and mistakes that later were corrected, then doing so would be available. As well, being clear from the beginning about my assumptions and perspective is important. Complete objectivity is impossible in qualitative work (and, I would argue, in quantitative work as well), making it imperative that reviewers of the study are made aware of the researcher's perspective. A final measure for ensuring that the reader is able to track my conclusions back to the data is to liberally quote from the interviewees' stories, as a means of showing support for my analysis.

Authenticity

Other terms for authenticity are "meaning in context" (Leininger, 1992) and "fit" (Glaser, 1978; Guba & Lincoln, 1981). The operative questions here are, "How well does the concept, phenomenon or interpretation fit the situation?" and "Are the results meaningful to those who read or hear it?" One way to adhere to this criterion is to ensure a wide variety in the data and participants. Chenitz and Swanson (1986) maintain that the more variation in the data, the better chance that the researcher has discovered any participants' experiences that would contradict the theory or any of its categories. They are referring to the importance of seeking out the negative case and attempting to discount the developing theory. This was accounted for by procuring a broadly based sample to increase the probability of discovering negative cases and explain as wide a variation in the experience of caring for schizophrenic sufferers as possible

The above three standards are not completely separate. They overlap and the provision of verbatim quotations from the data helps to assure readers that the researcher has attended to all three. Nonetheless, Glaser (1978) advises that quotations are merely a suggestion of grounding the theory in the data. "The credibility of the theory should be won by its integration, relevance and workability, not by illustration used as if it were proof" (Glaser, 1978, p. 134).

Specific Research Standards for Grounded Theory

Three criteria for grounded theory were identified originally by Glaser and Strauss (1967). That is, a grounded theory must fit, work, and be relevant to the experience of people in the setting. To these standards, Glaser (1978) added a fourth, modifiability. To ensure fit, the categories are generated from the data, rather than the data forced to comply with pre-conceived categories. When, however, common categories appear to fit, the task is "to develop an *emergent fit* between the data and a pre-existing category" (Glaser, 1978, p. 4). As an example, I quickly recognized that grief was part of the experience of being a disenfranchised parent, but "grieving alone" both delimited the concept to the parent's disenfranchisement and described it more clearly. To work, a theory should explain, predict, and interpret the experience of people in the setting. This criterion and also the relevance of the core concept were validated by a number of participants and professionals who work with them. Finally, modifiability becomes important in the future when the theory is applied. No grounded theory can be expected to account for changing circumstances. In future, new variations and conditions may be discovered but the basic social process of redefining parental identity is expected to endure. Although new treatments and the greater availability of psychosocial interventions for schizophrenia are anticipated, unless and until prevention of the illness or a complete cure is discovered, the diagnosis of schizophrenia in a child will necessarily initiate a redefinition of the parent's identity.

Human Subjects Protection

Ethical research protects the informants from any harm that could result from participating in the study. The University of Alberta Guidelines for the Protection of Human Research Participants were adhered to, and the proposal was approved by the candidacy committee and the Department of Sociology Ethics Committee before any interviews were conducted.

Participation in the study was completely voluntary. When prospective informants responded to printed announcements, they received a letter (Appendix 4) outlining a more detailed description of the research, their involvement and the safeguards used to maintain their anonymity and confidentiality. Both Dr. Northcott's and my addresses and telephone numbers were provided. A similar letter was sent to people who were contacted by snowballing. The letter included a self-addressed, stamped envelope and a form that indicated their willingness to participate (Appendix 5). Only when their reply was received did I contact them personally to arrange an interview.

The following measures were taken to protect the confidentiality and anonymity of participants. Before beginning the interview, I reviewed the consent form (Appendix 6) , stressing how their names and any identifying features would be protected. Two typists transcribed the tapes. One is employed as a medical office assistant; the other transcribes dictated medical letters and reports in her home. Both are required to honor confidentiality in their employment. Prior to engaging them, I reviewed the importance of complete confidentiality for my research participants and requested them to keep the tapes and computer disks in a secure location. I personally delivered the tapes and picked them up. Each participant was given a pseudonym and the tapes were labeled with this name only. Immediately after receiving the disks back, I printed transcripts and listened to the tapes to make any corrections and replace all names and identifying characteristics, e.g., street names. The final transcripts were identified by pseudonym only.

Additionally, at the time of the interview, all demographic data was recorded on face sheets (Appendix 7), rather than recorded on the audio-tape. Only the pseudonym appeared on these face sheets. Transcripts, tapes, and face sheets were kept in a locked filing cabinet. Only pseudonyms have been used throughout the thesis and will be used in any presentations or journal articles produced subsequently.

One potential area for concern about confidentiality was the fact that some of the participants know each other by virtue of common membership in either the Victoria or Vancouver branches of the BCSS. Participants were advised of the possibility that aspects of their experience may already be known to other participants or to members of the organization who read about or hear the research being presented. No one withdrew his or her participation when reminded of this possibility.

Finally, at the outset of the study I was concerned that, for some participants, these would be emotional and stressful interviews. Not being a trained counselor, I prepared a list of grief counselors, given me by BC Psychological Association (Appendix 8), in case a participant became very upset. This list was never required.

CHAPTER FIVE

REDEFINING PARENTAL IDENTITY

The basic social problem identified in this study for parents of people with schizophrenia is that, although the parents believe that they have the right and responsibility to care for, protect, and make decisions for a child whom they perceive as unable to care for and protect him or herself or to make decisions in his or her own best interest, society refuses to sanction their belief and denies them that right. In response, parents engage in a basic social process (BSP), redefining their parental identity. Chapter five will summarize the grounded theory of redefining parental identity, which is then described in detail in chapters six, seven, and eight of this thesis.

Before beginning, a short introduction to the study's participants and their families will familiarize readers with the participants' names and stories, prior to encountering their individual experiences in the quotations that personify and provide evidence for the written theory.

Participants in the Study

Nineteen families participated in this study, one of which has two adult-children with a diagnosis of schizophrenia. In another family, the mother and one daughter have schizophrenia and the father suspects undiagnosed mental illness in the other three siblings. I interviewed both parents in ten families, the mother only in six families, and the father only in the remaining three, for a total of twenty-nine individual participants (see Table 1).

Table 1. Characteristics of Participants at the Time of Interview***

	Parents						Ill Child						
Family	Name	Age	Mar. Status	Occupation		# Children	Name	Gender	Age	Age Dx*	Years Ill	Position in family	Residence
1	Jean	69	married	RCAF	/R	2	Maxine	female	38	19	19	2nd	group home
	Tom	79		photographers	/R								
2	Catherine	55	married	teacher		2	Bryan	male	29	16	13	2nd	group home
	Sam	57		college teacher									
3	Lorraine	59	married	teacher's aide		4	Melanie	female	32	15	17	3rd	apartment by self
	Michael	62		engineer									
4	Lois	66	married**	govt. worker	/R	2	Sean	male	39	19	20	1st	apartment by self
5	Gerald	57	divorced	artist		2	Jeremy	male	26	22	4	1st	with mother
6	Marianne	67	divorced	realtor	/R	4	Daniel	male	42	22	20	3rd	apartment by self
	Arthur	71	divorced	construction	/R								
7	Willow	57	divorced	self-employed		2	Ken	male	29	19	10	2nd	apartment
8	Margaret	69	divorced	psychologist		3	Derek	male	33	20	13	3rd	basement suite/self
9	Gwen	65	married	piano teacher	/R	3	Colin	male	35	25	10	1st	with parents
	Irwin	66		company VP	/R								
10	Ruth	69	widow	business	/R	5	Tim	male	37	14	23	5th	group home
11	Teresa	50	married**	nurse		4	Anne	female	26	21	5	1st	hospital
	Bruce	56		letter carrier									
12	Evelyn	54	married	nurse		2	Barry	male	25	20	5	1st	shared house
	Joe	56		TV cable tech.									
13	Gurpreet	53	married	quality control		3	Kal	male	24	15	9	3rd	group home
	Kulwinder	53		civil servant									
14	Maggie	70	married	homemaker		5	Geoffrey	male	42	20	22	1st	hospital
	Warren	72		civil engineer			Maureen	female	31	27	4	4th	apartment by self
15	Sue	61	married	nurse instruct.	/R	2	Ryan	male	30^{δ}	21	9	2nd	deceased
16	Jenny	50	married	home business		5	Melinda	female	21	19	2	2nd	with parents
17	Clifford	60	married	pub. relations	/R	4	Julie	female	30	20	10	4th	with parents
18	Donna	66	married	univ. employee	/R	3	Roger	male	42^{δ}	18	24	1st	deceased
	Philip	74		engineer	/R								
19	Fred	50	widower	tech.consultant		3	Trevor	male	23	23	6 mo.	2nd	forensic hospital

* Age at diagnosis ** Remarried after divorce from ill child's father *** from October, 1996 to August, 1997. $^{\delta}$ Deceased /R = retired

The participants are primarily of the older middle-aged group, with mothers' ages ranging from 50 to 69 years (mean=61.25 years) and the fathers, slightly older, ranging from 50 to 79 years (mean=62.5 years). Forty-one percent (12/29) of the sample is retired and four of those who continue to work are 65 years or older in age. Thus, over half of the sample (16/29) are retired or of retirement age and two of the men who are presently working have retired from their first occupation. Gerald, an artist, used to be a stock broker; Warren has opened his own engineering practice after retiring from a large firm. Apart from one immigrant couple from India, the rest are ethnically European — although one of the mothers came originally from South America. Their occupations would place the majority in the middle class, although the working class also is represented.

These nineteen families identified six daughters and fourteen sons who have been diagnosed as suffering from schizophrenia. The daughters average 29.7 years in age (range=21-38), having been diagnosed at an average age of 20.2, whereas the sons are now, on average, 32 years old (range=23-42), and were diagnosed at an average age of 19.6 years. None of these young adults has ever been married, no one was employed at the time of the interview, and two have died in the last five years. Those who are still alive have been ill for an average of 11.5 years since their diagnosis — a range of 0.5 to 23 years — although the majority were also ill for a protracted period before being diagnosed. Most of these adult-children have lived with their parents for extended periods during their illness, although only four are doing so at present. The living arrangements of the remainder are about equally divided between group homes[1] and semi-independent[2] or independent apartments.

If one applies the rule that one-third of people who have schizophrenia recover, one-third have a variable disease course, and one-third remain chronically ill, this sample probably represents a more chronic group than the average. The fact that the study is an investigation of caregiving and participants were parents who identified themselves as caregivers may explain why those who recover from this illness are under-represented. Nevertheless, qualitative research does not require a representative sample but, rather, one which encompasses a broad spectrum. This group includes a wide variety of the experience of parental caregiving for a family member who has schizophrenia and the grounded theory of redefining parental identity is representative of the experience of those diverse caregivers who participated in the study.

An Introduction to the Participants' Families

The following is a short introduction to each of the families who participated in this study. They are presented in the order in which the first parent in the family was interviewed, giving the reader the opportunity to become acquainted with them in the same order as the researcher did.

Maxine has had schizophrenia for nineteen years but does not admit openly to it. As a result, her parents, **Jean** and **Tom**, are unable to discuss the illness with their daughter.

---

[1] Group homes provide supervised living in the community for discharged psychiatric patients. To date, there is little standardization of the number and qualifications of staff or of the rehabilitation programs provided and, consequently, there is wide variation in available group homes. Some are little more than rooming houses.

[2] Semi-independent living in an apartment, with or without a room-mate, implies that there is some follow-up supervision from Mental Health.

Describing her in childhood as an "ambassador of goodwill," her parents became concerned about Maxine during high school. After barely managing to graduate, Maxine went to Toronto to work but returned unexpectedly months later. She immediately withdrew to her bedroom, neither speaking to anyone nor eating. Three days later, her parents contacted their family doctor who arranged an admission to psychiatry. Over the next decade, she attempted suicide twice and was hospitalized seven times — the last time in 1989. Since then, she has lived in a group home but visits her parents weekly.

Bryan was diagnosed with schizophrenia at sixteen. An honors student until high school, he failed to graduate. Initially when not in hospital, he lived at home, which was a difficult time for the whole family. Consequently, he moved to a group home before turning eighteen. In the first six years after diagnosis he was hospitalized three times — once to Riverview, the provincial psychiatric hospital. Over the past six years until very recently, neither **Catherine** nor **Sam** had seen him face-to-face, although they spoke frequently by telephone. During that time, Bryan believed that seeing his parents would cause his eyes to close forever. In the months between my interviews with these parents, Bryan's psychiatrist convinced him to meet with his mother, Catherine. Sam is hopeful that Bryan will soon consent to see him, as well.

Melanie, now thirty-two, is the third of **Michael** and **Lorraine**'s four children. Like Maxine, she does not accept her illness fully nor discuss it with her parents. Although she now refuses to see a psychiatrist, she sees her general practitioner, takes her medications quite regularly, and has been relatively stable for six years. She lives alone in an apartment but has several friends, also psychiatric consumers,[3] who live in the same building. To some extent, they all look out for one another.

Sean, at thirty-nine, has been ill for twenty years and lives semi-independently in an apartment, supported by Mental Health. **Lois** is remarried, having been divorced from Sean's father shortly before Sean's first psychotic break and suicide attempt. After hospital discharge, Sean refused to take medications and traveled for a number of years in the United States and Canada, living on the street or with people whom he met there. Occasionally, when obviously ill, he was rescued by street workers and returned home. Twelve years ago, at the age of twenty-seven, he entered a group home in his home town, became compliant with treatment, and has remained out of hospital for nine years.

Jeremy lives in Toronto with his mother and stepfather, a physician. His father, **Gerald**, moved to British Columbia four years ago, after retiring. For about eight years after the divorce, Jeremy and his brother lived with Gerald. Subsequently, during his difficult adolescence, Jeremy moved in with his mother. He also spent some weeks living on the beach and made two extended trips to Vancouver. On his return home to Toronto, his family began noticing paranoid behaviour but, before an appointment was made for him to see a doctor, he disappeared. A few weeks later, Jeremy phoned from California to ask for money and Gerald sent enough for food and a ticket home. A week later, the Los Angeles police called to report that Jeremy was psychotic and had tried to taunt them into killing him. He was flown home for treatment. At the time of the interview, Jeremy had just been discharged after his second hospital stay.

---

[3] Former inhabitants of psychiatric hospitals prefer to call themselves consumers — a shortened form of consumers of mental health services — rather than patient or client.

Daniel is the third of **Marianne** and **Arthur**'s four children. Although they were divorced many years ago, Arthur has shared responsibility for Daniel for several years now and both parents offered to be interviewed. After quitting university, Daniel took his father's car and disappeared. Two weeks later, police found the car in the woods, a completely burned-out shell. Later, Daniel returned to his mother's house and trashed it, searching for money. When he next contacted her, she called the police and he was taken to the hospital. Over many years, he periodically stopped taking his medications, became destructive, and was readmitted numerous times. Four years ago, he began taking clozapine[4] and has improved. Daniel is now forty-two years old.

Ken is the twenty-nine year old son of **Willow**. In his early teens, he was a gifted writer and published some stories. Ken began to change when he was fourteen after his depressed father's suicide, becoming "quite tyrannical." When he was nineteen, Willow moved to Vancouver and Ken followed later. Because living together was unsuccessful, he moved out. One day his new room-mates became concerned about his bizarre behaviour and took him to the hospital. Between my two interviews with Willow, Ken moved out of a church-run shelter for men where he had lived for some time into an apartment by himself. He is quite agoraphobic and Willow believes that the other men in the shelter occasionally took advantage of him (primarily in a financial way).

Derek, now thirty-three years of age, was diagnosed thirteen years ago. His mother, **Margaret**, is a retired psychologist who admits missing the early signs of her son's illness. A divorced mother, she says she grew up in a dysfunctional family and was a workaholic while

---

[4] Clozapine is one of the new, atypical neuroleptics which improves negative symptoms as well as positive ones. Because of its effect on the white blood cells (agranulocytosis), patients must have their blood tested weekly before receiving the next week's supply of medication.

her children were young. Derek spent a year at university, followed by an unsuccessful year at college, although Margaret states he had grandiose career aspirations. Eventually, he became increasingly withdrawn and she convinced him to see a psychiatrist. Now under the care of a community psychiatry team, he lives in a basement suite. He presently needs a new room-mate as his old one has been in Riverview for several months. For short periods he has managed to work at a library and for a tenting company.

Colin has lived with his parents, **Gwen** and **Irwin,** for the last two years. Colin first became ill during his second year at university. Despite this, after changing universities to one near home, he eventually completed a degree in linguistics. He was diagnosed with schizophrenia after returning home from the first university but a second psychiatric opinion reversed the diagnosis. For three years he was not treated with medication but saw a psychotherapist regularly. Eventually, he became extremely paranoid and was hospitalized. After discharge, he functioned well in a group home, graduating to semi-independent living. Then abruptly, having become fanatically religious, he gave notice at his apartment and moved in with several born-again Christians. When he began to relapse, his parents brought him home. Now thirty-five, his history has been a cycle of refusing medications, deteriorating until he is hospitalized, and then refusing medications again after discharge.

Tim, the youngest of five children, became ill while his father was dying of cancer. He was fourteen years old and is now thirty-seven. Tim has been in (and been asked to leave) numerous care situations. He has been seen by many psychiatrists and other mental health workers with very little continuity of care. His mother, **Ruth**, states that very few professional caregivers have listened to her, although Tim has lived with her when between group homes and other types of housing, some of which were poorly run, dirty, and dilapidated. He is presently living in a semi-supervised home with four other patients.

Anne has been psychotic with paranoid delusions and hallucinations for most of the last five years. When not in hospital, she has lived in many parts of Canada, either on her own, with her parents, on the streets, or in the woods. Anne believes that she was sexually abused by her step-father, who married her mother when she was a little girl. **Teresa** and **Bruce** categorically deny this. At Christmas, when on a pass from the hospital, Anne attacked her mother with a knife. Because this occurred during a blizzard, her parents had to restrain Anne for seventeen hours until the police and an ambulance arrived.

Barry was diagnosed five years ago, although he had been treated for depression for four years previously. He has never been violent toward others but has made several suicide attempts. His parents, **Evelyn** and **Joe,** are presently quite pleased with his progress. He lives in a semi-supervised house, with three other young men, all of whom have schizophrenia and whose mothers belong to the same support group. Evelyn and Joe hope that eventually Barry will be able to work at his brother's bicycle shop.

Kal, who has two older sisters, was born in Canada to immigrants from India, **Gurpreet** and **Kulwinder**. Developmentally delayed, Kal succeeded in special classes during elementary school but, when he was placed in the regular stream for junior high, he was bullied and did poorly. Following his diagnosis at age fifteen, he quickly grew tall and put on weight. Soon his teachers became intimidated by his temper outbursts and he was asked to leave the school. His parents tried valiantly to care for him at home but he has lived in group homes for the past three years. Unfortunately, he has been dismissed from a number of rehabilitative programs because of his acting out. When I spoke last with the family, he was in the hospital for a medication change.

Geoffrey and **Maureen** are the eldest and second youngest of five children. Geoffrey has been in Riverview for twenty-one years, since the age of twenty-one. While still in his twenties, he suffered a massive stroke and has been hemiplegic, aphasic, and confined to a wheelchair. His parents, **Maggie** and **Warren,** are waiting hopefully for a long promised tertiary care psychiatric facility on Vancouver Island, so that Geoffrey will be closer to them. Maggie believes that Maureen's schizophrenia is now more severe than Geoffrey's ever was. However, although diagnosed four years ago at twenty-seven years of age, she has never been in Riverview. Her history has included non-compliance with medications and several hospital admissions. Her parents were advised against seeing Maureen until she accepts treatment, due to Maggie's own health problems. An older sister who keeps in touch with Maureen reported (at the time of my interview with Maggie) that Maureen had begun taking her medications and was improving. Several months later when I interviewed Warren, they had achieved several successful visits together.

Ryan's behaviour changed dramatically when he was fourteen. After eight years of treatment for various psychiatric disorders, he was diagnosed with schizophrenia. A big man at six feet four inches, his mother, **Sue**, described him as gentle when not psychotic but frightening when he was. For the last seven years of his life, he lived at home and his father, **Ted**, gave up working to care for him. At age 30, Ryan died by lighting himself on fire on his parent's driveway. Five years later, Ted has not yet come to terms with Ryan's death nor has he resumed working. He did not wish to be interviewed.

Melinda, a promising high school student, diagnosed herself with schizophrenia after reading a magazine article and began skipping school for appointments with a psychiatrist, without telling her family. Melinda graduated with a scholarship and managed to hide her symptoms until she was admitted to hospital. Now, two years later and twenty-one years old, she is often suicidal and withdrawn and has been in and out of hospital several times. Her parents have recently built an attached suite onto their home for her. Her mother, **Jenny**, has given up selling real estate to care for Melinda and is beginning a home-based sales business. I did not speak with her father, a heating contractor, who is often away on business.

Julie, at thirty, is an intelligent and attractive woman with aspirations to become a nurse. She now accepts her illness, takes her medications, and has been stable for some time. After high school, she worked at numerous jobs, none lasting for very long. Last year she began a college nursing program but was asked to leave after a few weeks. She still hopes to become a nurse but intends to discuss her illness with instructors, prior to applying to any other school. Her father, **Clifford**, became a caregiver shortly after marrying her mother who also suffers from schizophrenia. Clifford believes that his other three adult-children have manifestations of mental illness, although none are presently under treatment.

Roger died nineteen months before I interviewed **Philip** and **Donna**. Initially diagnosed at eighteen, he lived with schizophrenia until he was forty-two when he was discovered in bed in his hotel room, three days following his death. For many years he lived alone, subsidized by his parents, but also lived in group homes for periods. He was severely burned in the shower of one group home and spent six weeks in intensive care and then endured months of major skin grafting. The autopsy was inconclusive but Philip and Donna do not believe he died from suicide.

Trevor's father, **Fred**, was the last family member I interviewed. At that time, Trevor was in the forensic psychiatric facility in Port Coquitlam, having killed his mother, **Elaine**. Earlier this year, he was tried in court for cutting the cables at a local television station and newspaper office. With no bed available at the time in the only forensic psychiatric facility in British Columbia, he was released to his mother's custody, with the provision that he see a community forensic psychiatrist and a probation officer weekly. At the time his parents were separated but working toward a reconciliation. According to Fred, before stabbing his mother, Trevor had never behaved violently.

A Grounded Theory of Redefining Parental Identity

The socially prescribed change in status for parents of teens and young adults is towards freedom from active caregiving (see Fig. 1). Parents are expected to socialize their children to become independent and, as the child's independence increases, the parents' responsibility to protect, actively provide care for, and make decisions for their child decreases. Ultimately, parents of an independent adult-child assume a new status which I am calling the "Emancipated Parent."

Figure 1, which depicts the BSP of Redefining Parental Identity, requires some explanation. In it, each identity and transition is depicted as a human figure, half black and half white. This image draws on Taoism, the Chinese philosophy of opposing forces, yin and yang (Palmer, 1997). Ideally, these competing energies are in balance, although their harmony arises out of the struggle between them. The smooth S-shaped curve signifies the unrestricted flow of energy back and forth. Although in Chinese philosophy the competing forces are morally neutral and equally valued, the dualistic world view of Western philosophy places the forces in moral opposition, some being good and others bad.

The model depicts the stages of redefining parental identity and the social processes in which the individual engages. Some of these processes may be negative, while others are more positive. In the socially prescribed developmental trajectory, positive and negative social processes balance out and energy flows back and forth across the smooth S-shaped curve. In the trajectory of parents who have a child with schizophrenia, as the child demonstrates signs of mental illness, the S-curve becomes jagged, signifying that the

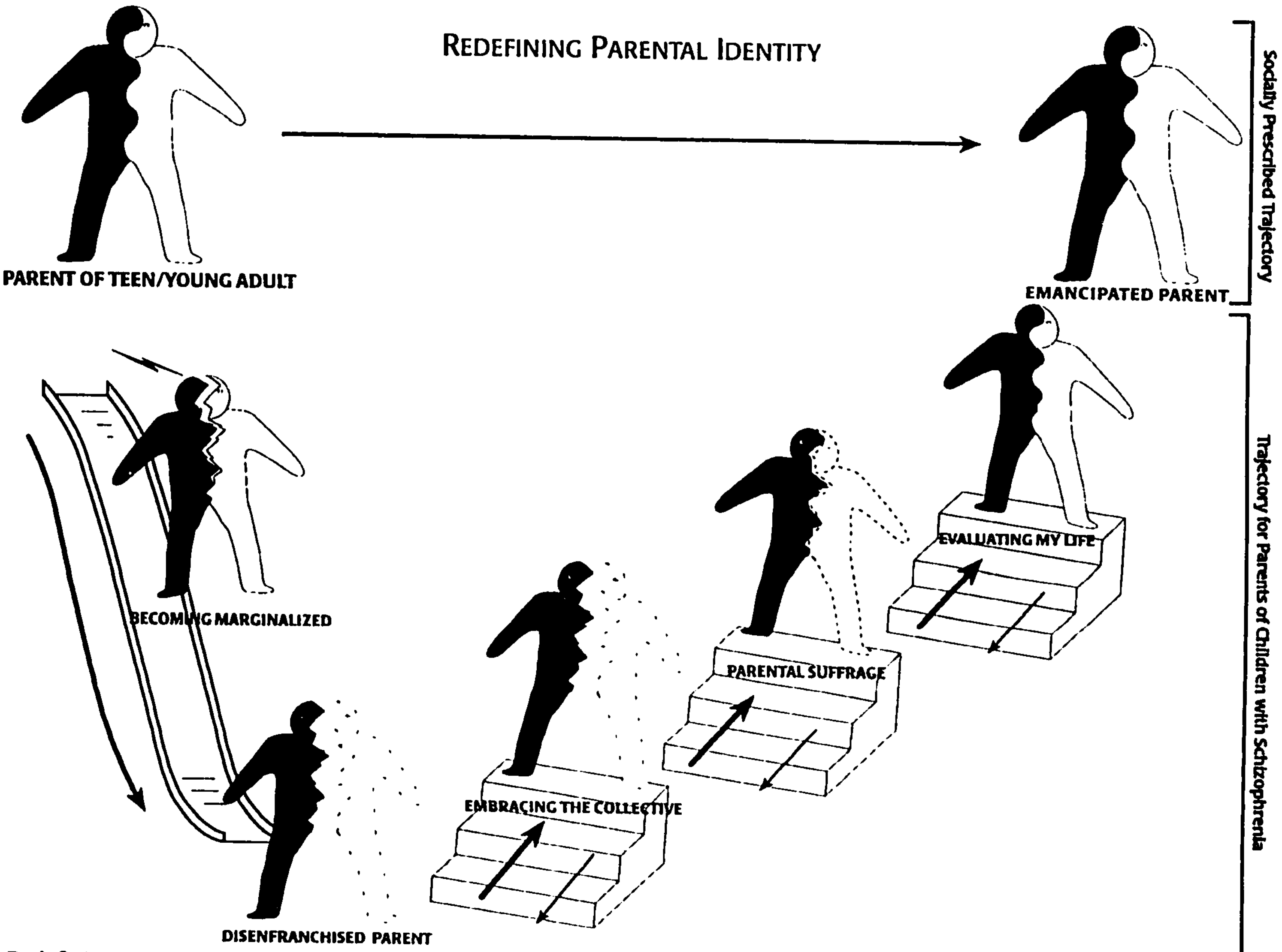


Fig. 1 Redefining Parental Identity

diagnosis splits the positive and negative actions of the identity as the parent becomes marginalized. In the disenfranchised status, everything that the individual does emanates from the negative side of the identity, completely disconnected from the positive side, which appears in a rather ghostly form. Subsequent stages of the model show the gradual reconnection as the individual engages increasingly in more positive social processes and the balance between negative and positive social activity is re-established along with the smooth flow of energy across the S-shaped curve. Note, however, that the parent caring for a child with schizophrenia never entirely regains the balance achieved in the socially prescribed trajectory and never becomes completely emancipated from active parental caregiving.

The remainder of this chapter describes briefly the trajectory of redefining parental identity for parents of a child with schizophrenia. After a child is diagnosed with schizophrenia, rather than progressing from their identity as "Parent of a Teen or Young Adult" to that of the "Emancipated Parent," parents instead enter two transitional statuses. Passage from one status to another requires them to redefine their identity and role as a parent. Thus, parents in this study redefined their identity from "the parent of a teen or young adult" to the "disenfranchised parent," then to "parental suffrage," and finally towards becoming the "emancipated parent." Between each two identities parents experience a transition period during which they redefine their identity. These transitions are called "becoming marginalized," "embracing the collective," and "evaluating my life." Combined in sequence, these identities and the transitions between them make up the basic social-psychological process[5] that I have termed, "Redefining Parental Identity." The

---

[5] Glaser and Strauss (1967) distinguished between two types of BSP: a basic social-psychological process, BSPP, and a basic social-structural process, BSSP. Although there are important structural influences on redefining parental identity which this grounded theory

following sections give a synopsis of each stage in the grounded theory. In each stage, parents engage in social processes, that are identified for the reader by italics.

Parent of Teen or Young Adult

A parent of a teenager or young adult *anticipates liberty* or freedom from active caregiving and the opportunity to focus more on his or her own interests and desires. This sort of "freedom 55" mentality is earned by having launched an independent adult into society. The parents' expectation of this happening is fostered by their children's aspirations and early achievements, behaviour, and personality. At the same time as parents observe their schizophrenic teenagers' deterioration in achievements and behavior, they are able to discount or normalize these aberrations as teenage rebellion and, because they anticipate the defiance to be time-limited, parents *tolerate* these *adolescent challenges.*

Becoming Marginalized

The first status passage or redefinition of identity for parents of a child with schizophrenia is entitled "becoming marginalized." Three processes are involved here: *becoming alarmed*, *assuming responsibility* for the child, and *encountering barriers*. Eventually the child's behaviour becomes so bizarre and perhaps even dangerous, reaching a crisis point which parents can no longer disregard and they become alarmed. Parents are instinctively propelled back into a more involved caregiving role, assuming responsibility for helping and protecting their child. Usually this entails consulting a doctor or mental health professional, taking the young person to hospital, or calling the police. Eventually, a diagnosis of schizophrenia is made. Adding to the strain of caring for a very ill child, parents find their

---

includes, redefining parental identity is primarily a social psychological process (see Glaser, 1978, p. 103).

efforts blocked at every turn. The law, mental health professionals, and sometimes even the ill-child refuse to grant parents the authority to take on responsibility for someone who has reached the age of majority or is otherwise deemed to be responsible for him or herself. Finding that their heretofore taken-for-granted parental rights are denied, parents take on the new identity of the "Disenfranchised Parent."

The Disenfranchised Parent

What parents describe to me at this stage is being overwhelmed by *maintaining vigilance, grieving alone,* and *grasping at straws.* Their life revolves around caring for a bizarre stranger (maintaining vigilance) who resembles their child in physical appearance and, usually in the initial stages, lives with them. Alternatively, if the ill person lives elsewhere, parents remain the only constant persons who care about and watch over their ill adult-child. In both situations, parents receive little recognition for the upheaval in their family and very little information about how to deal with their ill family member. Although some parents have good relationships with psychiatrists and other mental health professionals, many feel that no one really listens to them, even though they are the ones providing 24 hour caregiving. Parents also experience the stigma of mental illness, if not personally — although there are still professionals and lay persons who blame the parents — at least as a "courtesy stigma"[6] (Birenbaum, 1970; Goffman, 1963). Totally occupied with caring for their child, some parents avoid their friends. In other cases, the friends are uneasy with

---

[6] People who associate with stigmatized persons also become regarded by others as stigmatized. According to Birenbaum (1970) they are ambiguously defined as being "normal" but at the same time "different."

mental illness and may avoid the parents. Consequently, while they grieve for the person their child once was, they have little opportunity to communicate or share their grief with others. At this point, parents will grasp at any straw, looking for answers and especially for a cure. Obviously this identity requires a commitment that causes considerable role strain.

Embracing the Collective

Requiring more and better information about schizophrenia, someone to talk to, and support from someone who understands their plight leads many parents to a support group, which in British Columbia is usually under the umbrella of the BC Schizophrenia Society. This support group in time becomes their primary reference group. This status passage, "embracing the collective," involves *connecting with others* and *redefining my child*. What is meant by redefining my child is that parents, having been blocked when trying to take responsibility for the ill child, come to symbolically redefine their reciprocal role, that is, their child and the recipient of their parenting, as the whole schizophrenic community. When this happens, parents enter the transitional status which I have called "Parental Suffrage."

Parental Suffrage

Parental Suffrage is played out through *taking on the "system"* by doing volunteer work, advocating for the mentally ill, and improving public education and public knowledge about schizophrenia. Thus, parents develop and apply their personal skills and effort to improving the plight of all people with schizophrenia, and to gaining better community services and better understanding of this illness. Their hope is that through their efforts, life will also improve for their own child. The other activity or process that occurs during Parental Suffrage is that parents no longer are forced to grieve alone; instead they are *mourning together*. The activities that they engage in with the Schizophrenia Society are valued and shared by others and become the public expression of their grief, at last allowing these parents some avenues for coming to terms with their grief. Often years have gone by, their ill-child has become a little better, and some housing and community services are in place. Some of these improvements have appeared as a result of the support group's advocacy activities. Others may have been in place but were not accessed until the parent and child became aware of the maze of services provided in the community. Unfortunately the Mental Health System is not very well articulated, nor systematized. Eventually, parents may become tired and are no longer able to keep up the pace. Coincidentally, parents have likely achieved some self satisfaction from the activities undertaken on behalf of schizophrenia and, once again, they reach a stage of reassessing and transition.

Evaluating my Life

I call this transition "evaluating my life." What happens here are two processes: *acknowledging realities* and *identifying the parent's own needs.* Parents are now older. They may have developed some health problems — some of which are stress related — and they begin to focus more on themselves or on other long ignored interests. Their child may be functioning better, or at least better than other schizophrenic patients with whom they have become familiar. These realizations allow the parent to move towards the status of the "Emancipated Parent."

Although the above summary describes Redefining Parental Identity as a linear process, it seldom (and probably never) is. Parents identify themselves in relation to their child. Consequently, along the fluctuating course of the schizophrenia illness trajectory, parents' identities change in response to their child's illness. Once there is a confirmed diagnosis of schizophrenia, there is no possibility for parents to backtrack from the identity of Disenfranchised Parent — they will never be ordinary parents again. Beyond the stage of disenfranchisement, there is always the possibility of regressing along the trajectory of the BSP and this tends to occur with the child's relapses. For these family caregivers of adult-children with schizophrenia, however, emancipation is not attainable.

CHAPTER SIX

PARENT OF A TEEN OR YOUNG ADULT

This chapter describes in detail the parent's initial identity, Parent of a Teen or Young Adult, and the first transitional stage of redefining that identity, Becoming Marginalized. These are the first two stages in the grounded theory of reconstructing parental identity that was summarized in Chapter Five. The parental identity of someone with an increasingly independent teenage or young adult son or daughter entails gradually renouncing responsibility for the child in proportion to that child's demonstrated capability for independence. In this identity, a parent balances two social psychological processes: *tolerating adolescent challenges*, the negative social process, and *anticipating liberty*, the positive social process (see Fig. 2). When a child begins to show signs of mental illness, however, this model no longer fits the parent's experience. That is, when a child suffers from schizophrenia, adolescent challenges exceed tolerable limits and parents *become alarmed* (a negative process) about their child's behaviour and competence. In response, parents *assume responsibility* (a positive process) for protecting and caring for their child but they *encounter barriers* (negative) erected by professional caregivers and by their own child, who is legally defined as self-accountable. Thus, parents become marginalized when society assigns them a role that prevents their being able to enact their parental identity.

Adolescence, characterized by young people testing the limits of their own independence, can be a challenging time for both parents and teenagers. Parents need to find a comfortable balance between granting freedom and providing supervision, with the freedom gradually increasing and the supervision decreasing accordingly, until the child

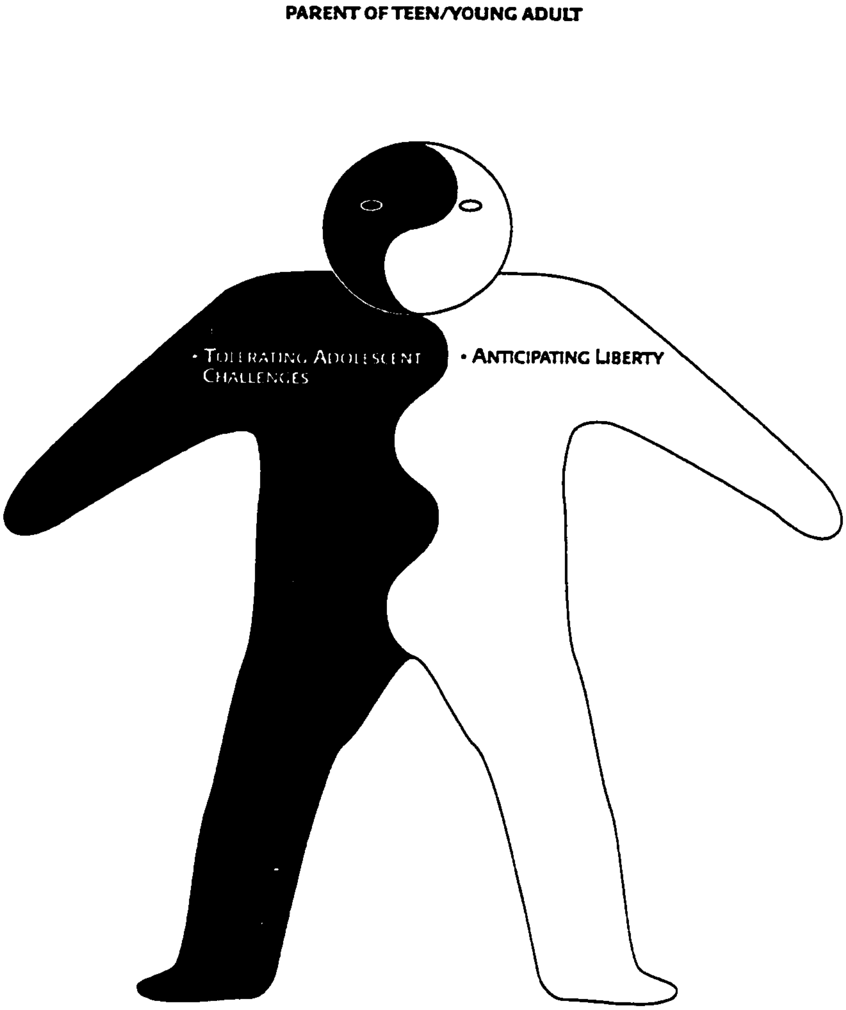


Fig. 2 Parent of Teen/Young Adult

achieves independent adult status. Parents expect that the adolescent period will be time-limited and that, as the active caregiving responsibilities lessen, they will be able to invest more time and effort into pursuing their personal interests and concentrating upon their adult relationships. This anticipation of freedom from the constraints of parenting is grounded in the promise of their child's aspirations, early achievements, behaviour and personality. Teenage rebellion is a well recognized characteristic of Western culture, so that negative confrontations and disruptive behaviour during the teenage years are seen as a stage that all teenagers go though. Thus, the experience of parents of teens and young adults can be described as anticipating liberty while tolerating adolescent challenges.

Anticipating Liberty

> ...we want to move out of here and get a condominium....We wanted to move to Latin America when I retire (Bruce, 1246-1247, 1250-1251)[1]

Parents in this study were asked to describe what their ill child was like before he or she became ill. Their descriptions of his or her behaviour were primarily positive, giving them reason to expect that their children would mature successfully into independent adults. These were happy children, characterized by their parents as easy going and not jealous of others. Using descriptors like helpful, truthful, a comedian, having a sense of humor or being quiet, the parents thought of them as normal, good kids. Parents also saw their children as capable, using words like intelligent, organized, athletic, and active. Other common traits were loving (affectionate, gentle, no fights) and outgoing (instigates things). An example is Jean and Tom's daughter, Maxine:

> She was a very happy child, a very happy kid. She was kind of the ambassador of goodwill type-kid, you know. She was one of these outgoing, happy kids, average in school, didn't work too hard, just as much as she had to, but she was rather a loving child, no problems (Jean, 7-8, 12-15).

Negatives attributes were present but less evident. A couple of these children were strong-willed or had a temper. Three were somewhat withdrawn or shy. Other somewhat negative qualities were sensitivity, hyperactivity, or laziness. Depending, however, upon the particular event, both sensitivity and a strong will also could be construed positively. Two

---

[1] Quotations from the data are identified by the pseudonym of the study participant followed by the text unit numbers. The NUD*IST program allows researchers to define the size of a text unit. In this study, a text unit is a line in the interview transcript. In several instances, the number 2 follows the pseudonym, indicating a second interview.

children caused their parents some concern because of hyperactivity. At one point, Sean was prescribed Ritalin and Melinda changed abruptly from being a hyperactive toddler to a withdrawn and quiet four year old. Having consulted an allergist, her parents attributed the change to her restricted diet. Ten years later, they revised their opinion upon learning that she had been molested while they were on holidays. In addition, although Maggie had no suspicions at the time, in retrospect she says of Geoffrey, the eldest of their five children:

> ...looking back on it now, without any experience whatsoever, knowing what a normal child is like and acts like, there were some differences right from the start with him (Maggie, 20-23).

Nevertheless, in general, these children's negative traits were outweighed by their positive qualities, for example, Willow remembers her son, Ken being both "artistic and sensitive." These essentially normal childhood experiences gave the parents no suspicions of impending mental illness.

Similarly, the children's school achievements and behaviour gave little cause for concern. School marks were described as average to excellent in the early grades, with about half of the group excelling. Colin is a good example: although dyslexic and a slow reader, his superior intelligence masked these difficulties and he performed very well. Three of the students were reported to be average; only three, Jeremy, Derek, and Kal, struggled during elementary school. Jeremy had academic difficulty throughout school. Derek was a slow reader and needed speech therapy, but did well in later grades. Kal managed quite well in special education classes, enrolled in regular classes for junior high school but then experienced difficulty again. Nevertheless, he was active in sports and a choir and won an award as a newspaper delivery boy. His father stated, "he was as normal as a person can be under his circumstances and ability" (Kulwinder, 47-49). Overall, the parents described their children as organized about their school work and active in extra curricular activities and sports, although a couple of the children were said to be somewhat lazy and needed to be pushed.

For the most part, these parents enjoyed their children's friends, although three families remembered having some concerns. Barry and Kal were the subjects of some bullying in school and Colin played primarily with his younger brother's contemporaries. At the time, however, as far as the parents were concerned, these incidents did not become big problems. Barry's family moved away from the town in which the bullying occurred; Kal initially told only his sisters and only later spoke to his parents; Irwin described Colin as a leader in the younger group. His wife, Gwen explained that Colin had begun school in Quebec and was almost a year older than many of his schoolmates when they moved to British Columbia.

At some time, most of these young people held a part-time or summer job, typically baby-sitting, newspaper routes, gardening, working in fast food restaurants or waitressing. Maxine volunteered with handicapped children. Several fathers noted that their personal or business contacts provided jobs for their sons, for example, Daniel had a surveying job and Jeremy worked in house construction. For the most part, these were entry level jobs requiring little training, although Colin (who was older than most when he became ill) obtained a summer job in a laboratory. Willow's son, Ken, was a talented writer who had some stories published. In contrast, a few, like Melanie and Tim, became ill at an early age and were never employed. For the majority, however, these jobs provided early successes and encouragement. As a group, the early development was unremarkable and parents looked forward to their child's increasing maturity and a mutual independence.

Tolerating Adolescent Challenges

> We, Bruce and I, have been parents of a teenage girl just for the first time. We have to learn. We have not gone to school to learn to be parents of teenagers. We thought well she's just going through that episode in her life, that you know she is going to fight with everybody. Her period came so her hormones were running wild. We thought well maybe that's what it is (Teresa, 128-137).

No one expressed surprise that their child's accomplishments and/or behaviour deteriorated during adolescence. In general, grades began to slip during junior high or high school, although Colin and Daniel were in second year university before displaying any difficulties. Of the twenty children, eight never finished high school. Several of these attended alternative schools or attempted correspondence courses to complete their education but without success. Only Colin managed to finish a university degree. Having dropped out of Queen's after not writing his second year final examinations, he later proved he could do well in some courses at the University of British Columbia and was accepted there. He eventually graduated and Irwin recalls:

> He was sort of taking one third load, roughly, at UBC in Arts and particularly in Language Studies and Linguistics but somehow, again, managed to complete his studies and got his degree, probably as a result of some supreme effort. I think in retrospect it must have been a tremendous strain for him to do that, but he did it (181-189).

Several of the others began, but were unable to complete, post-secondary education. At the time, parents explained such academic difficulties by saying that their children were not motivated or couldn't handle the stress.

Along with academic changes, parents recounted instances of school discipline problems. Some children were skipping classes and others were intimidating their teachers. Several of the parents recalled a change in their child's friends: either that the child had become a loner and anti-social or that there were new, less desirable friends. Gerald recalled:

> ...his peers were other losers, kind of, so to speak, you know, to be very blunt about it. He tended to gravitate towards the guys that were not doing well, which was in absolute opposite to his brother (25-29).

These and other changes, such as wearing dark or outlandish clothes, playing their music loudly or constantly using earphones, strange taste in movies, angry outbursts at parents and other people, staying up late or out late, or refusing to have a graduation picture taken, were assumed to be indications of adolescent rebellion, annoying but not particularly worrying. On the other hand, parents who found evidence of alcohol or street drugs worried more, but as long as it appeared to be experimentation, it could be discounted:

> In high school she'd go out and she'd have a drink and enjoy herself and they all smoked dope, but it wasn't her life, it was just an incidental part of her social life (Bruce, 87-90).

How did the parents respond? Despite being able to blame their child's behaviour on adolescent hormones, family life was often disrupted and Michael reports being "continually strung out" (55) when nothing they tried appeared to help. Parents struggled with how to respond and worried that if they overreacted, the child would rebel more. Some parents consulted counselors and were reassured that the behaviour would improve with age. A couple of the children had minor episodes involving the police, and both Lois and Bruce spoke of rescuing their teenagers, who were in trouble. There is a tension for parents between allowing children the freedom to make their own decisions and protecting them from making harmful ones. When parents were concerned about their child's poor decisions, they felt responsible for rescuing them whether or not it was convenient and whether or not the parent approved of the child's activity. As Michael recalled:

> ...she was answering ads in the paper, people that would offer to deal with their problems, you know. Do you have problems? Come to Madam So and So, or Mr. Psycho, or whatever. And, I know she was answering those and she would talk to these quacks and what do you do about something like that?...She would go downtown and try and fit in on the downtown crowd. And then we'd get a phone

> call from her that she needed a ride home and go tearing downtown to find her, and that sort of thing (57-72).

From time to time, relations improved with their children and parents had an attitude of trying to carry on and observe family traditions regardless. Eventually however, each of these parents reached the point where they could no longer accept their son's or daughter's conduct as normal teenage behaviour.

BECOMING MARGINALIZED[2]

At some point, these parents reached a crisis (see fig. 3). No longer could they disregard their child's bizarre and sometimes dangerous behaviour. Once they began to define this behaviour as abnormal and frightening, they could not continue to rely on the culturally defined parental responses to adolescent behaviour that accompanied their identity as parent of a teenager or young adult. That familiar role was insufficient to cope with a child who's actions were incomprehensible and who appeared to make decisions that, in the parent's estimation, were against the child's own best interest. Intuitively, these parents reverted to a prior conceptualization of themselves as parents, a parental role that allowed them to exert control over a dependent child. Relinquishing the socially approved identity of parent of a teenager or young adult and assuming power over their child (but

---

[2] Robert E. Park's (1928) notion of marginality describes a minority status originally applied to immigrants, who are caught between the old culture to which they no longer belong, and a new culture which they have entered, but in which they do not yet participate fully nor completely understand. Parents in this study could no longer rely on their cultural understanding of themselves as parents. They remained parents but were entering a new (to them) subculture surrounding mental illness in our society.

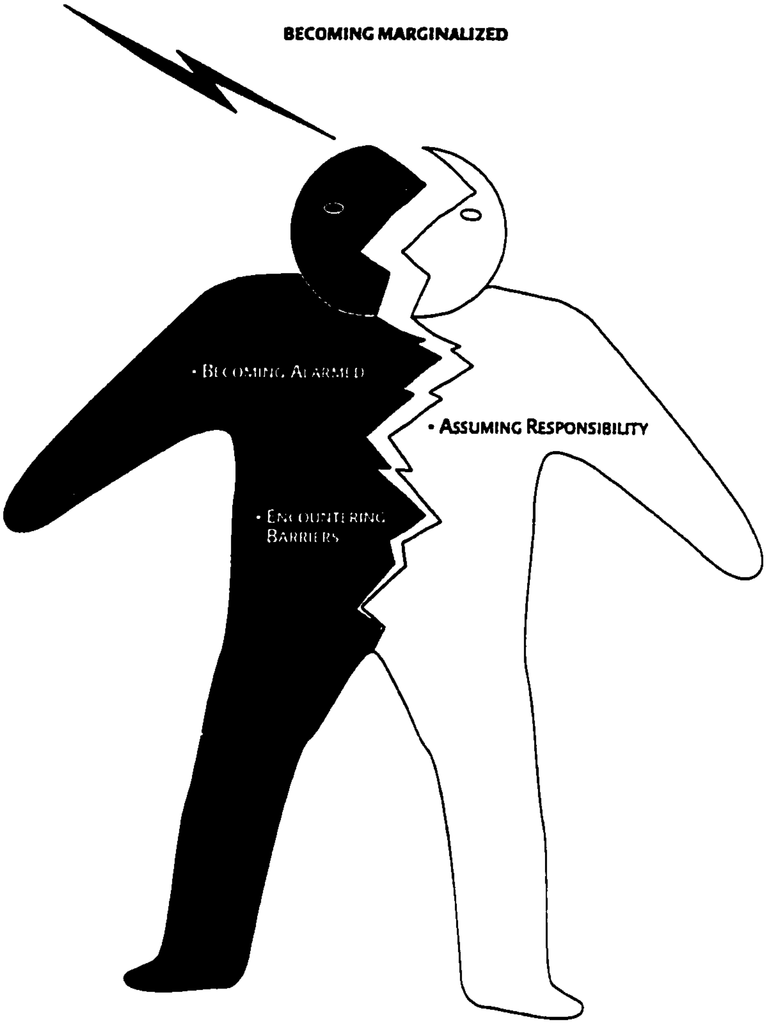


Fig. 3 Becoming Marginalized

lacking socially sanctioned authority[3] to do so), these parents took on a marginal parental status. Their marginalization was a result of the processes of becoming alarmed and assuming responsibility but encountering barriers.

---

[3] For a review of theories of power and authority see Grabb (1990). Max Weber (1922) distinguished among three ideal types of legitimate authority (rational-legal, traditional, and charismatic). Responding to Weber and disagreeing with Marx's contention that social inequality stems only from economic property relations, Dahrendorf (1959) contended that class differences arise between groups engaged in many kinds of authority relations. Conflict arose for these parents when they assumed traditional authority over their

Becoming Alarmed

> It got worse and worse and worse and worse, to the point that then I diagnosed Anne before the doctor did because I am a formally trained nurse too. The changes were so remarkable that I say this is beyond being a teenager, beyond hating parents, it just went too far. We were losing Anne (Teresa, 137-144).

Eventually, parents became concerned about their child. For some parents, the realization that their child was in difficulty grew slowly as separate instances of puzzling changes in personality and behaviour persisted for months or even years. Eventually, their perception of disconnected and disturbing events appeared to coalesce into an established pattern. For others, a strange but seemingly benign behaviour pattern escalated and became frightening, for example, when the rather solitary loner became completely withdrawn and paranoid, or when behaviour that had appeared to be eccentric became truly bizarre. Some parents' suspicions only became alarming when they were confirmed by other people. A number of parents in a sudden crisis situation, often involving violence, realized their inability to cope with a child who required some type of professional help.[4] Typically, in these families, parents became alarmed by some combination of changes in the child's personality, behaviour, and relationships with family and friends.

---

children, to which they were not legally entitled. Given the greater relative power of the "legal order" to define the rights of certain groups relative to others, I suggest that parents of people with schizophrenia, lacking the rights to which they believe they should be entitled, occupy a disadvantaged class position. Their lack of power contributes to their marginal status.

[4] Irving Zola (1973) identified five triggers that prompt people to seek medical help:

1. a crisis suddenly negates the ability to accommodate to perceived symptoms;
2. symptoms interfere with personal and social relationships;
3. symptoms interfere with work or constitute a threat;
4. symptoms persist longer than one ordinarily expects them to; and
5. someone else sanctions the decision to see a professional.

Personality Changes

For some, the initial clue was a change in personality. Anger and hostility were directed at teachers, at other authority figures, and at family members. Angry outbursts were both excessive and inappropriate responses to the situation, as Jean thought when Maxine reacted to her little cousin's death with anger rather than sadness. Willow described her son as tyrannical and controlling. When asked to elaborate, she described obsessive demands and his attitude toward his sister:

> ...he would call her a bitch and a whore and he'd call her every name he could. Um, he wanted everything really neat and clean. If you ate your supper and left your plate to go and do something, you'd come back and the table would be cleaned. Um, he just would get angry at anything (418-423).

Initially, Willow blamed her son's outbursts on three traumatic life events, a fire in their house, the death of his horse, and his father's suicide when Ken was 14. Eventually she found it impossible to live with him and she moved to Vancouver, leaving him at nineteen in the family home in another part of Canada.

Parents worried when, in addition to doing poorly at school, their children seemed to have completely altered their ambitions. Anne, with a very scientific mind and plans for a medical career, became very anti-medicine and intensely interested in crystals and new age philosophies. In contrast, Willow was upset at Ken's unrealistic expectations of being a wealthy international businessman and becoming President of the United States, when in reality he didn't appear to be succeeding at very much.

Parents also spoke about their children becoming depressed, anxious, forgetful, distant and preoccupied. In general, however, the parents' apprehension about these personality manifestations was aroused further by their increasingly strange behaviour.

Bizarre and Disturbing Behaviour

Withdrawal from friends and activities could be overlooked initially, until the parents recognized that their child was becoming extremely isolated. Parents recalled seeing very little of their children, who were spending more time away from home. When at home, many of these children conversed or otherwise interacted very little with the family, tending to stay in their frequently darkened bedrooms listening to music. For example, Evelyn recalled that Barry would not eat with the family and Margaret noted that Derek would sit with his back toward her.

Generally, it became very difficult for families to live with their young family member. Several exhibited signs of disturbed sleeping patterns, seemingly needing very little sleep or staying up all night and sleeping all day, causing difficulties for parents who had commitments during the day. Irwin recalled:

> He started suffering from insomnia quite early on and as a result of that he would get up in the middle of the night and walk downstairs and watch television or play his guitar or play his Walkman or whatever. I had a fairly intense job at that time and one thing that would get me really mad was to be woken up in the night by somebody thumping up and down the stairs or playing music. So, we certainly had some painful episodes when I'd go storming out of the bedroom and become relatively abusive about his behaviour (214-226).

Both social withdrawal and sleep disturbances can indicate depression and some of these parents sought help from health professionals at this point. For the most part, they were offered assurances that the child would grow out of it. Some, like Evelyn and Joe, were advised to demand less of their child who was under stress from his or her parents' expectations. When they consulted their doctor, Barry was given sleeping pills and on his seventeenth birthday, he took enough for three days "on the theory that if one pill made you better, a three day supply would make you a lot better" (Evelyn, 60-62). Not long afterward, he took six Neocitran. Worried, they tried to be less strict with Barry and continued seeing a psychologist for family counseling, who assured them Barry was reacting to the family's move to the lower mainland. Later, Barry took a more serious overdose of one hundred or more aspirins and had his stomach pumped in hospital, but refused a consultation to a psychiatrist and discharged himself the following day.

Another source of family disharmony was street drug use, mostly marijuana. Some parents became unable to excuse their child's involvement with drugs as experimentation. Evelyn and Joe noticed their son's use of marijuana and probably LSD becoming more obvious. When confronted, Barry reacted with anger, retorting,, "everybody does drugs, why should [you] have such a terrible reaction to it?" (Evelyn, 212-213). At sixteen, Sean was expelled from private school when caught using drugs a second time. According to Bruce, Anne went on occasional alcohol and marijuana binges, despite her athletic regard for a healthy body. Once she was apprehended by the police and then given a conditional discharge. Gerald suspects that "mushroom soup" caused Joe's extreme panic attacks. A number of parents retrospectively explained their child's use of street drugs as an attempt at self-medication against the symptoms they were experiencing. They now believe that street drugs can precipitate the appearance of overt symptoms in persons with a genetic predisposition to schizophrenia.

Parents also worried about the attraction of non-mainstream religion for some of these young people and rejection of their religious and moral upbringing. Several were drawn to evangelical, cult-like, or non-mainstream beliefs. For example, Barry was attracted to Scientology and Colin to the Jehovah's Witnesses. The most extreme example was Anne's obsession with a cosmic religion. Anne pleaded with her mother to run away with her so that they could become stars and get away from Bruce. She would go to a nearby mountain park to hunt for stars age rocks with baby stars inside, believing that all people originate from the stars and that:

> ...we're all going home again when we calibrate our energy to the vibration and the great cosmic, etc., etc. And she fell for it hook line and sinker. She still believes in it very strongly. She sent a lot of money. The head of it is a woman who calls herself Solar, who dresses up in a white sheet, and speaks this new age gibberish, you know, that seems to be meaningful to Anne. I really don't think that they are one of these dangerous cults, I think they are just very silly, and I guess Solar is probably seeing a good thing and is making a lot of money out of it (Bruce, 143-159).

A particularly upsetting occurrence for parents was the propensity of these children to "take off" and not inform anyone about where they were going or for how long. Often, their abrupt departure was in reaction to an altercation with the parents or just to the generalized upheaval that had begun to characterize their home life. At other times, the child left with no apparent motivation, as far as the parent could determine. The child would be gone for a matter of hours, a few days, or in some cases for several weeks or months. The scenario varied. Some just walked or drove around for hours. Several of these youngsters spent time living on the streets, on the beach, or in the woods. Some traveled long distances, occasionally phoning home, often to ask parents to send money. While they were gone, the parents worried. Some children came home as abruptly as they had left. Others ended up in a crisis and parents were contacted by police or social workers. For the parents who volunteered for this study, there was never any question about what they should do. They were always ready to rescue their child and bring him or her home, sometimes at considerable expense. On the other hand, these drastic changes in personality and behaviour tended to adversely affect the child's relationships with family and friends.

Relationships with Friends and Family

Unusual and aberrant behaviour alienated the child even further from friends and family. In fact, friends of some of these children sought out the parents to express their concern. Parents noted that their children had rejected some old friends, acquired new, weird friends, or had no friends at all. Michael remembers that, although Melanie was desperate to have friends, all but one or two of them "fell away." He recounted one episode:

> She wanted to play an instrument in a band, or with an orchestra or whatever, and I remember one incident where she took her guitar over to a place where a group said they wanted her to play with them and, and it was just a joke. She came home and they weren't there (29-35).

On the other hand, sometimes, as when the family moved or the child went to a new school, children lost friends through no fault of their own but seemed unable to replace them in the new setting.

Family relations were strained as well. Evelyn described Barry as being a difficult person and not getting along with his family. Eventually, she and Joe asked Barry to move out. Jean was hurt when, as a teenager, Maxine thought that "mothers were a pain in the neck" (364). Although they didn't always know how to respond, Joe pointed out that parents have a sensitivity that there is something wrong. Michael and Lorraine tried taking a parenting course, during which the topic of taking children to a psychiatrist arose. The psychologist who was speaking about behaviour modification, frowned on the idea, stating that:

> ...if the child wound up in the hands of a psychiatrist, they would be into medication and, I believe the words used were, 'you'll never get her back' (Michael, 87-90).

At the same time as the child was causing problems in the family, one must also recognize the effect of other disruptive family events, which happen concurrently and influence family dynamics. Traumatic events were particularly salient for four of the families in this study. At the same time as Tim was becoming ill, Ruth's husband was dying from cancer. He was the major focus of her caregiving, which involved accompanying him on lengthy and exhausting trips to Mexico for laetrile and to Indonesia for another alternative cancer regime. Trevor's parents separated and Sean's parents divorced. Trevor's father moved to the United States and visited every few months. Although Lois (Sean's mother) states that her children and their father maintained a close relationship, Sean had his first psychotic break within months of the divorce. As previously mentioned, Ken experienced three tragedies over four years: first, his father's depression and professional discrediting which, although Willow denies any truth to the accusations, culminated in suicide; second, a terrible house fire; and third, his unsuccessful efforts to save a horse from dying. While each of these events was traumatic for the whole family, they were also likely to exacerbate a child's developing mental problems.

Many parents were most frightened by evidence of their child's bizarre and illogical thinking or perceptions. Often, such evidence consolidated the parents' vague anxieties into fear that the child could be mentally ill. Later, they would interpret these episodes in psychiatric terms as hallucinations, delusions, and paranoia. Parents overheard children talking to someone when alone in their room or in the shower. Occasionally, the child would ask whether parents had made or heard a particular comment. Maureen, who had grown up with a brother in Riverview, accused her parents one night of talking about her. When they denied it, Maggie states that she insisted:

> ...can't you hear it now?" There was no voice. She said "somebody is saying 'there's a young woman with schizophrenia, who is slightly schizophrenic going into the building.'" And she said, "listen there it is again. This voice is not in my head! I have very good hearing." And we stood there rooted to the spot. Because then we had proof (163-170).

Paranoia was common. Several children were convinced that they were being watched or pursued by police, the C.I.A., or by some sinister character. Kal would cower in the house, terrified of the man in the black car outside, even when Gurpreet could see no black car. Others drew the curtains and Barry put paper over the windows to prevent people from looking into the house. One day, utterly distraught, Anne created a disruption at her mother's business, a weight-loss clinic. On the wall there was a poster depicting a little devil with a tempting piece of chocolate cake. Anne was convinced that the devil intended to gouge her eyes out and then kill her mother (Teresa), whom she accused of killing her patients and turning them into the butterflies that decorated the clinic walls. When Bruce arrived in response to Teresa's phone call, Anne ran out the door, into the traffic and was apprehended by the police. At the police station she convinced a social worker that she was merely under stress and was allowed to leave. She disappeared but was brought home over a day later by an elderly couple who found her wandering on a beach, dressed in light clothing and thoroughly chilled.

Violent or Criminal Behaviour

Sometimes the child's paranoid delusions prompted episodes of violence. Some of these episodes involved destroying property. In others, a person (often a parent) was attacked. In contrast, Marianne described an imaginary violent event. Daniel drove home one day to announce that he had hit and killed Carlos Castaneda[5] and then, calmly, that he would like to take a shower. The name meant nothing to Marianne. She checked with a policeman friend who ascertained that no hit and run accidents had occurred and reassured her that the car appeared to have hit a post, not a body. Later, she discovered her son,

---

[5] Carlos Castaneda is a controversial anthropologist who has written a number of books, describing his life and research among the Yaqui Indians under the tutelage of a shaman, named Don Juan. Much of his research was done while under the influence of hallucinogenic drugs. He has developed an almost cult-like following, among readers of his alternative philosophy. See, for example, the first book: The Teachings of Don Juan: a Yaqui Way of Knowledge (Castenada, 1968).

cross-legged on the floor of his bedroom, painstakingly crossing out every word in Castaneda's book.

Facing up to their suspicions about a child's mental illness was difficult for parents. Because of the stigma, parents hesitated to impose the shameful sentence of mental illness upon their loved one. Once that stigma is applied to your child and your family, it is not removed easily. Consequently, parents did not take the decision to approach psychiatric help lightly. Maggie describes the dilemma well:

> I mean there were all those sayings when I was growing up, you know, the worst scourge is there's madness in the family, like something Agatha Christie would write about, you know. It was just so unreal. And we talked about the lunatic asylum and it was like a world out there that is very strange. People wouldn't even think about it as being part of our lives, and then suddenly it becomes part of your family? So, I can understand, you know, how people think about it, because that's the way we thought about it too (1580-1590).

Parents were not alone in being concerned about their child's behaviour. Sometimes their children worried about themselves. Parents were of the opinion that taking street drugs was used by some of these children to overcome what were later defined as schizophrenic symptoms, as was their embracing of alternative belief systems. Similarly, abruptly "taking off" may be an attempt to escape from whatever is terrifying the child. At least four of these children appear to have worried about mental illness. Melinda diagnosed her schizophrenia from a magazine article. At least some of her truancy was to make secret visits to a psychiatrist. Joe discovered notes, written by Barry and describing himself as stupid, a loser, and psychotic. Similarly, Irwin discovered notes in Colin's room about being tormented by some problem from which he needed release. Anne consulted various alternative therapists. Eventually, she connected with a counselor on Vancouver Island who is well-known but controversial for uncovering repressed memories.[6] She then became convinced that Bruce had sexually assaulted her and that, somehow, Teresa had sexually assaulted her in the uterus before birth. Bruce and Teresa deny any sexual abuse but have endured the spectre of Anne's delusional accusations for years. She has publicly accused them and frequently been violently abusive toward both parents but, as Teresa reported:

> ...we never called the police. Bruce didn't have the heart to do it. So, she beat him, she broke a bottle on his head, a very violent act and totally unprovoked. She just would come out of her room and we said "Oh, Anne is on the war path!" (203-209).

At one point, they managed to convince her to see a psychiatrist but she refused to return ever again, stating that he sounded just like her parents.

To summarize, becoming alarmed involves parents realizing that their child's behaviour is not just adolescent rebellion, but serious and frightening. Parents become alarmed for the child and sometimes for themselves. Sometimes, there is an accumulation of numerous strange events and instances of weird behaviour, often culminating in complete withdrawal of the child. Some of the children were paranoid or had other strange delusions, from which their withdrawal or abrupt "taking off" may have seemed to be a means of

---

[6] There is no simple relationship between memory and schizophrenia. The controversy surrounding recovered memories and post-traumatic stress disorder (PTSD) is reviewed by Allen (1995). He divides memory into conditioned-emotional memory and autobiographical memory, stating that many persons with PTSD have too much of the former and not enough of the latter. The intertwining between memory and emotion leads to inaccuracies when individuals are forced to remember unclear events. He cautions that "flashbacks" are "reconstructions that can vary in degree of correspondence to prior experience" (p. 3). Up to a certain level, stress may enhance memory but beyond that level memory is impaired. Another point he makes is that "early traumatic experience may be associated with limbic-system dysfunction and hippocampal damage" (p. 4). Both these structures are implicated in schizophrenia. In schizophrenia, there is a decrease in size in the hippocampus (Andreasen, 1996). Torrey (1983) states, "the symptoms of schizophrenia...are a logical consequence of impaired limbic system dysfunction, given what we know about it" (p. 151).

protection or escape. Other young people reacted violently. In response, the parents' instinctive reaction was to take over responsibility for their loved one.

Assuming Responsibility

> ...of course, as most parents do, we feel that we are responsible, you know (Lois, 428-429)

Here, the verb "assume" carries two meanings. One is the notion of accepting something as true but without proof, i.e., taking something for granted. The other meaning is to actually undertake something, e.g., responsibility for one's child. Both elements are important here. First, parents who are worried about their child's competence accept as fact that they have a responsibility to take care of their child . Secondly, they take on that responsibility for their child's welfare. When these parents decided their child should seek psychiatric help, the child often balked. Nevertheless, some parents were able to persuade their child to see a doctor or a psychiatrist. When young people refused to take the parents' advice, parents tried their best to care for the child as long as they could. Eventually, during a time of crisis, they realized that they lacked the necessary skills to enact appropriate care and were forced either to contact someone with those skills (the police, their doctor or a mental health professional) or to take the child to the emergency department of a hospital.

Hospitalization

Because the child's symptoms waxed and waned, periodically reassuring the parent of the child's improvement, parents tended to delay the decision until a crisis arose. Often, the first contact with a psychiatrist coincided with the child's first psychiatric hospitalization.

When completely beset by paranoid delusions, these young people typically responded in one of two ways, either total withdrawal or violent outbursts. For example, Maxine, Maureen, and Colin became withdrawn. Maxine suddenly arrived home in B.C. from her job in Toronto and curled up in the fetal position in bed for three days, not eating or communicating with her parents, before Jean called the family doctor. Maureen, believing that the voices would kill her boyfriend if she got out of bed, phoned her brother. He contacted her counselor and together they took her to hospital. In Colin's case, Gwen hoped that, by taking him to Whistler for a holiday weekend, he might feel safe from the CIA, police and Mafia who were pursuing him at home. Instead, certain that the television was communicating directly with him and that he was receiving telepathic messages from Japan, he huddled in bed, pleading that no one answer the door or telephone or walk in front of any windows. After three days of phoning, Gwen finally contacted his psychiatrist who advised her to take him to hospital in Vancouver. When she asked how to get him there, she was told, "You'll find a way" (188).

When paranoid, many children reacted violently, presumably trying to protect themselves from their tormentors. Often, circumstances forced parents to involve the police. For example, Barry bought a handgun and sat in his room clicking it throughout the night. When they found notes hinting at suicide, Evelyn and Joe called the police but, because Barry had a license for the gun, nothing could be done. They applied for and received a court order, another difficult step for parents to take, and finally the police took Barry to the hospital.

Not long after the police released their daughter, Bruce and Teresa needed to call the police a second time. Rather than going home from the police station, Anne had taken off again. Much later, an older couple found Anne wandering along the beach, without appropriate clothing for the cold weather. After being returned home by the kindly couple and revived from the cold, Anne:

> ...became completely hysterical, throwing herself on the floor, hiding from monsters, and just totally disorganized, paranoid delusions. She was again convinced that Michael the arch-angel was after her and was going to gouge out her eyes. She thought that I had murdered her brother and chopped him up and buried him in the backyard, that I had murdered Teresa and replaced her with an android. I went downstairs...and phoned the police again. They came with two cars, four officers, and an ambulance. They took her to the hospital. This time they realized that she was ill and she was admitted (Bruce, 197-208, 217-219).

Unfortunately, getting the child to hospital doesn't ensure admission. Michael told of physically wrestling with Melanie to get her to the hospital. After waiting for half an hour in emergency, Melanie (on the pretext of getting a glass of water) ran away. Fortunately, she mistakenly ran into the psychiatry building where staff recognized her need for care. When a person is paranoid, the hospital may appear to be another frightening place and many mentally ill persons will try anything to avoid their admission. Some of them are able to pull themselves back to the appearance of sanity, long enough to convince an emergency room physician. As Evelyn described:

> ...the doctor just sent him home care of me, and patted my hand and told me not to worry so much, because Barry had totally fooled him. He told them there was nothing wrong with him. He was fine. It was his mother that was so foolish and overprotective, and that, as a matter of fact, it was as if he had a total personality change because in that doctor's office at the hospital he did sound quite lucid and I did look a total idiot (253-262).

Nonetheless, despite what he told Barry's parents, the doctor prescribed an antipsychotic drug, Loxapine, which Barry refused to take when he got home. "Two nights later he slit his wrists" (Evelyn, 270) and was finally committed.

Four of these parents' stories differed from the rest, in that there was not a long period of worry and inability to obtain appropriate help. In fact, these parents were somewhat surprised by their child's first hospitalization. Melinda, having seen the psychiatrist many times without informing her parents, entered hospital for assessment and her parents were then informed of her schizophrenia. With no warning except for his lack of motivation at school, Sean attempted suicide. Similarly, Tim was taken into hospital before his mother, Ruth, became aware of the need. Derek, a recreational long distance runner, went to the hospital because of a foot problem and ended up in psychiatry. His mother, Margaret, says, "I guess he knew he had a problem" (1229). While Melinda was secretive about her difficulties, it is quite possible that the mothers of the other three, (Margaret, Lois, and Ruth) were overwhelmed by other difficulties in their lives. Margaret suspects that working through her own residual problems stemming from growing up in a dysfunctional family prevented her from recognizing Derek's problems. Similarly distracted, Lois had been recently separated and Ruth was nursing her dying husband.

Getting the person admitted to hospital is no guarantee of a definitive diagnosis. Some parents were told that their child had schizophrenia during the first hospital admission. Alternatively, many of these young people were initially diagnosed with depression, or manic depressive (bipolar) illness. Jeremy's first diagnosis was panic attacks. Some parents were told that their child could possibly have schizophrenia but that it was too soon to be sure.[7] Often parents were informed that their child was psychotic but that it would take time to ascertain why. Parents became frustrated when the diagnosis changed, when different practitioners disagreed about the diagnosis and treatment, and when their children were in and out of hospital, with little overall improvement. Evelyn recounted a "nightmare" lasting nearly a year before Barry was diagnosed with schizophrenia. For Lois, it took four years. Sue noted that Ryan "was about 20 or 21 and he must have had every diagnosis available" (34-35). Seven years elapsed before Ryan was diagnosed with schizophrenia. Schizophrenia can present a confusing constellation of symptoms and, even

---

[7] DSM-IV stipulates that symptoms of schizophrenia must be present for six months before a diagnosis of schizophrenia is made.

now, several of these parents question whether their child actually has schizophrenia, particularly those whose children are dually diagnosed with schizophrenia and some other disorder, for example, obsessive compulsive disorder (Colin and Kal). On the other hand, Clifford pointed out the importance of diagnosing schizophrenia as early as possible, because "there is so much damage done before the actual final diagnosis of it" (3051-3052).[8]

No matter when parents receive the diagnosis, whether early in the illness or after years of frustration and heart-ache, schizophrenia is very difficult to accept. Parents initially responded with a number of emotions that are often associated with grief: shock, sadness, shame, denial and anger. Even though for most of these parents, the period leading up to a diagnosis contained months and often years of worrying, of watching their child deteriorate, and of frustration, the actual diagnosis was a shock. One parent, with a family history of schizophrenia, said that it was perhaps less of a shock for her than for someone else. Nevertheless, like many others, she remembered being devastated. Her son had always excelled and then deteriorated quickly. She said:

> I remember the first reaction was, um, Sam and I were out walking that night and he said, "Get off the curb there because you are going to get hit," and my reaction was, "Well, that would be lucky," you know? (Catherine, 518-521).

Others were sad, for themselves but particularly for their child, and several reported having cried. Many felt shame, aware of the stigma against the mentally ill which they and their child now faced, and also aware of their own past negative reactions toward people with a mental illness. Several said that they tried to hide the illness from their friends, not wanting to talk about this child and even avoiding social situations where they might meet

---

[8] Research shows that the earlier people with schizophrenia receive appropriate antipsychotic medication, the better their outcome (Lieberman, Jody, Geisler, Vital-Herne, Alvir, Walsleben, & Woerner, 1989; Williams, 1997).

friends who would ask about their family. Colin was diagnosed with schizophrenia three years prior to his psychosis and first hospitalization. For Gwen, the shock and crying were replaced almost immediately by rejection and denial of the diagnosis. Although her husband, Irwin, accepted the diagnosis immediately and started reading about schizophrenia, she insisted on a second opinion. When the second psychiatrist's opinion was that Colin was suffering from stress, her denial was confirmed but a "niggling fear remained" (Gwen2, 545). Later, when he became psychotic, she immediately joined the Friends of Schizophrenics[9] but, paradoxically, Irwin then experienced a period of denial. Marianne can not remember ever being in denial because Daniel's psychiatrist bluntly explained the diagnosis and Daniel's poor prognosis. Although Marianne eventually appreciated his honesty and forthrightness, she was initially very angry. She was able to accept that something was very wrong with her son, but not that it was incurable. She also remembers being angry at God, because "I'd done everything I could to hold the family together and to be a good mother" (1006-1007). Daniel's father, on the other hand, told me that he had never really thought about the illness being long term, stating pragmatically, "...you just cope with it, eh?" (Arthur, 1127). Although the parents' emotional responses to the diagnosis of schizophrenia varied initially, no one questioned that the responsibility for coping with their child's schizophrenia was theirs.

---

[9] Friends of Schizophrenics was renamed the British Columbia Schizophrenia Society (BCSS) in July of 1992.

Encountering Barriers

> And even when Maureen was in hospital the psychiatrist never phoned us. When she changed psychiatrists we were never told. When she went before a panel, to get out, to become a voluntary patient and check out whenever she wanted to, it was only by my phoning and asking questions that I found out anything. It was always one-sided. So, I got the message that they were politely telling me the minimum, and understandably, because of all the legalities (Maggie, 373-382).

Although the parents in this study without exception assumed responsibility for their ill son or daughter, almost all of them found their ability to influence the child's care was severely limited. The law denies them parental rights or responsibilities for a child who has reached the age of taking responsibility for him or herself. Even when their psychotic child loses the right to self-determination, professional caregivers rather than parents have the authority to direct care. The parents, believing they know their child and the child's history better than anyone else, were frequently not consulted or even listened to by psychiatrists and other professionals who, paradoxically, often discharged the patient from the hospital to the parent's care. Although some parents established good relations with some professionals, the majority discovered that their ability to take responsibility for their child was blocked by the law, by mental health professionals, and often by their own child.

The Law

Many parents are bitter about the anti-psychiatry movement and human rights legislation for the severely mentally ill. Despite recognizing the historical violation of the rights of psychiatric patients, they see harm being done to those who are under the command of delusions and hallucinations and whose insight regarding their illness is impaired. Mental health legal reform is no longer "on the side of justice and rationality and human rights, when they are swinging that far to rectify a wrong" (Maggie, 1559-1561). The parents believe that their loved ones have a right to protection. Instead, what their ill children have are "the rights of the patient to annihilate himself" (Gerald, 444).

The patients' right to self-determination is inviolable, unless their behaviour is judged to be dangerous to themselves or others.[10] Yet, for example, Catherine tried unsuccessfully to have her son's driving license suspended because he was endangering others with his erratic driving. Joe couldn't get the police to impound Barry's hand-gun, even with evidence of Barry's suicidal thoughts. Psychiatric patients have the right to direct their own care. They choose the type of care and the practitioner they wish, whether or not their parent approves. If patients choose not to seek treatment, to refuse treatment and sign themselves out of hospital, or to stop taking their medications, both the doctor's and the parents' hands are tied.

If, however, a person with mental illness is deemed to be dangerous, he or she can be forced into hospital and/or treatment. In that case, the mental health system and professional caregivers are given the authority over the patient, rather than the parents.

Mental Health Professionals

Some parents reported having a mutually cooperative relationship with the professional caregiver in charge of their child's care. When the parents had previously developed rapport with a family doctor who continued to be involved or when the doctor or other professional was a family friend, parents felt that they were both listened to and kept

---

[10] For a patient to be admitted involuntarily, all of the following three criteria are necessary: that he or she (1) is suffering from a mental disorder that impairs his or her ability to react properly to the environment or associate with others, (2) requires medical treatment in a hospital, and (3) requires care, supervision and control for his or her own protection and that of others (British Columbia Ministry of Health and Ministry Responsible for Seniors, 1997).

informed. Nonetheless, at the beginning of the child's illness and especially in the emergency department in the midst of a crisis, few parents are familiar with their child's practitioner. In these circumstances, parents often felt brushed aside and given no guidance in how to help their child. Michael said:

> Nobody had time to sit down and discuss with us how we might deal with the illness at home. We were left to live with a daughter who was seriously mentally ill and our GP knew nothing about it. Uh, the psychiatrists were almost inaccessible to us. I don't know how long we waited to see the first one, and the interest was in medication and treatment but, how in the hell we were going to survive with an ill child in the house was not something we could get advice on (742-749).

When parents had the opportunity to speak with professionals, they were often confused and dismayed by the variety of opinions and advice they received. Among mental health professionals, many parents discovered clear philosophical disagreement concerning the causes of illness and types of appropriate treatment. Even within a particular professional group, parents became aware of a rift between those who believe in using drugs and other psychiatric medical treatments, and those who prefer psychotherapy or counseling alone. Counselors, social workers, and psychologists vary in their understanding and approval of the medical model of psychiatry. Some do recognize psychosis, realize when a person's condition has progressed beyond their capabilities and make a referral. Others subscribe to anti-psychiatric motives and beliefs. Even within psychiatry, disagreement exists between psychoanalysts and more medically oriented psychiatrists. For example, Colin had established ongoing therapy without medications but, when Gwen and Irwin perceived little improvement, they convinced Colin to agree to an assessment by a second psychiatrist who recommended medication. Hoping that the psychiatrists would work together, Gwen approached the first psychiatrist:

> So, I was being very tactful and said "Could this other one supervise the drugs," and he said "No." He said, "He's my patient and he wants to stay with me." So he did (142-146).

Not only was this difference of opinion confusing, parents also discovered that they had no recourse if they disagreed with practitioners about appropriate treatment. That choice was made by the ill child or, alternatively, by the mental health system.

Another problem for parents was the tendency of professionals to normalize the child's symptoms initially, unless he or she was personally observed by the professional as floridly psychotic. Parents' descriptions of the child's behaviour often were ignored if they varied from his or her behaviour in the practitioner's presence. Consequently, a number of parents were unable to get help for their child the first time they make contact with one of the mental health professions.

Being blamed for the child's problems was even worse than being ignored, although several parents noted that mental health professionals blame parents less now than years ago. When Tim was first admitted to hospital his mother says:

> ...even at VGH there were some older doctors there who told the workers to isolate me from my son, because it is usually the mother's fault (Ruth, 440-443).

Nevertheless, it is not uncommon for a child's behaviour problems to be attributed to their inability to measure up to parents' expectations or to be blamed on some other family dysfunction.

The Ill Child

Sometimes the ill child prevents his or her parents from helping. The most impenetrable barrier against parental involvement in caring for their ill child occurs when the ill person lacks insight into the illness. Especially in the months or years leading up to the first psychotic break, many of these young people denied that anything was wrong. Others recognized their problems but would try to hide or cover up their symptoms. For some, like Barry, the initial hospitalization convinced them of being ill, especially if drug treatment improved their symptoms. In contrast three continue to deny that they have schizophrenia. Colin, Maxine, and Melanie still refuse to discuss anything about their mental illness with their parents, all of whom stated that their child would be very upset if they ever discovered their parents' participation in this research. Recently, however, both Maxine and Melanie's parents have noticed an occasional comment made by their child that indicates some recognition of their illness.

Those children who do not acknowledge their illness or try to hide their illness also prevent their therapists from talking to their parents. In general, mental health therapists feel bound by the constraints of confidentiality, particularly when it is requested by their patient. Jenny was not informed when Melinda attempted suicide. Although their general practitioner was not Melinda's doctor at the time, he recognized her in intensive care and insisted that her parents be phoned. Excluding the parents prevents their effective participation in caring for their ill child.

Even when the ill child admitted to being ill, there was no guarantee that the parents would be allowed access to their child's professional caregivers. Bryan had a different motivation for excluding his parents, believing that seeing his parents would cause his eyes to close forever. Bryan lives close by in a group home. He sees his brother regularly and phones his parents several times a week, but they have had no face-to-face interaction for six years. His father, Sam, reported having "pushed it" once, hoping that Bryan's fears would prove wrong. After glimpsing Sam, Bryan's eyes closed for a week. In the interim between my interviews with Bryan's mother, Catherine, and Sam eight months elapsed during which Bryan's psychiatrist managed to convince him to meet with Catherine in the psychiatrist's office. She now gets together with Bryan several times a week. After enough time elapses to build up Bryan's confidence, Sam is hoping Bryan will consent to see him. Their goal is to be able to spend Christmas together.

Sometimes children exclude their parents because they accuse their parents of causing their illness. As already stated, Anne blames her problems on being sexually abused by her parents, especially by Bruce. Alternatively, others, like Roger, may blame their parents for forcing them into the hospital.[11] Roger had come to his parents' home demanding a large amount of money. When Philip refused, Roger attacked his father, who managed to get away and call 911. Philip recalled:

> Now the police had been called to his suite by the landlord and fireman, and all sorts of stuff, but this was the first time that he had the police and there was an opportunity to lay a charge against him. Because this is a way to get an unwilling person into [hospital]. So the police said, "We can't do anything about treatment unless you want to lay a charge." And I said, "I do, In that case I want to lay a charge." And when they went back into the house, fortunately, he had taken out a large carving knife and put it on the counter by him (511-522).

For a long time, Roger refused to allow his father to visit him in the hospital. For all of these parents, deciding to take their psychotic child to the hospital was difficult enough. Being forced to lay a charge against their own child was heart-breaking, but when their children repeatedly refused (or for other reasons did not receive) psychiatric care, some parents were desperate.

What are the parents' rights in relation to their mentally ill adult-child? Every parent who was interviewed spoke about their lack of rights in regard to caring for a child who is severely mentally ill. Many spoke of having to fight for any information they got. They said that parents are not consulted; parents hands are tied; parents have no right to tell their child to go into hospital; parents are helpless. It seems that the only legal right these parents have

---

[11] See Chapter 2, footnote 12, re Goffman's conceptualization of the "betrayal funnel" (Goffman, 1961).

is to charge their own child, if the child physically injures them. Some do but no one really wants to. Three mothers spoke eloquently about their dilemma:

> I don't think the role of the parents is understood. And they don't understand the bind they put parents through. Yes, I could charge Anne because of that assault, but I don't think I can do it....this is what I said to the doctor, "This could be beneficial but if she has not realized what she has done, what's the point?"(Teresa, 1777-1781, 1788-1790).

> And you haven't the right to say, like you would have to if your daughter had cancer or something, she needs to be in hospital and have help. If any other part besides the brain is malfunctioning, the person is able to think "I have a sickness and I need help." Now, if the part that you think about and reason with is malfunctioning, how are you supposed to think — my brain is malfunctioning — when it's not functioning? It's like going around in a vicious circle. Yet, we put these people whose brains are malfunctioning and can't realize that, out on the streets, because nobody can say "that person needs to be hospitalized, that person needs medication". And we, the parents, stand by and watch this. Like you'd stand by and watch a cancer patient being pushed out in the street. And you're helpless (Maggie, 944-958).

> I said, "I've had this out with you and I've had this out with them before. I'm her primary caregiver and I have a right to know. I don't care whether she's 109. If I'm looking after her, I have a right to know. She's my child," and I said, "I don't get this." Under the Mental Health Act, they can make decisions for her without her consent, but I said I can't, and I'm her primary caregiver (Jenny, 990-997).

Without exception, like Jenny, these parents saw themselves as their children's primary caregivers. Whether their child lived with them at home or was in some type of housing provided by Mental Health or Social Services, parents were the ones who cared most about their children as people; who stood by them year after year; who were there to pick up the pieces when the mental health system failed them. When these parents realized that they had no formally recognized right to assume responsibility for their very ill child, they had, indeed, become marginalized and, consequently, they assumed a new parental identity. They now saw themselves as disenfranchised.

CHAPTER SEVEN

THE DISENFRANCHISED PARENT

Typically, parents ceded considerable responsibility for their child to professional caregivers during the first period in hospital. When their family member was discharged, however, they unquestioningly assumed full parental responsibility again. Whether or not the child returned to the family home, parents felt obliged to ensure that their child remained well or, alternatively, that professional help was obtained early to avoid another crisis. The parents' strategy was constant surveillance, ever vigilant against the danger of a relapse. Once again, they often found themselves blocked whenever they tried to intercede on their child's behalf. Their growing awareness that schizophrenia is a chronic condition was followed by grief and a frenzied search for more knowledge about schizophrenia and for a cure or, failing that, for more effective treatment. Thus, feeling disenfranchised because their rights and responsibilities regarding their ill adult-children were seldom recognized by anyone else, these parents described a miserable existence composed of *maintaining vigilance*, *grieving alone*, and *grasping at straws* (see fig. 4).

Maintaining Vigilance

> The only thing that keeps her alive during those periods is our resourcefulness. You know, our vigilance. So even though she is an intelligent 26-year-old woman it is still as though you have a 2-year-old you're worried is going to run out in front of a car, because she does do things like that (Bruce, 849-857).

Parents who participated in this study varied in their ability to affect either the professional care given to their ill child or the child's self care. Their influence hinged both on the relationships they established with mental health professionals and their child and

Fig. 4 The Disenfranchised Parent

also on the child's acceptance of schizophrenia and treatment. Whether or not they were allowed to influence their child's care, all of these parents felt responsible for observing the child's condition. In many cases, vigilance for increasing signs of illness was the extent of that which they were able to do. This vigilance consisted of three types: watching carefully, watching over, and watching out. Watching carefully refers to constantly observing their loved one's behaviour and symptoms; watching over involves caregiving by parents as well as overseeing the care given and prescribed by professionals; watching out means protecting their child and others, including themselves, from harm.

Watching Carefully

Constant observation of the ill-child's symptoms and behaviour provided parents with information about whether their loved one was improving or becoming ill again. In particular, parents monitored the positive symptoms of schizophrenia, that is, the hallucinations, delusions, and disorganized symptoms.

Visual Hallucinations

Although hallucinations can involve all five senses, these parents described only visual and auditory ones although, given the reluctance of many people with schizophrenia to talk about their illness and their attempts to cover up symptoms, hallucinations may have been more prevalent than parents realized. Parents of four of these children were aware of visual hallucinations. For example, Ryan saw "a hideous beast with fangs and red eyes" (Sue, 397) whenever he looked in his mirror and Melanie described seeing Brooke Shields on the school playground (Michael, 925-928), alien people walking down the street (Michael, 949-952) and a talking whiskey-jack sitting on her head (Michael, 955-959). In addition to Daniel's pre-diagnosis description of running over Carlos Castaneda, he told his father about seeing bugs in his guitar. Arthur tells of replacing several guitars that Daniel had discarded. After two years of believing this to be a recurring hallucination, Arthur discovered cockroaches in Daniel's apartment and now believes there actually were bugs in the guitars. Anne has experienced many visual hallucinations, which a counselor informed her were caused by repressing her memories of sexual abuse (Bruce, 250-254). In psychiatric intensive care (PIC), she was in a completely illusory world:

> She has a royal suite on Carnaby Street; she is married to her astral lover. They got married about a week ago and all her friends from Europe are in there with her. She doesn't want to come out of PIC. She's made that into her own little world (Bruce, 733-738).

> PIC, now, is the country she has, with avenues, with streets, with suites, with hotels. She is celebrating her wedding. Her lover, Tana, (like I said to her "I don't like that guy too much," I said to her, "He gets you into trouble") married her. We are, mom and dad are, her guests, so she serves us coffee when we arrive there. She wears a blanket pretending that's her wedding gown. She is worse every day (Teresa, 1115-1125).

When I asked how parents react to hallucinations, I was told that the hallucinations are real to the ill-child and that it doesn't help to negate them. Instead, parents tell their children that they are unable to see or hear what the child does. As Bruce explained:

> We sort of dodge the questions, say, "Well, Anne we don't have your powers, it's not for us to say whether these people exist or not, but we know they exist for you" and that's what we have to come to terms with. We try to show her that that's fine, you know, but she also can't avoid reacting with however she views this world (757-764).

Tim's mother, Ruth, believes that people with schizophrenia find visual hallucinations less frightening than auditory ones.

Auditory Hallucinations

If there is one symptom that these parents identified with schizophrenia more than any other, it is hearing voices. Apart from Sean, Colin, Derek, and Ken, all of these ill children heard voices. One could question whether Colin and Ken have auditory hallucinations. While Colin does not admit to hearing voices, he says he has thoughts and appears to be somewhat controlled by them. Ken very frequently asks questions such as, "Did you say 'nine?' Did you say 'seven?'"(Willow, 521); "Did you say you're my mother?" (Willow2, 835); "Did you say 'it's okay?'" (Willow, 529). Willow believes these questions indicate an obsession, possibly induced by the medications he takes, rather than by voices that he hears. Some of the ill children will talk about their voices, although not at the beginning of the illness. Many parents learned about the voices after the fact, when the child had some insight into the illness, was taking medications, and no longer heard voices. Other parents have never been able to discuss the voices with their children.

Sometimes the voices appear to be friendly. Jean, Jenny and Lorraine described their daughters as smiling and laughing in response, although in some social contexts this could be inappropriate. For example:

> She'd sit in the doctor's office and the voices would say, "Look at Dr. 'M's' hair sticking up," and she'd start laughing (Jenny, 1814-1816).

More often, the voices were characterized as destructive, derogatory, cruel, and negative. Jenny would often wake up at night to hear Melinda crying. Several parents attributed their child's low self-esteem to their critical auditory hallucinations. Barry could hear the neighbors laughing at him and other voices telling him he was no good. Violent behaviour was also blamed on command hallucinations telling the ill young people to hurt themselves or others. For example, Melinda's voices have told her to cut her wrists, put her hand in the fire and hurt the children whom she was baby-sitting. She resisted harming the children but now refuses to baby-sit unless the children are brought to her home when her parents are there. Trevor told his father that he felt relief after cutting the television station cables and slashing tires when commanded to do so by the voices.

Parents attribute a considerable amount of their children's strange behaviour to voices. Catherine thinks that Bryan's preference for wearing numerous chains engraved with sayings is something his voices have told him to do. Inappropriate emotional reactions are also seen as responses to the voices. Although Colin says he has thoughts and not voices, Gwen wonders if her son's sudden changes of mind (because he said, "it doesn't feel right") and his frequent inability to make any decision can be caused by hearing voices.

Knowing whether to acknowledge the voices or not can be troublesome for parents. Some choose to ignore evidence of voices, knowing that their comments are liable to make the child angry and upset. Now that Maxine's voices are friendly, Jean and Tom console themselves because she seems happy when she is conversing with the voices and hasn't much laughter and happiness in her life otherwise. Other parents, whose children have good insight into their illness, are able to discuss the voices with them. Jenny knows when Melinda's voices are bothering her:

> If she gets really spaced out and she's laying there all curled up, spaced out, I'll say to her, "Are you hearing voices?" and she'll say, "Yes."" "What are they telling you to do?" "Cut my wrists" (1741-1748).

Similarly, Ruth discusses Tim's voices with him. She calls them his "live thoughts" and, as other parents do, she acknowledges that the voices are real to the child but not to her:

> ...it's very real to him, and I apologize to him and I say I'm sorry I can't hear it. And once when he wasn't feeling so good, he said, "Well you oughta be glad you can't hear it"(2049-2052).

Gerald says that for a while the whole family became rather silly about Jeremy's voices, inquiring about the voices whenever Jeremy phoned to talk to them.

> ...her first name was Ala, not to be confused with the prophet and that was the predominant voice. It was a woman and I think she used to communicate to him...just about all the time. And I think that sometimes he was giving himself a hard time through that voice or other times he was feeling okay. But, there were other people involved, too. There was one person whose name changed frequently because that was the nature of that person, apparently (292-301).... I mean, you can carry on this conversation and it didn't have a whole lot of. I mean, it's hard to make a conversation like that cause you don't know what in the hell. You know, you don't know whether to laugh or cry (318-322).

Some behaviour demonstrated by people with schizophrenia is an attempt to counteract the voices. Many use noise to cover up the voices, for example, playing their music loudly or using earphones. Ruth's son sleeps with a fan going, even in cool weather. Others may try to rid themselves of voices with alcohol or street drugs. For example, both

Evelyn and Sue worried about their sons' drinking. Now that Barry is much better, he has told Evelyn that alcohol helped him to drown the voices.[1]

For some parents, voices appeared to be the key to their child's illness and they gauged how ill the child was by whether the voices had returned or not. Several explained that somehow the schizophrenic brain manufactures voices from random environmental noise. Sam, in particular, thinks that if researchers concentrate on understanding what causes voices, they will understand schizophrenia. A number of parents offered their personal explanations of auditory hallucinations. Jenny stated that voices are simply a person's own inner turmoil but, while healthy people may recognize this, those with schizophrenia are unable to make the distinction. Similarly, Arthur thinks that everybody hears voices in their minds. Most of us interpret them as our own thoughts but the ill person attributes them to someone else. Frequently, as when Barry believed that police who were pursuing him had planted loudspeakers throughout the house, the voices express the ill person's delusions.

Delusions

Every parent in this study talked about their child being delusional. Some were able to describe their child's delusions in detail despite the almost universal reluctance of the ill children to discuss their delusions with their parents. As an unquestioned belief, whether erroneous or based in some element of fact, the delusions guided the child's behaviour. Consequently, parents were often able to infer their child's delusions from their actions and

---

[1] In a study of street drugs and schizophrenia, 30% of the sample had experienced hearing voices in the past 3 months. Of those, ¾ stated that the voices improved when they took their preferred type of street drug. In the study, the preferred substances were alcohol and marijuana (Test, Wallisch, Allness, & Ripp, 1989).

interactions. Several types of delusions were described, most commonly paranoid delusions. The remainder can be grouped into four categories of delusions: sexual abuse, grandeur, those involving famous people, and a residual category.

Paranoid Delusions. When psychotic, over half of these ill adult-children were literally terrified by severe paranoid and persecutory delusions, usually involving other people. Sometimes a specific person was implicated, as when Ryan insisted on eating only in restaurants, convinced that his mother was trying to poison him (Sue, 140-144) and when Colin:

> ...thought this fellow in the basement suite had a key to his room and was coming into his room. He thought he'd taken one of his Bibles. I thought he'd misplaced it. And then he thought that this fellow had designs on his life, that he was going to kill him (Gwen2, 87-92).

More often, the perpetrator was not specified: people are out to get me (Anne, Barry, Jeremy, Sean, Roger); people are reading my thoughts or controlling my mind (Barry, Maureen); people are laughing at me, whispering about me, or spying on me (Barry, Maureen, Bryan, Roger). Others (Melinda, Roger and Maureen) were afraid of people breaking in to their residence, either to steal things or to harm them. Sometimes the police, the Mafia, or the CIA was following them (Barry, Colin, and Roger) in limousines and other unfamiliar cars (Kal's black car). A related fear is that the ill person is going to be punished for having done something bad or illegal. Barry worried about this, as did Colin, who made a practice of going to the police station to confess to crimes, particularly to being a "dangerous pedophile" (Irwin, 277).

Another kind of fear had nothing to do with people but involved some sort of catastrophe that would lead to death, for example, Anne's fear of tidal waves (Bruce, 1531) and Trevor's conviction that his mother's house was about to explode (Fred, 1473-1475).

Each time Barry has become ill, he seemed to have irrational fears involving the number thirty:

> ...on the 30th of February was going to be this terrible day that everything was going to happen. Now, as you know, there isn't a 30th. But unfortunately, he has this idea and this is what the voices keep telling him, that he is not worthy and that he is a bad person, and that they are going to get him. And he has this real fear that by the year 2,000 when he is 30, that he is going to die and he hopes it will be quick (Evelyn, 1196-1205).

Parents recognized that, although to them such fears appear nonsensical or, at best, a remote possibility, they are nonetheless very real to their ill children. Furthermore, using logic to allay the child's fears is fruitless. Several parents noted that you can't reason with psychosis but you have to deal with the resulting behaviour, when paranoia causes hostility, anger, and violent responses or, alternatively, social withdrawal. Philip and Donna believed that paranoid delusions were the reason why Roger preferred to live in Vancouver, because in a big city, it is easier to disappear and become anonymous (1612-1622). Teresa described Anne's reluctance to go out when she is ill. Here, she tells about going shopping:

> ...in recent years she goes but I have to hold her hand all the time, because she is too fearful. She looks around all the time. "Oh mom, get me out of here. Get me out of here." And every time we go out, she has to hold her dad's hand or my hand (Teresa, 1491-1497).

Anne is twenty-six years old and, paradoxically, her most pervasive delusion is of sexual abuse.

Delusions of Sexual Abuse. Unfounded charges of sexual abuse against family members are particularly difficult for parents to accept. Anne's beliefs and public accusations, beginning before her first psychotic break, have persevered throughout her illness and implicate her father, mother, brother, and school friends. Her parents credit the persistence of these beliefs to encouragement from a counselor at the local sexual assault center who has, they believe, questionable ethics and motives and who has also given Anne street-drugs when she was out of the hospital on a pass. Another mother, Maggie described being questioned when she was finally able to get her daughter's therapist to answer her telephone calls:

> "I'd like to ask you one question" she said in this authoritative, speaking to a lesser human being kind of voice, "Has Maureen ever been abused?" Now, nobody had ever mentioned even a possibility of this before, either Maureen or a counselor or the family. I mean she wasn't, but I know people can be falsely accused of this. But at the time and it still is, but particularly a few years ago, everybody was talking about being abused, if anybody was in trouble in the family. Well, she said that to me and it was like a knife going through me. And this person had never met us, never had gone to the trouble of seeing us face to face, and was saying these things over the phone to me (Maggie, 335-348).

Both Anne's parents and Maureen's mother told me that when family members are accused of sexual abuse, particularly when the accusations are supported by a mental health practitioner (Maggie, 731-733; Bruce, 243-265), parents have little recourse:

> And once it is said out loud, doesn't matter whether it is tried in court or not, your name is gone, your reputation in the community (Maggie, 1524-1526).

Delusions of Grandeur. Five of these children with schizophrenia experienced delusions of grandeur. Roger believed for a time that he was working for the FBI (Philip & Donna, 1634-1635). Trevor thought that he was now destitute because someone had cheated him out of a multi-million dollar estate (Fred, 1870-1872). Anne is married to her astral prince and living in a royal suite (Bruce, 732-736). Ken told his mother about owning an alloy business with international connections and expecting to become president of the United States (Willow, 91-100). Lastly, Jeremy wanted his whole family to go to Barbados so that they could be morfed:

> I'm not sure what morfed is, exactly, but it has something to do with, I know one of the things that schizophrenics tend to think is that they're a little bit, I was going to say, elitist. It's a little bit more than that. Supernatural. They're above everything. They're omnipotent. I guess that's the word. And, so he was going to share that with us, as well. Make us all omnipotent. Not as omnipotent as him, but omnipotent, or, that isn't the word he used but I can't think of it, but, superior, in some way (Gerald, 307-317).

Gerald then asked me how you can make a conversation with someone "when you don't know whether to laugh or cry" (321).

Three of these ill persons demonstrated having a special relationship with a famous person. Maxine still writes frequently to the Queen and Jean states that the Beatles "ran her [Maxine's] life" (1190) for years. Similarly, Melanie had a long standing fixation with Brooke Shields and tried to phone her (Michael, 940-942). These appeared to be friendly relationships, whereas Daniel's connection to Carlos Castaneda was more sinister. Daniel appeared to be trying to reduce Castaneda's power over him by destroying his books and running him down with the car. At one point, Marianne bought a Castaneda book to help understand his delusion but Daniel asked her not to read it. However, she thinks his identification with Castaneda was what convinced the hospital staff that Daniel would attempt suicide one time when he left the hospital without being discharged. Apparently, at the end of the book, the bird flies away from some high point. The hospital called the police, who searched for Daniel along a nearby mountain pass road.

Other Delusions. Some delusions could not be grouped into the above categories. Some of these had relatively innocuous consequences, such as Daniel telling people that he owned several dogs (Arthur, 861) and Anne shaving her head because she believed she was in a concentration camp (Bruce, 350-351). Other delusions held by these same two ill people had more serious and far-reaching consequences. Daniel stole a car, believing that he was to deliver it to his cousin's used car business seventy kilometers away. When he ran out of gas, he flagged down a policeman to ask for help (Marianne, 459-465). Descriptions of Anne living in a hollowed-out den in the woods, drinking on all fours from the stream, conversing with dogs, and being taunted as the town clown are particularly heart-breaking (Bruce, 366-373; Teresa, 488-499). As usual, when these young people got into trouble, friends or the authorities called the parents. Marianne went to the police station and arranged for hospital admission for Daniel. Teresa and her son flew to Banff to rescue Anne.

Religious Beliefs

A common perception holds that the mentally ill are drawn to religion,[2] particularly non-mainstream religious sects and cults because of their promise of spiritual healing. Under these conditions, religious beliefs may be an extension of their delusions. Gwen suggested that evangelism provides a crutch for many of the mentally ill (386). At least one-third of these ill adult-children received some degree of comfort from religious beliefs. However, only two have become fanatic followers of non-mainstream religions that are totally opposed to their parents' beliefs. Anne's cosmic religion (Bruce, 130-167) contrasts markedly with her mother's Catholic faith. Similarly, Colin became fanatically religious in an evangelical, born-again Christian sense and tries to convert his non-religious parents (Gwen, 510-523). Colin's religious mentor has convinced him that people connected with the mental health system are not doing their jobs out of love but for money and, therefore, cannot be trusted (Irwin, 475-505). Colin believes that the Lord will take care of him and, as a result, he refuses to take his medications until he becomes psychotic. Then he is committed, becomes stable on medications, and is discharged. Shortly thereafter, he refuses to take medications or attend follow-up appointments and begins to deteriorate again.

Others follow the same religious beliefs as their parents, although they may not be able to observe them as actively as their parents do. Melinda follows the Jehovah's Witness

---

[2] For a discussion of religious issues and schizophrenia, see Torrey (1995), pages 309-311.

faith as does the rest of the family but she cannot handle the large gatherings easily. Barry attends church with his parents but Evelyn observes that he no longer has the close spiritual relationship to God that he once had and cannot read the Bible. Their parents "don't push it," letting the ill person determine the appropriate degree of participation. Marianne also mentioned Daniel's difficulty with reading, however, she has found him occasionally reading the Bible. Kal attends the Sikh temple with his family and also with caregivers from his group home. According to Ruth, Tim has a belief in a higher power that has sometimes been helpful to him. These parents accept their ill family member's religious beliefs, whereas, Anne's and Colin's parents interpret their children's beliefs as akin to their delusional thinking.

Because the ill person seldom tells his or her parents about hallucinations and delusions, parents must usually infer them from the remaining positive symptoms of schizophrenia. These symptoms are directly observable and are grouped under the rubric, disorganized symptoms.

Disorganized Symptoms

These symptoms include bizarre appearance or behaviour, hostility and aggression, and incoherent, illogical and/or disconnected thoughts and speech. As with hallucinations and delusions, any increase in these symptoms indicates to parents that their child is becoming sicker.

Bizarre Appearance. After receiving a psychiatric diagnosis, the young person's bizarre clothing and adornments became associated with mental illness. Consequently, parents wanted their children to look normal. For example, Bruce was pleased when his daughter let her hair grow back (1303-1308) and Catherine said:

> Again, this is always my concern to have him dress normal and to look normal. Definitely, if you are wearing all these chains and that, it's not your normal dress and it would scare people, too (1097-1101).

A normal appearance is less likely to subject their child to the stigma surrounding mental illness. Joe believed that Barry would be accepted by other people better if he were properly dressed in a suit and tie. He suggested that his son's strange appearance could confirm Barry's suspicions of people talking about him:

> ...he's sure everybody's talking about him but he's shaved all his head off! His head's not bare; it's sort of got a half inch stubble on it. He's got rings on nearly every finger. He wears a leather vest and has a chain all hanging down here with his wallet on it and one of those packs here that he's got his Walkman in, so he walks down the street with [that]. Of course, music is a good idea for a schizophrenic. They are hearing voices all the time so the music sort of drowns them out a little. So he has these great big earphones on with a CD player dangling down the front like a Scotsman's sporran and a big chain with his wallet on it, and a beard. You know, I imagine people probably do think, "My God, look at that" (895-908).

Whereas previously the child's bizarre appearance was excused as idiosyncratic or an indication of adolescent rebellion, it became an indicator of illness after a mental illness was diagnosed.

Facial expression, particularly involving the eyes, contributes greatly to a person's appearance. In illness, the ill-child's eyes were described as "wild-looking" (Jenny, 2007), "staring" (Maggie, 1444), "haunted" (Gwen, 106), "preoccupied" (Gwen, 186), "different" (Gurpreet, 202), "darting around the room" (Marianne 46), or "glassy, almost as though he wasn't seeing me" (Marianne, 36-37). Both Bruce (492) and Clifford (596, 1310) said that if you look in their eyes, "there's nothing there," while Fred responded to Trevor's "tunnel vision and...staring off into space" (872) by saying, "I have really lost my son" (881).

Strange Behaviour. Several parents said that most of the time you would not suspect that their children had a mental illness, however, when they are ill, their appearance is not the only factor attracting attention. Often the illness is manifested by their demeanor and mannerisms. Sometimes it is a movement disorder or shuffling gait resulting from medication side effects but commonly, parents said, you see it in their eyes and demeanor. When paranoid, Maureen was deathly pale and cowering (Maggie, 671-672) and Anne held her parents' hands and looked around constantly when in public (Teresa, 1494).

Agitation. Extreme agitation can indicate an impending breakdown. Parents of twelve of these people remarked on their child's heightened activity level, which was described as "endless energy" or pacing.[3] Many of them spent hours walking or running, although parents did not always interpret this in a negative way. Instead, it was seen by some as the ill person's only recreation or exercise, e.g., Barry liked walking in the seedy parts of the city. Sometimes it was the child's major means of transportation. For example, Ken walked twenty blocks until he got to where he knew how to catch the bus, and Tim, unhappy at his group home, walked twenty-five blocks to get to Ruth's home each day. Eventually, Tim was allowed to move home. Other parents thought that walking was a response to other symptoms, such as voices.

Fred and Elaine were not worried about Trevor as long as he was able to expend his energy. Trevor biked and played hockey (alone because others would not include him), cleaned beaches at his father's suggestion, and identified with Forrest Gump, running and feeling "safe in that persona" (Fred, 991). According to Fred, Elaine described him thus:

> "Sweet little Trevor. It's not our son, but he's sweet and he's okay." And he was, as long as he managed his energy by doing a lot of physical exercise. Elaine said he used to run for six hours, up to the university and back four or five times a day, and then he would go clean beaches. He was always doing something but he could sleep at nights. He was sleeping. And his energy was growing and growing and growing (995-1003).

---

[3] Rather than being symptomatic of schizophrenia, some if not all of this restlessness, pacing, and inability to sit still is likely caused by antipsychotic medication. This common side effect is called akathisia (see Torrey, 1995, p. 200).

Lacking any knowledge of schizophrenia at that time,[4] Fred felt that "as long as he kept that going, there was hope" (984). Only when Trevor stopped running and became more withdrawn, did his parents begin to worry (1028-1030).

When walking might expose the child to danger, however, parents did worry. For example, Jean could not sleep when Maxine went walking alone in the middle of the night. Anne once walked fifteen miles through a snowstorm in Newfoundland, improperly dressed. Similarly, Julie walked twenty miles in the rain to her friend's house after calling the crisis line, just days after being discharged from hospital before Clifford thought she was ready. He was even angrier about the hospital staff's lack of supervision in the hospital on another occasion:

> ...she outsmarted the whole system. They had an electric tether and an electric door. Breakfast time, she confiscates a fork, jams the electric tether, opens the electric door and walks out of the bloody place. It was pouring rain and cold. They knew. I get a phone call from down there. "Well, we have the police looking, they will get her." They made her walk 2½ miles in bare feet in a hospital cotton gown until she walked up our driveway, and she was blue (Clifford, 2421-2431).

Disregard for Belongings. Many parents found it difficult to understand their child's lack of interest in material goods. Several parents described their children giving away their belongings. This was sometimes explained as their being overly generous and kind-hearted. Gwen related Colin's generosity to his religious beliefs. Such generosity means, however, that their ill children are left without things that they need — sufficient food and attractive or warm clothing.

Parents have even more difficulty understanding when their child throws good articles in the garbage. Joe commented that, as a working class person who buys special

---

[4] This was before his parents had received a diagnosis of schizophrenia. Trevor had already attempted suicide but at the time his parents believed his diagnosis to be depression.

items for his sons that he and Evelyn do without, this is hard to accept. Bruce explained that when Anne's belongings (clothing, money, keys, identification, everything) "get full of bad spirits," she "sends them home" by throwing them into the nearest large body of water (1099-1104). Nevertheless, no matter how parents explain this behaviour, they frequently need to replace items many times over, adding to the financial burden of having a child with schizophrenia.

Hostility and Aggression. The majority (although not all) of these ill people were prone to often unpredictable angry outbursts,. Being the recipient of the ill person's hostility adds to the burden families experience, keeping them "on edge" (Sue, 494) and sometimes "frightened" (Lois, 402). Kal, who is also developmentally slow, loses his temper and hits people, like a "spoiled kid" (Gurpreet, 167-180).

> ... he became six four and 240 pounds, and he used to scratch my face quite a bit to get my attention, or break the windows, or [he] wanted to have his way, wanted to have sweets, Indian sweets, or chocolates, or soft drinks, or anything like that (Kulwinder, 233-245).

When Barry was angry and rude, Evelyn and Joe responded firmly, only increasing his anger. Several times, they asked him to move out. He found roommates but eventually the roommates threw him out and he returned home (Evelyn, 606-614). Rather than aggravating the situation, many parents learned to ignore the outbursts, recognizing that any response they could make was going to be wrong.[5] As Jean said, "you learned the gentle art of sitting on the fence" (Jean, 192-195).

Sleep Disturbance. Another disturbing behaviour pattern was the inability of many of those with schizophrenia to sleep at night. Parents described their children as turning day

---

[5] Terkelsen, (1987) observes that relatives of the mentally ill, "take to 'walking on eggshells'"(p. 138).

into night and night into day, disrupting other family members' ability to sleep, making them hard to live with (Arthur, 1137) and causing friction (Sam, 68). For the most part, the ill people did not ask anyone to keep them company, although two mothers described their sons talking to them at length. For example, Sue recalled:

> I remember being really, really tired and I would be in bed and he'd get some idea and he would be in one of his manic stages, and he would come in and he'd want me to listen to him. I can remember sort of sitting in bed and then lying in bed and he was still all wound up and talking and talking, and I kept thinking, "Well, if I let him talk, if I listen to him enough, he will get tired and, and he will get it all out of his system, and then he will be able to sleep." But more frequently than not, I would have to say (I would wear out before he would wear down and I would have to say to him) "I'm really tired Ryan, I can't listen anymore, I have to go to sleep," because I knew I had to go to work the next morning. Then he would be very angry and frustrated because I <u>never</u> listened to him, we <u>never</u> talked, and he would storm off in great anger, and then because he was angry and upset I couldn't get to sleep anyway. So, there was a lot of frustration (495-512).

Taking Off. After diagnosis, many ill people remained prone to "taking off," often without warning. Their departure could follow an angry episode but often parents had no warning or clues as to why. Once, for example, when Arthur was moving and he asked Daniel to help him remove a mirror from a dresser, Daniel turned immediately and left. He was not seen for a week. Arthur thinks Daniel was responding to voices (308-342). Sometimes parents believe that the ill child is paranoid and trying to escape his or her pursuers. This was the reason Anne went to Banff. When her mother and brother traveled there to bring her home, she fled to Prince Edward Island, buying her ticket with money from social services. After spending part of the winter there, she lived on the streets in Toronto, then Montreal, and finally Quebec City, phoning her mother periodically to ask for money. Afraid to give her large amounts, Bruce eventually trusted a motel owner in Quebec with his credit card number, so that she could stay there and charge forty dollars a day (335-416). In two cases, when the ill child demonstrated forethought and announced plans ahead of time, parents tended to hope that they were better and would be all right. Lois recalls:

> ...he was affable, and he was clear-headed, and he was okay, and his planning wasn't much, but, you know, so be it. I didn't, I couldn't persuade him to do anything that I thought he should be doing (243-246).

At least one third of these ill-children left precipitously, some of them repeatedly. Generally this happened when they denied being ill and refused to take medications. Their parents were very apprehensive but, as they said:

> What can you do? I mean when she was taking off for Toronto, you know, she's over 21, and she wasn't doing anything that we could prove was a danger to anybody or to herself. She took off for Toronto twice on us. We thought we wouldn't see her again (Jean & Tom, 386-392).

For Jean, these disappearances were the worst times during Maxine's whole illness. She was certain that they were "a march off to suicide" (Jean, 1629). Like Jean, other parents were under severe stress, not knowing whether their loved one was dead or alive. Parents were frantic when they had no idea where their children were; when they knew that their loved ones were living on urban streets with no apparent means of support; or when their son or daughter was living with new-found friends they had met on the streets.

Most of the children phoned periodically to report in or to ask for money or credit card numbers. After bailing Maureen out repeatedly, the family were advised that there was no hope of her accepting treatment until she experienced the consequences of her actions. The next time Maureen ate a restaurant meal and then had the waitress phone, Maggie, after a family conference in the kitchen, refused:

> I asked for Maureen and I said "I'm not going to give you the credit card number." And she said, "So God love you." I have a habit of saying to people I am very close to, especially kids, "God love you" when I'm at the end of a phone call or something. She said, "Well, as you say, God love you. That's what you say to me." She was digging it in. And the waitress came on the phone and said "You do realize

> your daughter has nowhere to stay tonight." And I said to her "I can't make that my problem. You don't understand the situation. I'll have to say goodbye." When I came back in, the kids, they all hugged me and patted me on the back and said, "We know what that cost you." So, that's the kind of stuff you do, the good mother. And then you have to live with yourself after that (Maggie, 1838-1853).

Other ill young people phoned constantly and the phone bills were staggering. Sometimes, phone-calls brought the parents relief but at other times the child's conversation revealed evidence of delusions or other signs of illness, as when Lois received abusive letters from Sean (1342-1347). Almost inevitably, their travels ended in a crisis, when parents received a phone call from police, a street worker, a priest, or a hospital and arrangements had to be made to return the ill child home, often at great expense. Three of the mothers commented that their child must have a guardian angel.

Taking off was not restricted to lengthy disappearances. Parents became frustrated when their son or daughter capriciously disappeared from or quit an activity suddenly and for no apparent reason. If questioned, the child was liable to reply, "it doesn't feel right" (Gwen2, 235, 848). In addition, several parents noted that people with schizophrenia move frequently, often on a whim. Jenny found this tendency paradoxical, when Melinda "moved three times in a year (so that's consistent with schizophrenia) and yet they hate change" (3019-3020).

Disconnected Thoughts and Speech. As evidence of their loved one's illogical and unclear thinking increased, parents recognized that the young person was decompensating.[6] Several parents observed their child becoming more forgetful and absent-minded, for example, leaving the stove burners on or losing things. Daniel's parents

---

[6] After years of having an ill child, many of the parents in this study used psychiatric terminology. Mentally ill persons often hide signs of their illness (compensation). Eventually, as symptoms become more severe, they can no longer cover up (decompensation).

commented that he took things apart, such as the door-bell, the TV, and the telephone, and then lost the pieces. They suggested a connection between this activity and paranoia: he may feel safer if he need not answer the door or telephone, and if no voices can emanate from the television. Other behaviour indicated an inability to make the connection between cause and effect. Similarly, making irrational decisions or being unable to make decisions increased with the degree of illness.

Colin's negative symptoms were escalating when I interviewed his parents. Colin was unable to concentrate or read, play chess, or watch television for more than ten minutes. He would suddenly decide, when out somewhere with family members, that he should not be there. Also without explanation, he had recently stopped giving the dog his usual Milkbone biscuit after eating (Gwen, 836-847). The most frustrating change, however, was his sudden refusal to take telephone messages for his parents. He confessed this to them one morning and when they asked him to reconsider, he said he would think about it and let them know at five o'clock. After spending the day in his room and thinking about it for six hours, he told them, "I have nothing to say, I have nothing to add" (Gwen, 1353-1354). Irwin who, in spite of being retired, still has business commitments and connections then requested:

> ...would you promise not to answer the telephone at all, because if you don't answer it at all at least I'll get a message on the thing, you know, on the speaker." "No, I can't make such a commitment." "Why won't you pass messages around?" "Well some people don't have love in their voice, and if I don't hear love in their voice, I can't pass the message" (729-737).

Rituals. Some parents recalled their children observing strange rituals. These could sometimes be explained as observance of a religious belief, as with Anne's searching for rocks with tiny stars inside. In other cases, there was no apparent explanation as in the following:

> Daniel, always, for years, before he got on this clozapine, used to make a circle with newspapers in the middle of the floor. There was a big circle of newspapers and an area in the center where there were no papers. And they were always piled quite neatly, overlapping, and I often wondered — it would be newspapers like that [she demonstrated how they were arranged], and then the next one, and then the next one, and they'd go around until they circled (Marianne, 1346-1354).

The above are positive symptoms of schizophrenia, startling and worrisome for parents to observe. Yet, sometimes it was even harder for parents to watch their children live with the negative symptoms of schizophrenia.

Negative Symptoms

From the parent's perspective, the negative symptoms[7] are less readily identified with illness than positive symptoms and more readily associated with the person that their child has become. Watching their child deteriorate and feeling powerless to intervene is painful for parents who see their loved one becoming increasingly socially withdrawn, emotionally deprived, and lacking in motivation.

Social Withdrawal. Withdrawal may be the most prominent negative symptom of schizophrenia. It was noted in all of these ill persons except Geoffrey, Anne, Julie, and Melanie. For Geoffrey, withdrawal would be difficult for his parents to assess because of his aphasia and the length of time he has been in Riverview. Given that he lives on an organic brain syndrome unit, however, one wonders how much social contact he has beyond the

---

[7] Varcarolis (1994) compares the ways in which the positive and negative symptoms of schizophrenia correlate with the patient's prognosis and associated biological changes. Onset tends to be acute for positive symptoms and insidious for negative symptoms. Positive symptoms tend to be absent prior to the illness, respond to antipsychotic drugs, and disappear during illness remission, whereas negative symptoms appear as emotional problems prior to illness and respond poorly to medications (although new medications promise better control of negative symptoms). Positive symptoms are associated with normal psychological test results and tomographic brain scans but negative symptoms correlate with abnormal psychological tests and brain atrophy on computerized tomographic scans.

hospital staff. Anne has never demonstrated withdrawal: "Everything she does is active, puts her in danger in the community" (Bruce, 685-687). Julie was withdrawn as a child but less so since, although she spent most of a recent two week trip to Switzerland reading in her room. Nevertheless, she managed to plan the trip with her parents consent and to travel on her own. Consequently, Clifford views the trip as a victory for her (Clifford, 1560-1609). Finally, Melanie is the most socially outgoing of the ill adult-children in this study sample. Although she has kept none of her school friends, she has made good friends who are also consumers of mental health care and live in her apartment building. The remaining eighty percent of the sample became withdrawn at least part of the time. In fact, several parents generalized this attribute of people with schizophrenia, stating that "all of them are loners."

Different people when ill demonstrated different degrees of withdrawal. Some retreated to their bedrooms. When Bryan lived at home, he locked his room, preventing his parents' access. During a hospital admission when the decision was made for him to go to a group home, his parents entered his room:

> ...it was quite a shocking experience when he barricaded himself in his room when he was living at home. He built like a tent and he barricaded it in. He built it in the closet. It was almost like a small space that he could feel more comfortable in. It was very strange but I think he just felt like he needed that (Sam, 1015-1021).

Others were described as agoraphobic, preferring to remain in the house but not confined to their room. For example, when very ill, Maxine lay on the couch, fixated on negative news stories on television (Jean, 489-499) and Melinda preferred the couch in her family's part of the house rather than the one in her own attached suite. Possibly she feels safer there, as her mother, Jenny, believes that she withdraws when the voices are telling her to hurt herself (Jenny, 1661-1664, 1741-1748). Several parents endorsed group homes as preferable to the ill child living with parents, because they may counteract the propensity for withdrawal. According to Catherine, the group home manager encourages participation in daily chores and arranges outings, including occasional restaurant meals. Nevertheless, Bryan still manages to avoid many of these. In any case, parents gauge the severity of their child's illness by their withdrawal versus their willingness to socialize.

Parents are torn between trying to initiate some social contacts for their isolated children and trying to protect them from uncomfortable situations. Certainly, when the child cannot avoid large gatherings, parents try to provide some time-out for the child. For example, Evelyn intends to arrange opportunities for Barry to be alone when he takes part in his brother's wedding this fall (1061-1074).

Parents explained their child's need to withdraw in various ways. Joe said that Barry "always wants to try to be invisible" (1278). Jenny observed that Melinda avoids social gatherings because noise irritates her. She manages better in a one-to-one situation than in groups (822-827). Willow thinks that some of Ken's isolation is intentional. He refuses to go to the local club-house for the mentally ill because he does not want to be associated with mentally ill persons. Much of the isolation of these ill people is not self-imposed, however, but results from the rejection people that with schizophrenia experience from others (Clifford, Willow, Sue). For paranoid children, withdrawal was explained as a means of escape. Finally, many parents drew a connection between withdrawal and depression.

More than half of these ill people were subject to bouts of depression. The most frequent indication of depression was the child's withdrawal from social contact. Parents attributed their child's depression to feelings of hopelessness (Gurpreet, 415), to low self-esteem resulting from hearing derogatory voices (Evelyn, 1340-1341), to the number of losses he or she had endured (Lorraine, 262), and possibly to medication side-effects (Marianne, 1117). In response, parents tried to be encouraging (Evelyn, 1342) but they were also frightened for their child (Fred, 1029).

Lack of Motivation. Another yardstick of their children's illness was motivation. Children were assumed to be improving when they began to take responsibility for themselves and their belongings and when they began to display initiative and achievements. Deterioration in responsibility and initiative was interpreted as a sign of worsening illness.

Along with their confusion and inability to concentrate, lack of initiative may contribute to the ill person's apparent disinterest in recreation activities, such as reading and playing cards. Usually, however, parents pointed out their child's lack of initiative in performing the daily activities of living. Joe spoke of Barry lacking a "clear sense of direction" (1235) and Lois found Sean's lack of a "scheduled type of living" (378) frustrating. Parents were confused when the person appeared responsible in one area of his or her life but not in others. For example, Catherine commented that Bryan, paradoxically, was able to organize a legal change of his name but sometimes could not figure out which bus to take (1061-1071). When completely psychotic, people with schizophrenia may be unable to assume even very basic responsibility for themselves. As Bruce described Anne before one admission:

> ...she doesn't eat when she is very psychotic, and when she is really bad she doesn't drink either, and she retains her urine. You know, she won't urinate, so that she starts to get toxemia (417-421).

One measure of responsibility was personal appearance. Unkempt or dirty clothing and poor personal hygiene became markers of illness. Thus, parents descriptions of illness included:

> ...she would never wash. Oh, God! She smelled like a goat when she'd get into these moods....her hair would just hang in strings and she would just stink. She just didn't care. And it was just so sad because, you know, she used to be quite normal in keeping up her appearances (Jean, 1049-1060).

> As he got sicker and sicker his personal hygiene went down the drain. He frequently smelled bad the last few years of his life because I guess he just didn't have energy to shower. One of the people that came to his memorial service was the barber. The

> barber was a big deal in our life because when we could get him to agree to go to the barber, quite often he went to the barber's home so he wouldn't have to meet other people, and this man was very understanding. He would cut his hair at home, rather than, when Ryan was feeling really ill and he couldn't handle people, going into his shop (Sue, 144-156).

Similarly, Lois noted that at times Sean would forget to shower, whereas, at other times "his skin crawled" (599) and he took several showers in a day, always leaving the bathroom in a shambles. Another indication of poor hygiene is poor dental care. Melanie has had several teeth pulled (Michael, 233) and Maxine has no top teeth and refuses to see the dentist (Jean, 1937-1951).

The inability of these people to motivate themselves was also reflected in their surroundings. When the young people lived at home, mothers tended to pick up after them or remind them constantly to pick up after themselves. This sometimes caused friction but:

> If you leave them asleep on the sofa, that's where they will stay, with the chips and the cigarettes, and the coffee (Evelyn, 566-568).

If, instead of living at home, the ill person lived in an apartment, supported by parents, Mental Health, and/or Social Services, their state of illness was reflected in the state of their living quarters. Sometimes the Mental Health system provided home support help but, particularly when the child became ill, the amount supplied was insufficient (Arthur, 105-109, Lois, 1238-1244).

Lack of Achievement. When acutely ill, none of these young people was able to hold down a job. None of them was even remotely interested in working or going to school. Although Barry was not fired from his security guard job when he attempted suicide, it was "virtually over at that point" (Joe, 421). After Barry came home from the hospital, Joe suggested that he might do some painting in the house:

> He sort of painted that hallway up to there but every time he painted it, I had to open the paint can, I had to go and find the brush, I had to wash it out afterwards, I had to go find the ladder for him, I had to set it up, I had to hand him the brush, I

> had to hand him the can of paint. It was, you know, he works [but] he doesn't, he just sort of stands there worrying and doesn't do anything. Finally, I gave up on it (497-505).

In contrast, Anne, who has positive symptoms predominantly, worked on a farm caring for sheep. Bruce believes the tranquillity of the country lifestyle was helpful:

> ...she worked for a very eccentric old pioneer lady who had been farming since the death of her husband in 1939, and is still there, wandering around on one leg. And they seemed to hit it off together, you know. She is in her 80s and she didn't mind if Anne went off in the woods and screamed at the spirits and everything, so long as she came back and did the sheep. I think it was very good for her but she did continue to deteriorate and she lasted a year and had to be hospitalized again (454-464).

Lack of Emotion. For Jenny, apart from Melinda's suicide attempts, the worst thing about Melinda's illness is her inability to enjoy herself. She never laughs and is never happy. Several other parents despaired their child's lack of emotion. Jeremy used to have a good sense of humor and now he never laughs and almost never seems to get a joke (Gerald, 702-709). When the only emotion a child shows is anger, it hurts (Jean, 2105-2110) and when you cannot tell what your child is feeling, it is difficult to know how to respond (Donna, 573-583). Fred's description of Trevor at Christmas time reveals someone who is very ill:

> No emotion. He was so detached. There was no emotion. When he would turn, it was more like an automaton-type individual. Very, I think, inwardly managing an intense amount of pain (1072-1076).

It is painful for parents to watch a child's pain as revealed in their illness symptoms and feel helpless to relieve it. In addition to watching their child carefully for changing symptoms, parents also maintained vigilance by watching over the child's treatment by others.

Watching Over

Both the psychiatric and rehabilitation treatment given by professional caregivers and the social treatment their ill child received from family members and friends came under the watchful gaze of parents. Parents became very busy supervising their child's psychiatric treatment and trying to assure themselves that their child was receiving optimum care from professionals. As well, they placed themselves in a position of intermediary between other family members and the ill child, and between family friends and the ill child.

Supervising Treatment

When the child came home from hospital, parents assumed a watchful eye over their ongoing treatment. Usually, the cornerstone of treatment was medication, however, sometimes other treatments were required. Sometimes the child became ill again and needed hospitalization and, once again, parents often had to make this decision. Parents also felt responsible for overseeing their child's visits to psychiatrists and other mental health professionals.

Medication Compliance. Most of these parents subscribe to a belief in the usefulness of medications, despite the serious side effects of many drugs. However, several parents wish for a more natural alternative. There is a belief that once the child begins antipsychotic medications, he or she will always need them. These parents hope that the newly available drugs that promise better therapeutic effects without the distressing side effects will work for their children. Willow would like to see her son taken off all medications, suspecting that the medications have done him more harm than good (1406-1411) but, surprisingly, she also said that at times she relies on the medications and watches them as carefully as other people do (2466-2472). Parents oversee their child's compliance with taking prescribed medications and the side-effects that are produced. They try to prevent, but sometimes are witness to overdoses and sometimes are dismayed by the child's use of drugs that have not been prescribed.

Almost none of these people with schizophrenia has, from their diagnosis onward, been completely compliant in taking antipsychotic medications,[8] with the possible exceptions of Melinda, who diagnosed herself and sought psychiatric help on her own; Kal, who because of his slowed social development may take his medications when told to by an authority figure; and Geoffrey, who has spent most of his illness in hospital. The rest followed a pattern of becoming ill over many years, followed by admission to hospital, stabilization on medication, discharge from hospital, sooner or later refusing to take their medications, becoming ill again, and rehospitalization.

Most parents explained their child's refusal to take medications as resulting from the ill person's lack of insight and their denial of mental illness. When people who have schizophrenia believe that they do not, there is no reason for them to take antipsychotic drugs. Two of the parents, however, suggested that their children may actually be very aware that they are mentally ill but also of the consequences, forcing them to deny its reality as a type of defense mechanism:

> ...probably having seen her older brother going through all this garbage, she was probably totally terrified at the notion that she might be coming down with the same thing. I can't imagine any fear worse than that. So, she probably will spend an awful lot of time denying that she has anything. And she may spend the whole of her life denying that she is mentally ill, or has this schizophrenia thing. I know I think I probably would under the circumstances (Warren, 503-512).

---

[8] Torrey (1995) estimates that by two years after discharge from the hospital, as many as 70% of people with schizophrenia are non-compliant in taking their medications. Three reasons are given: lack of insight, the discomfort of side effects, and a poor doctor-patient relationship. Not taking their medications is the most frequent reason for readmission to the hospital.

> ...and I don't think people realize how painful mental illness is to the individual with mental illness. They kind of think, "Well, they are 'looney tunes,' they are kind of tuned out." Oh God! Most likely the reverse is true. They are painfully aware and they are tortured. They are tortured individuals (Fred, 2299-2305).

When parents realize that their child is not taking the medications, parents become frustrated and worried. Unless the child admits to being ill, they are unable to even try to convince the child to reconsider. Some parents are tempted to give the drugs surreptitiously, as has been suggested to Irwin and Gwen:

> ...I wouldn't do that. And anyhow, would he taste it? But even if he would, I wouldn't do it. I wouldn't do it. Irwin is seriously considering it and I say I'm not having anything to do with that. Can't. I mean we can't be here every day. And no matter what the medication is, it does have some effect that he would know. Either he can't sleep or something. But this doctor says he, he's done that....But I mean that's not going to help because we can't always be there (Gwen2, 314-325).

Jean did slip her daughter's medications into food for a while. Although she felt forced to do so, she also felt guilty (1691-1693).

There are other reasons why people with schizophrenia stop taking their medications. When they are forgetful about other things, they may also forget their medications. If the child is living at home, parents slip into the role of policing medications, checking whether they have been taken, physically administering them and sometimes even watching whether the child swallows them. They become very suspicious, thinking that every sign of illness means the child is refusing to take medications, when it may be that the medication has stopped working and needs to be changed. Most of the parents in this study were not made aware of this possibility until it happened.

If the medication is working well and symptoms have disappeared, people with schizophrenia may stop taking their drugs, believing themselves cured. Alternatively, they may believe that their improvement occurred in spite of taking the drugs. For example, Anne, abetted by her counselor, believes that the medications are poisonous and are only being given to make her forget her history of sexual abuse. Each time she is discharged from hospital, she refuses to take any further medication. Over time, most of these ill young people became accepting of their illness and of the usefulness of medications. As Warren stated:

> ...this acceptance thing may turn out to be a kind of a gradual osmosis anyhow. I don't know. It's probably not a sudden momentary epiphany that occurs, I think. (702-705).

Medication Side Effects. A major reason for refusing their medications is to stop the uncomfortable side effects. Parents described their children suffering from movement disorders, weight gain, agitation or sedation, dry skin or rashes, and one case each of water toxicity and goiter. Antipsychotic medications were described as "very hard medications," causing "nasty" and "exaggerated" side effects.

Abnormal movements. Uncontrolled movements contribute to the stigma of mental illness by making the illness visible to others. Jean described Maxine as having uncontrollable kinetic energy:

> ...she would almost be out of sync when she was walking or she would be like this [demonstrates movement of arm] with a cigarette. Always in movement (Jean & Tom, 486-488).

Maxine's tardive dyskinesia[9] has improved of late, but is occasionally noticeable when she is out walking. Bryan displayed abnormal facial movements:

> ...one of the medications left him facial movements, almost like the fish. Fortunately, that has disappeared. I was afraid that that would not disappear, and that was actually on risperidone, which I thought was interesting because that's

---

[9] Tardive dyskinesia refers to involuntary purposeless movements of the limbs or, more commonly, of the tongue and mouth, estimated to occur in 20% (Varcarolis, 1994) up to 35% (Sundram, 1986) of people on long term antipsychotic drugs. Torrey (1995) contends that the incidence is difficult to estimate because in some patients these symptoms may be due to the disease process rather than drug-induced. It is more common among women, older patients, and those with more affective symptoms, e.g., depression and mania.

> supposed to be one of the few medications that doesn't have side effects, but for him it did (Catherine, 231-237).

Often parents referred to their children as appearing "drugged" or "like a zombie" on the medications. This is Maggie's description of Geoffrey, home on pass from Riverview:

> He came out a month later for his 21st birthday and I did not know this person getting off the bus. He was drugged. Oh, just walking like this; eyes staring, head shaved, a robot (1441-1445).[10]

Weight gain. This common side effect was noted by several parents. For Kal and Ryan, their large size added to the intimidating effect they had on other people (Kulwinder, 118; Sue, 886-890). This changing body image was difficult for both parents and their ill children to accept, for example:

> She was beautiful with long blond hair, lovely looking, and shy, and charming, and sweet.... she started to just get bloated out. And Sandra [Maureen's sister] said now she is absolutely huge (Maggie, 530-532, 706-708).
>
> ...he's good old Barry and he's just getting fatter and fatter and picking up his cheque on time (Joe, 1564-1565).
>
> She came home and she said, "Dr. 'T' said I can't, I don't have to gain anymore, if I exercise, but I can't lose what I"...what she's gained and she's, you know, she's only five foot two and 150 [pounds], but she doesn't look it, but you'd never convince her of that (Jenny, 676-678, 683-685).

Agitation or sedation. Restlessness was observed in many of these young people, although not all parents blamed it on drug effects. One who did was Gwen:

> ...he was either pacing up and down, up and down, up and down, because the medication was just terrible. It didn't agree with him at all. So, he had this terrible muscle restlessness and he couldn't keep still for a minute. So, he was constantly wanting me to rub his back. And so he would either be lying in his room or he'd be pacing (Gwen, 262-269).

---

[10] Improvements in medications and their usage have occurred over the two decades since this event involving Geoffrey. Nevertheless, parents still describe their medicated children in a similar way.

As Gwen noted, when he was not pacing around, he was lying in his room. Sedation was another frequently noticed side effect, which may produce changes in sleeping patterns. Marianne believes that Daniel's nightly sleep from 8:30 p.m. to 10:00 a.m. stems from his medications (1113-1120).

Dry skin or rashes. Skin reactions to medications can be very uncomfortable. Maggie (629-630) recalled that Maureen had been given something to relieve her dry nasal passages. Sometimes relatively simple measures can provide at least partial relief but patients and family caregivers need prior information about them. Jean recalled:

> ...she was on, now, what was that, Stelazine? And it was in the summertime and they didn't tell her about the itch in the sun. So she had a real hard time there. And finally, I went to the library and I looked it up in one of those books and it said don't go in the sunlight (Jean & Tom, 472-478).

Other side effects. It may be less useful to inform parents of all of the less common side effects, although when their appearance indicates the need for a medication change, family caregivers should be informed. Kulwinder described Kal's adverse response to two drugs:

> ...he became quite plump and he just could not stand without drinking water. His water level intake went haywire and, whenever he could, he would drink water. Finally, they found out that Lithium[11] is causing this, so they cut down on it. Then they tried Tegretol on him. Tegretol made a severe reaction on him. All his body came out with bruises and cuts and everything (121-128).

Watching their loved ones endure side effects was painful for parents, who worried about the long term effects of potentially toxic medications and felt guilty because they encouraged their children to take them. Willow wondered whether the medications cause Ken's obsessive compulsive behaviour of incessant questioning (557-558). Jenny worried

---

[11] Extreme thirst is an indication of a build-up of lithium in the body and could indicate an impending overdose (Canadian Pharmaceutical Association, 1996).

about potential liver damage (2992). Some examples illustrating the parents' dilemma follow:

> ...he is speeding, he is being more and more sped up. We still think it's the meds. The meds are supposed to slow him down and topple him, which of course is tragic as well, and it does the reverse. Just sends him sky high! So, they have put him on this new Zoloft medication and he is just going faster and faster and faster. So, when he falls, he is going to fall (Willow, 792-799).
>
> Sometimes I still feel guilty about the medication, yet I felt if he wasn't on medication and stabilized, he may not be alive. But then you look at what the medication, when they develop things like tardive dyskinesia and things like that, you think, "What have I done to this person?" (Catherine, 697-703).
>
> ...something in me felt, "Maybe he's right. Maybe he shouldn't be filling himself up with all this toxic stuff." And, in the last month that he had been on medication before he came off it, I mean, he was still – weird, and it was the new medication, Risperidone. So, I am constantly sort of torn with thinking, "Perhaps he shouldn't be on medication." I see what the medication does to him. He can't sleep. He loses all motivation, although he doesn't have much motivation even now without it. So, you know, I did feel I was betraying him (Gwen, 648-659).

While parents felt responsible for overseeing their child's medications, they were not always well informed about the medications' effects, the side effects to watch for, or the prescribed dosages. Nonetheless, almost all of them believed that prescribed antipsychotic drugs offered their best hope for a cure. They were less optimistic about their child's use of social drugs.

Social Drug Use

Several parents spoke about their child's use of marijuana, alcohol and cigarettes. They expressed concern about the adverse effects of social drug use and wished the child would stop using marijuana and reduce cigarette and alcohol use. Particularly when the ill child was younger, this was a problem. With older adult-children who had suffered from schizophrenia for a long time, there was a partial acceptance by some parents of their child's social drug use. They explained that if these drugs made the child feel better,[12] then they, as parents, could not strictly object. As Jean noted, people with schizophrenia smoke, drink and take drugs because "life is just such a pile of crap, to quote a phrase" (553-556). So, although she and Tom used to disagree about their daughter's heavy smoking, she now looks the other way when Tom buys cigarettes for Maxine. Other parents kept their children supplied with cigarettes, knowing that the social assistance falls short of supplying their cigarette requirements. Joe even started smoking to keep Barry company for a while, but had to stop when he developed respiratory symptoms (Joe, 1305-1311).

Because marijuana is illegal, parents worried about that more than about smoking or alcohol and some of them were relieved when their ill-children stopped using it after a few years. As Lorraine explained about Melanie:

> ...she soon learned – not soon, it took a long time but – she learned that she might feel better for the time being but then she would feel worse in 24 hours or 48 hours, and she'd feel really sick (168-172).

Sue's comment is typical of parents who have partially accepted their ill child's use of social drugs. Ryan could make his own decisions about this as long as it involved himself alone:

> He liked to drink. He was a smoker. He used marijuana. At one point he tried to grow marijuana in his closet, which I discovered and I made him destroy. At one point his brother grew marijuana in his home for his brother. And I guess from what I've read it makes them feel a lot better. I don't think he used any other street drugs but he certainly smoked a lot of pot. He drank beer to a certain extent but I

---

[12] Torrey (1995, pp. 251-257) reviews a number of studies of alcohol, street drugs, nicotine, and caffeine use among people with schizophrenia. Parents described to me their child's cigarette smoking, marijuana use and alcohol use but not excessive coffee drinking. Test, et al. (1989), interviewed patients about their substance use. The most important reasons they gave for taking drugs were (1) to relieve boredom, (2) to have something to do with friends, (3) to feel less anxious and more relaxed, (4) to help them sleep and (5) to relieve side effects from their prescription drugs. The authors discovered that substance use did not always relieve symptoms, however, in general, subjects reported improvements in anxiety, sleep problems, depression, voices, and side effects. In contrast, the majority of subjects reported exacerbation of paranoia after taking street drugs.

> don't think he drank hard liquor. And when he was feeling good he would go to certain beer parlors and hang out (Sue, 157-167).

Treatment Programs

Although rehabilitation programs are vital to reintegrating patients into the community, few programs, such as training in employment skills or independent living, were available while the child was living at home. The exceptions were Ryan, Melinda, and Kal but their experiences were disappointing. Ryan took several employment skills programs but never managed to finish any of them, although Sue thinks he finished an independent living program the second time through the course (483-493). Melinda completed the course-work for one pre-employment program but could not handle the practical experience in an art center, because it exposed her to too many people. When Melinda was denied her certificate, Jenny complained to the Schizophrenia Society until Melinda was awarded it (436-473). Kulwinder believes that Kal needs a good behaviour modification program but, instead, he has received "Mickey Mouse programs" (990). Now, Kulwinder is disillusioned with a system that fails to deliver what it promises:

> When they create [an] action plan, they mean they develop a plan. They put lots of good things in it but when the delivery time comes everything falls down. Nothing substantiates. It looks really good on the document when they try to get the contract. They don't deliver. There is no accountability in this system. We talk too much. No substance (1467-1473).

Whether the lack of rehabilitation programs for people with schizophrenia living in their parent's home reflects a true lack of community programming is unclear from this data. It may be that those who are living with their parents are too ill to benefit from such programs. As well, persons with schizophrenia who reject their diagnosis and consequently any contact with the Mental Health System will not avail themselves of whatever programs are available. What is certain from the data is that, no matter which of the above scenarios applies to an individual case, those ill children who reside with their parents have poor access to rehabilitation programs.

Although the literature suggests that some people recover after only one psychotic episode of schizophrenia,[13] this was not true in any of these families. Eventually, when the child's condition deteriorated, he or she returned to hospital.

Hospital Care. Hospital admission is usually not voluntary, although sometimes parents or psychiatrists are able to persuade the ill person. Voluntary admission is not likely unless patients have good insight about the illness and, if so, they may even go to the hospital themselves. Hospital admission may be for observation and treatment or for regulation on a new medication. However, during the first few years of illness, the usual reason for admission to the hospital is that the illness has relapsed into another psychotic break and the child is in crisis. Then, more often than not, the ill individual is committed involuntarily on the basis of being a danger to self or others.

Getting a psychotic person to the hospital is not easy. Often they resist. Parents then may need to resort to using force or, failing that, calling the police. Neither option is easily chosen and reflects the parents' feeling of desperation. To struggle with an adult-child who is out of control may damage future relations with the child and also place the parent at risk of injury or social censure. In Clifford's words:

> ...if you manhandle that individual that is ill yourself, you leave yourself wide open for all kinds of horrible social backlashes and legal backlashes (1458-1461).

---

[13] According to Torrey (1995), up to 25% of people with schizophrenia recover completely. Those who do recover, do so within two years of their first episode and tend to have no more than two separate psychotic breaks.

The alternative, to call the police, is difficult for a parent to do. It is seldom chosen until all other measures have failed (Teresa, 203-211). Catherine expressed the parent's dilemma well:

> ...the second hospitalization, we had to call the police and have them take him away and that is a very dreadful experience too. The policemen were great. Again, I have nothing but praise for them, but to call the police and have your child taken away is a hard thing (655-660).

Calling the police is no guarantee that the child will be taken to hospital and parents may be faced with laying a charge against their child, in order for the child to receive help (Philip, 513-519). Jean observed that schizophrenia is difficult enough for psychiatrists to assess. Consequently, the police, not surprisingly, may have difficulty deciding whether the person is ill, stoned, drunk, or just belligerent (867-870). Still, many parents in this study expressed admiration for the assistance and sensitivity demonstrated by police. Under many circumstances, police are "the first line of mental health care" (Donna, 1413).

Getting the ill person to hospital is no guarantee of admission. Several parents said that the reduced availability of hospital beds[14] means that unless patients are certifiable, i.e. a danger to themselves or others, they are liable to be seen in emergency and discharged. Philip and Donna recognized that Roger was ill years before his first hospital stay, but they had been unable to convince him to seek psychiatric care. Once, however, when he was paranoid and hallucinating and his landlord had threatened to call the police, Roger agreed to go to the hospital, when talking to his father on the phone. When Philip got there, Roger

---

[14] The Canadian Psychiatric Association recommends 50 adult acute psychiatric beds per 100,000 population (Gordon, 1997). Applying this ratio to Greater Victoria's 317,989 citizens (Statistics Canada, 1997), would give Victoria 159 acute care beds, almost twice the 83 presently available in the Eric Martin Pavilion, the only psychiatric hospital in the area (G. Beddows, secretary to the Regional Director, Mental Health, Capital Health Region, personal communication, July 30, 1997).

was already seeing the emergency room physician, so Philip gave the nurse a note for the doctor:

> "Please, as his father, I beg you do not release him onto the street, but take this opportunity to advise him to be committed to EMI. This has been needed for two or three years and this is a chance to do it because he will agree. He is under the threat of police." And I sat and waited and waited and waited and Roger didn't appear. Eventually I went up to the desk and the nurse said "Oh, I saw him going out 15 minutes ago." The doctor had just said there was nothing really wrong with him and he should go out on the street (904-915).

Philip was not the only parent who felt ignored when accompanying a psychiatric patient to emergency.

Several parents observed that emergency is not a welcoming place for people with mental illness. Psychiatric patients are often not given priority and when left to wait they may "take off." If the staff realizes this, security may be called and the patient may be chased, caught and restrained, thus confirming his or her fear of the hospital. Irwin attributes some of Colin's refusal to accept treatment to such an episode (557-581).

Even in the emergency department, parents observed the stigma against mental illness. For example, Ruth felt slighted one night when Tim was segregated away from everyone else in the end bed, although there were eleven other empty beds. Teresa said, "You hear some doctors say about these readmissions, you know, 'she has been here too many times' "(955-957). Clifford described driving his psychotic daughter to the hospital under the pretext of picking up some medication for her mother. Once there, he went inside to ask for assistance:

> "Could somebody come out please and talk to Julie for a minute. My daughter, I don't think she is well and I think she needs some assistance here, or at least give me some advice." "So what's the problem sir?" "Well, Julie is afflicted with schizophrenia." "Sorry, we can't come out"....I said, "What do you mean you can't come out?" "No, you'll have to bring her in" (2320-2326, 2338-2340).

Angry, Clifford created a scene, saying:

> "Damn it, if my daughter was out there getting a heart attack, half this bloody place would be out here making a hero of themselves." You'd be surprised at how quickly somebody was there. Nobody was going to come out because it was a psychiatric problem (2346-2351).

Once the ill person became a hospital patient, some parents were complementary of the excellent care they received. Others reported observing less than ideal, therapeutic conditions. Whether pleased with the care or not, however, the majority once again discovered their inability to influence any decisions that were made regarding care. Parents were limited to watching. Some saw that professionals do not always act in a professional manner and spend little time talking with patients.

Visiting their child on the psychiatric ward was hard for many parents. They recoiled when they saw a loved son or daughter restrained, locked alone in a time-out room (Ruth, 1200), or treated roughly and without respect:

> You don't tell them to shut up when they are screaming with pain. You don't say, "Well smarten up now, go for a walk." You don't do that to an open heart - a patient who has just gone through open heart, or any surgery, or any broken bones. But she is mentally ill, they take the liberty to do that (Teresa, 948-955).

Parents described watching confusion and chaos. They saw patients engaged in "TV therapy"[15] or sitting alone while the staff kibitzed and drank coffee at the desk. Consequently, some felt obligated to protect their child even when in hospital:

> ...they have to be vigilant and say to the staff "Listen you guys better do your job or I'm going to sue the hell out of you if something happens to my child" and they spend an awful lot of time in the hospital because no one else is there (Willow2, 592-596).

Some found that their ill child had nothing in common with the other patients or wanted to have nothing in common with them, although others noticed that patients have

---

[15] This refers to patients who spend virtually all their time sitting in front of the television.

empathy for each other and will look after one another (Ruth, 2075-2087). Thus, having their child in the hospital provided relief for some parents (Sam, 88-90; Fred, 776-779) but not for others.

Sometimes legitimate psychiatric treatments were frightening and difficult for parents to see. An example is electroconvulsive therapy (ECT). Respondents told me about four of their children receiving ECT. Barry and Maxine benefited (Evelyn, 733; Tom, 52) but not Bryan (Catherine, 1253-1254). Willow believes that, although ECT was the only treatment left for Ken's catatonia, it left him with permanent neural deficits (2101-2108). Parents also despaired as they waited for medications to take effect and again, later, if their child developed side effects.

As well as medication side effects, some parents pointed out the iatrogenic effects of being in hospital. For example, Maggie said that Geoffrey "learned how to be insane" (1445) in Riverview, which he referred to as his prison. Willow blames Ken's outcome on his treatment, as much as on his schizophrenia:

> ...the medication has really screwed him up. I think the hospital stays have screwed him up, so I think what started off as a small mental illness has reached this level. So, that, I think if he had been handled differently, he wouldn't be where he is today (1183-1187).

Decisions about when and under what circumstances their child could leave the hospital was another problem over which parents had little control. When allowed out on a pass, their loved ones could go where and with whom they pleased. For example, Maxine and other patients went to a nearby park to smoke pot (Jean & Tom, 1755-1768). Similarly, after Anne left the hospital with her counselor, she returned high on drugs and indoctrinated with anti-psychiatric polemics (Bruce, 310-316). When Bruce and Teresa protested to the staff, they were informed of Anne's right to see whomever she pleased (Bruce, 306-316).

Bruce and Teresa were further dismayed when a Review Board acquiesced to Anne's appeal for release, against both their own and the psychiatrist's judgment:

> ...she filed for a discharge that she didn't want to be there, put it to the Review Panel, named one of her friends which was the counselor from the Women's Sexual Assault Center to be an advocate for her. The Review Panel released her and it was the counselor who took Anne out of the [hospital]. Dr. "B" felt so strong about it, that he went himself to the meeting and [used] very strong words for a doctor but he said this was a travesty. She was let go. It was the counselor that came for Anne and pick up all her belongings and took her out, and we were not allowed to say a thing. Not a word (Teresa, 405-419).

More frequently, however, parents complained about their child being discharged by the doctor prematurely (Jean, 974-979) and without appropriate planning (Arthur, 94-103).

Two of these families believe in long term psychiatric care as the only solution for some patients, including their own children. Teresa considers that Anne has been poorly served by the "revolving door syndrome" (763) in acute care hospitals and that:

> ...the best insurance is keep the institutions because I know, although Anne is suffering she is protected and she is safe — safe from hurting herself and others. And I don't believe in that community connection, at all, and I have reason not to believe (1690-1695).

Conversely, Roger was very well served by long term hospitalization in Riverview until he was deinstitutionalized:

> That was probably the best place he was ever in, as far as his own completeness of life, because they eventually found him a job to do. He washed trucks in the morning and eventually was made foreman of the truck washing gang. You know, there were only three of them and Roger was the leader. And he got satisfaction out of that and nobody bothered him. He didn't appreciate the grounds greatly or anything like that. We thought of him walking on them, but no. They had a nice smoking room. People didn't bother him. He got his meals and he was safe. He wasn't on the street (Philip, 568-580).

Donna confirmed that Roger was happy and safe, "But then they pushed him out" (584). These parents fervently support asylum as a necessity for some mentally ill people.

Both inside and outside of the hospital, problems experienced by parents in dealing with the mental health system continued to reinforce their disenfranchisement. Neither the mental health system nor professional caregivers endorsed the parents' understanding of their rights and responsibilities as regards their ill son or daughter.

System Support. Parents relied on support from the mental health system for two reasons, lack of knowledge about schizophrenia and the perception of needing to help their ill child (despite their uncertainty about how to help). Although most parent caregivers did find helpful and supportive practitioners, none was satisfied with all practitioners nor the system as a whole, particularly as regards its ability to meet the needs of families. Parents discovered that the mental health system focuses on the patient, paying insufficient attention to the family. This creates barriers to family participation and fails to address the negative effect of one member's illness upon the family in total.

> It seemed like there was a wall between the provision of services and the parents that were standing outside wanting help (Michael, 770-771).

Like Michael, many parents expressed the sentiment that hospital and community mental health staff are dedicated on the whole, have good intentions, and are busy with clients but they fail to support the parents' endeavors or even to recognize what families need. As a result, parents felt isolated from the mental health system and disenfranchised by it.

The problems of professionals misunderstanding families are compounded by the problems of families misunderstanding the system and, secondly, by a lack of fit between twenty-four parental caregiving and a mental health system that is fragmented and not always available. Coordinating their child's professional care, when "there are so many titles and so many layers" (Maggie, 316) that parents are "lost in the maze" (Maggie, 323), is frustrating. Hours can be spent on the telephone and "on hold" (Evelyn, 1402), making appointments and ferreting out information about treatment options and their availability (Evelyn, 2047-2066). When parents do connect with useful services, they are often only available during regular business hours and there may be a long wait for an appointment. As Bruce noted, "the mental health community can't always be there" (843-844). Parents, on the other hand, "never seem to go off duty. You're always sort of going to bat for them. And if you don't go to bat for them, nobody else will" (Evelyn, 2070-2072). Consequently, parent caregivers assume the role of patient advocate, negotiating with professional caregivers on behalf of their child.

Professional caregivers. Parents in this study referred to their child's doctor or psychiatrist more frequently than they did other professional groups. Whether this was because they perceived the doctor to be the focal person in the treatment team; whether parents had more personal contact with physicians than with other types of caregiver; or whether this tendency was restricted to this particular research sample is unclear. Nevertheless, the qualities that differentiated good relationships with physicians from poor ones were similar for other practitioners. Time and communication were the cornerstones of mutually respecting relationships with mental health professionals. Practitioners who spent time listening and talking to both patients and parents in an atmosphere of respect and equality were commended. Marianne stated that professional care in her city was exemplary:

> I have nothing but praise for the mental health workers, for the hospital, for the staff, and doctors have been cooperative with me and I've just had great support (433-437).

Unfortunately, not everyone was as complimentary. Although all parents could relate some good experiences with professionals, most had encountered problems. These are addressed under four headings: poor continuity of care, variation among professionals, professionals who exclude parents, and professionals who blame parents.

Poor continuity of care. Ruth says that Tim has had "over eleven doctors in a short space of time" (2153). When people with severe mental illness are in and out of hospital;

when they move between home and various supported housing situations; and when they start and stop various mental health sponsored programs, they tend be assigned to the psychiatrist and professional team attached to each particular treatment setting. Couple this with the movement of psychiatric staff among different programs and treatment settings and you have very poor continuity of care, along with little opportunity for patients and family members to develop trust and rapport with any individual practitioner (Irwin, 393-403).

> ...they can spring a new therapist and a new doctor on you without anybody knowing — without anybody, the patient included. And, if I'm buying shoes, I want to try and find a pair that fit me. I'm not going to buy the first pair of shoes I put my feet in, if they pinch me. I go from store to store. But we're not given that privilege (Ruth 2163-2170).

Despite the number of mental health professionals involved with their children, many parents had difficulty contacting anyone who knew their ill child, except during regular office hours. Where parents had access to an available and trusted general practitioner, the GP had not always been updated by the psychiatrist. Even within the community mental health system, there appeared to be poor communication between successive psychiatrists and programs. In some cases, when the ill child had been quite stable, new psychiatrists opted to ignore previous treatment, preferring to personally evaluate the patients. Once, a newly assigned doctor discontinued all of Melanie's medications and was abrupt and rude to Michael and Lorraine when they eventually managed to contact him. Their concerns were based on previous observations:

> Each time she has taken herself off medication, her recovery has only been maybe 90%. So, every time she has come off, she has slipped, she has regressed a bit. So that, you know, she's not nearly as good as she was when she was twenty (Lorraine, 176-180).

The confusing succession of care providers is likely even more pronounced for those ill persons who live in any level of supported housing, where there are numerous mental health workers, including care aides, dietary aides, housing helpers, recreation or activity workers, and so forth. Parents observed that these people vary in training and effectiveness and are often burdened with large caseloads, thus introducing a danger of burn-out, as well as allowing little time to address the needs of families (Joe, 104-109; Margaret, 1144-1149; Teresa, 1292-1300). Their working conditions may also explain the staff turnover in programs and treatment settings. Nevertheless, whatever the reason for personnel changes, given the likelihood of people with schizophrenia having difficulty dealing with new people or with many people concurrently, this is not an ideal situation.

Variation in practitioners. Within any professional group there are different personalities and different approaches to practice. Evelyn, a nurse herself, remarked that some nurses are nicer than others and some treat patients as though mental illness is due to the patient's lack of effort (1486-1516). In Jean's estimation, choosing a psychiatrist from the yellow pages is like picking "a pig in a poke" (1544). She described one of Maxine's psychiatrists as having "a personality like a barracuda" (1553). Parents feel that they need to shop around to find psychiatrists who can relate to the ill person and who will relate to the parents (Evelyn, 430-441). Not all psychiatrists choose to treat the severely mentally ill and few specialize in schizophrenia. When parents have finally established a satisfactory professional relationship, the ill person may argue with and fire the psychiatrist (Jean, 346) or enter the hospital. Often parents have no choice but to accept whomever they get (Margaret, 450).

Professional relationships are no different from social ones in being influenced by many complex factors. Whether parents approve of the way in which a professional treats their child or not will depend, to some extent, on personality factors and on the parent's ideas about what constitutes good psychiatric care. Thus, different parents will see eye-to-eye with different professionals. For example, Irwin's son and Margaret's son have been treated by the same psychiatrist. Irwin had complete confidence in this doctor and felt comfortable talking with him:

> He was good at handling him I thought. Not at all condescending and also prepared to have us come to sessions with Colin (Irwin, 451-454).

In contrast, Margaret thought that, although this same psychiatrist professed to have an interest in families, he was much more interested in his research:

> He figured people in research with him should all work and see a patient, but I think, "Hey you've gotta see more than the patient." Especially since it was explained to me that he doesn't have much time to see Derek because he isn't a full-time there, so he just sees Derek for 10 or 15 minutes. Not good enough (Margaret, 903-909).

Parents know their child more intimately than professionals whose only contact occurs during office appointments. As well, parents have a long-standing personal knowledge of the course of their child's illness and after several psychotic episodes learn to recognize early symptoms of relapse.[16] When Gwen tried to warn one of Colin's therapists about a prodromal symptom, his response was insulting and rude:

> Colin was off medication and he was becoming more and more ill. We could tell. And one of the first symptoms is this obsessive reading of the Bible and we'd come to recognize this as one of the early symptoms. I had phoned his counselor who actually had an MA in psychology, and I said to him, "You know, Colin was definitely becoming ill again, heading for a breakdown. I don't know if you realize this because he is very clever at concealing it." And he said "Oh well, what makes you think he is?" And I said "Well, one of the things is that he is reading the Bible constantly and this has always been one of the early symptoms." So he said in a very sarcastic voice, "Oh, I see. Because your son is reading the Bible, you think he should be on medication?" (Gwen2, 1643-1641).

Other parents had similar experiences (see, for example, Lorraine, 757-777).

Differences among practitioners in philosophical orientation toward treatment was a problem for parents when they encountered disagreements, such as the Freudian

---

[16] Fuller Torrey states, "Each person with schizophrenia has their own particular symptom pattern when relapsing, and that pattern tends to be similar from relapse to relapse" (1995, p. 290).

psychotherapy versus biological psychiatry debate, both within and between professional groups. Within psychiatry they met those who primarily administer medications (Irwin, 393-398), those who reject medication and rely on long-term psychotherapy (Philip, 817-828), and those who use a combination. As well, parents heard about a variety of less well-accepted treatments, for example, vitamin therapy. When parents received conflicting opinions about the best way to treat their child, they, not surprisingly, had difficulty knowing whom to trust. The occasional parent became quite cynical:

> I might say that I've probably dealt with 12 or 13 psychiatrists now, you know, that I've met; and that I've met some excellent people, but I've met some real scoundrels; and that unfortunately I believe that psychiatry is a refuge for incompetent people because it is so difficult to measure the results, and so it's possible for incompetent people to exist in that profession where they wouldn't exist in other branches of medicine or as engineers or something like that, because their bridges would collapse or their patients would die of whatever. Anyway, we met a few of those (Irwin, 154-166).

Outside psychiatry, parents encountered many different mental health professional groups and, once again, there could be disagreement as to the best way to treat schizophrenia. Some parents noticed the rift between many psychiatrists and many psychologists, although Michael believes this has improved in recent years:

> ...the appreciation of the division seems to be stronger among the psychologists than it does among the psychiatrists because I think, well, one's narrower, I think, in outlook than the other is. Not today. Today I think the need for a psychologist is probably a lot greater because once people with the illness get into treatment and they start to respond to the medication, if they need medication, then they really need emotional support and understanding and all the rest of it that psychologists, presumably, are trying to provide (Michael, 115-123).

Bruce pointed out the wide variance in outlook, training, and regulation of counselors and therapists, stating that "there's just unlimited freedom of so-called therapists to treat people however they want, and get paid for it" (1228-1240).

As scientific knowledge of the brain and its illnesses increases, these wide disparities in approach should begin to disappear. At this point in the development of knowledge about treatment, what works well for one patient may not work at all for the next one. One parent summed up this general problem for the mental health professions when he stated:

> ...how do you help somebody when you don't really know exactly what the best way is to treat the illness? It's strictly empirical. You try this and if it works — good, and if it doesn't work, then you try something else (Sam, 551-556).

Those parents who expect professionals to know exactly what will work for each individual patient are liable to be disappointed and frustrated, particularly when professionals fail to inform them fully about their child's treatment and about the complexity and uncertainties that characterize psychiatric care.

Professionals who exclude parents. Throughout their child's illness, parents view schizophrenia as a family problem. Yet, with very few exceptions, this study's participants had less contact with professionals, less information from professionals, and less opportunity to contribute their observations than they wanted. A minority, like Daniel's family, have had ongoing family consultation and were satisfied with their level of participation (Marianne, 594-599). More commonly, parents felt excluded by professionals:

> ...parents don't count. If the child is an adult, you know, the medical staff doesn't consult you. They are going to treat her. There is no consultation. The treatment is for her (Teresa, 864-868).

Most parents believed that, because of their intimate knowledge of their son or daughter, they deserved to be included and wanted to be part of the treatment team. Instead, many found that they were being told the minimum and, when they attempted to contribute, "I just felt I was imposing — that I was intruding" (Maggie, 386-387). Even those parents who were kept informed by professionals about their child's condition felt that no one was listening to their observations and concerns.

Although they believe their exclusion from their child's care is wrong, parents are aware of various reasons why this occurs. Of major importance are the legal barriers erected by laws written to protect the rights and privacy of individuals:

> We kept asking for records. They said under Freedom of Information we can't get the information. So here we are - we're not allowed to know. He is 23 years old. [But] He's living at home, we're paying for everything (Fred, 1216-1221).
>
> I hope one day people will understand the bind parents are in, because Anne was an adult and they have to go by this in the famous Charter of Freedom of Rights. We were not allowed to say much (Teresa, 334-338).

Fear of litigation may be another reason for professionals keeping their interactions with patients confidential (Maggie, 1509-1517). For several years Ruth has tried unsuccessfully to obtain copies of Tim's health care records from a particularly upsetting event, during which he was certified and she was shown considerable disrespect by professional caregivers (Ruth, 1135-1143).

Two parents were initially not informed when their child was mistakenly given a medication overdose by professional caregivers. For example, prior to hospital discharge, Margaret's son's medication was changed. He was given a long acting injectable antipsychotic but was not advised to stop taking the oral one. Eventually, he became suicidal and remained so for two weeks until his blood levels of medication subsided. Margaret says that the doctor "had to be pushed into admitting that he had overdosed my son" (Margaret, 455-464). In the second case, Melinda was given an undiluted (10 times the proper dose) injectable medication by the home care nurse and had be admitted to hospital for observation. Only through considerable detective work was Jenny able to discover the amount of medication Melinda received and that there was a danger of irreversible toxic damage to vital organs (Jenny, 861-950).

In addition to legal disincentives for informing parents, professional groups have their own ethical canons regarding patient confidentiality (see, for example, Donna, 1049-1050). Some professionals will make exceptions for parents, but generally only if the ill child consents to family involvement. As many parents recognized, the therapeutic relationship between professional caregivers and their patients is primary and anything that professionals suspect could compromise the patient's trust will be avoided.

Some parents were not just excluded by professionals, they were told that their continued close involvement with their child was inadvisable and could be slowing their recovery. When parents assume responsibility for protecting their child, it is heartbreaking to stand aside and watch, while a mentally ill loved one is forced to learn the consequences of his or her behaviour. Evelyn was afraid that Barry would not look after himself if he moved away from home:

> I used to get the little pill bottles and put them out, into the little counters, you know, and I fussed around making sure he went to the doctor and the dentist. They said "no, he has to learn to take responsibility and also he is perfectly capable of vacuuming." I said "Is he?" (540-546).

Maggie and Warren were told that if they kept bailing Maureen out, she would never accept her need for treatment:

> ...the only way is to not help at all, not even with love or money or time, so that the patient, somewhere along the way will work out in the malfunctioning brain that there is something wrong with them, because otherwise they wouldn't be out here without a job, without friends, without a family. That somewhere along the way maybe what other people have been saying is right. And that takes years of agony, pain, humiliation without a roof over their heads. Surely there's a more human way than that (Maggie, 960-969).

In summary, parents continued to assume some responsibility for their child's condition, especially when the ill child lived at home or independently without mental health supervision. Consequently, they believed in their entitlement to enough information exchange with their child's professional caregivers to fulfill that responsibility properly. The following is an excerpt that Margaret read to me from a letter she wrote to Derek's psychiatrist:

> I would like to be able to consult with you regarding Derek's treatment and the course of his illness. I do not wish to know about Derek's private conversations with you or with the social worker. I do however, want to know the amount of medication, the type of medication, and your observations of his behaviour and your concerns. I want to be able to share with you my observations of his behaviour and to have you answer my questions regarding his medication and the possible long-term outcomes (Margaret, 1009-1019).

As other parents in the study would agree, these requests are not unreasonable.

Professionals who blame parents. Although psychodynamic theories that blamed parents, especially mothers, for their child's schizophrenia are largely discredited today, some parents experienced remnants of this negative attitude from professional caregivers. Those whose child had been ill for many years noted, however, that this tendency has lessened in recent years. Although prior to their child's diagnosis, several of these parents were blamed for causing their child's aberrant behaviour, once the diagnosis of schizophrenia was made, such accusations usually subsided.

Probably partially because of the contemporary political climate, several parents in this study were accused of abuse and were given little opportunity to defend themselves. As previously mentioned, both Anne and Maureen made allegations of sexual abuse. Clifford's elder daughter (not Julie) accused her father of sexual impropriety when she sought psychiatric help for depression and "suddenly, I was garbage, absolute garbage and I couldn't understand it" (Clifford, 1269-1271). As well, although Melinda later denied having said that her parents beat the children, a doctor informed Jenny of it long afterward:

> Melinda was telling him things that we were hurting her and we weren't. We never abused our kids. We spanked them, yes, but not the little one. I don't think she ever

> got more than three spankings in her life, but this is what was being told and so we changed doctors because he wouldn't tell me anything and he treated me like I was doing something wrong, even though I wasn't. I couldn't figure it out (Jenny, 187-194).

Parents told me that if accusations made while the child is psychotic appear on the patient's chart, other professional caregivers may accept their veracity without verification:

> ...we were not allowed to say much and we found that it was very unfair the way they felt toward my husband, because some nurses already formed their own opinion about the sexual abuse and treated him as a sexual abuser (Teresa, 338-343).

Professionals must also recognize that parents of a psychotic child are under considerable stress and require thorough explanations about schizophrenic illness and treatment. Unless a mutually respectful relationship is cultivated between parents and therapists, misunderstandings are liable to occur. When they react angrily or criticize a child's treatment, however, parents are liable to be branded by therapists as interfering or uncooperative:

> I was getting criticism from the team, you can believe that! And the rollover of doctors was unreal, I mean, the therapists. And of course all they do is pick up the file and read it and I'm stereotyped. You're burned (Ruth, 2269-2273).

Thus, in their role of advocating for their ill child, parents often felt disenfranchised by a complex and poorly articulated system and by professionals who ignored them or were antagonistic. Although their primary caregiving focus was watching over their child's illness, parents were also very aware of the family and social context surrounding their child's illness.

Relationships within the Family

Because a family member's illness affects everyone in a family, caregiving included watching over relationships among family members. Maintaining a relationship between the caregiver and the ill person was of primary interest but all family relationships both impacted upon and were impacted by a family member's mental illness. Thus, the relationships among spouses, siblings, and extended family members required attention.

Parents' Relationship with the Ill Child. The quality of interaction between the parent-caregivers and their ill child was almost like a barometer, measuring how ill the child was. When well controlled by medication and/or psychotherapy, everyone seemed to get along better but relationships suffered when the person with schizophrenia denied being ill and refused to cooperate with treatment. In addition, because family relationships hinge on emotional affection, when schizophrenia dulled the child's ability to feel pleasure and express positive emotions, parents tried not to feel unappreciated. As an example, Jean said that for years Maxine appeared to "take all, give none" (1637) and "I don't ever remember her thanking us" (1634). Other parents said that their child was often manipulative (Jenny, 1031-1072) and resentful if the manipulation failed (Philip & Donna, 324-328, 1773-1782).

Parents noted that their child's personality changed with the illness. With exacerbations, the child's positive characteristics disappeared, but when the child became better, parents would sometimes see glimpses of the child's personality again. The volatility of these ups and downs was difficult for parents. Nevertheless, half of the parents described their child as basically gentle, sensitive, or kind-hearted. At the same time, angry outbursts were frequent.

Parents learned ways to prevent these angry outbursts. Keeping the peace at all costs was what, for many parents, characterized their relationship with their ill child. Parents would, above all, avoid arguing, confronting, and interfering. Especially when the ill child was responding to hallucinations and delusions, trying to reason with them was perceived to be useless. Many parents noted that their ill children can not help but react to the way in which they see the world. Jean described her husband and herself as "pacifists" (773):

> We have to sort our words out so carefully or we're afraid she's going to be off on another tangent (Jean and Tom, 931-934). I mean, she'd say these mean things, terrible things that she'd say which had no truth, whatsoever, to them, but she just said them. And, you learned just to ignore it. You learned the gentle art of sitting on the fence. You didn't say, "No, that's not so," and you didn't agree because no matter what you did, you were in trouble (Jean, 189-195).

Parents said that you have to learn to accept what you can't change (Michael, 518-519), ignore irritations and not criticize (Gwen, 709-728, 881-889), and try not to impose your own standards (Marianne, 1210-1218, 1333-1361). Other advice was to always remain calm, never raise your voice, and dodge questions (Bruce, 753-761) because arguing only increases the tension. As Gwen perceptively remarked, "We can't change him and so what we have to do is change ourselves (475-477).

A major aspect that parents changed was their communication with the ill child. Several parents observed that some subjects were off limits. Many ill children refused to discuss their illness, especially the most painful times, or their innermost thoughts and feelings. Parents thought that they might be able to help their ill children if only they could talk about what was bothering them. When an ill child hardly converses with them at all, parents cannot know what he or she is thinking and find it difficult to know how to respond. Knowing how to respond is also a challenge when the child's speech is illogical, incoherent, and repetitive.

When the lines of communication with their ill child were interrupted, some parents were able to find a go-between who was trusted by the child and would report back to the parent. This might be a friend of the ill-person (Lorraine, 414-428), another family member (Maggie, 719-727)), or often a professional caregiver, such as the manager of the child's group home (Sam, 164-190). Donna called the people at Triage[17] "our life-line and his life-line really" (Philip & Donna, 472). Nonetheless, many parents were afraid that the ill child might discover their deceit.

Dishonesty also may characterize the conversation in families where the child denies being ill. Several parents were forced to hide their membership in the B.C. Schizophrenia Society. An example is Jean:

> You try not to be behind her back, but, sometimes you've really got to. Like, she doesn't know, since '84 I've been involved with our Society and I go to a monthly meeting and I also belong, I did belong to MADD[18]. She always thought I was going out to a MADD meeting, you know. So, if she knew that I was involved in that [BCSS] she would be quite annoyed (776-782).

Maggie wished for professional help to advise families of more honest ways to converse under these circumstances:

> ...and she said "Would you do me a favor?" in this very nice voice, "I would really appreciate if you would explain to me Mommy, why nobody wants to live with me". And we're two feet apart and she's pleading with me. "Could you please tell me?" she says. What can I say? Because you're crazy? Because you're schizophrenic? Do I say that? Is shock tactics [the right thing to do]? I don't know. There is nobody to advise me. So we carry on with this dishonesty (Maggie, 1773-1781).

Receiving only monosyllabic answers or no answer at all to their attempts to communicate, parents became frustrated and felt unable to establish any connection with their ill child:

> ...you see I lost my cool last night, not seriously, but I said "Colin, you know I'm not being inquisitive. Can you not understand that when you live in the same house with other people, you've got to have some sort of social interaction. You must. And all I'm trying to do is have a little social interaction with you. I am not trying to be inquisitive. Can you not understand that?" No answer (Gwen, 821-829).

---

[17] Triage is a not-for-profit shelter. Roger lived in a single room occupancy hotel at the time, but he could walk to Triage every day for meals, medications, and some socialization with other consumers. At Triage, there are also rooms where, when in a crisis situation, consumers are able to stay for a few days.

[18] Mothers Against Drunk Driving

At the same time as many parents were struggling to discover ways to communicate with their ill children, they saw communication as vital to establishing and maintaining a good relationship. Catherine noted the importance of keeping the lines of communication open with the ill child. Then, if ever the ill person was threatened or abused, she or he would have someone to go to (1478-1484). When conversation was sparse, some parents discovered other ways of establishing a relationship, for example, activities that they could share, like tennis or golf (Sue, 740-745, 755-759,) or working in the garden (Margaret, 686-688).

Sometimes, in spite of everything they do to maintain a relationship with their ill child, rejection is what parents experience. Parents feel rejected when the ill child excludes them from talking with professional caregivers but it is even harder to accept complete rejection by the child. Jean was particularly hurt when, for years, Maxine refused to accept that she was her mother (Jean, 194-199, 484-486). Sometimes, as already discussed, rejection accompanies the delusion that a parent has done something reprehensible to the child, for example, sexual abuse. At other times, the parent has acted in the child's best interests but against the child's wishes, as when Philip was forced to press charges as the only way of getting Roger into the hospital. Once in hospital, Roger prevented his father from visiting and, occasionally, threw his mother out as well (Philip & Donna, 765-808). Donna said, "You can't take it personally but you do" (808).

Attempting to set limits on the child's behaviour can cause strain between persons suffering with schizophrenia and their parents. The dilemma for parents is having to choose between (1) accepting the child's behaviour and thereby providing no incentive for change and (2) requiring a behaviour modification that the child finds impossible to meet. Two examples from this data are particularly poignant. Maggie and Warren issued Maureen an ultimatum that she could not see them until she accepted treatment for schizophrenia. Although this decision was a last resort, chosen for the sake of Maggie's health, the guilt of abandoning her daughter seems to have added to Maggie's stress (277-289, 400-410). Warren also finds it stressful when Maggie insists on using the answering machine to screen all phone calls (559-577). Similarly, Irwin had Colin sign an agreement during his last hospitalization that he could live at home only under several conditions, one of which was taking medications. Colin has breached every condition of the agreement but Gwen hasn't the heart to turf him into the streets and Irwin worries that Colin now regards agreements as unimportant (Irwin, 595-677). These two stories highlight the challenges parents face in setting limits for their ill child while, at the same time, maintaining their relationship with one another.

Parents' Relationship with Each Other. The pressures of having a child with schizophrenia can drive a wedge between marriage partners (Bruce, 1502-1511). Several participants reported knowing families that had broken apart, noting that the mother usually has the ill person to care for after the father leaves. Among this study's participants, five were divorced (from four families). These couples divorced prior to their child's diagnosis and appear to have developed ways of sharing the care and decisions regarding their ill family member. Although Fred and Elaine separated around the time Trevor was becoming ill, the separation was due to Fred's personal and working difficulties and they were working towards a reconciliation when Elaine died. Although Elaine had the day-to-day responsibility for Trevor, they maintained close contact by phone, shared a Caribbean holiday, and Fred visited home regularly.

The majority of participants in this study were married. Twelve couples have managed to keep intact marriages throughout their child's illness. One of the divorced mothers has remarried and one of the widowed mothers has established a long-standing partnership. Two major strategies seem to have contributed to their stability: either the decision was made for the child not to live at home or, alternatively, the couple focused on the child's illness to the exclusion of almost anything else. In other words, their own relationship was largely put on hold while they shared their ill child's care. Several husbands noted that their child's illness has been more difficult for their wives and attributed this to the strength of the mother-child bond, although Evelyn noted that a son's illness is probably harder for a father to accept. Certainly, Ryan's father has had more difficulty than his mother in accepting Ryan's death. Several people drew attention to their spouse's strengths and emphasized the importance of discussion for working out their differences. As an example, Kulwinder called his wife a good planner while he is the main executor (1709):

> We do agree with each other. I mean, I do listen to her and she does come up with lots of good points and we make the decision and then we go....I think we supported each other, me and my wife. Me and my wife are two different personalities. We do argue a lot. We did argue a lot over life, but on this we were together (Kulwinder, 798-801, 1700-1703).

Time together often had to be sacrificed, particularly holidays, although some couples arranged for other family members to care for their ill child on occasion. Because they have had to work hard together to help their ill child, some said that their marriage has become stronger. "It either makes you or breaks you" (Jean, 1885). Michael's suggestion was that these marriages were strong in spite of the child's illness:

> ...our marriage survived it and is stronger but I, I think it's as much that we have a pretty strong marriage and it survived it, as anything. That [it] passed a certain test. I think statistically, schizophrenia is pretty hard on a marriage and there are a lot of casualties, so I guess, if you can survive schizophrenia and hanging wallpaper with your wife, you'll [he laughed] probably make it to the end (Michael, 1108-1114).

Another thing that several people mentioned was the struggle to maintain a balance between the needs of the person suffering from schizophrenia and the needs of other family members.

Relationships with Siblings. Having a brother or sister with schizophrenia means growing up in a certain amount of emotional turmoil and parents were concerned about the effect on their other children. Many siblings lived, and continue to live, in fear of developing schizophrenia themselves or of passing it on to their children. Often their strategy for dealing with the ill child was avoidance. First as teens and then as adults, older siblings became busy with their own lives and careers and several siblings in these families left home as soon as possible. In some cases, when a sibling reached university age, even when families lived close to the university, parents paid for an apartment or some other living arrangement so that the sibling would be able to concentrate and study. These broken relationships sometimes mended in later adulthood, but not in all families.

When siblings are close in age and their social and school paths cross, they may be embarrassed by their disruptive brother or sister. For example:

> ...she would say very inappropriate sexual things to [older daughter]'s friends, and [older daughter] has always had male friends that are not boyfriends. She would just say horrible things to them. Horrible. So, it was very difficult (Lorraine, 1191-1196).
>
> And my very sensitive middle son still cannot get over the fact that when he was in his teens, he saw his brother on the street begging. And he was with a friend and he passed by and pretended he didn't know him. And that's how far you come down. I mean your standards not only of your expectations about the conduct of the sick person, but your standards about what you expect from yourself, go down, down, down until you would not - a lot of people only admit to themselves a lot of their feelings (Maggie, 1052-1061).

Then, in adulthood, ill children often resent the successes of their well siblings.

In families with more than two children, the sibling who had the closest relationship to the ill child before schizophrenia struck was often the most negatively affected. This seems evident for Trevor and his younger brother, Scott. Similarly, in the family with five children, two of whom have schizophrenia, Sandra, the eldest girl, was closest to Geoffrey while growing up and Maureen was inseparable from her middle brother. Sandra became so distressed when visiting Geoffrey in Riverview that she stopped visiting him at her husband's request. Sandra is the one sibling who keeps in contact with Maureen, however. On the other hand, the middle son has stopped seeing Maureen since she became ill but he visits Geoffrey in Riverview.

Some parents said that the worst damage to sibling relationships happened during the disruptive period before the ill child was diagnosed and before there was an explanation for their bizarre and angry behaviour. Some children reacted by becoming very supportive to their parents and suppressed their own angry emotions for fear of upsetting their parents further. As well, parents can become so embroiled in dealing with the ill child that the others may lack attention. As an example, both Lorraine and Michael wondered if they might have helped their other children by discussing Melanie's illness more thoroughly and obtaining counseling for them (Lorraine, 1155-1158; Michael, 207-210). Jenny mentioned that her family seldom goes camping anymore because Melinda doesn't like it. When her husband does take the rest of the family, Jenny stays home to care for Melinda (2120-2137). Several families eventually made the painful decision for the ill child to move out, so that the other children would have a less stressful home life. Nonetheless, it is also important to recognize that some siblings maintained fairly close and protective relationships with their ill family member.

Extended Family Relationships. The majority of these parents reported receiving support from their extended family or from certain members of their extended family. Some had better relations with one side of the family than the other but this difference appeared to have been established prior to the child's schizophrenia. That is, those who had established good relations before the illness continued their support following the diagnosis and were not likely to reduce it afterward. Support varied in type from acceptance of the ill child at family gatherings and listening when the parent needed to talk, to providing occasional respite care. Only a small minority remembered incidents indicating stigma against mental illness. For example, Evelyn's sister in England warned Evelyn to keep Barry's schizophrenia a secret from the rest of the family (Evelyn2, 1279-1306). Marianne's sister barred Daniel from family outings on their boat, fearing violent behaviour. Yet, Daniel had never been violent towards people (815-825). Marianne credits a second sister, however, with helping her to accept her son's limitations (1197-1211).

Twelve of the nineteen families identified other instances of mental illness in their extended family. Often no definitive diagnosis was known because, as both Jenny and Jean observed, a generation ago such misfortunes were not discussed openly. In five families there were confirmed cases of schizophrenia but this did not seem to affect whether the extended families were supportive or not.

As well as possibly providing support, some extended families required support. Parent caregivers of young adults are also at risk of having elderly parents needing care. This was true for Evelyn, whose mother-in-law lived with them and died from cancer after Barry was diagnosed (1069-1080). Similarly, Donna moved her ninety year old mother to their home after Roger kept harassing his grandmother for money. Later, when she needed more care than Donna could provide, she went into a nursing home (Philip & Donna, 287-324, 1921-1941). Under such circumstances the strain of caring for someone with schizophrenia is likely to be increased by other caregiving responsibilities. Overall, although the degree of support received from extended family members depends on many variables that may not be related to the child's illness, most of these families received some help and comfort from their extended family. Another source of help for some parents were their friends.

Relationships with Friends

When your child develops schizophrenia, "you find out who your friends are" (Jean, 1396). About half of these parents said that they could not have survived without supportive friends and that speaking openly to friends about the illness is important for maintaining friendships. Evelyn drew comfort after Barry's suicide attempt from her long-standing girlfriends because they "knew that I wasn't a bad mother" (373-374). Commonly, however, parents reported losing some or even many friends after their child became ill. Various reasons were offered. For example, when parents are forced into making difficult decisions about their ill child's welfare, they expect support from their good friends. When this is denied, the friendship is likely to suffer:

> ...to me that was one of our times of greatest need and you just don't refuse. Right? Right. You just don't refuse a friend. It was hard enough for us to have to make the decisions that we had to do without people refusing or challenging what we are doing (Catherine, 689-693).

The stigma against mental illness and the inability of some people to speak openly about it creates a distance between friends. Frequently, friends avoided these parents and parents (especially at the beginning) avoided their friends, rather than admit to their child's mental illness. The need to explain schizophrenia time and again to people who don't understand can be demoralizing and parents may lose patience. In the end, several people said that they have little social life now but, for many parents, losing their own friends was less painful than watching their children lose theirs.

Almost none of these ill children retained even one friend from before their illness. Then, those who continue to deny that they are ill and those who remain severely withdrawn have difficulty making any new friends. Those who refuse to recognize their illness tend to reject other consumers who might accept them, by refusing to attend programs and clubhouses set up by the mental health system.

> Schizophrenics can't stand each other generally speaking. They don't understand why they have to hang around with such a lot of crazy people. You know what I mean? (Joe, 653-656).

The exceptions tend to be people that their parents find suspect. For example, Bruce describes Anne's friends as "new age people" (54), connected with the Sexual Assault Center. Gwen says that Colin's born-again Christian friends are "a bit lost" (390). In contrast, Trevor still had several of his old friends before he entered the forensic facility but his illness had not been apparent for very long by then. Those ill people who remain socially withdrawn have few, if any, opportunities to meet anyone.

Many of the ill young adults with insight into their illness made friends among mental health consumers they met while in the hospital, in psycho-social rehabilitation programs, or in a group housing arrangement. These were primarily same sex friendships and, at least as far as their parents were aware, few have been romantically or sexually involved and none have married. Interestingly, one father believes that the medications have made his son impotent but another told me that people with schizophrenia have a heightened sex drive. Several parents were worried about their ill child's romantic relationships (and especially about birth control) and were relieved when these relationships ended. One young woman, Melanie, became pregnant when living in a group home but had an abortion before her parents were even aware of the pregnancy. In addition, two mothers mentioned the possibility that their sons had experienced homosexual advances from room-mates.

Because this data came from parents and not from the persons suffering from schizophrenia, it may inaccurately portray the ill child's social experience but it does reflect their parents' understanding and concerns. Parents whose ill children live outside the family home may not have an opportunity to meet any of their child's friends. In fact, Donna and Philip met many of Roger's friends for the first time at his funeral.

Along with watching for evidence of the status of their child's illness and watching over their psychiatric treatment and social relationships, parents recognized the potential for harm to their ill child and to others.

Watching Out

As long as the ill child denies being ill and as long as the child's behaviour is not stabilized by antipsychotic medications and other treatments, fear is a relatively enduring emotion for many parents. Before diagnosis, the child's bizarre behaviour raises the fear of mental illness. Once that is confirmed, a parent's fears and worries coalesce into three broad spheres: fear of schizophrenia, fear for the ill-child's safety, and fear of the child's violent behaviour.

Fear of Schizophrenia

Schizophrenia, itself, is a frightening word. When a psychiatrist applies that word to your loved one, schizophrenia is terrifying. In part, the fear stems from what parents know about schizophrenia; in part, it comes from what they do not know. When I asked one father how much he knew about the illness in the beginning, his reply was:

> "Nothing. Nothing. No, nothing. I didn't have any idea what it was even. When I was a kid, they called them crazy. You know, and went to North Battleford"[19] (Arthur, 637-639).

Most parents' knowledge of schizophrenia was limited to what they had gleaned from the media, which usually portrays the worst scenario involving violence, severe psychosis, or people who have escaped from long term institutions. When their child was diagnosed, few parents were well informed. Even Evelyn, a nurse, who trained thirty years ago said:

> ...even though I did some psychiatric nursing, I don't believe I ever really looked after anybody like this. They were away in mental hospitals and totally away (Evelyn, 411-415).

While hoping for a cure, parents feared that their child would never recover. With a poor education, no job, poor financial prospects, the possibility of living in a long-term institution, and "no light at the end of the tunnel" (Bruce, 583), the child's future now appeared very bleak.

One fact about schizophrenia of which many parents were very aware was that having lost one child to this dreaded illness increased their risk of losing other children or grandchildren in the same way. Gerald said:

> ...it scares the living shit out of me to think that, you know, if it doesn't come on until he's 21 or 22, that's how old Nick is. That really scares me (1097-1100).

In addition, parents became afraid of their own ignorance about schizophrenia and, consequently, of their inability to cope. Were they likely to say something that would provoke violence or increase the symptoms? As Sam said, "I'm just trying to do what's best for him, but I don't know what's best" (125-126). Suddenly, parents no longer knew how to behave towards their own child.

---

[19] The provincial mental hospital in Saskatchewan is in North Battleford.

> Do we get tough? Do we say you've got to get out there and look for a job? Sell yourself. He couldn't sell himself. And he was just, he was, he was completely incapable (Gwen, 123-126).

Schizophrenia is an unpredictable illness and parents found it very difficult to cope with the uncertainty. How would their child be next week, tomorrow, an hour from now, or a minute from now?

> I've realized that it's not so much the things that happen, though a lot of really painful disturbing instances have happened, but they are quite short, the instances in themselves. It's the fear in between. It's the remembering and the anticipation and the wondering if you can cope with it. It's like waiting for the other shoe to fall all the time. If you could just get that under control, you would be stronger to deal with the instance and you would recover from them more quickly because you wouldn't be anticipating the next one (Maggie, 1672-1682).

As their knowledge of schizophrenia improved and experience with it increased, new fears surfaced. Parents worried about medication side effects when their child was taking medication and about permanent deterioration when the child was not:

> I know there is evidence that each episode will tend to do some damage. I have a gut feel that the sooner you catch these things and forestall a complete breakdown, the, the less damage it's going to do to his brain. So, from a clinical standpoint, you know, he should be treated just as soon as possible. If we do nothing and wait, he's going to get worse and perhaps worse in the long term, too (Irwin, 800-807).

Even when their child complied with treatment and improved, parents were afraid to hope that this would continue:

> ...it's the unknown. I have just no idea whether Maureen will stay on medication. Either I start to see her as going well [or] is this going to end up with my pleading with her to leave, like I did before and she wouldn't leave. Can I believe what she is saying? Can I trust that she isn't reporting everything we say to some therapist who has been turning her upside down? It's a lack of trust in her physical health and in her emotional health (Maggie, 1645-1653).

A second source of fear was not directly related to schizophrenia but more to the lifestyle of people with schizophrenia.

Fear for Their Ill Child's Safety

When parents knew that their child was ill but not where he or she was, they were frantic with worry. However, because the child was ill, they feared for the child's safety wherever the ill person was, even if the child lived at home. Parents worried about accidents, the children's inability to care for themselves, and victimization by others. Their ultimate fear was suicide.

Accidents. Distraction, distress, and distorted perceptions make psychotic persons vulnerable to accidents. When not psychotic, persons with schizophrenia often still struggle against agitation, inability to concentrate, and other medication side effects that may make them forgetful and reduce their reactions to stimuli. Consequently, Bruce worries about Anne running into traffic (687); Evelyn worries about Barry being on medications and riding his motorcycle (777-778); and Jenny worries about Melinda driving:

> That's her little car out there. At this time she will not drive it. She'll just say, "I'm not safe to drive today." And, that's good, as long as she keeps telling me. My scary thing is that one day she's not going to tell me (Jenny, 1889-1893).

Fire and burns are a big concern for many parents. Some parents worry about their family member cooking while unsupervised. For example, Ryan's suite in his parent's basement had no kitchen, so that he would have to come upstairs (Sue, 787-791). Careless smoking is another dangerous habit, doubly so in an untidy apartment (Arthur, 897-902). Smoking was always a big worry for Jean who was unable to sleep at night when Maxine was awake:

> I was so afraid of fire. We had smoke alarms here and there. We had them all over the place but just as an added precaution because, you know, she was quite careless when she'd been taking her medication with cigarettes and smoking, sitting up in bed smoking and that (1898-1903).

Accidents can occur if the ill child suffers a seizure. This, in conjunction with negligence by the group home staff, was the cause of Roger's severe burns. After he was eventually discovered in the shower, he spent six weeks in intensive care followed by lengthy rehabilitation and extensive skin grafting (Philip & Donna, 43-48, 609-645, 2083-2089).

Inadequate Self Care. Even when they are able to be relatively independent, people suffering from schizophrenia live an unhealthy lifestyle. Their parents worry about the long term consequences of negative symptoms such as poor hygiene, lack of exercise and excess weight. At least two of these children have already lost a number of their teeth. Many neglect their diet, eating either too much, too little, or the wrong kinds of food. As well, they may smoke constantly, drink excessive amounts of coffee and Coke, and use alcohol or street drugs. In our health conscious culture, parents know that these habits can lead potentially to a less fulfilling and shorter life.

More immediate are the problems inherent in running away from home when psychotic. When their children take off for unknown places without money or a job, and with inadequate clothing, parents feel helpless and fear for the worst, as the following quotations from Bruce illustrate:

> ...when she was on the streets of big cities back east and every day we thought she was going to be dead. Yeah. You know, I have no hesitation in answering, that is the worst for me. I don't know what Teresa would think; I suspect it's the same for her. Yeah, that's just a horrible feeling. You know, it's time to go to sleep so you can get up for work tomorrow, and there she is wandering around with no shoes in Toronto — winter. Yeah. That's the worst (1411-1421).

> ... when you don't know where they are, there is nothing worse than that, nothing worse than hearing your child on the streets of Toronto with a bad cough, saying "Well this nice man is going to take me to meet the star people." You know? And then you don't hear from her for two days. We had written her off for dead so many times (475-482).

This last quote introduces the next concern of parents regarding safety: victimization.

Victimization.[20] Parents worry because people who suffer from schizophrenia are vulnerable. On the street and in many of their housing situations, there are "so many predators" (Philip, 941). During these interviews, parents described incidents in which other people had taken advantage of eleven of their loved ones. Of these eleven, three had also been brutally victimized.

Taken advantage of. People with schizophrenia are particularly vulnerable when they are living on the streets, because they frequent the kinds of places where desperate and often dishonest people live. Parents told me of their children having money, belongings, and bus passes stolen. After returning home once, Maxine confided in a friend who later told this story to Jean:

> ...she was sitting there waiting for the bus to leave and, 'cause that's as far as she could go and this guy came up to her and said that's a nice sweater you've got. She had a Cowichan, you know, one of those Cowichan-type sweaters that a friend of ours had knit for her and she treasured it. That's right, she had her sweater on. And, he said, "I'm so cold, can I put it on for a minute?" And, so I don't know what kind of a guy this was. He sounded like a real creep. But, anyway. She said okay, she took it off and he sat there and said, "I have got to go to the washroom." So, she never saw him again (598-609).

Even ordinarily safe places are not safe, however, when people appear vulnerable. For example, Kal was the victim of extortion by children in his junior high school (Kulwinder, 67).

Sexually transmitted diseases are another danger that parents worry about, usually but not exclusively, for their daughters:

> ...she has certainly been taken advantage of by predatory men, who.. just awful people. She thinks they're the greatest people on the face of the earth, you know. Just absolute slime-balls. You know, they take her money and have their way with her.... Yeah, that really hurts. It really does. You wonder, I mean AIDS for one

---

[20] The victimization of mentally ill people in the community is well-recognized (see, for example, French, 1987; Lehman & Linn, 1984).

> thing, you know? I mean these people aren't the most careful, cleanly people in the world. It's really horrible to think of her having sex with someone — some moron out of the beer parlor, you know? [long pause] I guess these people can smell people like Anne a mile away, when they've got some Welfare money, or they're vulnerable women (Bruce, 947-953, 961-970).

Unfortunately, people who are relatively well and living either semi-independently or independently are also easy prey. Thieves know when and where they pick up their cheques from social services. Melanie has had her CD collection stolen and Daniel's apartment has been burglarized several times:

> ...he'd end up in the hospital and they'd break into the place or, most of it stolen, I think. He had a couple of thousand dollars worth of music, equipment and stuff. Guitars, he's went through many. He plays the guitar, so we always try to keep him in a guitar. They get stolen (Arthur, 260-265).

Like Ken, who "so desperately wants to have friends" (Willow, 708), they are likely to lend articles, including money, that are never returned and trust "friends" who are dishonest. For example, Sean has had friends run up enormous long distance charges on his telephone (Lois, 739-744,775-781). If they are withdrawn and agoraphobic when living in an apartment, they are definitely at the mercy of others. For example, Ken pays friends to buy food for him (Willow, 657-659). Melanie lent her bank card to a friend so that he could withdraw money for her. He stole an extra two hundred dollars (Lorraine, 649-656).

As usual, parents do what they can to fix these situations. They replace stolen articles. They learn that Call-me telephone cards are safer than Calling Cards. They dole out money more frequently but in small amounts or they arrange for social services to either pay more frequently or directly into the ill person's bank account. These are a few things that parents do to prevent future incidents of stolen property. Sadly, parents have less opportunity to prevent or fix incidents of brutal victimization.

Brutal victimization. Anne, Roger, and Sean have all been beaten up on the streets of major cities (Bruce, 944-946, Donna, 948-952, Lois, 157-171), but their parents are not the only ones who live in fear of this happening. Jean worried every time that Maxine went out walking in the middle of the night:

> ...she might take off at 2 o'clock in the morning to go for a walk or go out to mail a letter and, you know, [area of city] is not that dangerous, but, still, women, walking by themselves at that time of the morning, and I knew if I followed she would, you know? I'd just be on pins and needles till she got home (Jean, 314-319).

Again, the places where the mentally ill can afford to live are not luxurious and parents worry about their loved ones' neighbors. Jean was horrified when Maxine suggested moving into one apartment building. "That God awful place! That the police are always talking about and somebody's getting murdered?" (720-722). Melanie, however, lives there quite happily and when given the opportunity to move to a newly built complex "for low income, seniors and families, and handicapped" people (Lorraine, 493-494), she declined:

> She desperately wants to be a part of the sane half of the world, even though, every time she goes out there, it boots her. It won't have anything to do [with her], it puts her down. That's why she likes [name of apartment building]. People in there aren't a threat. There may be more than the average number of drug pushers and, and people that have been put down in life but she understands that, and they are, they're kindred spirits (Michael, 532-539).

More horrifying for many parents than the damage others may inflict upon their child is the fear (and for some, the reality) of self-inflicted injury and death. Suicide fits into one type of violent behaviour perpetrated by some people who have schizophrenia.

Fear of Violent Behaviour

The ordinary person's primary source of information about schizophrenia is the violent stories in the media. In these families, however, violence was relatively infrequent and seldom reached the severity found in the popular press. What several parents did say about violence is that their child's moods changed very quickly and sometimes when it was least expected. After long experience, some parents are able to recognize danger signs. Both Gurpreet and Teresa become concerned when their child becomes extremely quiet.

"You read those eyes," Teresa said. Two explanations for violent behaviour were given: that their children were responding to commanding voices or were attempting to protect themselves from paranoid delusions. The described acts cluster into a classic four cell typology by the intersection of two variables: whether the violent act is directed against property or a person and whether the harm is done to the ill person or to someone else (see fig. 5). Mentally ill people appear to have a right to damage themselves or their own property but when the object of their violence belongs to someone else legal sanctions may apply. Only two of the twenty mentally ill people in this study were ever charged with a criminally violent act.

		Object of Violent Act Belongs To:	
		Others	Self
Object of Violent Act	Property	Illegal Property Damage	Legal Property Damage
	Person	Assault or Murder	Self-injury or Suicide

Fig. 5 A Typology of Violent Behaviour

Illegal Property Damage. Breaking windows, punching holes in walls, and damaging furniture were the most frequent types of damage described by the parents of Kal, Jeremy, and Barry. These examples occurred while the young men were living in their parents' homes and, because the parents recognized these as symptoms of illness rather than willful destruction, no charges were laid. Damages were quietly repaired and articles replaced at the parents' expense. Following his move into a supervised group home Kal's temper outbursts against family members continued to occur relatively frequently during weekend visits at home. Gurpreet described short outbursts that were usually initiated by Kal's failure to get something he wanted. Generally, he settles down and apologizes as soon as he realizes that something or someone has been damaged. Often now, his parents are able to recognize behavioural warning signs.

> ...when he is getting quieter, when he is getting really serious, then you know that something is coming. Sometimes you can talk pleasantly to him and divert him, pat him sort of like you would a dog (Gurpreet, 209-213).

Trevor alone has been charged with property damage. Fred's description of the incident, less than three months before Elaine died, follows:

> [He] dresses up in army fatigues wearing a mask on his head with all the body covered in tin foil underneath the clothing so the radiation wouldn't get him. And he put on a carpenter thing I have in the house and on one side of it was strapped on a — I don't know if you know what a caulking gun is, with those, it looks like a gun, with a caulking tube in it for caulking bathtubs — he sticks that in one side like a gun. In the other side he got a knife and he had a knife and he crawled over the fence at [call letters] Television and cut the cables. Then he went to the [name of newspaper] and cut some cables and then he was arrested for a misdemeanor, put in jail (1295-1308).

Because there was no space in the only forensic psychiatric facility in British Columbia, the judge gave Elaine the option of caring for him at home with weekly visits to a forensic psychiatrist and a parole officer. Otherwise, Trevor would have to be in jail until a bed was available (estimated to be three months). Certain of his gentle nature, Elaine chose the former (Fred, 1360-1365). Later, Fred discovered that neighbors suspected Fred of slashing more than twenty car tires, wrapping a satellite dish with aluminum foil and other misdemeanors over the next few weeks. Police were involved on several occasions but, as far as Fred knows, just one neighbor approached Elaine, angrily threatening to sue.

Legal Property Damage. People are legally entitled to destroy their own property. Thus, when Maxine ripped up special articles of clothing during fits of anger, Jean was saddened but not overly alarmed (Jean and Tom, 1204-1222). Similarly, when Sean and Daniel trashed their apartments, the illness rather than the person was blamed. Parents once again assumed responsibility for repairs and replacement (Lois, 1151-1167, Marianne, 484-488, 501-503) and no legal or professional barriers stood in their way. Violence directed at objects was more common and less worrisome than violence directed at people.

Assault and Murder. Apart from Roger, whose father laid charges as a strategy for obtaining treatment, none of the other ill children has been charged with assault. Although Anne's attacks on her parents have been serious, the police were called only after the two knife attacks and only to take Anne to the hospital. Lately, Bruce thinks that Anne's attacks have become more frightening:

> She doesn't go into a rage anymore. She isn't angry anymore. But she's increasingly violent. This violence is not in anger, it's totally like an automaton. She's like a zombie. You look at her eyes — there's nothing there. She's not mad, she's not screaming "I'm going to kill you." She's just, you know the voices have told her that that's what she has to do. It's more frightening than anger, it really is, because it can just click in any time. She can be sitting here, she'll get up and just casually walk over, pick a nice knife, you know, just come to Teresa (487-501).

Tragically, Trevor's attack upon his mother using a ceremonial sword was fatal. Fred maintains that Elaine fervently believed that Trevor's love for her would prevent him from harming her. In retrospect, however, he now can see some indications that she was becoming afraid of Trevor, in the last few days before her death.

Kal's attacks have been less serious but frequent, both at home and in care facilities, where his aggression has initiated his removal from education and rehabilitation programs and led to one admission to Riverview. When immediate gratification is denied at home, he has often scratched Kulwinder's face and less often set upon other family members.

> I think he pulled his mother's hair three, four times and maybe he has hit Sarb two, three times or pulled [her] hair couple times, but they were not his targets (Kulwinder, 944-847).

The only other physical attack of which I was told[21] was a single incident by an otherwise very gentle person. Willow's experience with Ken happened in the hospital:

> ...he was so frustrated by all that was going on at him that in the middle of an interview he came and he put his hands around my neck and I think everyone went into a state of shock and the only thing I did was I just went like this [demonstrates by throwing her hands up] and I said, "Let go." And, I wasn't frightened (Willow, 503-508).

Threats of violence were more common than acts of violence. For example, Roger wrote threatening letters to the other tenants of his apartment building and threatened his grandmother several times for refusing him money. As well, Ken and Barry's parents recounted a single threatening incident each:

> One day he was in the house and he said very quietly, "Please call the police. I want to strangle you." And I did. I called the police and I stood by the door. Um, but I don't think he would have hurt me (Willow, 497-501).
>
> No, he never was [violent] but he did tell Joe. He said "Look Dad, I have to tell you the voices are telling me to kill you and I don't want to do it. It's going to be very tricky" (Evelyn, 1547-1550).

Joe and Evelyn were able to convince Barry to come with them to the hospital. Like Willow, several parents said that despite threats they were never really afraid of their child. What frightened a number of parents more, however, was evidence of violence directed at the child's self.

Self-injury and Suicide. Included in this type of violence are various types of self-inflicted harm. Examples from this study were burns, suicide, and attempted suicide.

---

[21] There were also reports of psychotic patients struggling against hospital staff administering antipsychotic injections. This would seem to be a different issue, in that the patient has been identified as psychotic and staff know that their actions may be misinterpreted as aggression by the patient.

Burns. Four of these ill people have burned themselves. When non-compliant with medications, Daniel, Barry, and Anne have burned themselves with cigarettes. Anne has even done so while in the hospital. Marianne's words convey the horror felt by parents who discover self-injury:

> ...he didn't have a T-shirt on and they were all over his body, and I thought it was chicken pox but I, something within me said, "You had chicken pox when you were a little kid," and then, as I watched and talked a little more, I realized that they were cigarette burns, and that just, just devastated me, just, that was really hard to cope with, to think that anybody, 'cause to know that one little burn from a cigarette, how bad it burns, and to think of somebody self inflicting (553-562).

Suicide. The utmost form of self-injury is suicide. Most parents were aware of the statistical association between suicide and schizophrenia and they were wary. Parents of eight of these ill persons have had personal experience — seven of their children have threatened and/or attempted suicide and Ryan died. Sue said that she can never remember Ryan threatening suicide and he was not psychotic when he died, although he had left the hospital against his physician's advice the previous day.[22] "I guess he had strength enough to commit suicide at that point" (Sue, 829-830). Ironically, she and her husband were at a meeting of parents concerned about the impending patients' rights legislation and returned home to find police and fire engines in front of their house (828-883). Ryan, who was spending the evening with his brother, had pled fatigue (which was not unusual) and asked to be driven home early.

---

[22] The risk of suicide increases at remission following a psychotic episode, when patients gain insight into their illness, its chronic course, the losses they have suffered, and the limitations placed upon their future. Thus, suicide frequently occurs shortly after discharge from the hospital. Consequently, the greatest risk occurs just when families are relaxing their guard because the ill person appears to be getting better. Other risk factors include being young, male, single, and unemployed, as well as concurrent drug or alcohol abuse (Earle, Forquer, Volo & McDonnell, 1994; Health Canada, 1994; Torrey, 1995).

> ...my rationale after his suicide was that he was just exhausted. He had had enough suffering and I could understand why he did it. I certainly could understand why he did it and I didn't feel any guilt but, boy, his brother had a horrible time with guilt after Ryan's death (Sue, 942-947).

Attempted suicide and the threat of suicide. Three sons, Barry, Fred, and Sean, have attempted suicide, as have three daughters: Maxine, Melanie and Melinda. Maxine, Melanie, and Barry have tried more than once. Except for Melinda, all six have taken an overdose. Barry, Melinda and Melanie have slashed their wrists and Maxine has tried to hang herself. Nearly all of their parents have been aware of other times when their children were suicidal. In addition, Julie has told her father that she would rather be dead than have schizophrenia (Clifford, 2502-2524) and Colin and Daniel's parents have had doctors inform them that their sons were suicidal.

Years after a child's suicide attempt, parents continue to worry. For example, Melanie functions fairly well now but each time that her symptoms return, Lorraine worries because Melanie lives on the fifteenth floor of an apartment building (365-368). Even after their children develop insight into their illness and take their medications quite faithfully, parents can not let up their guard. While all four of Barry's attempts took place before he was diagnosed (although two attempts were less serious than the others), he continues to have periods of being suicidal.

> ...when he feels so very suicidal it is good that he can always phone me up and we can talk it through. He will make a cup of tea and take a Largactil and will [She laughed a small laugh and I commented that he has pretty good insight] Tremendous. I thank God for that because if they don't, how hard it must be. That was why last week it was so frightening when he lost that insight, just for a minute (Evelyn, 733-746).

Thus, the ever present danger of suicide contributes greatly to parents' fears and worry.

When I asked one father, whose daughter was in the hospital at the time of the interview and presumably being looked after, if he ever stops worrying and feels carefree, his reply was:

> I can't, no. Sure, maybe sure for, you know, for a few hours while you're occupied with something. But it's never more than a few hours, you know. Even then, you know, the thought is popping in. I wonder what she is doing now. I wonder is she bopping the security guards again (Bruce, 1428-1433).

Constantly having to watch for changes in the signs of illness, watch over the treatment, and watch out for danger signals adds up to stress for these parents.

Caregiver Stress

The amount of parental stress waxed and waned in concert with their child's illness. These parents described their stress as including a lack of control, feelings of powerlessness, and a lack of self-esteem. Fred said:

> Elaine and I watched the powerlessness that we sensed, that grew in over the two year period. You know how sometimes you have a gut feeling you are in a losing situation? That's how I felt the entire time. Every time we'd lose something (1445-1449).

Several parents said simply that "it hurts." Many said that their stress improved if the child lived elsewhere, but only if they knew where the child was and that someone else was alleviating them of some of the responsibility. The stress from constant vigilance appeared to come from five sources: finances, impotence, fragmentation, frustration, and determination.

Finances. Having a child who suffers from schizophrenia is expensive. Before a diagnosis is made, parents may cover all their child's expenses. Although some costs drop off when a child runs away, others mount when parents bail them out with periodic handouts, pay "many thousands of dollars" (Bruce, 387) in long distance charges, and finance flights to find a child or to bring him or her home. Sometimes a ticket home also includes buying a return ticket for an escort (Jean, 402-408).

Medical insurance pays for basic care, but parents may be required to augment that for privately hired psychotherapists (Willow, 794-799), dental expenses (Evelyn, 1375) or for some medications, for example, $500 to $600 per month for Melinda to take olanzapine (Jenny, 2763). Social services may provide limited money, but not enough to cover extra expenses incurred by heavy smoking, replacing discarded and damaged clothing and furniture, cleaning up apartments after daughters or sons are evicted or paying for damage deposits each time they move (Philip & Donna, 325-328, 1825-1847; Warren, 518-531). Often the ill child's food budget is used to buy cigarettes and street drugs. Parents fill in the gaps with extra groceries, cigarettes and small luxuries, and deposits to their children's bank accounts. For a long time, however, Anne's parents paid for all of her expenses, totaling $50,000 for the four years ending in 1995, because she refused to sign the social assistance forms (Teresa, 779-817). Teresa observed that schizophrenia is not just a medical issue but a socio-economic one and that parents lacking two incomes must be suffering terribly.

Financial assistance for the mentally ill comes from several sources. When in hospital or on assistance, the mentally ill receive a "comfort allowance" to cover any discretionary spending above their subsistence. Willow called this sum of $86.00 a month "an insult" (794). Once established that the ill person is never likely to be self-supporting, people with schizophrenia may receive a permanent disability pension. Unfortunately, mentally ill people are not known for handling money well, often spending it quickly or neglecting to pay their bills:

> ...when he lived on his own, he couldn't quite figure out why if he just put the hydro bills in the drawer, eventually his power would be cut off. Because if it goes there, it's gone, you know, and he didn't make the connection that something might

> happen. And rent was the same problem. We finally dealt with that by making sure his rent was paid just so that there was a roof over his head (Donna, 261-267).

Thus, many parents assume responsibility for paying the child's rent, telephone, cable company, and power bills. They may establish joint bank accounts and occasionally make these payments from their own funds. As well, they can spend many hours helping their ill child navigate through government red tape (Evelyn, 2049-2065). For years, Arthur organized Daniel's cable and telephone payments. Later, when he moved eighty kilometers away, he made certain that the mental health worker took over. Apparently, that worker left without passing along this responsibility. Twenty months later the telephone company disconnected the phone and then contacted Arthur, looking for Daniel (122-180):

> I said, "How much's the phone bill?" "Oh, we're not really supposed to tell you." I said, "You phoned me. I didn't phone you, eh?" They're trying to find him. "Well," I said, "if you want to phone that number you got there, he'll be there." [He laughs.] "It's that simple. You can just hook it up and phone him and save all this" (Arthur, 174-180).

Therefore, these parents incurred substantial financial costs in both money and in time lost from their paid work.

Social Impotence. Impotence relates to the helplessness and powerlessness felt when "you see them getting iller and iller and you can't help them" (Catherine, 623-624). There's the helplessness parents feel before they know what is wrong, "when you don't know where they are" (Bruce, 473; Jean, 257), and when parents know they need treatment but refuse to take the drugs. Parents also know that the longer their child is ill, the worse the final outcome is going to be. Donna said that the worst thing for her was watching her son's character slowly change and not being able to reach him or help him (1821-1823). Her husband agreed, commenting that cleaning up a revolting apartment with "excrement plastered all over the walls" (1831) was not nearly as hard, because you could do something about that (1826-1851). One mother described her helplessness as being worse than being lost in a tunnel when you can see no light. You have no idea which way to go to reach the end or whether there even is one (Ruth, 1492-1496). A father said there was not:

> ...the worst thing about it is that you can not see a solution. It's just going to be an ongoing problem (Gerald, 468-470).

Fragmentation. Particularly those parents with other children felt that they were being pulled in several different directions at once. Because there was always a crisis with the one who had schizophrenia, the others tended to be neglected and then parents felt guilty (Jenny, 1117-1126). Parents also had jobs, elderly parents, and other obligations but often their ill child needed care for eighteen hours (Sue, 901) or twenty-four hours (Evelyn, 433; Gwen, 690) a day. As Bruce said:

> It's hard to work. When you try to organize your thoughts, I find now that I really don't know what I think. It's more just putting one foot in front of the other, you know. What's the crisis for today? (Bruce, 1105-1110).

Crisis was a word that came up time and time again in the interviews. It took a crisis before Barry could get help or accept that he needed it (Evelyn, 296-299). Gwen called Colin's illness "an extremely stressful crisis in my life" (1143). Jean said that many families split apart because they "are really in a crisis" (Jean and Tom, 80) and that parents are afraid to relax because another crisis is "right around the corner" (Jean and Tom, 1627). When a person is either in a crisis, getting over a crisis, or watching out for the next one, life is fragmented.

Frustration. Parental frustration was triggered by negative symptoms (Evelyn, 1690-1692; Gwen, 641-645, Willow, 464) and inconsistent behaviour (Gwen, 944-948), by being unable to reason with delusions (Irwin, 705-713), by the child's refusal to accept the illness and treatment (Irwin, 964-971), and by the ill child's manipulation (Jenny, 1040-1048). There was frustration with a system that didn't listen (Kulwinder, 431-443), that had long waiting lists for appointments, and that had no hospital bed available when the child needed it (Catherine, 893-896). Parents were also frustrated by their own inadequacies: not knowing what to do, losing patience (Sue, 904) or confronting the ill person (Gwen2, 984-987), being unable to ignore the irritations, and finding that nothing you try seems to work (Michael, 648; Sue, 671) and your child continues to suffer (Catherine, 1457). Although they said that the frustration varies as the child's illness varies, the consequences for parents are tension, negative health effects, and guilt — guilt augmented by realizing that, as frustrating as schizophrenia is for parents, it is much more frustrating and stressful for their ill child.

Determination. Despite fragmentation, impotence, and frustration, these parents refused to give up. Although "very tired," Teresa said, "I will not allow myself to burn out" (1317-1318). Although caring for someone with schizophrenia is exhausting and "you never seem to go off duty" (Evelyn, 2069), I think that every parent who talked to me would agree with Evelyn and with Bruce:

> You're always sort of going to bat for them. And if you don't go to bat for them, nobody else will (Evelyn, 2070-2072).
>
> ...we know that she suffers from a serious organic impairment, she is never going to get better, but we do believe that she can have a life that she can manage and get some enjoyment out of and some fulfillment out of. We just haven't let any other thought come into our mind for five years and no matter what it takes we are going to be there for her (Bruce, 701-709).

Maggie's words provide a summary of the toll paid for years of painful experiences and social and psychological suffering by parents who care for a loved one with schizophrenia:

> ...it does force one to become one with the suffering of the world. Your ego has to give way and all the prestige that your ego cries out for, that's gone anyway, even within yourself. Your self-esteem, that awful word that we talk about, is gone. And then you have to let the ego go to another level and that is the containment of your pain, because your body alone cannot contain that amount of pain. So, you have to blur the edges, which sounds almost as if you're getting psychotic. I mean it's funny, when you talk about all this mystical experience of accepting your pain as part of the world, you get very close to schizophrenia (Maggie, 1882-1894).

Coping with Caregiver Stress

Although parents spoke at length about ways in which they dealt with the objective problems and crises that seemed to present daily, they had more difficulty thinking of any skills they had developed for coping with their subjective stress, which was overwhelming at times. Several recommended doing some enjoyable activity with the ill child, particularly those that involved going outside and into nature, such as gardening (Margaret, 687), golf (Sue, 738-749), or walking (Evelyn, 1945) . While the exercise was healthy, there was the additional benefit of seeing the ill child engaged in doing something, rather than morosely sitting or lying around the home. Another simple pleasure was reading and listening to taped books (Ruth, 943-945). Several people needed more formal help: individual psychiatric treatment (Fred, 1519; Gwen2, 1168-1197; Lois, 1044-1045; Maggie, 882-886) or family counseling (Catherine 1563-1585; Sue, 649-699).

Any change of scene was helpful. For example, Clifford described his home life as being like the tea party in Alice in Wonderland:

> That's how our household was. That's how it was. It was nuts. It really was. It was so difficult. Alice in Wonderland's tea party. That's why we used to do an awful lot of hiking, outdoor things, camping, rafting, just to get out, just to be active other than getting into each other's hair. And that's how we seemed to bear through it (873-881).

Solitary walks in peaceful surroundings were also helpful (Clifford, 1313-1318; Jean, 227-231). Work also provided a change of scene where occupational demands blocked out the concerns and worries (Catherine, 493-497; Warren, 183) and "it was the one thing that I had some control and predictability over" (Sue, 53-54).

Talking About It. Although some parents shied away from telling anyone at first, later they needed to talk. Others needed to talk to someone from the beginning. Some had close friends or extended family who were sympathetic listeners but Catherine noted that there is a limit to how long you can impose on friends (1023-1025). Sometimes nobody, mental health professional or otherwise, wanted to listen (Clifford, 3404). Gerald who recently moved to the West Coast knows no one well enough to discuss his son:

> ...there's a couple of ladies that I've mentioned it to, but, I mean, I can't really talk about it, you know. What's to talk? They don't want to know, and they don't know, and most people don't understand it anyway. I guess maybe nobody does. They don't even understand the ramifications of it, I don't think. Everybody's got their own problems (Gerald, 738-745).

Teresa has felt hurt and insulted by some people and is now very cautious:

> I have learned to get to know who I can talk to, who I can explain, who I can be open to, otherwise I don't bother. It's fine if they know, if they want to ask. Yes, if not I just don't bother. I'm very careful. Because there is a lot of ignorance (1956-1961).

Thus, writing about your experience is more helpful for some parents than talking about it.

Writing. I was surprised at the number of parents for whom writing was useful. Although Philip (19) and Tom (1025-1033) pragmatically wrote out details about their children's illnesses to assist a new doctor or their own memories in an emergency situation, several women used writing for what appeared to be more therapeutic purposes. Sue (1111-1113), Ruth (2073), and Maggie (1379-1383) have kept journals. "Sometimes when I read the stuff, I wonder how I could have endured such pain" (1381-1383), said Maggie. Like Willow, Maggie has also written poetry and Willow has had some of hers published.

Faith. One third of these parents drew comfort and strength from their faith (Clifford, 2453-2455; Evelyn 1478-1484; Fred, 616-618). Faith provided hope (Jenny, 2671-2683). Several parents talked about prayer being helpful (Kulwinder, 1191-1195), especially with learning to accept the illness (Marianne, 1016-1017). Gurpreet's story reveals how difficult it was for some to sustain their faith:

> I used to be very religious when I was younger. When Kal got sick I couldn't pray to God to make him well. Everybody said to me that I should pray and I would feel better and I couldn't do it. Maybe I was angry with God. I would go to the temple

> to observe the religion but I couldn't pray. Only in the last few months can I pray to God now. People for many years said I should pray to God and that it would help my son. For many years I wasn't able to pray (487-496).

On the other hand, Teresa provided the most illuminating explanation of why, for her, religious belief is sustaining:

> ...it has for me been very good to be a Catholic, because Catholics believe in sacrifice. It is not that I take the martyr role. No, by all means. 'Cause the church doesn't dictate to me my social values. And if the church takes over my intellect, I'll just leave the church, because that's not really, I think, what God wants. But there is a point in the Catholic church where it teaches to sacrifice for a good reason or for others, and this is really where I go with Anne. I have to sacrifice myself at times to keep myself alive for Anne and for myself. So, that faith is part of my support too — that I could say, "Well, that's what is ahead of me." And I won't just go into the church and just pray to wait for miracles, but for strength. That's why I don't lose my hope (1596-1614).

Many parents admitted to crying. Some said they did so for years. Others continue to do so quite frequently, but Teresa only allows herself to cry privately:

> ...people don't like tears. People, if you break down and you show that, then you have lost control. So, they deal with you differently. If I talk to them the way I talk to you in a calm, collected way, they take me seriously then.... So, I have my private life and I cry and I get sometimes very angry, but it seems now that that's enough for me to then bounce back and regain my control. That's the way I deal with it. It would be silly to say I don't cry. No, it's a lot of tears (1881-1886, 1889-1894).

Many parents whose child has schizophrenia cry to ease frustration and tension but they also cry because they are grieving.

Grieving Alone

> What I grieve every day is the ways of the functional life. I grieve that every day, for Anne. Every day. Anne is never out of my thoughts and I say, how could that happen? How could that happen to others too? Not just Anne, but how could the illness be so cruel? Cruel, right in the bloom days, that's when it flares up. Anne will never see those years again, Mrs. Milliken. Ever. I remember when I was going to university and college were my best years: 20, 21. Ooh, the world belonged to me! It was just fun. It was really a good life. Nothing to worry about. Anne has never seen those years. And they will never come back. They are gone. I grieve that functional life (Teresa, 1499-1516).

From the diagnosis onward, these parents experienced emotions that are associated with grief but, for almost everyone, this grief differed from grief that follows a death. The difference was that this child is not dead in a literal sense and with life there is hope (Warren, 1045-1048; Catherine, 1547-1550) for a return to what Teresa called "functional life." Over time and with evidence that the illness is chronic, most parents had difficulty sustaining that degree of hope. Several parents described their grief as worse than grieving for an elderly person, when death is expected and may follow a painful illness (Catherine, 1519-1538; Lois, 1709-1713). Ryan and Roger's parents suffered both kinds of grief, during the illness and then following death. They observed that their sons' deaths ended their intolerable lives and, hence, their deaths were easier to accept than their lives had been (Philip & Donna, 1509-1533; Sue, 943-947):

> ...his death was a big shock because it was very unexpected. On the other hand, we'd lost him way before that.... Your grieving is done while they are still here (Donna, 923-925, 1525).

Nevertheless, Sue told me that her husband has been unable to accept Roger's death five years later.

The grief that accompanies watching your child live with schizophrenia appears to have three dimensions. Parents grieve for a child who is gone but not dead; they grieve about the life their child lives; and their grief is ongoing with minimal resolution. They continue to see the physical body of their child but without the characteristics and personality they have loved. In Bruce's words:

> Anne is still there but it's not Anne, you know, it's somebody else, and that person that existed then isn't there anymore, but you can't sort of come to terms with that and move on because there she is still walking around doing things. It's her face and her body (1331-1337).

Parents said that you grieve for "the person that you once knew (Catherine, 1547), for "what might have been" (Evelyn, 866), for "what is not" (Lois, 1716). Parents grieve in response to changes that occurred directly because of schizophrenia and indirectly because "they're just destroyed so terribly by the medication, and by poverty, and [by being] non-productive" (Willow, 1916-1917). In reply to my asking what had been the worst thing about this illness, Lorraine said:

> Just seeing my daughter, in effect, die. You know, so many illnesses that people have, long-term illnesses, they can still have a life, when you lose limbs or you have your brain that functions normally. But it's just like she's in a little bit of hell all the time (1461-1467).

Losing the child they knew was hard enough but observing their child's pain and joyless existence compounded a parent's own pain. Several mothers spoke of identifying with their child's pain (Gwen2, 1313-1320, Maggie, 49-50). Even when the child was missing, parents imagined their dire circumstances. Not knowing whether her errant child was dead or alive, but knowing enough about the hazards of her lifestyle, Teresa began to grieve in anticipation of Anne's expected death:

> I don't know how many times I bury Anne. And I used to rehearse the burial so I would not be hurt. I used to rehearse it so well. I will think this way; I will act this way. We didn't know where she was and we knew she was in big trouble, big trouble (Teresa, 645-651).

Whether the child was missing, lived with them, or lived elsewhere, these parents' grief was compounded by present injustices as well as past injuries. As Maggie commented, "I have memories as regards to both of them that hopefully most mothers don't have to endure" (93-95).

The third characteristic of their grief is its length. Joe said that having a child with schizophrenia is a "slow motion experience" (1221). A parent's grief, like the illness, goes on and on, with "a great feeling of incompletion" (Bruce, 1339). Gwen described her grief as a "wound constantly being reopened" (1277) and Marianne said:

> ...it's kind of like dropping a crystal glass and trying to put it all back together and it just never quite goes back together, and, and sometimes something very simple will trigger tears or, um, memories (1507-1510).

Parents described at some length the losses that both they and their child had endured since the onset of schizophrenia.

Parents' Losses

When their child became ill with schizophrenia, life changed for the whole family, and not for the better. Parents lost their own independence, as the balance of attention shifted toward the ill person and away from everyone else. They spent little time alone or together, and limited their activities with the other children. Family celebrations took on a different tone. Several parents who had enjoyed active social lives stopped entertaining. Two of these parents gave up their jobs to be full-time caregivers. One of them, Jenny, said that it ties you down more than a baby who could go to day care (Jenny, 2156-2160). For parents, the loss extended beyond losing their child to schizophrenia but also prospective grandchildren. In several families, siblings of the ill child vowed never to have children themselves (Catherine, 1500-1507; Sue, 216-221). In particular, parents had to give up their hopes and dreams in regard to their ill child who was now replaced by a stranger and also their anticipated enjoyable retirement. If the child lived with them, the lack of privacy could be a problem.

Hopes and Dreams

None of these children has achieved either their own aspirations nor their parents' expectations. Most show little evidence of their former talents and interests. Two fathers told me about subscribing to university scholarship plans when their children were born (Kulwinder, 1123; Sam, 687). As Marianne said, "your children are supposed to do better than you did" (1136-1137). Instead, parents had no choice but to lower their academic, occupational, and personal expectations and to struggle to accept their child's drastically reduced life circumstances (Gurpreet, 321-325; Irwin, 202-207). Their struggle is evident in the following quotations:

> I had a great deal of resentment that I had to get over and the anger I guess you'd call it, when I would see her peers and see the stages they were going through, and the stages that Melanie never seemed to be able to follow through anymore. It was like her life stopped at 15, intellectually and emotionally, every way (Lorraine, 816-822).
>
> I was always careful not to see his future as anything other than what he wanted it to be....And so, since I didn't corner him into this or that, that he didn't take up on, I can't honestly say I was disappointed at any stage. Except, the trouble with his choices as time went on later is that they got, um, what's the word for this, um, he lacked a sense of clear direction (Joe, 1225-1226; 1230-1235).

Evelyn observed that Joe, especially, struggles with acceptance, although they are both happier when they can accept Barry's limitations (421-424).

My Child is a Stranger

In place of their former child, these parents now were presented with a different person who seemed to have no connection to their loved one beyond physical appearance. Seven parents said that their child had become a stranger or that someone else had taken over their child's body. Suddenly, they no longer knew how to react to this person or how to talk to her or him. Maggie observed that, not only had Maureen become a stranger to her family but that the rest of the family had also changed in response to their agony and the pain, and so Maureen and her family were strangers to each other. On the few occasions when she has seen her daughter in recent years, "she comes in like a child you know. 'Hi Mom.' The first moment is always great" (Maggie, 1728-1730). Briefly, it seems that everything is going to be fine and then comes the heart-breaking realization that it is not (Maggie, 1778-1784). Similarly, Lorraine said that over the years she has seen flashes of the old Melanie less and less frequently (875-879). In contrast, Jean is beginning after twenty years to perceive occasional signs of Maxine's character, including her sense of humor (1717-1726).[23]

Retirement from Active Parenting

When parents foresee no end to caring for their ill child, they may have to forsake long anticipated retirement plans, that are usually predicated not merely on retirement from employment but on reduced responsibilities in other areas of their lives.

> ...you stop and think, when am I ever going to stop being a parent? You know, I think my dad stopped being a parent when I grew up. I'm mean he always was my dad and we had a wonderful relationship but my worries and things, I didn't lay them on him. I dealt with them myself....When do you stop being a parent? You don't. You just keep it on because this person needs you (Jean & Tom, 889-899).

When a disruptive adult-child lives with parents, plans such as selling the family home and moving into a condominium are no longer feasible (Bruce 1245-1248), although a smaller house with an attached suite for the ill person might work (Gwen2, 875-881). Bruce and Teresa no longer consider retiring to Latin America because even if Anne would consent to come, the psychiatric care is primitive there (Bruce, 1249-1268). In fact, for many parents, planning is no longer useful; they live from one day to the next. For example, several years later, Ruth continues to live in a small house that she bought hurriedly several years ago, after a social worker allowed Tim to move out of the group home and in with his mother. She says she is "camping" in this house (996-1006, 1929-1935).

---

[23] The long term course of schizophrenia appears to be more favorable than previously thought. From middle age to late middle age, many patients symptoms improve (Harding, 1988; Harding, et al., 1987a, 1987b; Torrey, 1995). Nevertheless, having failed to establish employment, a social network among non-consumers, or nuclear families of their own, the majority of these people continue to require comprehensive support from social agencies.

Lack of Privacy

Several parents bemoaned their loss of personal privacy and felt that they had no life of their own. Parents had little opportunity for time together or for private conversation. Jenny recalled that Melinda used to accompany her everywhere. Once, when a friend wanted to discuss a personal problem, Jenny refused to take Melinda who responded by acting upset for days (1069-1081, 1451-1468). Before Willow lived with her present partner, Ken had to be included whenever she had company. Now Ken lives semi-independently but, when he visits Willow and Pete, Ken follows Willow around incessantly. He does, however, respect Pete's privacy to an extent (Willow, 452-465, 761-769, 800-812). Although an ill child's presence robs their privacy, parents also are obligated to describe their private life in detail to health care providers. Lorraine states that she used to be a very private person, reluctant to discuss problems with anyone but:

> I couldn't stand back and have people think that she was the way she was because she was acting out, just that they had to know that she was ill and that this was part of the illness. And so, you just end up talking about it where you wouldn't before (Lorraine 1095-1101).

Difficult as their own losses are, the losses suffered by their ill child are even harder to accept.

The Ill Child's Losses

People who suffer from schizophrenia lose many character traits that allow people to live "a normal life" (Gwen, 394; Jenny, 1204). One thing they do retain is their intelligence. For parents, this is both hopeful and tragic. With recovery, an intact intelligence offers the opportunity for a satisfactory life. Without recovery, ill persons are painfully aware of stigma and of their limited life circumstances. As Gerald notes "no wonder they're depressed" (273). Sometimes their intelligence may help them develop defense mechanisms against being hurt and becoming depressed (Irwin, 1118-1146). Their intelligence can sometimes work against their recovery, when they hide psychotic behaviour from health care professionals, delaying the diagnosis or hastening a hospital discharge (Bruce, 877-880; Evelyn, 251-262).

Alternatively, some parents believe that schizophrenia damages intelligence and the psychotic person's bizarre behavior may give that impression. In fact, Lorraine reports that Melanie's IQ has declined (984-989). Several factors are liable to influence the measurement of intelligence, especially when perception is influenced by hallucinations and delusions. Irwin's attempts to convince Colin that his delusions are illogical provide a case in point:

> Well, he says, "I know what you're getting at and I'm not going to discuss it with you." And he can be quite articulate in his rebuttals you know. He'll go through a dinner often saying not a word. Other times he will defend his position, and his old intelligence comes through. So, you know, that's another very strange thing of how somebody, who somewhere in there still has a high IQ, can be so incredibly stupid at the same time (Irwin, 1045-1054).

As well, when medications dull a person's awareness and when negative symptoms reduce motivation and concentration but increase agitation, then intelligence test results are likely to be negatively affected whether or not intelligence, itself, is affected. Whether or not intelligence is affected, people with schizophrenia also suffer from changes in their social abilities and personality that, in turn, limit their future prospects.

Social Skills

Isolation from friends and the inability to cope in groups of people, coupled with their often bizarre behaviour, ensure that people who suffer from schizophrenia lose or fail to develop many social skills and social graces (Catherine, 180-182; Jean & Tom, 678-688), for example, table manners may deteriorate (Gwen, 712-723). As Michael pointed out "mentally ill people are not pin up people. They are liable to tell you to bugger off as not"

(846-847). Consequently, they have little opportunity to form new or lasting relationships or to marry (Evelyn, 867-873).

Communication skills are essential to establishing social relations but parents described their ill child's speech as unintelligible and mumbling (Fred, 1850-1860), repetitive (Sue, 904-907; Willow, 832-844), or contradictory, at times (Gerald, 696-702). Their speech may reflect their disconnected thoughts or be spoken so quickly that others are unable to interpret what the ill person is trying to say (Willow, 792-796). Alternatively, at other times, there may be no attempt to carry on a conversation at all (Gwen, 751-761, 774-784).

Personality and Emotions

Personality changes with schizophrenia may be so great that the child is completely different after the onset of schizophrenia than prior to the illness. Some parents noted that their child's emotional responses, particularly the pleasurable ones, were now missing. Gerald said that Jeremy had lost his sense of humor (702-708) and others said that their ill child seldom laughed (Bruce, 234-237; Lois, 913-919), or laughed inappropriately (Jenny, 1810-1816). Jean felt that Maxine had lost the ability to have fun (Jean 679-696). Some people with schizophrenia showed almost no feelings of affection (Philip & Donna, 433-456); others were overly demonstrative (Willow, 714-715). Several parents noted that although their children are (or probably are) aware of how much they have lost, there is no overt expression of jealousy or envy. Overall, what the adult-child lost as a result of illness was his or her personality:

> ...schizophrenia destroys a person from within. It's a bit like cancer in that sense. It seems to metastasize and affect more and more of the person's personality (Philip, 1941-1944).

Abilities and Talents

Elsewhere I have already described the loss of academic ability, something that every one of these ill children has suffered. Before becoming ill, a number of them had clear musical (Marianne, 892-900; Gerald, 643-654) or artistic talents (Lorraine, 968-984) and these have either disappeared or not been developed further. Although Roger remained an accomplished pianist, he seldom played and could not achieve the discipline necessary to develop his talent further:

> ...to develop as a pianist, you have to start understanding music, construction of music, and the whole business of harmonics. I'm absolutely nonmusical, but he couldn't get beyond that, there's no question. But he produced music, composed music, and arranged music in a very, very nice way (Philip, 1205-1211).
>
> The theory was discipline and logic and so on, you see, and that was something he couldn't cope with (Donna, 1226-1228).

Athletic ability is another talent that requires dedication and motivation to develop. Anne was a middle distance runner training for the Olympic trials before she became ill (Bruce 19-22) and Ryan excelled in basketball (Sue, 24-29). Sue noticed that Ryan's coordination suffered after he began taking medications. It seemed to be a no-win situation: either the illness destroyed his capabilities or the medications did.

Thus, the combination of poor social and communication skills, personality and emotional changes, and decreased abilities and talents conspire together to create their most pervasive loss: their future prospects.

Future Prospects

Present circumstances for these ill persons are difficult to accept but, sadly, there is little hope for a better future. With no education and no job, people with schizophrenia are likely to live a life of poverty, stigma, and possibly victimization. One father said that it really hurts when periodically his daughter is better and begins again to talk about her original future plans, now unattainable (Bruce, 1342-1348). Another father described the tragic consequences of schizophrenia in these bleak terms:

> ...even a paraplegic can poke things out using their mouth and poking on computer keys in a sensible fashion. Even a, even a person with any number of, my mind boggles, with handicaps can do something because their mind works. But when you've got a perfectly healthy young man with a dysfunctional mind, it doesn't do anything, you know. It's not that he does anything wrong....I mean, he's not causing trouble. It's just, the trouble he causes: he takes up space and doesn't do anything (Joe, 1552-1559, 1569-1571).

The combination of a bleak present and a bleak future has prompted at least four parents in this study to consider the horrifying question of whether their child would be better off dead:

> Once when we were at a support group, when somebody brought up somebody had committed suicide and everybody was saying how awful it was, and she [another mother] said, "what do you really think of suicide?" And I said "You think it's maybe not as bad as living with this?" And she said, "I wondered" (Maggie, 445-450).
>
> ...the horrible question, would we prefer him to be dead? And-um, if you asked Gwen she would clearly say, you know, "That's a terrible thought. I won't even entertain that thought." Um, and I find it hard to face up to that question but I ask myself it. And again, it's very hard to answer (Irwin, 996-1002).

While an ill person lives, there may be hope for research to produce a miraculous cure but, as Irwin stated, that remote possibility is unlikely to help Colin because of his firm principles against accepting treatment. For parents whose child lives with schizophrenia, the above question may be unanswerable but, as already stated, for those parents who's ill child died, the answer was clear. Death was a release from a deplorable existence that was not going to improve. With each new realization of the losses they and their child had suffered and will suffer as a result of schizophrenia, parents grieved.

Falling Apart

Parents described a "rollercoaster" (Fred, 2336) ride of emotions that correlated fairly well with the ups and downs of the illness course. Each sign of improvement brought new hope, which was not sustained, for example:

> Briefly, about a month to six weeks ago, he was sketching. And that, you know, that sort of buoyed us up. And he'd started playing chess. Now, Irwin tried to get him to play chess a few nights ago and Colin sat down, and did one or two moves. I was sitting here reading and he said "I'm sorry dad, I can't play." Can't concentrate. And we have noticed he's not reading the newspaper again. He had started. He'd take the newspaper to his room every morning and he's not doing that anymore (Gwen2, 1326-1337).

Also, Maggie says that the first time Maureen came home on a pass from the hospital, she was smiling, relaxed, and loving, but a day later she refused her medications and continued to do so for years (613-633). Parents can never foresee what the next stage is going to look like:

> The parent thinks it's over. And you all want to think it's over and then it goes back and it goes around in circles, not knowing. It's a very difficult thing to see as it's coming at you (Fred, 2337-2340).

> ...you think you're over with it, and then along comes Christmases and times like that and you find that you're, you think you're back to square one again (Catherine, 1643-1646).

In response to the uncertainty and disappointments, several parents described themselves as "falling apart" (Catherine, 514) and panicking (Gwen2, 1006). Lois remembers being frightened and upset and wondering "what do I do now?" (414-415). Jenny's advice to other parents is to hope for the best but expect the worst (2637):

> ...enjoy the good times when you have them because you're not going to have them in a few months or a few weeks or maybe a few days, but then, when you're in a bad time, you know it's going to get better because it can't get a whole lot worse (Jenny, 2646-2650).

Denial

Early on, parents may reject the diagnosis. When parents are initially informed, Evelyn says that "there is an element of denial which keeps us comfortable" (395-396). Alternatively, denial may surface later in the disease course. While Irwin appeared to accept Colin's diagnosis immediately, Gwen refused to read the books Irwin brought home (Gwen2, 532-536). Later when Colin was hospitalized, Gwen became convinced of Colin's schizophrenia and Irwin began to deny it.

Parents may watch their loved one for evidence of normal behaviour or scrutinize old photographs and review past events involving the child to reassure themselves that nothing can be wrong (Evelyn, 410-412). Fantasies and day-dreams in which the child is well may help to sustain hope for a recovery. A common fantasy envisions the ill child in serene, pastoral surroundings where he or she is gradually weaned off antipsychotic medications and is able to enjoy a peaceful life (Joe, 989-996; Kulwinder, 832-836; Willow, 2114-2145). For example, Kulwinder wonders if Kal would be better in India, where the pace of life is slower and a large extended family would always be available, however, Gurpreet thinks that is not a practical solution.

Another example of wishful thinking involves changing past events in hopes of preventing the onset of mental illness. Jean provides a good example: if only Maxine had been accepted into the course at Camosun and if only she not gone to Toronto where she had an ill-fated love affair, then maybe she would not have become ill (Jean, 71-73, 1235-1239). Unfortunately, when this kind of thinking evolves into the thought that if only I had done something differently, my child would be fine, then parents feel guilty.

Guilt

Because parents are responsible for raising their children, when something happens to a child, parents tend to blame themselves. When the problem is schizophrenia, parents may blame poor parenting skills and family upsets for causing the illness initially and then later for making it worse. Other sources of guilt are a family history of schizophrenia (Sam, 634-640) and the tendency of other people to blame the parents, especially mothers, for their children's mental illness, although this last source of guilt is less prevalent now than a decade or more ago (Maggie, 36-43; Margaret, 131-147).

Insecurity about their abilities as parents was the major source of guilt for these parents. People worried that they had been too strict or not strict enough (Evelyn, 967), that they had spanked their child too often or too little (Catherine, 1158-1181; Evelyn2, 826-829). Parents also worried that family arguments (Evelyn, 967-969) or family break-up may have precipitated schizophrenia (Fred, 2315-2317). Several mothers referred to the cultural imperative giving women the responsibility for creating perfect children and preserving domestic bliss (Evelyn2, 823-825; Gwen, 661-664; Maggie, 992-997). Nevertheless, in the same sentence in which she blamed herself, Jenny noted that "We raised our kids all the same and this was just, just a fluke" (582-583).

Guilt grows when parents second guess how they have dealt with the child's illness and treatment. If we had recognized the problem sooner (Gurpreet, 31-37; Margaret, 1215-1219), he or she might be better. Parents felt guilty for criticizing or being angry with their ill loved one (Gwen, 812-818, 840-846). Some parents felt guilty for neglecting the other children in the family (Michael, 204-210); others for abandoning the ill child in favor of the siblings (Maggie, 52-56). Even when they felt confident about a decision regarding treatment, they were guilty if the child protested. For example, Maggie felt guilty returning

Geoffrey to Riverview after he had run away (1457-1459) and Jenny felt guilty for insisting that Melinda stay in hospital when she wanted to sign herself out (2463-2467). Parents even felt guilty for accepting the illness, blaming themselves for giving up on the child and sentencing him or her to a life of mental illness.

Not all parents were as ready to blame themselves. For example, Gerald said that guilt is irrational (1309-1311). Over the years, for many, the guilt subsides. Eventually, as Michael said, "you say to yourself, beating myself up isn't going to change anything" (658-659). On the other hand, it can be helpful to parents to be reassured from the beginning by health professionals as Marianne and Jean and Tom were:

> ...this same psychiatrist had said to me that first day, that, "Lots of people may tell you it's how you diapered him, how you burped him, how you whatever, but," he said, "Tell them to go to hell. You didn't cause it. You can't cure it. You're only his mother" (Marianne, 1030-1035).

Despair and Depression

As stress and guilt increased, and especially when their child was refusing or not responding to treatment, some parents began to despair of ever seeing an improvement. Evelyn described "something you can't even name. It was just the pain. A terrible empty feeling of pain" (854-855). Parents said that despair comes from "powerlessness" (Fred, 1445-1453); "the extreme frustration that you're subjected to over and over again" (Gwen2, 1311-1312), and from having no alternatives:

> I've spent all my working life solving problems and, you know, this methodology and how you go about it: consider the alternatives, and compare the alternatives, and go after the one that looks most promising, and, you know, maybe solve the problem or [maybe] you don't, but at least you're working at it. Here, there aren't any alternatives(Irwin, 845-852).

Not surprisingly, some parents began to think that life was not fair and that they deserved better. As an example, Maggie was proud of her parenting style. Having taken courses in child psychology, she changed from being primarily a disciplinarian to talking about feelings and having more fun with the younger children. Consequently, Maureen's accusation that Maggie had neglected her was doubly hurtful (1164-1190). Margaret had made a successful career following a disastrous childhood and a dependent marriage. When Derek was diagnosed, she asked, "Did I really deserve this?" (1000-1002). Finally, Willow told this story:

> I joke about it now, but at the time I think I was just in a total sense of despair and [then]one day everything worked well. You know, it was one of those days that you want to remember forever, except our boxer dog had just come to live with us and he got out of the yard and he wanted to come back in and he went around to come in through our neighbor's yard and they grew prize winning roses, and he dug their yard up and so, I thought, "Holy smoke!" You know, my kids are okay for one day and our dog destroys this magnificent yard (1590-1600).

When asked how they cope with the despair, parents had few suggestions. All they really wanted was denied them, because "there's nothing on the horizon that's going to fix things" (Gerald, 156-157). Gerald answered, "there's always the sunshine in the bottle, but that doesn't really work" (729-730). With no one to talk to who understands about it, he usually goes out for a walk. Maggie said, "You get used to a level of pain. You have to." Other parents refused to get used to it:

> ...you have to put that aside and still keep on struggle, and struggle, and continue your struggle. You know, you don't stop struggle. You keep on going (Kulwinder, 1284-1287).

Anger

One common response was anger, although Gerald said that anger is pointless when the illness is no one's fault. In contrast, anger was Marianne's strongest emotion and expressing it, if only to herself, helped her to accept Daniel's illness (1474-1486). For Maggie, anger was second only to guilt as an emotional reaction. She has been angry at Maureen, Maureen's counselor, various teachers, doctors, therapists, and at her eldest daughter for leaving the family at one point (1213-1252). To her, anger is one reason that schizophrenia is not an individual illness but a family illness:

> I think that anger is not admitted or recognized as part of the pain of a family. I think there is anger in any family when a person becomes chronically ill because it has upset your life, but when the patient is paranoid and says terrible things about you, both to your face and behind your back, I mean you just, if you're a human being, you are going to be angry (1087-1094).

Anger may be directed at the illness itself (Teresa, 1652), at those who are more fortunate (Lorraine, 813-821), or at oneself (Michael, 645-646) and sometimes at the ill person, although that can increase a parent's feelings of guilt. Sometimes, however, the anger is suppressed, because "anger takes energy" (Maggie, 1159) and families have many drains on their energy.

Willow believes that anger is the more positive side of grief, because anger is directed outward and may influence change. In speaking of a friend whose mentally ill daughter has just died, she said:

> Her grieving will come back but the anger is going to get her changing some of the things that could have prevented this...grief will be the process they carry with them always, but anger is the way they express it. I think. And then there are some of us, who I suspect grieve and are angry, and are the ones that fall into that category of being activistic (Willow, 1050-1052; 1139-1144).

A major reason for their anger and a catalyst for their grief is the stigma attached to mental illness.

The Stigma Against Mental Illness

Mentally ill people face constant rejection when what they need is compassion. Social disdain may have a worse effect on families and on those who are afflicted, than the illness itself (Clifford, 3236-3268). Social disdain may cause suicide or lead the mentally ill to live on the streets. The stigma against schizophrenia prevents many ill people from acknowledging their illness and, thus, deprives them of participating in psychosocial programs and accepting other forms of treatment (Michael, 491-526). Stigma produces the NIMBY syndrome (not in my backyard) that prompts neighborhoods to lobby against the establishment of group homes (Jean & Tom, 1165-1188). Although discrimination in general has lessened in recent years and although there is now more public awareness about mental illness, there remains a clear stigma against the mentally ill, even among the younger generation (Evelyn2, 1312-1314; Gerald, 1398-1403).

These parents have experienced stigma first-hand. Jean was shocked when friends were embarrassed about coming to her house (1397-1400). Clifford asked for the hospital chaplain to visit Julie and was informed that he did not go to the psychiatric ward (1042-1060). Teresa tells about a shoe clerk who refused to sell a pair of shoes to Anne (1994-2020). She says now that when people comment about Anne, "I just answer right back. I don't care anymore" (2014-2015).

Some of the parents in this study recognized that their own formerly negative attitude toward the mentally ill had changed because of their personal experience (Maggie, 1579-1590; Michael, 522-526). Fred, who's son faces a charge of murder, admitted that he used to think the insanity defense was merely a legal ploy to have people acquitted:

> ...ten years ago when we used to hear the press well, "Somebody got let off through mental illness" and so, "Yeah right, that's a good excuse." I used to say that myself. I was one of those people. So, I have no problem with that opinion. I understand where it comes from. It comes from a lot of ignorance. "Oh yeah, that's the way the lawyers get people off." Yeah, right! (Fred, 2030-2038).

According to several parents, the key to overcoming ignorance is public awareness, through real people telling their stories. The unfortunate dilemma is that, as long as there is a stigma, many families and ill people fear exposure and value their privacy (Clifford, 2286-2305; Teresa, 854-863). Jenny's story illustrates why. Her fourteen year old daughter spoke about schizophrenia at a school assembly, ending her presentation with:

> "Don't make fun of somebody, because you may be one of those one in a hundred," because she had said it's not diagnosed till you're between a certain age. "So don't laugh about it, don't make fun of me. I may have it" (Jenny, 2275-2279).

Although her talk was well received, another young girl in a different school made a similar point during a class discussion and was teased unmercifully afterward by the other children, with taunts such as, "Oh, when are you going to get psycho?" (Jenny, 2306).

Two participants suggested that raising awareness of schizophrenia could be accomplished better if the language was changed. Maggie believes that if publicity stressed schizophrenia as a neurological disease (1338-1351), there would be less stigma. Gerald contends that the erroneous association with "split personality" would be overcome by changing the name:

> Schizophrenia is not only a hard word to say, nobody can spell it, and it means something that it isn't. I mean, it's just wrong from start to finish. You know, they used to have rapeseed here. Now they call it canola. Everybody's happy and I don't understand why the same thing couldn't be applied to this disease. Just give it a new name (Gerald, 995-1001).

For people who suffer from schizophrenia and for their families, the stigma against schizophrenia is unfair. In addition to the emotional damage it causes, it delays their acceptance of the illness. One consequence is that both consumers and their family members become isolated from the treatment and support that can help them to survive this devastating illness.

The Effect on Parents

Having a child with schizophrenia becomes the focus of a parent's life overshadowing everything else (Kulwinder, 1648, Maggie, 107). Life is emotionally overwhelming and the stress and strain of trying to keep emotions under control is wearing (Lois, 1933-1934). According to several of these parents, mothers feel the emotional stress more than fathers (Jenny, 2228-2232; Michael, 664-680; Sam, 72-76; Warren, 264-297), which may be a function of full-time caregiving rather than gender. Clearly, when the traditional roles were reversed in one family, Ted suffered more from emotional strain than Sue did. The ability to immerse oneself in work outside the home was helpful in relieving the stress of caregiving for Catherine (493-497) and was one motivation for Warren opening a consulting engineering practice after retiring (186-201).

Parents live in the present, dealing with one crisis after another, and put their own plans for the future on hold. According to Catherine, schizophrenia in the family changes your whole life philosophy. There is little use planning when you know that "life can change very dramatically in a very short course of time" (829-831). In replying to a question about her future, Gwen said, "I have no realistic best guess" (911). Unfortunately the present is painful, with "large amounts of unhappiness which never entirely goes away" (Irwin, 1228-1229):

> ...it becomes your sad part of your life. You worry quite a bit. Element of apprehension is always behind [the] back of your mind. There's lots of pain (Kulwinder, 1649-1651).

Fairly constant stress, unhappiness, and apprehension can take its toll on a person's health.

Effects on the Health of Parents

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. Maggie notes that the mental health system fails to take into account the illnesses that other family members develop, when practitioners focus on the primary patient alone (935-937):

> We're just human beings, like my sick son, like my sick daughter, I am made of the same stuff. And there's a limit (Maggie, 932-934).

Parents attribute their suffering from many psychiatric problems, sleep disorders, and physical illnesses to their caring for a family member with schizophrenia.[24]

Psychiatric Illness. At least five mothers in this study have received psychiatric treatment themselves. In addition, Sue believes her husband, Ted, to be clinically depressed, although he refuses to seek treatment for it. Although early in Bryan's illness, Catherine found the psychiatrist to be less helpful than her friends (1567-1573), she has now become concerned about her ongoing grief and its long-term effects on her health and plans to seek counseling again (1666-1675). Elaine was on stress leave from work for six weeks this spring, returning to her job just before her death; Lois has taken anti-depressants off and on for years. Gwen and Maggie gave the most articulate descriptions of their illness.

Gwen describes the physical effect that stress had for her:

> ...for quite some time, I had had this peculiar thing at night, sort of. The only way I can describe it, like a pneumatic drill inside my chest. It was a regular "blleerr." And it would go like that — "Blleerrr Bllerrr. Blleerrr." And this went on for quite a long time and I thought it was the furnace. At this point we still had an old oil furnace. And I would say to Irwin, "Does that furnace," because it constantly woke me at night. It was only at night. And I would say to Irwin, "Does that furnace not wake you up?" I thought it was when the furnace switched on that it made this noise. But, "No, I don't hear it." I said "Don't you feel that? It makes the house shake." Because [at that time] I didn't realize it was inside me (1081-1097).

---

[24] The causal link between high levels of stress (or distress) and illness, both psychological and somatic, is well-established (Hansen & Hill, 1964; Holmes & Rahe, 1967; Lazarus, 1974; Mirowsky & Ross, 1989; Pearlin, et al., 1981; Selye, 1976). This is particularly true when a person has no opportunity for alleviating the stress-provoking situation. Many aspects of this caregiving experience fit the former pattern, including powerlessness (Mirowsky & Ross, 1989), isolation (Belcher, 1988), and repressed anger (Munhall, 1994). The BC Task Force of Families of People with Mental Illness reported that, when asked about the effect of having a person with mental illness in the family, 99% of respondents said that their mental health had been disturbed (35% severely). Effects on their physical health were reported by 75% of respondents, with 25% reporting severe physical health problems (British Columbia Ministry of Health and Ministry Responsible for Seniors, 1993).

Cardiac problems were eventually ruled out and she was given anti-depressants for six months, however, the drilling and tightness in her chest returns from time to time. She has also experienced panic attacks and what she has termed, "paralysis of the will:"

> I've never really heard anyone use that expression. It's my term for it because I was sort of paralyzed in that I could move but I couldn't use my will to make me get up and do anything or make a decision, or shop. You know, if I went shopping well I would almost get a panic attack in the supermarket. Mostly, the panic was because I couldn't do it. You know, I couldn't look for anything on the shelves, or I couldn't think what I was going to cook. You know, and so that created panic because I thought I was getting Alzheimer's (994-1006).

As Maggie aged, her emotional tension became unbearable to the point that she feared for her physical survival (418-421). Her increasing health problems prompted her decision against seeing her ill daughter until Maureen accepts psychiatric treatment.

> Depression, anxiety, chronic anxiety to the point of panic attacks just around the corner. Just my whole life is geared around, is centered around reducing pressure, reducing anxiety. I meditate, I do Reiki. Every few hours I have to lie down and do one of these things. I have more inspirational tapes than the whole of Canadians put together. I mean, it's just an everyday process, working on it, working on it. I have insomnia, I'm up in the middle of the night, I'm up several times in the night. My whole life is centered around managing my emotional pain. And most of it is stemming from the illnesses of my children (905-916).

There is no doubt in the minds of these parents that the emotional turmoil from seeing their child suffer and their own inability to alleviate that suffering influences their own health, mentally and physically. Among the members of a schizophrenia parent's committee to which Lois now belongs "over 80% of the 16 members have had at one time some psychiatric help themselves" (Lois, 1050-1052).

Sleep Disorders. Maggie is not alone in being unable to sleep. In fact, most of these parents mentioned some difficulty with sleeping; some have developed a chronic problem. For example, Clifford has had varied success with sleeping pills through the years; Kulwinder reported lying awake for two or three hours every night (772-773) and Gwen attended a sleep disorders clinic for investigation of her "drilling" sensation (Gwen2, 1128-

1197). For these people, constant fatigue made it harder to cope with their ill child's problems — problems that seemed even more severe while lying awake worrying through the night (Lois, 1512-1513).

Physical Illness. At least six parents have physical diseases that they attribute to their child's schizophrenia and the resultant upheaval. According to Gwen, both she and Irwin have periodic tightness in their chests (Gwen2, 487-496). Stress is blamed for Sue's metabolic problem with mineral absorption and severe osteoporosis at an early age (312-325), Maggie's chronic illnesses (886-899, Warren, 307-312), and Jean's hypertension and weight gain (1373-1376). Finally, Clifford has suffered three heart attacks, chronic neurological problems, and is now on permanent disability. The neurological problems began when medications he received to help him sleep led to a severe fall and a fractured skull. Later he discovered that he had been given antipsychotics without his knowledge (1917-1933).

Thus illness, both physical and mental, is an outcome of caregiving for many parents of people suffering from schizophrenia. Many parents of the severely mentally ill believe that if more were done to improve the care of people with schizophrenia and increase support for their families, less illness would result:

> ...for one sick person who is receiving good attention, you would have a much healthier family all around. I don't think people realize how much it is costing for medical attention for the patients who are not recognized in that family (Maggie, 1622-1626).

As things stand now, parents feel alone in their struggle to remain vigilant for any change in their child's illness while they grieve for the family member who used to be. At the same time they are searching for anything that promises to restore their loved one to health.

Grasping at Straws

> At that time I really wasn't with it. I didn't have enough knowledge to know what was a good thing and not a good thing or I was just grasping at straws like everybody else is in the early stages. I find a lot of people are grasping for answers and hopes and solutions (Lois, 112-116).

Desperation describes the state of mind of these disenfranchised parents who are beset by grief and unable to stand aside while strangers (including the person their child has become) pilot their loved one through this devastating illness. Unable and unwilling to accept a life sentence of chronic mental illness, many parents are driven to find a treatment somewhere that offers the promise of a cure, while concurrently scrutinizing the ill person's behaviour for any change that signifies the return of their remembered child. Catherine is a case in point. "You will chase any dream to try to get the child well (Catherine, 625-626). Her husband worried about the effect on his wife's own health, because of her insistence that "if this didn't work today then you try that tomorrow, and if that doesn't work, you try [something else] the next day" (Sam, 669-671). He described her as "trying frantically to find something, some key, some solution" (683-684). Thus, a degree of denial combined with hope is the foundation for "grasping at straws."

Requesting a second opinion was often the initial response, in desperate hope of disproving the diagnosis. Then, even when proposed treatments were frightening, parents pinned their hopes on every new drug, treatment, or program that mental health providers suggested:

> ...even the shock treatments, my husband and I, certainly that first batch, didn't even want to approve it but we felt our backs were against the wall and it was sort of the only way that we were told that could maybe break this depression of his (Catherine, 704-709).

> ...one of the hospitalizations, they said that they didn't feel he was getting anywhere and there was a better rehabilitation in another hospital and a different psychiatrist

> and if I was agreeable I could help him to be transferred and they would facilitate it for me, and I did (Lois, 104-109).

> ....we got him into a program at UBC for people with schizophrenia. And he didn't last, because at that time it wasn't a very super program....And then finally a Dr. "A" took it over and Derek didn't last the first time, but the second time he did get in and he was on the older medications that weren't working very well for him. It was an excellent program. It is an excellent program for Derek. That was when he was at his worst, you know. I think they just went and sat around half of the day there, but somebody was on top of it. At that time Risperidone just came out and I asked Dr. "A" if he would put Derek on risperidone (160-173).

Seeking Different Treatment

Sometimes parents look beyond the treatment options offered by their child's professional caregivers. Catherine heard of a promising program in Texas:

> ...if we had sold everything we owned, I think we would have had enough for the six months treatment. I wanted to but my husband said no and people talked me out of that. They said, "you still have to have a home for your other son" (630-634).

She admitted to some continued guilt for denying Bryan that chance. According to Sam, she continued searching:

> Catherine would go out on these expeditions to find — One time she went off to Toronto because she heard that there was someone there who had a different way of treating schizophrenia. My perspective on it was [that] this may be an opportunity for her to find out that there is no panacea (77-83).

Some parents believe that the psychiatric emphasis on medication as the treatment of choice is wrong and have been trying for years to convince professionals to change their approach. For example, Kulwinder believes that an intensive behaviour modification program is the key to changing Kal's acting out behaviour but, to date, he has not received a sophisticated program (368-384, 982-1000). Similarly, Willow wants Ken's treatment to center around psychotherapy (2438-2476) and gradual withdrawal from medications in "an environment and a support network that really is going to be therapeutic" (2475-2476).

Other people look beyond the mainstream for alternative approaches. Jenny is convinced that without "unorthodox treatment or a different treatment" (2660), Melinda will still be ill twenty years from now. She hopes vitamin therapy will help and has made an appointment with a naturopath for a referral to Dr. Hoffer who, she states, has an eighty-five percent success rate. Margaret learned about fatty acids (fish oil) treatment, consulted her pharmacist, and discovered where to obtain a supply. She has decided, however, against trying it until Derek's new medication, olanzapine, is given a fair trial of several months. Alternative health care may be chosen by the ill child, as well. For example, Bryan believes that he will eventually be cured through hypnosis.

The desperation felt by many parents can be heard in Jenny's vow to "try anything" (420):

> Because if it doesn't help, you know, so you're out some money. To me, that's nothing if there's a chance (Jenny, 427-428).

Some parents initiated their own informal psychosocial treatment programs, often trying to reactivate the ill child's interest in any activity that used to provide enjoyment. Parents lined up courses in cake decorating (Catherine, 225-231), art (Gwen, 1156-1162; Lorraine, 968-985), counseling, computing, and graphic arts (Margaret, 939-976) but for various reasons their child either refused to take the course or was unable to finish it. Encouragement to undertake a specific project around the house was another tactic tried by both Gwen (862-979) and Joe (489-505) but in both cases after organizing, encouraging, and prodding, neither Colin nor Barry was able to follow through and complete the project. Many parents attempt to make up for their child's lack of friends by organizing activities, attending social and community events, going for walks or out for coffee or meals, sometimes wearing themselves out. In this self-assigned position as recreation director, they will try anything in order to coax their loved one into doing something. In Gwen's words:

> I could not function knowing that he was, you know, he was in the house doing nothing, or pacing up and down. I couldn't do it. So, I constantly was trying to find ways of entertaining him, getting him to do something, but he was so zonked out with the medication (Gwen, 269-274).

Learning About Schizophrenia

Parents are also desperate for knowledge about schizophrenia. Even the two nurses, Evelyn and Teresa, admitted to having only sketchy knowledge in the beginning. The occasional parent knew of someone with first-hand experience (Marianne, 620-621) but the majority had no one to approach for guidance.

Whether or not parents received information about schizophrenia from their child's psychiatrist was a matter of luck. Some, like Bruce and Teresa, Lois, and Marianne had good experiences in which a doctor was helpful and forthright in telling them information and the possibilities in terms of prognosis. According to Lois, what she was told was shocking, initially, but some things were clarified and she was spared from unrealistic expectations (1212-1228). Others, like Gwen and Irwin (told to prepare for a "bumpy ride") and Jean and Tom were given the diagnosis and nothing else:

> ...there was nobody there to catch you, you know. You didn't have any handles to hang onto. We were just, we came out of the hospital thinking we'll be the only people that this ever happened to (Jean, 1014-1018).

Luckily, Jean's family doctor was a good resource (Jean & Tom, 218-225), although general practitioners were not always helpful (Michael, 210). Overall, Michael says that the information they received from various sources was conflicting:

> We got as much bad information as we got good information, so what do you believe if you get a range of things that don't, don't turn out to be [helpful] (Michael, 213-216).

Many parents scour the library and bookstores for information and two have recently used the internet. Those parents whose child became ill years ago say that printed information has improved in recent years. What was available a decade or more ago was overly technical, although Jenny finds the available literature confusing still (597-599). In any case, during the emotional early stages, parents may not take in everything they read:

> ...you almost need to read it twice, once when you suspect it. Or three times, once when you suspect it, once when you are diagnosed, and later just to totally get all the information (Evelyn, 391-395).

Although reading about schizophrenia provided these parents with some information, usually parents need more and different sorts of information. They need to know practical things about how to approach the health care system and advice about family survival and caregiving (Michael, 725-730) and, more than anything else, they need to talk to people who understand because they have been through it too. Early in Geoffrey's illness Maggie attempted to contact other parents through a phone-in radio program[25] but no one replied to her request (1471-1486). Reaching out for help is not always easy. According to Ruth "it requires courage to get out there and find out about the very thing that's so painful (397-399).

EMBRACING THE COLLECTIVE

Connecting with others who have also cared for a family member with schizophrenia signals progress and a redefinition of parental identity beyond being disenfranchised (see Fig. 6). One reason it takes courage to reach out is that in doing so people make a public statement that they have a mentally ill family member (Jenny, 2081-2083). To make that

---

[25] This was before Friends of Schizophrenics was formed.

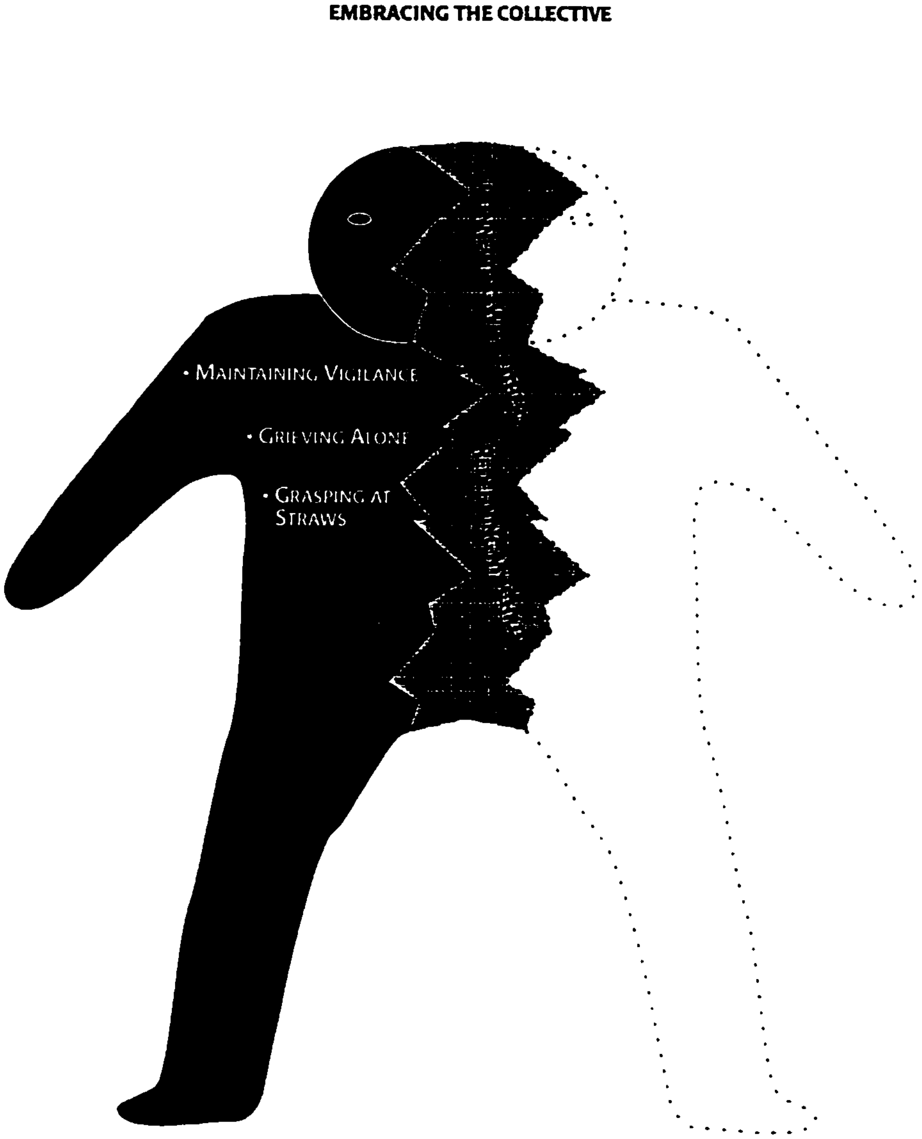


Fig. 6 Embracing the Collective

commitment means personally overcoming both a parent's comfortable denial of the illness and the fear of exposing one's family to the stigma against mental illness. Only when Colin was eventually hospitalized was Gwen forced to overcome her denial and, suddenly, she had an urgent need for information. She immediately became a very active member of the

Friends of Schizophrenics, reading voraciously about schizophrenia and nothing else for five years (Gwen2, 558-568).

Although the need to learn about schizophrenia drew many parents to the Schizophrenia Society or some other mental health group, once there, they quickly learned that they no longer faced mental illness alone (Jean & Tom, 315-316). Feeling welcomed and valued, the support group became a major reference group[26] for these parents and they were encouraged to take part in the group's initiatives to improve the lives of all those with schizophrenia. Realizing that by doing so, they could make a positive, although indirect, difference to their ill family member's existence (when their direct efforts to do so had been blocked) they *redefined their child* symbolically, to encompass the entire community of people affected by schizophrenia.

Connecting with Others

> ...you meet some great individuals. You form some lasting friendships from among the people that have experienced the same thing that you have and you don't have to explain or even discuss that experience that you share. It's just, you have a level of understanding with these people that you don't reach with people that haven't been through the same thing (Michael, 700-706).

How parents came to make the connection with other people with schizophrenia in their families differed. The occasional parent, like Jenny and Fred, knew someone who recommended attending a meeting of the Schizophrenia Society. Some of these parents were charter members who started BCSS in their community. Although several parents could not remember exactly how they originally found out about the organization, Evelyn

---

[26] Strauss (1969) draws on the writings of Sherif (1948, p. 164) to define a reference group as one from which a person draws his or her "standards, attitudes, and status aspirations" (p. 151).

remembers responding to a small notice on a hospital bulletin board where Barry was admitted after his suicide attempt (Evelyn). She and Joe began to attend a support group before receiving a definite diagnosis. For some parents, the doors immediately opened to friendships and a support group; for others, the first meeting was frightening:

> ...they were talking about twenty years of this and I thought, "Not for me there isn't" (Jenny, 2657-2659).
>
> And then when this lady, a 70-year-old came, I thought "oh my gosh, now what?" You mean I'm going to be at this until I am a 70-year-old? And I just sat listening to her and I just couldn't believe it....Technically speaking, I knew the illness. I never knew the suffering. Ever. And the tormenting these poor people go through. When I listened to that 70-year-old mother, I just couldn't believe it. I couldn't believe it. In our group, three have committed suicide. So, you know, as a parent, you sit there "What?" (Teresa, 1852-1855, 1860-1867).
>
> At first her [Elaine's] feeling was "You know they're not really going to help me solve Trevor's problem. They are just all [sitting] around talking about their problems. There is no solution here" (Fred, 1176-1179).

Joining a support group was beneficial for many parents. For example, Ruth, after several unfortunate encounters with hospital staff and the treatment team and after enduring criticism from many fronts, including her own family (2268-2270) has found that "strength is there for us to borrow if we don't have it within ourselves" (2254-2255). Through the understanding, encouragement, and the practical advice offered by other parents, many people felt less alone in their daily struggle with their child's mental illness. They could speak honestly in "caring and sharing groups" to empathic people who understood:

> You don't have to measure your words. You don't have to think first before you speak (Teresa, 1939-1941).
>
> ...those families that came to the support group meetings knew what you were talking about. They were living the same bizarre, weird, uncontrolled, out of control, angry, paranoid existences (Sue, 694-698).

They also learned how to speak truthfully to those who might not understand:

> Because the only way the stigma can be removed is if people are willing to talk about it. And so, gradually more of my friends learned. Either I told them or it came up.

> You know, people would say, "Oh what's Colin doing?" and I would say, "Well actually Colin has been ill now for sometime and he has schizophrenia" And if they knew nothing about it I'd tell them a little about it (Gwen2, 598-607).

Support groups were not as helpful for everybody but the Schizophrenia Society offered other benefits, such as a library with books and videotapes, organized educational programs like the Journey of Hope,[27] and monthly meetings with knowledgeable guest speakers. In whichever way people became involved with the Schizophrenia Society, they began to learn more about how this organization works to improve the lives of people with schizophrenia and their families and, coincidentally, they made friends:

> ...we don't go anywhere. We see other people with schizophrenic children at the Schizophrenia Society (Bruce, 1147-1150).

When I asked Willow about whether many of her friends were involved with the mental health community, she replied, "I would say ever single one of them does" (Willow2, 549). Thus, other people who were dealing with schizophrenia on an ongoing basis came to comprise the major reference group for many parents.

A subgroup of parents formed their primary connection to the community of people with schizophrenia not with other families but by befriending patients they came to know through their ill family member. Ruth has a number of discharged patients who keep in touch with her and Clifford provides another good example. When visiting his wife who was in and out of the hospital over many years, Clifford began playing cribbage with other patients (696-698) and inviting them for coffee at his office after they were discharged.

---

[27] The Journey of Hope is a twelve session family education course, taught by Alliance for the Mentally Ill (AMI) trained family member volunteers. It was developed by Joyce Burland for the Louisiana Alliance for the Mentally Ill. BCSS was the first group to bring this course to Canada (Burland, 1993).

Now, people with mental illnesses are the only friends who visit his family in their home. He says:

> ...the one thing that has kept me as a caregiver is interacting with other afflicted ones and seeing how much loneliness and pain (Clifford, 685-688).

Therefore, most of these parents began to identify with the community of consumers and with other families. For some, and particularly for those who had become isolated from long-time friends, the people they met through schizophrenia became their major reference group[28] and, consequently, many parents began to view their parenting role differently.

Redefining My Child

> She is the President of the [location] Friends of Schizophrenics Association. Her son is at Riverview right this moment and is very psychotic. She is really being blocked from knowing what is going on with her son because of this whole thing of confidentiality and that sort of thing. And her whole life is spent dealing with the laws and legislation and confidentiality and, what's the word? Ulysses Agreement[29] (Willow, 558-566).

---

[28] People tend to adopt the attitudes, beliefs, and actions of a group with which they identify. Such a positively valued group is known as a reference group. To modify one's self image to be consistent with the group, the person must be a member (or aspire to membership) and must value the group's assessment of him or herself. Through continued activity in the group, the person eventually incorporates the self-image that is approved by the group (Cavan, 1962). According to Shibutani (1962), when people have undergone a long period of frustration, disturbed interpersonal relations, and alienation, they are particularly predisposed to conforming to the norms of a group that provides positive experiences.

[29] The Ulysses agreement refers to "an advanced directive document in which mentally ill persons, not the courts, appoint someone they trust to make treatment decisions for them in the event that they become incompetent to do so" (Torrey, 1997, p. 160). It is named for the Ulysses of Greek mythology, who ordered his crew to tie him to the ship's mast, so that he would be unable to follow the sea-nymph Sirens' beckoning towards dangerous rocks where they would be ship-wrecked. Although Ulysses agreements are legal in some States, they have not been approved in Canada.

Parents began to look beyond their own child to see the desperation of so many people who suffer from schizophrenia. They began to notice the many people with schizophrenia who have no family to care for them (Fred, 2347-2358; Lois, 1274). At one point, Evelyn's dentist stopped taking patients with government dental coverage because the reimbursement to dentists was reduced. Although she says that she and Joe could pay for Barry themselves, she took on the responsibility of sorting out the problem.

> So, I got myself into quite a state phoning around all these people. And it's all really rather ridiculous. I shouldn't get myself so emotionally involved in what really isn't even directly my problem, because Joe's got a good job and we can afford it, but I just feel for the ones who can't, you know (Evelyn, 2060-2066).

Other parents began to help with the projects and organization of the Schizophrenia Society or with other organizations, such as the Canadian Mental Health Association. Having been blocked so often in their attempts to help their own ill child and to influence his or her care, these parents began working for the betterment of all those who suffer from this devastating illness. They realized that improving the lot of everyone who has schizophrenia would benefit, in turn, their own child. Thus they appeared to have expanded the scope of their parenting and to have symbolically redefined their "child"[30] as the community of people with schizophrenia. Once they have embraced the collective, they enter a new status, which I have called Parental Suffrage.

---

[30] Here, the word "child" refers the recipient of their parenting activity, that is, the reciprocal role (Hoult, 1977) of the parental role. Like the reciprocal or complimentary roles of parent and child, many other roles are at least partially defined by their reciprocal role, e.g. husband-wife, teacher-student, doctor-patient, employer-employee, etc. When the parents in this study identified with the support group and the Schizophrenia Society, they, in effect, broadened the recipient of their parenting to encompass people affected with schizophrenia, in general.

CHAPTER EIGHT

PARENTAL SUFFRAGE

Suffrage, as commonly used today, refers to voting power, but it also means to gain a voice or to voice an opinion, particularly a collective opinion. A less political meaning is to provide help, support, or assistance. The word originated in the church where suffrage refers to prayers of intercession, that is, praying for someone else or asking God to intercede on someone's behalf (The Compact Oxford English Dictionary, 1971). Parents of people with schizophrenia employ suffrage in all of the above ways. Having identified with the schizophrenic community, they work together to help and support those who have schizophrenia and to influence public opinion toward compassion for those suffering with this illness. Through their prayers and through their petitions to those people with political power, they strive to benefit both patients and families. That they are beginning to see some positive results is evident in the following statement:

> ...when I spoke to the staff at Riverview, I said that finally family members are being included in a discussion and a treatment plan and I said it's a little bit like women getting the vote, that it was something they had to fight for, and it should have been a natural process and so I say the whole question of including family in the treatment and discussion isn't something that should have been fought for. It should have been there from day one (Willow, 2105-2113).

Nevertheless, many parents are not satisfied with their child's care, nor with the amount of input they are allowed. Therefore, in their new identity of Parental Suffrage, parents engage in three processes: ***taking on the system***, ***being disillusioned***, and ***mourning together*** (see fig. 7).

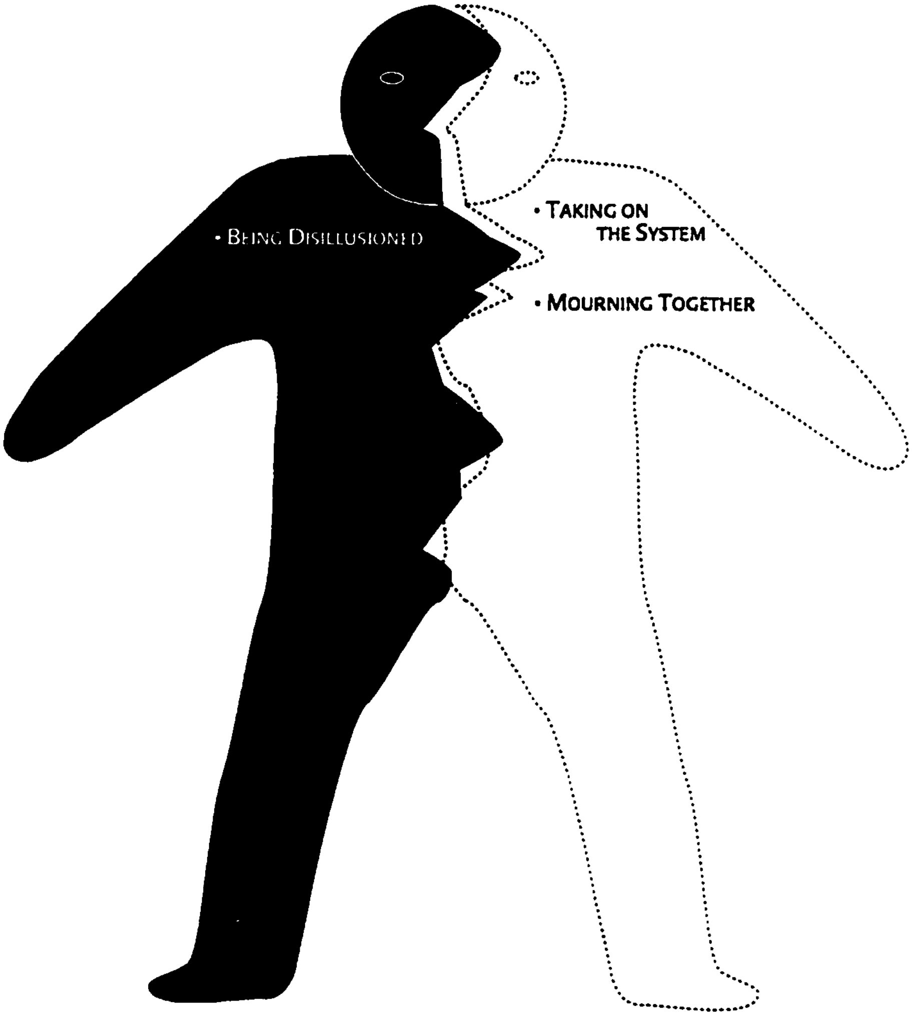


Fig. 7 Parental Suffrage

Taking on the System

...so I, I'm going to be there and if I'm not there, I'm going to yell and scream and make a lot of noise. But it's a very constructive dialogue and I think it will continue to be a constructive dialogue but also, my name is really known in the mental health system and I sit on enough committees [and] that means that people know that I'm really there and I'm going to be part of this whole change process (Willow, 1422-1429).

A major advantage for parents of belonging to an organization like the Schizophrenia Society is that these new friends have an understanding of the mental health system. Without guidelines for navigating through the numerous professional groups, agencies and programs, parents can easily be "lost in the maze" (Maggie, 323; Fred, 2269), unsure of the services available and of how to access them.

The Mental Health Care System

> For some families in this study, the mental health system is working quite well. Their adult-children are relatively stable, living in group homes or semi-independent housing and supported by a number of services and mental health care providers. These parents have established communication with one or more of the professional caregivers who keep them informed and are available when parents notice their child having difficulties. For example, Arthur says that Daniel now lives in a nice one bedroom apartment, subsidized at $260.00 per month, with some home help and an activity worker who arranges a weekly social outing (112-122). Similarly, Lois's son lives in low cost housing and regularly attends a medication clinic. Lois speaks regularly with the psychiatrist, mental health worker, the people at the drop-in center and to "anyone else that happens to be involved with him" (514) and states she "really appreciate[s] being able to share the load" (504). Evelyn describes a comprehensive list of mental health professionals, including the social worker, the housing placement worker, a nurse, a diet care worker (who helps with menu planning and shopping), and a care aide (who motivates Barry and his room-mates to keep their house clean). With Barry living only six blocks away, Evelyn is thankful for a mental health system that allows parents to "be supportive without them living under your roof" (636-637).

Not all families are so fortunate. A major problem is that:

> ...there are supposedly all these supports in the community but they only work if people are well enough to fit into them. And there are a lot of people that don't (Lorraine, 1251-1255).

When people like Melanie and Colin completely reject their illness and refuse treatment and services, families are left with no formally organized support. For Trevor, the system failed tragically and then swung into action too late. When Fred discovered his son coherent and stabilized in the forensic hospital, he was angry at the injustice of a system that could not accommodate Trevor prior to killing his mother but admitted him immediately afterward (Fred, 2183-2207). In addition, many parents bemoaned the fate of those mentally ill people who have no family and of those who are homeless, whether they have a family or not. Thus, while there are success stories, many people slip through the cracks in the system (Lorraine, 1316).

Availability of Services

Although there are good examples of programs and facilities, these are not universally available. There appears to be no standard model of care that exists in all communities. Local governments support mental health services to differing degrees. According to Kulwinder, Kal was doing very well in a day program until they moved to a different city in the lower mainland. Kal was transferred to the new area and, although the same Community Living Society ran the program, it was not nearly of the same quality and Kal's behaviour deteriorated (197-220). Similarly, Margaret noted that many of the services that are available in downtown Vancouver are absent from her area. Therefore, the presence of particular services in one community is no assurance of comparable ones elsewhere.

Many mental health services are provided by charitable groups and non-profit voluntary organizations which may or may not have contracts with the government. For example, the court advocacy program that assisted Elaine is paid for by Mental Health but is administered by the Schizophrenia Society. As well, the house occupied by Barry and his three room-mates belongs to the Mennonite Church:

> It is usually charitable organizations. In [part of Greater Vancouver], because the Mennonites were very good men but you can get [housing] with people like the Lion's and so on. And they buy them and then rent it through Mental Health to the consumers, the people who are mentally unwell. It is taken directly from their Welfare cheque, the house payments, you see (Evelyn2, 160-168).

Consequently, the ad hoc nature of services created by altruistic organizations in response to specific needs ensures that the availability and quality of programs and services varies in different communities.

The high cost of services presents another problem, particularly because a range of services is required to meet the varying needs of different people. A major consequence of cost is the large case loads of many professionals (Arthur, 105-109). Although several parents compared mental health services in Canada favorably against other countries in the world (Bruce, 1250-1262; Joe, 1184-1185, 1583), parents were also aware of the economic reality of trying to provide comprehensive services for everyone who may require them (Gerald, 951-954). Similarly, parents noted the tendency of governments to finance new programs and then later to reduce the amount of financial support. As Kulwinder told me:

> ...Dual Diagnosis Team, when it came into existence, they did quite wonderful job, made a profile - medical history, mental history, and all that, but now they are short of funding, all the people are gone, the psychologist who started that, he's gone. Four doctors changed in the meantime (305-310).

Joe, who praises the mental health system, worries that it may not last:

> I hope the country stays stuck together enough, like I say, the royal treatment he is receiving now, continues on. As long as we all have the fantasy of money and the fantasy of a social system, and the mental health care money keeps flowing like it is now, well, I guess he will be okay, because he gets taken care of and fed and piped lots of pills into him (1176-1183).

Housing

The availability of good low cost housing also varies. Those who are in group homes or semi-independent living with full disability pensions appear to be better off than most. Unfortunately, the need for housing units far exceeds the supply. Greater Vancouver has a waiting list of 920 people (Willow, 2294). A friend of Willow's applied five years ago to the Coast Foundation[1] because her accommodation is no longer safe. She is now 400th on the list (Willow, 2293-2311).

People who live in single room occupancy hotels in the inner city core are at the other end of the housing spectrum, although here too there is a wide range. For example, Ruth was pleased when Tim was chosen to live in a newly renovated hotel in downtown Vancouver. Her visit to the building just prior to the opening was encouraging. Four days following Tim's move, she visited again:

> I was aghast at the mess in the kitchen to start with. Somebody had thrown up in the sink. There was feces all over the floor in one of the bathrooms. There was one door had a crack across it. This is a piece of wood — thick, you know, I don't know how you would describe it. It had been kicked — right next to him. My son was the color of green, a shade of green. His eyes were bloodshot. He hadn't slept all night (647-656).

In contrast, Roger lived in a single room hotel in downtown Vancouver but was well cared for at Triage six blocks away, where he was given his medications and meals by a caring staff (Philip & Donna, 348-393).

Group homes also vary widely. Some parents, like Catherine, have had good experiences and open communication with the group home manager. In contrast, Tim, who

---

[1] Coast Foundation is a registered non-profit society in Vancouver, BC, dedicated to providing housing, vocational training, and social opportunities for people with mental illness.

is now in a group home, tells Ruth his problems when he visits every third weekend. He is afraid to voice them at the group home for fear of being sent back to the single room occupancy hotel. Philip and Donna also had experience with good and bad group homes, for example:

> ...that group home in Richmond, she had a rule apparently that they leave the house at 9:30 in the morning and not appear again until supper time (Philip, 416-419).

According to Donna, the patients were taken to a day care center with "really nothing going on" (423). Philip and Donna concluded that, with numerous widely-scattered facilities there is little chance of proper supervision or of frequent and thorough inspections, especially when group homes receive advance notice of an inspection date (2158-2199).

Poor Communication

The transfer of information about their child among programs and mental health professionals within the mental health system is lacking in the estimation of these parents. For example, the fact that patients have been in the hospital and under the care of a psychiatrist is no guarantee of the Mental Health system's awareness of them (Jenny, 2480-2500). Similarly, there appears to be poor coordination within and among government departments, such as Human Resources[2] and the judicial system, that share jurisdiction with the Ministry of Health over the mentally ill. As Philip and Donna said, "the social worker usually didn't know who he was [when Roger] moved from file folder to file folder" (1014-1017).

Communication between parents and the mental health system tends to be initiated by parents only and often their overtures are not welcomed:

---

[2] In British Columbia, Social Services has been renamed Human Resources.

> ...there is lip service given to families being part of the whole treatment, okay? But when you try to be helpful, you're considered to be intrusive (Lorraine, 1258-1261).

For example, Arthur has been unsuccessful in discovering the amount of money Daniel receives in social assistance. In another example, a crisis intervention team was established and a presentation was made by them to a Schizophrenia Society meeting:

> ...the Crisis Team was established but they couldn't give us the telephone number of it because they were only supposed to deal with other, basically it seemed, other institutional groups like the police or the, or whoever it was they dealt with. They would give educational talks and it just seemed strange to me that finally when the service was offered that we'd been lobbying for, that we couldn't get the number because they were back in the system. It seemed like there was a wall between the provision of services and the parents that were standing outside wanting help (Michael, 763-771).

Services for Families

Just as mental health services vary from one geographic area to another, the provision of family support is also uneven. Shortly after its formation, the Family Advisory Council for Mental Health[3] (Lois, 936-940; Maggie, 1310-1313) surveyed the Mental Health Centers on Vancouver Island regarding whether they provide counseling for families. All professed to offer such a service but some had insufficient staff to implement their program and others required the ill-person's permission for parents to participate (Lois, 953-956). When Maggie, a member of the Council, learned that her local Mental Health Center offered family counseling, her reaction was:

> It's wonderful to hear it's there, why is it that I've never discovered it? So, there's a lot of good stuff on paper but I personally have never received it (370-373).

---

[2] In British Columbia, Social Services has been renamed Human Resources.

[3] The Family Advisory Council was established following the Task Force of Families of People with Mental Illness (British Columbia Ministry of Health and Ministry Responsible for Seniors, 1993). The Task Force recommended that caregivers have better access to information, education, respite, support, and counseling.

Government funding has recently established a respite service for caregivers of people with mental illnesses in Victoria, modeled on the successful one established by BCSS in Vancouver (Lois, 986-1042; 2027-2123). Respite is periodic care provided by someone else to allow the primary caregiver some privacy and freedom. Other family services that parents in this study have found helpful are the Journey of Hope and the Kids in Control programs[4] offered by BCSS and the West Coast Connectors.[5]

Cultural Appropriateness

Ethnocentricity was identified as a problem of the mental health system by only one parent, Kulwinder, which is not surprising when Kal's family is the only non-white family in the study. In their experience, Kal has been subject to discrimination. For example, Kulwinder stated:

> When there is a discrimination at the group home, he should know how to cope with that. If he is not being given a cup of tea when other person is getting a cup of tea, he should be able to cope with that, but he does not have that coping skills (Kulwinder, 387-391).

Because most East Indians prefer to have their ill family member living at home, no other East Indian lives in Kal's group home or participates in the programs he has attended. Thus, living in a group home isolates Kal from his East Indian culture, although there is one East Indian staff member who occasionally accompanies Kal to the Sikh temple.

---

[4] Journey of Hope is a 12 session education program run by volunteers for families of persons with serious and persistent mental illness. Kids in Control is another education program, specifically for siblings.

[5] The West Coast Connectors is a local program in a town on Vancouver Island established initially by mental health nurses as a partnership among professionals, consumers, and family members. They have a drop-in activity center for consumers and offer various courses for consumers and families to take together (Lois, 1538-1576).

In summary, parents are concerned about the short comings of the mental health system. While they see many promising initiatives, these are not always available for their adult-child or for their own family and they worry about the future of the system given the political climate of economic cut-backs to social programs. Consequently, many parents undertake to influence the political process.

Advocating

Parents want to be consulted about the services their child needs but according to Sam, "The system just says, 'We know what's best.' I mean nobody has ever asked us what we think is best" (1203-1205). In response, some parents persist in informing those who have the power to make decisions about mental health care:

> We have to convince the politicians. The politicians are listening but they are listening to the wrong people. Our hospitals, our wards, are very poorly staffed. The resources are very, very few. Very slim. When it comes to closed beds, it seems like it is a big scandal if it was in an active ward in the hospital but if we said, in [psychiatric ward] it is routine (Teresa, 1724-1732).

Thus, advocacy is important because the "squeaky wheel gets the grease" (Jenny, 2520; Gerald, 982). Better patient services and family services are two main areas of concern.

Health care reform is a third target of their advocacy efforts. A major concern is that mental health has not been guaranteed representation on regional boards of health:

> ...if you have a regional board that may not have anybody on the board who understands or knows about mental illness, [then] their focus would not necessarily be on that kind of service, so it's up to us to, to get 'in their face' (Lois, 1985-1989).

The lengthy process of health care reform is frustrating for parents when promised facilities are delayed time and again while the new regime becomes operative (Warren, 440-454). Even more frustrating are instances in which the government reneges on long promised reforms. Willow, having participated as a family representative on a steering committee for the replacement of Riverview by the year 2002, was shocked when suddenly several years of work costing half a million dollars (Willow2, 453) was shelved:

> ...for me that indicates how scary the water is. The sense I got was that families may take a class action suit...family members at Riverview are thinking very clearly of taking a class action suit against the government if, indeed, they don't stay with their promises (Willow2, 1027-1029, 1032-1035).

The law is another focus of their efforts. Parents despair the disastrous consequences of human rights legislation for the mentally ill, which has swung too far in protecting the rights of people who may be "incapable of running their affairs" (Fred, 2148). Some legal provision for trusteeship, similar to that for patients with Alzheimer's, ought to be available for the severely mentally ill (Fred, 2147-2169). As it now stands:

> We have given this adult child powers that, you know, we are saying, you be the psychologist or the psychotherapist. You be the doctor. You determine if you are okay - and you tell us what's wrong. And if you're not, you can kill your mother and do anything you want. Kill yourself until — and then we kick in the current system. Then we'll really help you (Fred, 2170-2177).

Given the criterion for certification as being a danger to oneself or others, then danger to oneself must be interpreted more liberally:

> ...a danger to yourself is not taking care of yourself, as far as I am concerned. You would not let an Alzheimer's patient do that. And this is what I don't understand. There is one set of rules for the elderly and there's another set of rules for people with mental illnesses. I mean, what's the difference? Someone's not taking care of themselves (Lorraine, 1336-1343).

Yet, parents also remain aware of the difficulties inherent in changing the law:

> ...when you get down to legality, I mean, how do you have both sides: protect the rights of the individual and at the same time take some of those away. It's a dichotomy. If the law could be revised specifically for people that have mental disorders and not be written in a way that violates their rights, but just asks for all possible inputs to help to create a way to help the person enjoy life, why wouldn't you do that? (Sam, 1210-1219).

Although several of these parents, like Fred, Lois, Michael, Warren, and Willow, have been active and visible advocates, others are less comfortable with public scrutiny. In fact, Jenny worries that some parents may be discouraged from joining the BCSS because of their reticence to be politically involved (2029-2073). Two parents noted that by criticizing the mental health system, people may antagonize professionals or set themselves up to be ignored (Ruth, 1336, 2268-2277; Michael, 1053-1060). Thus many parents, like Catherine, Donna, and Clifford, utilize less threatening and less public ways to work for change, such as writing letters,[6] or advocating on an individual basis for other families. Jenny is a good example. She would rather not serve on the executive of the local BCSS chapter but often helps individual families who need help to access services. When a seventy-eight year old deaf woman was experiencing difficulties with her ill son, Jenny approached the Mental Health Clinic and was told:

> "Well, he's not a patient." I said, "He's a patient of Dr. [N]." I said, "Now I would hate to write to Victoria, but that's the next step I'm taking." Well, I tell you, I wasn't even home here and they had phoned. "We have a geriatric psychiatrist, or psychiatric nurse, and he will see this patient immediately" (2496-2404).

In whatever way parents are comfortable contributing to advocacy, they work toward three major results: better family consultation and input into their loved one's care, better mental health services for patients and for families, and a more humane law regarding the rights of the mentally ill.

Volunteering

Whether or not they were active in advocacy, the majority of these parents volunteered in some other capacity and would agree with Evelyn's statement that:

---

[6] British Columbia's Pharmacare program declared that after April 8, 1997 the novel antipsychotics, olanzapine and respiridone would no longer be covered as first line drugs. This meant that only after an unsuccessful trial of traditional antipsychotics, such as Haldol, would the government drug program pay for these medications. The Schizophrenia Society quickly organized a letter-writing campaign to MLAs requesting a reconsideration of this policy ("Curb on Drugs," 1997). Respiridone has now been reinstated as a first line drug.

> ...probably the most therapeutic thing has happened in the last couple of years, has been helping other people, because as you help others then you feel better (636-629).

Parents appear to choose their volunteer job to suit their personalities, skills, and available time. They may serve as a family representative on various government committees and boards, assist with the programs and projects of a voluntary organization such as BCSS or the Canadian Mental Health Association, or accept a position in the administration or executive of such a group. Many volunteer jobs, however, are less high profile, such as clerical work or assisting with social activities. Others prefer to work directly with consumers or with family members of newly diagnosed patients in support groups or separately. As well, many parents teach others about schizophrenia, believing that the only way to replace the stigma against mental illness with compassion is to educate the public.

Raising Awareness

Improving public knowledge is crucial for overcoming the stigma that prevents community acceptance of the mentally ill and that prevents those who are ill from seeking treatment early and from accepting the reality of a diagnosis of schizophrenia. As long as people confuse schizophrenia with a split personality (Gerald, 1428; Jean, 1443) or multiple personality disorder, or newly diagnosed families are unaware of the Schizophrenia Society (Jenny, 2801), or communities lobby against group homes (Jean & Tom, 1165-1174), more effort at public education is required. Jean's story of sitting in a shopping mall at a BCSS information table a few years ago when the only people who approached the table already had a family member afflicted (1422-1447) shows that many people would rather not know about mental illness (Teresa, 1776).

On the other hand, public understanding has improved over recent years. Fewer people blame the family for causing a child's schizophrenia (Catherine, 1804-1809) and there are examples of less sensational and more balanced coverage in the press (Jean, 1447-1451). Parents are finding that the police are more understanding (Jean & Tom, 1093-1100); that more people express an interest in learning about mental illness; and that people are more willing to discuss schizophrenia openly. Jean's recent experience at an information table at the university is more promising:

> ...there was ever so many come, well the university students, quite a few of them come up because they are taking related things and they will come up and talk about it (1466-1469).

Public education can take many different forms, from public forums to private talks over coffee. One successful educational program in British Columbia is the Partnership Program, in which a consumer, a family member and a professional care provider present a team workshop about schizophrenia to schools, business people, and community groups. Another new option is the internet. Sam is planning to set up a Web page for the Victoria BCSS that includes current in-depth technical information but is written in plain language (447-460). One criticism of the available educational literature, in Clifford's estimation, is it's accentuation of positive stories. He believes that in order to stimulate compassion for sufferers and their families, people must also be exposed to the "ugly side" in order to understand caregivers and the pain they suffer in trying to reach the person they loved (3213-3233).

Promoting Research

Hope for improved treatment and, eventually, a cure is behind the firm belief that parents hold in the value of research. Gerald, especially, promotes research over raising awareness or providing services as the most important goal for the Schizophrenia Society. He states, "If you could spend the money to get rid of the problem, then you wouldn't have to explain it or deal with it" (1461-1463). On a more cynical note, however, he notes that the pharmaceutical companies are more likely to research long term treatment options than a cure (1494-1500).

Thus, through their work in taking on the system by advocating, volunteering, raising awareness, and promoting research, parents hope to positively impact the fate of all people who suffer from schizophrenia and, indirectly, help their own son or daughter. Their efforts take courage and determination but the process and the results can be satisfying. As Michael said, "It made us feel like we were actually doing something instead of waiting for more bad news" (1095-1096). At the same time, their volunteer work frequently meets resistance from the mental health system, thus setting parents up for discouragement and disappointment.

Being Disillusioned

> I think the term I would use, even though you are using "taking on the system," is "working together" or "something together," because even though it's taking on the system, it's working together to bring about change and all that kind of stuff, but being very disillusioned with what's going on as well (Willow2, 480-486).

Although parents approach their volunteering and advocacy projects with enthusiasm, change is not easily won and the difficulties inherent in taking on an entrenched bureaucracy soon become apparent. Being disillusioned with the system centers around three broadly defined problem areas: money, accountability, and political processes.

Problems with Funding

Those who champion better care for the mentally ill quickly discover that mental health has been funded less well historically than the more technologically exciting fields of health care. Just as the stigma against mental illness affects people on a personal level, it also interferes with an equitable allocation of funding for the mental health system (Clifford, 3531-3539). When pointing out the favorable position of cardiac care as compared to psychiatry, Teresa says, "We don't want more. We want equal" (1765). In addition to the inequities, parents worry about government efforts to reduce health care costs overall.

Within the mental health care system, insufficient funds translate into overworked, underpaid, and poorly qualified staff (Fred, 2260-2262), longer waiting periods for services (Willow, 2270-2272), and insufficient time spent by professionals with patients. Consequently, Fred is convinced that, had the forensic psychiatrist spent more time to fully assess Trevor, he would have recognized Trevor's potential for violence (1195-1196). Some levels of staff in community programs and group homes are poorly paid (Philip & Donna, 2178-2188) while, at the same time:

> We put a great deal of money into administration which means creating offices and having people sitting around talking to each other, and filling out forms. But nobody is on the ground (Philip & Donna, 2129-2133).

The most frequently cited consequence of limited funding is the reduction in the number of hospital beds. As a result, patients are seldom admitted until they need to be certified and then they are discharged too soon (Lorraine, 1246-1250; Ruth 250-255). Consequently, Anne's discharges and passes from the hospital have placed family members in danger. Teresa observes that when Anne is violent in the hospital, the nurses are protected. At home, parents lack equivalent resources:

> I don't have security guards in my house. I don't have shots to tranquilize Anne. I don't have rooms that I can lock and throw her in. They do....They cannot imagine what the parents go through at home. Because they are protected there (Teresa, 1239-1243, 1253-1255).

Parents conclude that as long as their ill children are discharged before achieving sufficient insight to accept ongoing treatment, the revolving-door cycle of acute admissions and precipitate discharges will persist (Ruth, 251-255; Teresa, 837-848). Not only has the reduction in long-term institutional beds been excessive (Jenny, 1656-1657; Lorraine, 1437-1438), there is a need for more acute psychiatric beds in hospitals and in short-term crisis centers (Lorraine, 1407-1437). Thus, had sufficient hospital resources been available, Elaine would not have felt pressured to care for Trevor at home as the only option to three or four months in jail while awaiting a forensic hospital bed (Fred, 1324-1342).

Lack of Accountability

The lack of communication and coordination that they see in the mental health system contributes to the perception by parents of little accountability in the system.

> There was no service delivery cohesion here....even if somebody could be assigned to the case as a non-expert person — a project manager walks us through the system. There was nothing like that (Fred 1411-1416).

Parents are desperate for someone who accepts overall responsibility for their child's care and who will give them information. As Philip and Donna stated:

> ...for ages nobody seemed to have his file and he didn't seem to be under any doctor. He was just kind of nowhere....The social worker took the view that it was none of our bloody business. No, they wouldn't give us any information. It was all confidential (1037-1049).

There appears to be no continuity of care among different levels of staff or from one time period to the next (Teresa, 1160-1172; 1206-1207) and people appear to be more worried about their jobs than about their patients (Kulwinder, 501-505; Philip & Donna, 2188). Parents see professionals leaving the system and not being replaced (Willow, 2264-2267), concurrently with policy makers and program directors making promises that they fail to deliver (Willow, 2261):

> ...they develop a plan, they put lots of good things in it, but when it's come, when the delivery time comes, everything falls down. Nothing substantiates. It looks really good on the document when they try to get the contract. They don't deliver. There is no accountability in this system. We talk too much. No substance (Kulwinder, 1468-1474).

Recently, according to Willow, a team of assessors evaluated mental health programs across the country:

> ...we met with these men and we were the ones who set the guidelines for what they were looking for and assessing the teams in Vancouver and the men said that Vancouver has one of the finest mental health programs in the country, if not the North American continent and my response is, "God help us" (Willow2, 2249-2254).

Accordingly, Willow has little confidence that the system will look after Ken. She presently pays privately for psychotherapy in addition to the care he receives from the mental health team. In the final analysis, "I think anything that comes at Ken will be self established" (Willow2, 994-995).

Political Maneuvering

Discouragement sets in when parents perceive good care to be more the result of political games than suitable planning. Why should appropriate care be predicated on knowing the right people (Gerald, 196-204) or writing letters to politicians (Jenny, 783-787; 2510-2520; Philip & Donna, 1463-1471)? An example follows:

> His name is Tom Perry and he was the minister of higher education a number of years ago and Tom is a friend of ours, and Tom came from Victoria to go visit Ken in Riverview with me and Ken was on a very long wait list to enter a group home and Tom and I came into the board and sat down and the social worker said, "Good news. Ken is accepted into a group home tomorrow." Now, somehow or another, that tells me that that was really a manipulation to look good to Tom (Willow, 1326-1334).

On the other hand, Willow notes that power does not solve everything given that children of wealthy families live in the inner city and the former Premier of the province's brother has been treated in Riverview.

Nevertheless, parents are concerned that government funding of mental health care is subject to the whims of politics. Teresa attributes the relative lack of funds for mental health to the fact that few psychiatric patients vote (1750-1753). Thus politicians, worried about reelection, can ignore the mentally ill. Political pressure, rather than clear evidence of efficacy, may determine which programs are supported and which are not (Michael, 813-

819). Bruce, particularly, believes that mental health care must follow the dictates of scientific evidence:

> ...it's time for the mental health community to clean house I'm afraid. And not just repressed memories, all sorts of other nonsense, primal scream therapy. I mean people shouldn't be paying for this drivel. You know, the taxpayer shouldn't be paying for that. If they can show, yes we've done studies and this seems to help that – fine. Just because somebody thinks if you sit and bay at the moon for a week you'll get better is no reason the taxpayer should pay for it. There's just unlimited freedom of so-called therapists to treat people however they want and get paid for it (1227-1239).

When they see political games influencing mental health care, parents are not confident about proposed health care reform. One concern is the growth of private agencies and non-profit societies at public expense but without clear evidence of government scrutiny (Kulwinder, 339-354; Philip & Donna, 2043-2075). Another is the question of how closely their loved ones will be followed by community mental health:

> If Anne is set up in the community it will be like anything else [that] has not worked out. It could be there, half of the time untrained people; half of the time they are left on their own; half of the time they will not be supervised. And, the best insurance is keep the institutions because I know, although Anne is suffering she is protected and she is safe (Teresa, 1684-1692).

The cost of providing sufficient numbers of qualified people in the community to keep many psychiatric patients safe looks prohibitive (Fred, 2257-2262; Willow2, 978-985) and there is still no planning for how to care for those who deny their need for treatment.

While the health care system usurps a parents' responsibility towards their ill adult-child, it fails sometimes to follow through. After Roger's accidental burn in the shower of the group home, Philip wrote to the Public Trustee:

> "...it seems to me that you, as trustee of my son's affairs, have reason, on behalf of the government as well, to sue the operators of the group home for the damages etc. etc." There wasn't any level of interest at all. It's your [the parents'] business. And yet I had been told I had absolutely no control of anything to do with Roger and the money he got and so on, it's not my business (Philip, 2089-2096).

Although the group home was subsequently closed, Philip and Donna believe no financial sanctions were applied and that the proprietors may be continuing to run other group homes (2103-2112).

Therefore, for many reasons, parents are anxious about proposed changes in mental health care. They do not believe that families' concerns are being addressed as well as they should be. Even when there are sympathetic people in the system, there is doubt whether the families' concerns will be endorsed. At the meeting where a representative from the government relayed the retraction of the Riverview replacement project, Willow states:

> The question was, even though he heard what we were saying and understood the issues, would he take that message back to Victoria, and he said "No." He would not say, "these are the issues and this is what needs to be done." And, you know, would he fight for these issues? And he said, "No." So even though he was sympathetic, he is not going to put his neck out at all. 'Cause you play the game (Willow2, 1006-1014).

Consequently, while parents are busy working together to change the mental health system, they are frequently disillusioned by what they see happening there. To some extent their disillusionment with the system is counteracted by the support they receive from the other parents.

Mourning Together

> You see, when you first go to the group, people share things, their concerns, and it is sort of peer encouragement, because as people will share their concerns there is usually somebody in the group who has been through that and can help you, you see? As we were at the very beginning, I just felt the sympathy. I just felt that they cared. I think empathy is a better word, isn't it? And they all encouraged us that things were going to get better. Through the months and through the years, each month as we came with new concerns, there was always somebody who could meet it (Evelyn2, 50-61).

Attending a support group allows the communal expression of a parent's private grief for the child that was. By joining a support group, a new member gains both the ear of others who empathize because of their own experience and the benefit of their practical wisdom, accumulated first hand over many years of living with mental illness. Support group members discover that everyone, new and old, profits from sharing information and caring for one another:

> ...you get to be able to offer advice to people who are just running into it and that takes away the feeling of hurt that you picked up, because you can see people benefiting from what you have experienced (Michael, 689-692).

Not everyone attends a support group. In general, women attend support groups more than men do. Sam explains that the sympathetic sharing of experience is more acceptable to women than men (Sam, 529-538). Evelyn believes that women are able to talk about mental illness more readily than men, because women can accept imperfection in their children more easily than men. Often people will attend regularly at the beginning and drop out as their confidence increases or their child responds to treatment (Evelyn, 101-114). They may return later whenever their child relapses. For some people, one-to-one support is more helpful. Support group members usually exchange telephone numbers for such help between meetings.

Practical Advice

Although parents can learn a lot about schizophrenia from books, much of their practical knowledge is gleaned from one another. When they work alongside other volunteers or attend a support group, parents receive advice about how to deal with their ill child and how to deal with the system from "somebody that knows the ropes" (Jean, 428-429). Because parents encounter new problems as their child progresses through the illness, ongoing contact with other parents is helpful. Comparing stories with other parents may reveal previously successful ways of approaching a particular problem (Lois,1727-1737), and reinforce the value of setting priorities:

> ...letting go of some things and not trying to solve the whole, the problems of the world. [You] can't do that. It kills you....It keeps you from coping at all if you, if you let things get too overwhelming (Lois, 1735-1737; 1743-1744).

Although they can read about services for the mentally ill in a general way, caregivers need advice about what options are available locally and recommendations for individuals who can best provide those services. By default, parents need to prepare themselves to act as their child's case manager. For example, when Barry was being discharged from the hospital after his suicide attempt:

> ...the Welfare worker was discharging him to a regular accommodation and through this group I was able to hear about houses that are set up where there are caregivers and so I knew enough then to ask the psychiatrist what he thought (Evelyn2, 143-148).

A major concern for parents is what will happen to their loved one when they die or become too old to care for their ill child. Catherine noted how difficult it is to organize a trust when one is unsure how incapacitated the ill person will be in the future (173-179). Wills and discretionary trusts are a frequent topic of discussion at support groups. The Schizophrenia Society provides information, which was developed in conjunction with PLAN, the Plan Lifetime Advocacy Network, a group formed by parents of mentally disabled people in the lower mainland (Margaret, 1825-1851). Although many parents say that their other children accept eventual responsibility for their ill sibling, they worry that these siblings will be living in a distant city and will have their own families as their top priority. Evelyn's support group has suggested appointing an independent third party as trustee, as a way of preserving the sibling relationship and preventing possible disagreements over money (200-219). Another consideration for the ill person's future security is housing:

> ...there are some of us who are looking into purchasing a house with separate suites or an apartment complex that our family members can go into to be taken care of and, you know, investing in some sort of security for our family members but, again, that's a long way down the road, as well (Willow, 1002-1007).

No matter how carefully parents arrange for their child's financial safety after their own deaths, they continue to worry that their ill child will essentially be alone in the world (Willow, 1620) without a fully committed caregiver (Bruce, 1010-1015).

Coming to Terms

Being able to talk about their experience with parents of other consumers helps grieving parents progress toward acceptance. As Ruth observed:

> I realized that the illness of schizophrenia requires a grieving time and it requires an acceptance time (393-395).

Coming to terms with the chronic nature of schizophrenia may take a long time. In Catherine's case it took "at least five to seven years before I could even talk about it" (1563). In addition to professional help and attending a support group, Catherine's friends and colleagues at work were her major support.

For these parents, acceptance meant recognizing that schizophrenia is a chronic illness and that one's loved child is always going to be different (Evelyn, 421). Jenny's advice for parents was to expect the worst and thus prevent disappointment:

> ...it's going to get worse, it's not going to get better, and if it gets better, that's a bonus (2628-2630).

Jean has set her memories aside consciously (1168-1171, 1605-1612) but for Evelyn acceptance came gradually with "three steps forward and two back" (630). Margaret spoke about coming out on the other side of her grief by being realistic (1925-1928). Only when parents began focusing on the present and future instead of wishing for the past could they begin to come to terms with their child's schizophrenia.

Many parents displayed a determination to accept reality. Willow said, "that's where life is and let's go with it" (1732). Joe commented that wishing for a cure would only make parents depressed (1598-1600). Marianne's story conveys this determination better than any other:

> I took a whole day off from work and I sat at my kitchen table and I had a scribbler and I just wrote out line after line, "My son, Daniel has schizophrenia," and I wrote it, and I thought, "I'm not going to leave this house until I can say that without shame or embarrassment and it's a fact and I will accept it. I can't change it. I can't do anything about it. I will accept it and I will never love him less because of it." It was a hard day of acceptance, but I did it and I'm glad I did it. And, from there, it was an accepted fact (629-639).

Part of acceptance is learning to be thankful for what one still has. Having a strong family upbringing (Ruth, 1804-1806) or having a husband or wife to share the load (Michael, 662-664) gives one the strength to endure unhappy times. There are also wonderful times to enjoy with the ill person, if one remains open to these "fleeting treasures" (Clifford, 731-734) and "little victories" (Fred, 2611). Again, Marianne describes her thankfulness well:

> I was saying, sort of, "Why me, Lord? Why, why in our family?" And it was just like a light bulb went on all of a sudden one time and it said, "Why not?" If there has to be one in a hundred, what other home could he come into where, having this mental illness, he would still have the love and the care and the sharing that he had, and by taking that attitude, it was almost like this was a total new learning experience for me (1853-1861).

Mourning together helps parents work through their grief and reach a level of acceptance. Evelyn said, "when my husband accepts it, he is a lot happier than when he fights it. And I am too" (422-424). According to Michael, by accepting your child's schizophrenia, you may still experience discouraging and unhappy times but you never return again to really deep despair:

> ...that seems to be a past page, a completed chapter, and I don't think we'd ever get, regardless of what happens, I don't think we'd ever get as down as we were at the time because simply — this happened before" (1229-1232).

To summarize, Parental Suffrage describes an identity that allows parents of people with schizophrenia to symbolically regain their parental rights to care for and take responsibility for family members whose illness has removed insight and the ability to care responsibly for themselves. Despite frequent resistance against their efforts to improve their individual child's circumstances, parents know that if they can ameliorate conditions overall for schizophrenia sufferers and their families, their own child will also benefit from their accomplishments. Advocating, volunteering, and raising public awareness about schizophrenia helps parents overcome their disenfranchisement, despite frequently being disillusioned with the mental health system. By sharing their grief and exploring new ways to help themselves and their loved ones cope, parents mourn together and work toward acceptance. For most parents, affiliation with some organization that addresses the needs of the mentally ill is important at this stage.

> If you want to get on top of the disease, you have to get access to that information, and experience, and counseling, and support. And the monthly meetings for some people are tremendous. Right off the bat they can unburden themselves and people will just understand and they will say, "Well, when you do so and so," "If you try such and such" or "This piece of information will tell you how to access that." And that's when the support starts to roll out. [long pause] That's the one piece of advice that just stands a mile high in my view. Talk to people that have been there (Michael, 1069-1078).

Parents may spend many years moving between the two statuses of Disenfranchised Parent and Parental Suffrage. Despite an overall progression from disenfranchisement through Embracing the Collective to Parental Suffrage, there is no prescribed time interval. Instead, the sequence depends, to a large extent, on the status of the child's illness. When he or she is very ill and in crisis, parents are focused on trying to alleviate the ravages of schizophrenia upon their child and their family. Thus, even after having taken on the identity of Parental Suffrage, parents are likely to slip backward toward disenfranchisement whenever the child suffers a relapse or new crisis. Nonetheless, having established a supportive network guards against the parents ever again feeling completely alone and disenfranchised. As their child begins to recover, parents are once again able to take the

Parental Suffrage role. Eventually, after years of concentrating their interests and efforts upon schizophrenia, many parents begin to reassess

EVALUATING MY LIFE

At some point parents may realize that they have been totally focused upon their child's illness and that they want to expand their interests in other directions. Usually, but not always, their adult-child's illness has stabilized (or begun to stabilize) and a level of community mental health service and housing support has been established. Some of this has resulted from the parent's advocacy efforts and increased knowledge of available services. Concurrently, the community mental health system has expanded in conjunction with widespread health care reform initiatives. For the first time in years, parents may feel less pressured to concentrate every waking moment worrying about schizophrenia and its devastating effects on themselves and their ill child. Confronting their own aging, they reassess how they wish to spend their lives (Fig. 8).

For some parents, this evaluation occurs because of disillusionment with the system and its resistance to change or because of despair over the chronic heartache and misery that has overwhelmed them for too long. Sometimes changes in their own health, stress-related or otherwise, force parents to retract from a chaotic lifestyle or, perhaps, they are worn out. In some cases retirement from paid employment may prompt a general life-review. For whatever reason, parents reach of stage of *acknowledging* the *realities* of their child's and their own lives and *identifying* their *personal needs* and desires.

EVALUATING MY LIFE

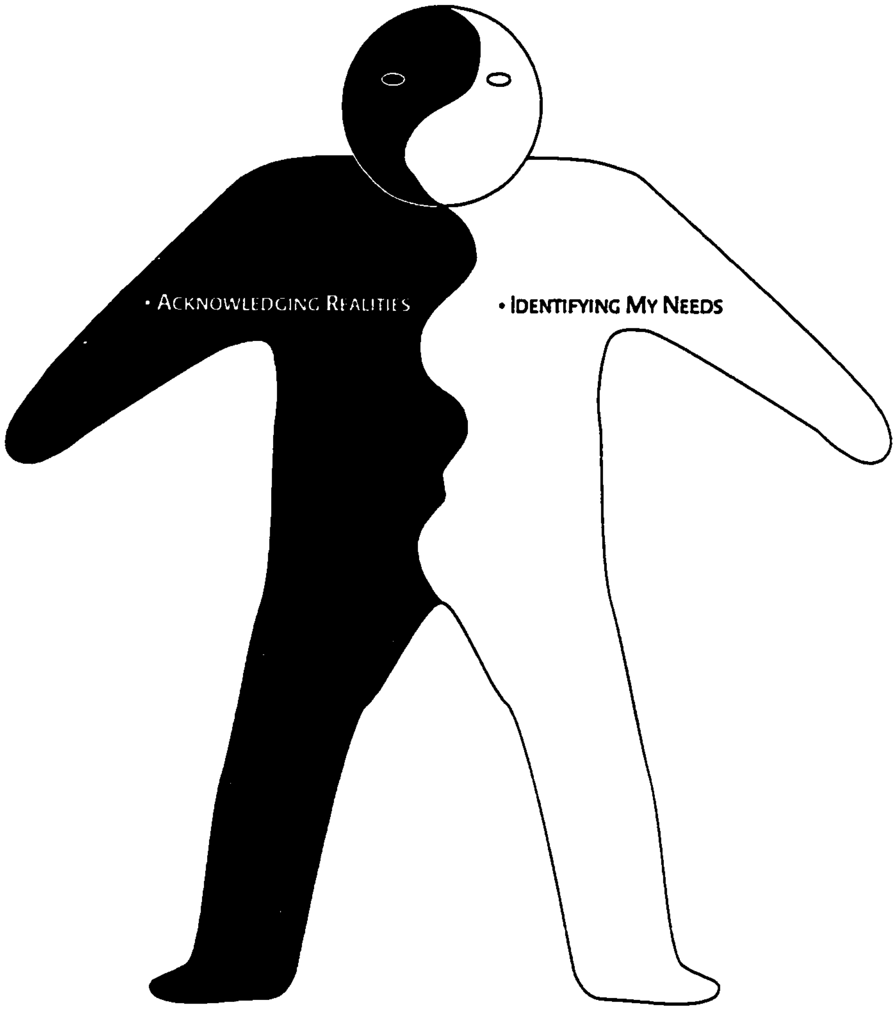


Fig. 8 Evaluating my Life

Acknowledging Realties

> So, if I would say acknowledging my needs, I would say acknowledging my realities, because to me a need is one thing, but a reality is another (Willow2, 257-260).

For parents to acknowledge realities involves evaluating the ill child as well as themselves. Evaluating the ill child is essentially achieved through comparison of the present status of their child's illness and life circumstances with changes over the illness trajectory thus far. In the same way, parents review their role as parent of the ill child and compare it with how they have fulfilled that role over the course of the illness. In most cases, parents can identity some improvement over time. In addition to comparisons over time, their connections in the mental health community allow parents to compare their own and their child's situation with that of other parents and people who suffer from schizophrenia. Both these comparisons point out some positive aspects that help parents identify themselves and their children as survivors rather than victims of schizophrenia.

The Ill Child's Reality

When their child is in recovery, parents can see their child developing positive character traits and other accomplishments that reveal improvement. Often parents see the return of personal qualities that were common prior to the illness:

> Now, we're seeing more and more of the old Maxine you know, a very loving person, coming back (Jean & Tom, 1441-1443).
>
> I guess it was two years ago at Thanksgiving, he sat down at the piano up at his sister's and played for about 20 minutes and I hadn't heard him play for 20 years, I don't think, and it really sounded great and I went off by myself and cried....It's sort of like we're getting parts of him back that we had lost. I often think it's sort of like Rip van Winkle, waking from a sleep after that 20 years (Marianne, 878-882; 910-913).

Often parents describe these character traits as glimpses, rather than the development of a stable attribute. For example, although Marianne now hears Daniel play more frequently, the quality remains variable:

> ...then later on in the day, when someone came, we tried to talk him into playing and then it was frustrating to him. He did, but just for five minutes and it wasn't as good as the first when he'd done it spontaneously. And with the guitar it kind of seems the same. Sometimes he'll pick up mine and play for, almost every time he comes up he picks up my guitar, but he sometimes only plays for five minutes or so, or tunes it, or, or putters around (Marianne, 888-897).

Nevertheless, each glimpse is encouraging.

Parents take comfort in any sign of improvement. Displays of affection (Evelyn2, 469-475; Jean, 481-483) and attempts to be helpful (Evelyn2, 426-430; Willow, 1943-1947) give promise that the ill person is becoming less self-absorbed. Any indication that their adult-child is becoming less withdrawn (Gwen, 1045-1090) and more independent is encouraging (Catherine, 76), as is evidence that an ill person is beginning to accept the illness and the importance of taking medications regularly (Jean & Tom, 666-672). In the final analysis, though, one of the best measures of their child's improvement is the length of time since he or she has had a relapse necessitating hospitalization (Catherine, 76-79; Lois, 468-470). Thus, parents notice improvement in their child's illness by comparing present social functioning with past performance.[7]

Comparisons with Other People

Through their connections in support groups and with other consumers, parents see many people who are in worse circumstances than their own child. There are those who have no one to care for them (Clifford, 3529-3530; Lois, 1274), those who are living on the streets or in slum areas (Fred, 2350-2351; Jean, 582-583; Willow, 2082-2084), and those who

---

[7] Studies have found that the mentally ill contribute to their families in various ways. Applying an exchange perspective, Horowitz, et al. (1996) contend that the norm of reciprocity is demonstrated in families with a seriously mentally ill member. That is, the amount of support that individual family members receive from the ill person is proportional to the caregiving they provide. Types of social support provided by ill members include expressing affection, gift exchange, and participation in family activities. Another study that investigated the ways in which the mentally ill contribute to their families discovered that 59% provide companionship to the family along with over 50% providing help with the following: chores, shopping, passing on news about other family members, and listening to problems (Greenberg, 1994). In this study of families with a member who has schizophrenia, as symptoms subsided over the long term, the adult-child began to contribute to family life in more ways.

will never get out of hospital (Willow, 2080-2082). Melanie's father recognizes that males with schizophrenia are often more severely affected (Michael, 1205), while Ryan's mother observes that "daughters brought home even more weird people than sons did" (Sue, 699-701). Parents also become aware of people without mental illness who have terrible lives (Maggie, 1874-1880). In consequence, a certain degree of comfort comes from knowing that, desperate as one's ill child's life is, it is better than many others and, hence, parents console themselves with statements like:

> ...her surviving on the street? I don't think she'd survive very long. She just doesn't have the street smarts like you'd need to have out there. Well, she doesn't do it anymore, thank goodness (Jean, 590-593).
>
> It's a terrible life he still has...but he continues to live on his own as well as he can, and there are people who make contact with him, and he is not on the streets, and financially he will never have to be on the streets, if my finances survive (Willow, 489; 497-502).

Alternatively, parents may see other people with schizophrenia who are significantly better than their own child but, instead of being discouraged at the relatively poor state of their family member, seeing other people get better gives them hope (Bruce, 1624-1632; Evelyn, 2105-2132).

The Parent's Reality

Looking back at the history of their caregiving during their child's illness trajectory, and looking around at other parents who are coping with schizophrenia gives parents an opportunity to recognize their own advantages and that their own circumstances have improved along with their child's illness. For example, some parents have more financial resources (Gerald, 618; Teresa, 802), more education (Teresa, 811-815), or better connections with health care professionals who can help them navigate the system (Gerald, 619). Parents know of other parents whose child has died, or continues to be psychotic and non-compliant with treatment, or has disappeared. An example follows:

> ...one night at a meeting I was telling one of the other people in the Society my troubles and then he told me his. And their son was a paranoid schizophrenic homosexual and he wound up down east following some notion and he froze to death in a field in Ontario in the wintertime and I thought, now, it's a worse situation than ours (Michael, 1200-1205).

They also see marriages disintegrating under the stress and families breaking apart when the other children leave because of the upheaval (Jean & Tom, 68-80). In addition, several parents, for example Clifford (1159-1161), noted that the pain of those afflicted with schizophrenia is greater than that experienced by caregivers.

Although initially every parent was taken aback when asked whether anything good had happened because of the child's illness, a number could identify positive effects. Several, like Catherine (1761-1771) and Michael (1106-1107), cited the friends they had made through BCSS. In fact, being part of the group that organized BCSS on Vancouver Island is an accomplishment of which Michael is proud (1089-1100). Meeting the needs of a very ill child has made parents strong (Teresa, 2032), more spiritual (Kulwinder, 1324), and more tolerant (Catherine, 1750-1755; Irwin, 1235-1242). Jean and Tom maintain the Maxine's illness has drawn them together (63-64) and Catherine says:

> I've become a much better teacher, much more understanding because, even though the child can be very, very difficult, I'm always willing to go that extra mile, because I think if a child, I always worry, I think children need as normal a childhood they can get because if they are hit with something like this in later years then they're just sentenced to a life of hell, really. So, that is something that I feel — it's definitely helped my career because I always try to find out where the kids are coming from (1720-1730).

Marianne, who has served on many committees, local and province-wide, has become a recognized family advocate and volunteer for better mental health care:

> I never got to go to university like the rest of my family did, and stuff, and I always sort of felt a bit on the dummy side that way, but I don't anymore and haven't for

> the last many years because it seems like this was a whole education unto itself. Totally different, but it's sort of a, a nook and a cranny where I do feel knowledgeable, as knowledgeable as a family member maybe can be (1874-1882).

At the same time, these positive outcomes are small comfort for the tragedy that has come to them and their children.

Realistic Expectations

Accepting the chronic nature of schizophrenia does not mean abandoning hope. With the recognition that, although ill, their child has made progress, parents begin to look forward again. Rather than wishing in vain for a cure and the miraculous transformation of their ill child back to the person of their memories, there is an acceptance of the person their child has become and an acceptance of their own scaled down ambitions. In essence, parents have now adopted the stranger but they continue to hope for a better future. Now, however, their hopes center upon their child achieving contentment (Gwen, 1144) and experiencing what Margaret referred to as "reasonable times of happiness" (819).

Scientific research into the causes and progression of schizophrenia and the development of new medications still offers the best promise for a better future but most parents recognize that, given the length of their child's illness and the inevitability of some irreversible neural deterioration, the best scientific result that they can expect is to arrest the disease process. As Bruce said, "it's an entirely different matter putting back what isn't there anymore" (1375-1376). For some, like Colin, Maureen, Maxine, Anne, and Melanie, the first hurdle is to obtain better insight into their illness, thus enabling them to take full advantage of available medications and psychosocial rehabilitation.

Most parents wish for some type of occupation or productive activity for their child. Although no one expects full-time employment in a competitive job, most hope for involvement in some type of meaningful activity. Consequently, when she retires from teaching in a couple of years, Catherine plans to be Bryan's job coach. She believes that with Bryan's cooking skills, there must be a volunteer or paid job with a regular enough routine that he could succeed in it. Earning a living through employment is less important to parents than the increased self esteem their adult-children would gain by participating in a productive enterprise. Lois sums up the aspirations of many parents when she says:

> I would like his day to be more fun and happy and involved in something. That's what I'd like, to go to bed at night and [have the] feeling that he had a good day (1829-1832).

Parents' hopes also focus on improvement in their loved ones' living conditions, in terms of better housing and a "bit of a social life" (Gwen2, 924), combined with safety and relative independence. Several foresee their family member living, not with them, but close by, for example:

> ...my goal is to have him, perhaps in a side-by-side townhouse or an apartment across the street, you know, and me on one side, him on the other, and the rule — just phone once a day, do your thing, go the way you're supposed to go, take your meds (Ruth, 506-511).
>
> ...if somebody would say to me, "What would be my ideal goal for Ken?" I would say, "A home that is permanent, in which he feels wanted and productive and loved. Things that he can do....feeling very useful, very productive, as much as he could, with a treatment team and people who like him" (Willow, 2051-2054; 2075-2077).

Some parents envision a sanctuary, not infrequently in the country, where their adult-child will have asylum:

> I wish I would have been three, four years older than now so that I could have taken early package retirement, buy some 16 acres land around [place on Vancouver Island] somewhere, and put couple horses, few cows, chickens, llamas, fish pond, keep two, three people, farm hands, and him (Kulwinder, 1449-1453).
>
> ...we sure would like to see her, you know, happy or getting something out of her life. Even if it's something very simple. We picture her on a farm or something like that. She really has a way with animals (Bruce, 1390-1395).
>
> ...we have some really good friends, who are professionals as well as friends...they love Ken and will spend time with him as much as they can, which isn't much, but one or two of them have said that if there was any way that they could make a

> sanctuary for Ken, that they would do it — one, to the point of saying that she doesn't know if her relationship is ending and that, if it was, she would want to take Ken into her home, along with maybe one other consumer (Willow, 980-989).

Because persons who suffer from schizophrenia differ in ability and limitations, a wide range of housing and rehabilitation settings will be necessary to provide appropriate levels of care in the least restrictive surroundings.

Acknowledging the realities of their child's illness and recognizing some positive accomplishments is a major part of a parent's life evaluation. After years of being engulfed by their child's illness, parents begin to think again about other things that are important to them in their personal lives.

Identifying My Needs

> ...you say, "Well, we've beaten ourselves up for several years over this now. I guess, I guess we're going to survive and we're going to get on with our lives and now we" — and then you compartmentalize it. You say, "Okay. That's that part of my life. But, my life is all of these other parts, too, and I can accept that and I can close the door on it and I don't have to live with it every moment that I'm awake (Michael, 681-688).

The point comes when parents can no longer think, talk, and read about schizophrenia to the exclusion of almost everything else. "It's almost that you get saturated with it" (Catherine, 999). There is a limit to how much one human being can do, as Maggie observed (931-934), for this ill child or for the cause of schizophrenia and mental illness. Eventually, parents have to relinquish some of their responsibility for their ill child and expend some of their energy on themselves. As a hospital psychologist told Lois, "maybe it's time to cut the strings" (422). Consequently, parents find ways to create a distance between themselves and the schizophrenia community, including their own child, in order to get on with their own lives.

Distancing

Distancing oneself from one's ill child is not equivalent to rejection. Parents maintain an active interest in their loved one, as well as continuing to be actively involved in caregiving. They do, however, reduce the amount of time and energy they spend on a daily basis by creating an actual or symbolic distance from their ill child, from their volunteer and advocacy activities, and from their painful memories.

One way of creating distance is for either the child or parent to physically move out of direct proximity with one another. Jean and Tom's solution was for Maxine to move into a group home. After living with her parents for eleven years, Maxine was not easily convinced to do so but:

> ...the way we saw it, we couldn't have her at home all the time. Not only was it just driving us around the bend, but she has to get established on her own (Jean, 444-446).

Lois moved forty miles away from Sean but their relationship has continued to be close. She maintains frequent contact with his mental health team, as well as with her ex-husband who shares in Sean's care, although neither parent can manage the daily care and upkeep.

When the stress of caring for a mentally ill family member becomes overwhelming, parents may be forced to distance themselves from the ill person, as a respite. Periodically, Willow reaches that point with Ken and sends him home:

> I sometimes will take him to the bus stop and I'll be so frustrated and he will say, "Well, I don't know what I'm doing now." And I'll say, "I don't care. Get on this bus. Get home the best way you can." And he does, but I know that that's not treating him with the kindness and gentleness that he deserves, but he has to recognize the fact that I've had it (1973-1980).

Maggie's longer-term solution of refusing to see Maureen was not easily chosen:

> It was the tug-of-war all the time between my love for her and my wanting her to see the reality that she couldn't come back as my little girl. I couldn't take care of her for the rest of her life (Maggie, 430-434).

Moving to another city where their older daughter lives was counterproductive and, missing their friends and home town, Maggie and Warren returned after only eight months. Recently, they have had several successful visits with Maureen who, while still not accepting her diagnosis, is taking her medication under close supervision from the mental health system (Warren, 611-640).

Symbolic distance can be achieved by compartmentalizing painful memories and thoughts. To some extent this occurs unconsciously when memory fades over time or through writing, which sometimes creates closure:

> For me it was a therapy, and it definitely worked for the therapy there, but I always thought some day I would look over those and see what exactly I was feeling or was going through at that time because the pain dulls in years gone by (Catherine, 1839-1843).

Other people make a conscious effort not to dwell on painful memories. During Jean's first interview, she said, tearfully:

> ...there are so many thoughts I haven't thought of for so long because they hurt, they still hurt. Because they are not joyful thoughts, I just, sort of, all but set them aside (326-329).

Then, near the end of the interview, she resolved, "I sort of took all those old dusty memories out....Oh, I guess I will just neatly put them back again" (1605-1606; 1612).

Immersing oneself in work is another strategy for creating distance but is generally feasible only where there are two parent-caregivers and a division of labor between them. One parent, usually the mother who may also have a paid job, assumes the major responsibility for caregiving, thus allowing the other, generally the father, to assume the major wage-earning role. Recall, however, that these roles were reversed in Ryan's family.

Giving up some volunteer activities is another effective distancing strategy. People may stop attending their support group, because:

> ...sometimes I'm very selfish, I've just come home after a hard day or a long day and I really don't want to go and listen to other people's problems (Catherine, 740-743).

> I'm just getting too busy or too tired or too something (Lois, 1961-1967).

Michael, who became the national president of the Schizophrenia Society for two years, stopped volunteering:

> ...because I started to get into this way of, you've seen it all three times and all you can think of is where things are not going to work, you know? So, I said, "I'd better get off and let fresh blood fight the battles (341-345).

Getting On

With distancing comes an opportunity for parents to pursue some of their own individuality (Sam, 1629). For the first time since their child became ill, parents are relieved of some of their obligations to their ill child and/or to their voluntary work. Consequently, parents have the luxury of thinking once again about their long delayed plans for parental emancipation. For example, Catherine has always wanted to take two courses: conflict resolution and a stock broker's course (849-854). Other people take opportunities to travel (Marianne, 1902-1904). Willow tells this inspiring story:

> ...a friend of mine, Marjorie Morton is her name, is an amazing lady and her husband and her two sons are all schizophrenic, and so, if you would ever meet Marjorie, you would say to her, "Boy, you're a strong lady." But what she does is the same as I do and other people do and that's make sure that we take time for ourselves and ski and hike and all that kind of stuff. Yeah. Her son and husband all live at home and so I think, "Holy smokes!" you know, and she survives (1822-1831).

Obviously, not everyone who participated in the study has reached this stage. For example, Gwen and Irwin have reached a stalemate, unable to think beyond their present circumstances, as have Teresa and Bruce.

> ...Irwin says he [Colin] can't live here any longer. I can't go on living like this. I just know that I couldn't put him out. If we got an apartment he wouldn't live in it. Supposing we bought an apartment and furnished it and everything and he won't live in it. What do we do? I suppose the best thing really would be to have a house with a separate suite where he could... live separately but come and have his meals with

> us. I don't know if that would work either. I'm just taking it one day at a time. I can't sort of look ahead and plan (Gwen2, 869-881).

> ... you can feel yourself growing older. I'm in good shape but I'm 56 and I mean I'm still going to be doing this at 66, you know, chasing her through the woods and, you know restraining her when she is violent. I guess the thing on our mind is we feel before we can go on with our lives, we won't be satisfied or comfortable until she seems to be settled, at least getting some enjoyment out of her life and not in constant distress and danger. So, it's you know, an acute situation that turns into a chronic situation. You get all these acute peaks and then all the time we have to look after her in between and there doesn't seem to be any end in sight (Bruce, 885-901).

With Trevor committed to the forensic facility, Fred has begun thinking about getting on with his life (2390) but how long he will be able to do so is unknown:

> In my life, do I plan that he's out in five years, ten, twenty, one, two, six months? I haven't got a clue. Do I need to know? I mean, can I know? No. It's unknown isn't it? So, as long as it's unknown there are certain parts of my life I can't go forward with. So, I'm going to design my life to go on and do something about my life, and then when things change, I will change it (2090-2097).

Therefore, in evaluating their lives, parents are moving towards their emancipation as parents. According to this data, however, no caregiver ever reaches emancipation.

THE EMANCIPATED PARENT

> I guess for every person, you bring the baby home from the hospital and you teach them to be independent and you look forward to the wedding day when they are totally off your hands, and yet if you have a child who is affected with an illness, a chronic illness like schizophrenia, the pattern is going to be slightly different. In a sense, you are never totally the emancipated parent (Evelyn, 1417-1425).

Schizophrenia is a chronic illness. Having a family member with schizophrenia never completely goes away. Therefore, a parent's sense of responsibility for that child never completely disappears either. Accordingly, the model describing how parents reconstruct their parental identity can be interpreted as a journey towards the ideal-type identity of the Emancipated Parent. In essence, at any particular time, a parent's location along this journey towards emancipation depends on where their ill-child is.

Whenever the child's illness exacerbates, a parent is liable to backtrack along the path to a point where his or her identity is defined in consideration of the state of the child's illness and his or her role matches that which the child needs. Consequently, some parents may never be able to move beyond a particular identity:

> A number of my friends who have been around a long time, think their life sucks....And that is because they see what is going on and it's just not good. When I think about it, you know it's the fact that their child's life is pretty grim and their child's life intrudes on them still, so they are not able to separate themselves. And, there is not a let-up. A lot of my friends right at this moment have had children with a mental illness for a long time and it is still a very desperate lifestyle for them (Willow2, 225-226; 229-238).

Realistically, the end point of the journey is probably a hybrid identity combining (at various times) Parental Suffrage with periodic reflection and indulging of their own identified needs. Having made life-long friends through their connections in the mental health community, and having achieved satisfaction through their suffrage activities, many parents will tend to return to that identity, if with somewhat reduced role obligations. For example, at the recent annual meeting of his local chapter of the BCSS, Michael, once again, was elected to the executive. He evaluates his life as follows:

> ...life is, for the last few years for Lorraine and I has been very livable. We kind of went through hell for about, about ten years there and didn't think that we'd ever survive it....the effect on the person, the effect on the families from which they come are deadly (Michael, 311-313; 1024-1025).

Thus, although complete emancipation for parents of people with schizophrenia appears to be a myth, the lives of many of these parents improves to a point. Parents may strive towards the identity of the Emancipated Parent but, at least for the parent caregivers in this study, it is an unattainable goal. Once their child's diagnosis is confirmed, the spectre of schizophrenia, a serious and chronic mental illness, never completely disappears.

Alternatively, it may be that parental emancipation is a relative thing for all parents and complete emancipation is a myth that only occurs in the "airy fairy TV family" (Willow, 665) and no parent ever truly gets there, whether their children are healthy or not.

CHAPTER NINE

DISCUSSION AND CONCLUSION

Reviewing the literature in the substantive area within which a grounded theory study is situated begins only after the basic social process has emerged and the researcher is fairly confident of its fit with the data. By then, the researcher is also fairly convinced about the integration and patterning among important categories and theoretical constructs and, thus, unlikely to be unduly biased by previously described concepts. Consequently, as Hutchinson (1986) advises, the major literature review occurs near the end of the analysis, with the objective of "discovering literature that supports, illuminates, or extends [the] proposed theory" (p. 119). A grounded theorist searches out related studies and theoretical work, in order to locate his or her theory within the literature and illustrate its contribution to knowledge (Glaser, 1992). Literature that contradicts the emerging theory initiates more theoretical sampling and may help to locate and account for negative cases. Consequently, this discussion will connect and contrast the substantive grounded theory of Redefining Parental Identity with important prior research in the topic areas of caregiving, caregiver burden, feminist theory regarding the negative effects of silencing, and the formal grounded theory of status passage. Concluding this chapter and the thesis are sections addressing the limitations of the study, the implications for research, and the implications for practitioners in the mental illness and mental health fields.

Caregiving

Caregiving Compared with Caring

In the caregiving literature, the terms caring and caregiving are often used interchangeably, although some authors draw a distinction which is important for the grounded theory of Redefining Parental Identity. Fisher and Tronto (1990) define four interconnected components of caring: caring about, taking care of, caregiving, and care-receiving. The caring of a parent for a child encompasses all four phases and each phase is predicated on the previous phase. "Caring about" involves paying attention to the needs of the child. "Taking care of" implies assuming responsibility for those needs and for the child's welfare, while caregiving is "the hands-on work of maintenance and repair" (p. 40). The fourth phase, care-receiving, is the child's response to caregiving, which depends on how well the caregiver and receiver agree about what is required. With schizophrenia, the care-receiver who is unable to appreciate his or her need for care is a frequent source of conflict.

When a young adult-child becomes ill with schizophrenia, the connections among the four components of caring are disrupted and conflicts arise among parents, the ill adult-child, and other caregivers. Parents care about their ill child, assume responsibility for taking care of the child, and take on the function of caregiving — sometimes at the behest of professionals but often by default. Nevertheless, they frequently lack the requisite time, material resources, knowledge, and skills to provide this care. More fundamentally, they lack legal and societal permission for taking care of this ill child. Thus, the vital link between parents' "caring about" and their "caregiving" is disrupted. Their lack of authority makes their responsibilities for caring and caregiving ambiguous. As Fisher and Tronto note, "One of the most pervasive contradictions involved in taking care of concerns the asymmetry between responsibility and power" (p. 43).

The mental health care system functions like a bureaucratic organization in which, according to Fisher and Tronto, hands-on caregiving and the responsibility for taking care of are separated. The bureaucratic requirements for a division of labor, a hierarchy of power and authority, and the standardization of routines and policies all cause contradictions and poor integration among the phases of caring. In contrast, true caring "crosscuts the antitheses between public and private, rights and duties, love and labor" (Fisher & Tronto, 1990, p. 56). Working toward resolving these conflicts requires a view of caring as a contextual process. The context of schizophrenia is the family within which it occurs and, in order to address the contradictions that exist among the components of caring, care for people with schizophrenia must incorporate the needs of the family.

Caregiving as a Process

Most theoretical models of caregiving for people with mental illness, or with schizophrenia specifically, have been limited to measuring caregiver burden at a point in time. Nevertheless, Redefining Parental Identity is not the first attempt to conceive of caregiving as a process in which sources of stress and the buffering factors that may help to alleviate stress change over time and with evolving circumstances. Two such models have been proposed by Tessler, Killian, & Gubman (1987) and Howard (1994).

Tessler, et al., described a series of nine stages of family response to mental illness and outlined the coping strategies, both adaptive and maladaptive, employed at each stage.

The nine stages are:

1. Awareness of a problem without recognition of symptoms.
2. Denial of mental illness.
3. Labeling of the patient as mentally ill.
4. Faith in mental health professionals and expectations of a quick cure.
5. Recurrent crises, including, for example, suicide attempts and aggression.
6. Recognition that the illness is chronic.
7. Loss of faith in mental health professionals.
8. Belief in the family's expertise.
9. Worry about the future.

Howard's (1994) model of learning to live with a child who has schizophrenia delineates five stages superimposed on three overlapping concepts of care: watching, working, and waiting. Her research focuses on mothers, although the present study suggests that her findings could be applied to both parents. Watching is defined as vigilance; working is both physical and mental caregiving; and waiting describes periods between acute exacerbations of the illness when parents hope for a better future for their child, yet dread what they fear is coming. The stages are:

1. Maternal care.
2. Perceiving a problem, which includes perception of a problem with the child, the realization of its severity, and shock.
3. Searching for solutions. This includes searching for information and assistance and struggling with the episodes of illness and the resulting anguish and distress.
4. Enduring the situation. This includes persistence and perseverance in caregiving, as well as an acknowledgment of chronicity.

5. Surviving the experience. Here, she identifies acceptance, hope, and determination to help the child, the self, and others.

The themes described in both these studies are supported and extended in Redefining Parental Identity. Table 2 compares the above studies with the basic social process of Redefining Parental Identity.

TABLE 2
The Process of Caregiving in Schizophrenia: Comparison of 3 Models

Tessler, et al. Stages of Family Coping Response	Howard Learning to Live with Schizophrenia	Milliken Redefining Parental Identity
	maternal care	parent teen/ young adult
		tolerating adolescent challenges,
		anticipating liberty
aware of problem, not symptoms	perceiving a problem	becoming marginalized
denial of mental illness	searching	becoming alarmed
labeling patient mentally ill	realization and shock	assuming responsibility
expecting a cure	searching for solutions	encountering barriers
faith in professions	searching for information,	disenfranchised parent
recurrent crises	struggling and suffering	maintaining vigilance
recognizing chronicity	enduring the situation	grieving alone
loss of faith in professions	acknowledging chronicity	grasping at straws
belief in family's expertise	persevering in caregiving	embracing the collective
		connecting with others
		redefining my child
worry about the future	surviving the experience	parental suffrage
	determination	taking on the system
	hope	mourning together
		being disillusioned
	acceptance	evaluating my life
		acknowledging realities
		identifying my needs

Caregiver Burden

The review of studies employing a variety of measures of caregiver burden in Chapter Two reveals the difficulty social scientists have encountered in trying to conceptualize and measure the concept of burden. The grounded theory of Redefining Parental Identity highlights this complexity and the variation in caregiving experience among parents who are caring for a child diagnosed with schizophrenia. This study describes in detail the objective and subjective burdens experienced by these parents. In their stories, while the objective burdens are very difficult to deal with, the subjective burden that parents sense can be overwhelming. As parents encounter support through connecting with a group of people who personally understand their disenfranchisement, it would appear that their subjective burden is at least partially alleviated and, as a result, they are better able to attend to and manage the day to day objective problems.

In the quantitative studies of caregiver burden reviewed for this research, the most sophisticated analyses used were ordinary least squares regression and network analysis. This study of parents who are caring for adult-children with schizophrenia reveals that the causal relations among the health of the caregiver, family disruption, stigma, and stress are complex and likely bi-directional. This is probably true of other variables that have been used in caregiver burden scales, and may explain why some investigators have included variables such as the ill persons' disruptive behaviour as evidence of caregiver burden, while others have conceptualized it as predictive of caregiver burden.

Once the conceptualization and measurement problems inherent in defining caregiver burden have been clarified, more sophisticated analysis procedures, for example, structural equation modeling, will be necessary to tease out the strength and directions of the causal connections among the variables. Until that happens, the role of qualitative research in describing and explaining complex social processes like caregiver burden must be recognized. Indeed, qualitative research is particularly useful for generating theoretical models for quantitative researchers to test and validate.

From this study of parental caregiving two variables stand out as important to the experience of caring for a son or daughter with schizophrenia. The variables are grief and mastery. To date, each has been incorporated into only a small minority of the quantitative scales used in research on caregiver burden as it is associated with mental illness.

Grief

This study highlights that any study of caregiver burden must account for the dimensions of grief. Furthermore, it is imperative to study grief over time, as it is a process that changes as caregiving and the status of the illness change. Parents begin to grieve during the process of becoming marginalized when they respond to confirmation of their child's severe mental illness with shock and denial. As disenfranchised parents, their grief is deeply personal and isolating, although through connecting with others and working with other parents they have the opportunity to mourn openly.

The single statement that Reinhard (1991) employed in her caregiver burden scale to estimate the grief experienced by caregivers cannot begin to convey the extent or the complex nature of a parent's grief. Reinhard asked respondents to estimate the frequency of being upset due to the change in their loved one. This provides a rather gross measurement of how often a person is consciously aware of experiencing grief. It cannot account for the depths of despair, the periods of denial, or the guilt, stigma, and anger that parents experience in varying degrees from time to time. Thus, although Reinhard's study found grief to be a significant contributor to caregiver burden, I suggest that the magnitude of the grief reported by her participants was underestimated because of the way in which grief was conceptualized for her study. Grief was probably even more important to their subjective burden of care than Reinhard's regression analysis reveals.

Two explanatory models in the literature are helpful for understanding the grief process that parents in this study experienced. They are Martin and Elder's (1988) Pathways through Grief model reviewed in chapter two of this thesis and Doka's (1989) descriptive theory of Disenfranchised Grief.

Pathways through Grief

Martin and Elder's (1988) model (Appendix I) depicts the experience of grief for parents in this study of parental caregiving quite well. The lower circle in the figure eight with its processes of detaching, despairing, and protesting displays the lonely grief felt by these parents when they are disenfranchised. Once they connect with others, however, their grief is transformed into the upper circle of investing, exploring, and hoping. Each time these parents begin to feel disenfranchised, their grief process reenters the lower circle. However, for parents who are caring for children with schizophrenia, there needs to be a symbolic way of representing the difference in the circle of influence surrounding the upper and lower portions of the figure eight pathway. While disenfranchised, parents perceive little support from others and many of their interactions with health care professionals seem negative. When, however, they can share their mourning, they have many more people to support them. Thus, to apply to the grief experienced by parents of people with schizophrenia, the circle of influence surrounding the upper circle would need to display more human figures than are evident around the lower circle when parents are grieving alone.

Disenfranchised Grief

The circumstances that lead to disenfranchised grief (Doka, 1989) distinguish this experience from most grief situations because the loss precipitating the grief reaction is not "openly acknowledged, publicly mourned, or socially supported" (Doka, p. 4). With schizophrenia, periods of florid psychosis combined with ongoing negative symptoms change the ill person so significantly that families perceive the person they used to know as dead. According to Doka, the severely mentally ill suffer a "psychosocial death" (p. 6). When a loved child suffers such a psychosocial loss, parents are prevented from gradually detaching from the person who has changed because caregiving demands increase, along with "stress, shame, guilt, anger, and helplessness" (Doka & Aber, 1989, p. 192). Disenfranchised grief is a form of complicated grief in which, paradoxically, emotions are intensified but sources of support are minimized and public mourning is denied. The grief experienced by disenfranchised parents in this study matches Doka's description of disenfranchised grief. The loss these parents suffered was not publicly recognized as causing grief because the afflicted child did not die. Consequently, it was only when parents connected with others who had experienced the same loss and the same disenfranchised grief that they received the support needed to begin mourning and working through their grief.

Mastery

Any study attempting to measure caregiver burden must include some measurement of mastery (Noh & Turner, 1987; Noh and Avison, 1988) or, alternatively, of powerlessness. Noh and Turner (1987) speculated whether subjective burden negatively affects the perception of mastery or vice versa. This study indicates that the perception of powerlessness (very low levels of mastery) for parents of people with schizophrenia stems from parents being disenfranchised of their right and responsibility to care for a loved one who is incapable of caring for him or herself.

In their study of spousal caregivers of the mentally ill, Noh and Avison (1988) found a gender difference indicating that women caregivers had more burden than male caregivers because they perceived themselves as lower in mastery. Feminists would argue that the difference is attributed to structural gender inequality. This study suggests that, for parents caring for a child with schizophrenia, if a gender difference in the level of mastery were found, it may also be related to the likelihood of mothers, rather than fathers, remaining at home to be the primary caregivers. In contrast, a parent who is able to maintain employment responsibilities and other interests outside the home is likely to retain a perception of mastery from the successes earned in those other pursuits and the periodic relief from the stresses of hands-on caregiving. The parent who is primarily engaged in caregiving and who continually encounters barriers that prevent successfully carrying out that responsibility is likely to have his or her sense of mastery undermined more completely.

Most studies of caregiver burden provide us with a snapshot understanding of subjective and objective burden measured once, usually relatively soon after the patient has left the hospital. Of the studies reviewed in Chapter Two, only Pai and Kapur (1982) measured burden over time, with a period of six months between surveys. Caregiving for someone with schizophrenia goes on over a protracted period, often decades. Were burden (including the concept of mastery) assessed when a caregiving parent has reached the stage of Parental Suffrage, the expectation is that mastery would have increased and burden would have decreased. Thus, there is a need for long term studies of caregiving to track the changes in burden over time.

Silencing

A feminist explanation of the gender difference in level of mastery (Turner & Avison, 1988) hinges on gender inequality. Feminist theorists contend that a major reason for women's oppressed condition is that women are silenced, that is, a woman's voice is not heard in the patriarchal power relations of society (Belenky, et al., 1986; Gilligan, 1993). Women's absence of voice results in "an extreme denial of self and in dependence on external authority for direction" (Belenky, et al., 1986, p. 24). Women experience oppression because their perspective, or voice, is either not heard or is distorted when represented by those with power. Consequently:

> ...women come to question whether what they have seen exists and whether what they know from their own experience is true. These questions are raised not as abstract philosophical speculations about the nature of reality and truth but as personal doubts that invade women's sense of themselves, compromising their ability to act on their own perceptions (Gilligan, 1993, p. 49).

A parallel can be drawn to the experience of parents who are disenfranchised by legal limits on their responsibility toward their adult-child who, because of a severe mental illness, is incapable of acting out of self-interest. Parents voices are silenced when they are brushed aside by professional caregivers and not consulted, informed, or even listened to in regard to their child's illness, treatment, and prognosis. Parents of people with schizophrenia are disadvantaged in many of the same ways as other oppressed and marginal groups in our society and this marginalization extends equally to fathers and mothers. At the same time, like women in our society, they are expected to care for their ill children. If not overtly asked to do so, they assume that responsibility by default, when no one else takes a perpetual and concerned interest in the child's well-being.

The notion of silencing is similar to one found in Glaser and Strauss's (1964, 1967) theory of awareness contexts. To return to the original understanding of symbolic interactionism, Mead's (1934/1962) theory is predicated on an open and cooperative context, where access to information allows the individuals involved in the interaction to role-take freely. Thus, interaction in Mead's terms is situated in what Glaser and Strauss describe as an open awareness context. In a closed awareness context, however, information is kept from one party in the interaction, thus preventing that person from achieving a definition of the situation that is shared with the other participants and, hence, being able to act and interact in congruence with the situation. In the present study, a closed awareness context arose between mental health professionals and parents in regard to the adult-child's illness. This places parents in a disadvantaged position in reference to their caregiving interactions and, paradoxically, also puts mental health professionals in the position of basing their treatment on incomplete information.

Status Passage

After Redefining Parental Identity was conceptualized and the categories and relationships among them were quite well delineated, it became apparent that this substantive grounded theory is an empirical example of the formal grounded theory[1] of "status passage" (Glaser & Strauss, 1965, 1967, 1971). Status passage involves "movement into a different part of a social structure; [with] a loss or gain of privilege, influence, or power, and a changed identity and sense of self, as well as changed behavior" (1971, p. 2).

---

[1] Glaser and Strauss (1967, 1971) distinguish between substantive grounded theories that evolve from a specific, empirical area of inquiry and formal grounded theories that apply to a conceptual area of sociology. Thus, a formal grounded theory explains human behavior at a higher level of abstraction than does a substantive grounded theory.

Throughout life, individuals occupy multiple social statuses[2] simultaneously and also sequentially. Status passage refers to the period of change from one status to another. Identity refers to an individual's perception of him or herself, i.e., self concept, as an occupant of a particular status. Consequently, while traversing a status passage, a person's identity is also transformed.[3]

In "Redefining Parental Identity," parents take on the new identities of the "Disenfranchised Parent" and "Parental Suffrage." Each transition between successive identities involves traversing a status passage. Ordinarily, when a child has no severe mental illness, the "Parent of a Teen or Young Adult" passes into the status of "Emancipated Parent," through a status passage that involves the parent and child achieving mutual independence. When a child becomes ill with schizophrenia, the usual status passage is interrupted and, instead, the parents enter the status passage of "becoming marginalized" on their way to a new status, the "Disenfranchised Parent." Role strain associated with this new status, eventually drives parents to seek information and understanding by "embracing the collective" of other people with family experience with schizophrenia, leading into a new status, "Parental Suffrage." A number of factors initiate the status passage of "evaluating my life." Some of these are the successes parents achieve in the "Parental Suffrage" status, their own aging, and improvements in their child's illness course and social circumstances. The next status passage, "Evaluating my life," moves parents toward the "Emancipated Parent"

---

[2] Some authors use the terms role and status interchangeably. Others distinguish between a status as a position within social structure and a role as the behavior expected of someone occupying a particular status.

[3] See Chapter 4 in *Mirrors and Masks* (Glaser & Strauss, 1969), entitled "Transformations of Identity."

status but, as long as they remain caregivers, they never attain the independence from their child to allow them to occupy that desired status.

Any status passage can be analyzed according to two major dimensions, the length of time required to complete the passage, i.e., the duration, and the shape of the passage. Describing the shape of a passage requires describing its properties. Glaser and Strauss identify the following 13 properties (1971, pp. 4-5):

1. desirability of the passage,
2. inevitability,
3. whether the passage is reversible or not,
4. whether it is repeatable or not,
5. whether the person goes through it alone, collectively (as members of a group) or in aggregate (individually, but at the same time as others),
6. if in aggregate, how aware is she or he of the others,
7. ability to communicate with others about the passage,
8. whether it is voluntary or the person has no choice,
9. the degree of control a person may exert in shaping the passage,
10. legitimization, whether the passage requires the permission of someone in authority,
11. the clarity of the signs of the passage,
12. whether or not relevant parties disguise the signs, and,
13. the importance of the passage in a person's life.

Applying these dimensions and properties to the three status passages described in Redefining Parental Identity allows us to summarize these status passages.

Becoming Marginalized

Applying the above thirteen properties to "becoming marginalized," no one enters this undesirable status passage voluntarily. It quickly becomes central to their lives, to the extent that the problems they are encountering in parenting eclipse other statuses and interfere with their other roles. People traverse the passage alone or with their spouse, isolated from anyone else who may be entering the passage. The signs of entry into "becoming marginalized" are unclear for two reasons: first, the ill person attempts to disguise and explain his or her aberrant behavior in normal terms, and, secondly, health professionals exclude parents from actively participating in decisions about their child's care. Clarity and legitimization both come with the identification and labeling of the diagnosis, a turning point in the passage beyond which there is no returning to ordinary parenthood. From this point on, "becoming marginalized" is inevitable, given the law and the lack of insight most patients have regarding their illness. Through this passage, the most pervasive property is the parents' lack of ability to control anything, including the time frame. Fortunately, most people never repeat the passage, except those families in which more than one child develops schizophrenia.

Embracing the Collective

Given the extremely unhappy and difficult existence of the "Disenfranchised Parent," moving beyond that identity is both desirable and voluntary. It is, however, not inevitable and the timing varies greatly. Some parents are disenfranchised by their child's schizophrenia for many years. The start of the status passage is clearly marked by parents' reaching out for information and support. "Connecting with others" is vitally important for opening the lines of communication and acts as a catalyst for parents' beginning to exert some control over their lives. However, their ill child remains their most central interest, such that each psychotic episode can pull them back towards disenfranchisement, making the passage reversible and repeatable, although not completely so. The connections with the support group remain, making reentry into a subsequent passage easier and faster to complete. Estimating the duration is problematic because of the difficulty in knowing when the end point, the entrance into the status of "Parental Suffrage," has been reached. This is because the symbolic "redefining [of] my child," happens subconsciously.

Evaluating my Life

Although the "Parental Suffrage" identity is stimulating and satisfying for many people, moving beyond it into "evaluating my life" may become desirable at some point. Entering this status passage is usually voluntary unless the individual's health deteriorates and the decision to do so is completely under the individual's person's control. Movement into this status passage is usually communicated to others with whom a parent has worked on voluntary endeavors but it is usually undertaken alone. It is not inevitable — many people choose to stay in the "Parental Suffrage" status or they are held back by a child's illness that fails to respond to treatment. The duration of this status passage is highly variable. As long as people identify themselves as caregivers, they do not enter the "Emancipated Parent" status. Thus, they are quite likely to re-enter the "Parental Suffrage," status once they feel rested and renewed and are drawn back by a personal desire to make a difference in the lives of those afflicted with this severe mental illness. Consequently, because it is easily reversible and repeatable, parents of people with schizophrenia may enter this last status passage intermittently.

Limitations of this Study

The primary limitation of this study is the recruitment of parents of people with schizophrenia through the newsletters of the Schizophrenia Society and the Caregiver's Association introduced. Although efforts were made through snowballing and a radio plea for participants who are not associated with a support group or mental health organization, these were unsuccessful. In addition, exploring the experiences of parents who were caregivers made it impossible to account for the experience of parents who do not presently define themselves in that way. It also proved impossible to learn about the experience of those parents of the estimated 25% of people with schizophrenia who recover following one psychotic episode. Nevertheless, as pointed out in chapter four, the sample represents a broad variation in the experience of caring for a child with schizophrenia.

Other possible limitations of this study are common criticisms of qualitative research. On the one hand, twenty-nine parents from nineteen families is a small number of participants and a convenience sample is less representative in quantitative research terms. On the other hand, lengthy interviews, and for some participants repeat interviews, yield a large amount of richly descriptive, in-depth data from each person. These data are used inductively and are sufficient to generate a theoretical model of parental caregiving for adult children suffering from schizophrenia. In the final analysis, the standard of representative sampling for purposes of generalization to a population is inappropriate for judging qualitative research, the goal of which is to facilitate theoretical insight.

My belief is that these limitations are counterbalanced by the potential benefits that may be achieved from understanding the complex nature of this caregiving experience. Caring for a child with schizophrenia is difficult enough without the barriers, misunderstandings and stigma that these parents encounter from professional caregivers and the public in general. Consequently, this study highlights for mental health practitioners the importance of viewing this illness in its family context. Once this is recognized, professionals will no longer be able to justify excluding family members when treating schizophrenia. Instead, parents will be kept fully informed and their perspective will be solicited and recognized. For parents, viewing their child's illness from the standpoint of its effect on their identity as parents will help them understand their caregiving experience more fully.

Recommendations and Conclusion

Implications for Future Research

Possibilities for future research lie in the area of caregiving for family members with schizophrenia and other severe mental illnesses. In particular, overcoming the sampling difficulties would allow the grounded theory of Redefining Parental Identity to be extended to account for those parents who have children with schizophrenia but who, for one reason or another, have severed their ties with that child. Similarly, the theory may in future be modified by including the experiences of those parents whose children have suffered from schizophrenia and recovered. Once these children are able to be independent, how do parents progress to the status of the "Emancipated Parent" or do they?

A prospective, longitudinal study (lasting at least a decade) of parents caring for a child with schizophrenia might reveal differences in their caregiving, their grieving, and their redefinition of parental identity. Falloon has developed a short screening instrument and a checklist of prodromal symptoms for identifying young people at risk for developing schizophrenia (Model Program Successful, 1996), which, if used in schools, could identify a sample and a control group. The growing body of persuasive evidence showing better outcome from early treatment dictates, however, that such a study would examine a very different parental experience than the present one.

A longitudinal study could be approximated by examining other types of data. For example, many participants wrote about their experiences throughout their caregiving. Diaries and poetry written by parents during their child's illness would provide a rich resource and avoid selective recall. Nevertheless, this type of data is produced by a self-selected group.

One means of testing and extending a grounded theory is to investigate how well the theory applies to other groups whose experience is in some way similar to that of these parents. Such groups may be parent caregivers of adult children who are disabled by other mental illnesses, such as manic depression, or by catastrophic physical injuries, such as accidents that cause quadriplegia or brain injuries. Another group to which the theory might be extended is siblings of people with schizophrenia or another illness who must redefine their identity as brothers and sisters. As well, the applicability of the model to parent caregivers from diverse cultural backgrounds needs to be assessed.

Issues arising in this study that will be important for quantitative researchers to address relate to the validity and measurement of the caregiver burden concept, as previously outlined in this chapter. In particular, this study reveals the necessity of measuring the effects of mastery and grief in any study of caregiver burden. Once these conceptual and measurement issues are resolved, a large scale survey of caregiver burden in parents of people with schizophrenia, perhaps using the membership of the Schizophrenia Society of Canada as a sampling frame, could be undertaken.

Implications for Professional Caregiving of People with Schizophrenia

A major finding of this study is the disenfranchisement of parents of people with schizophrenia. Professionals in the field of mental illness are partially responsible. Therapists of all professional designations must recognize the importance of family as the context within which a child's schizophrenia is situated. As well, they must recognize and value the ongoing contribution the parents make to their ill child's care and social well-being. Parent caregivers must become respected members of the treatment team, valued for their knowledge about the ill person's history and existence outside the hospital and their many contributions between scheduled appointments with professional caregivers. By excluding the patient's parents, many professional caregivers cut themselves off from a key source of information on which to base their interventions and a key resource for implementing care.

In addition to listening respectfully to concerned parents, therapists must recognize their professional responsibility to these parents, supporting their initiatives and teaching them about the illness. Family education should be part of the treatment plan, not left for family members to seek out or provide for other parents on an ad hoc basis. But families need more than education about the illness and treatment, they need practical advice about how to interact and communicate with a psychotic person and ideas that they can use for motivating and assisting someone with severe negative symptoms. In addition, they deserve compassion and help with recognizing and understanding their own personal reactions and experience with this illness.

When an ill child lives with his or her parents, better availability of respite care is essential. This should include providing replacement caregivers, both on a regular basis and on special occasions, including emergencies. There needs to be the provision for more outside activities and recreation for these ill persons, allowing family caregivers the opportunity to periodically relax in their own home. A comprehensive respite program also arranges for periodic short stay psychiatric hospital treatment and day and weekend programs in the hospital and community. This will require greater numbers of beds, both in active treatment and tertiary care settings, and more places in community programs than are presently available.

There is an urgent need to recognize and accept that humane and coordinated community care for the severely mentally ill and their families will not be accomplished inexpensively. Nevertheless, community care is preferable for many seriously ill persons, provided the community supports are sufficient. The cost of treating patients with schizophrenia and other mental illnesses is not the only factor in the financial equation. Provision of a comprehensive community care program is certain to reduce the morbidity, both physical and emotional, for stressed and depressed parents as well as other family caregivers.

Case management and the implementation of assertive community treatment appears to be the cornerstone of a safe and comprehensive community program. Such a program would stress the ethic of psychosocial rehabilitation, rather than merely administering medications and policing compliance. Care must come to the ill person and his or her family, not the other way around. To do so, community programs must be staffed sufficiently well to ensure that case loads are manageable.

Community programs need adequate and appropriate housing facilities. More new housing units are essential, while both regular, unannounced, and comprehensive inspection and the upgrading of existing housing according to clearly defined standards are crucial.

Finally, policy makers must address how the legal system defines "danger to oneself and others" and institute a more liberal application of commitment to psychiatric care.

Refusal of treatment and the inability to provide an appropriate level of self care should be considered as dangerous to self. These patients do not choose (in any meaningful sense of the word) to sleep huddled in doorways, to be victimized, or to eat garbage. Outpatient commitment[4] is one strategy that could be utilized more frequently, with appropriate sanctions to ensure compliance with treatment. Although such measures are defined by some people as a return to patriarchy and the loss of patients' rights, they are necessary to achieve a return to humane treatment of the mentally ill and necessary to counter the disenfranchisement of caregiving parents. While parents who are caring for a son or daughter who is suffering from schizophrenia may not become emancipated, they would at least be less disenfranchised.

---

[4] Outpatient commitment refers to a policy allowing patients in recovery to live in the community so long as they comply with treatment. If, however, they refuse treatment and medications, they must return to hospital.

REFERENCES

Allen, J. G. (1995). The spectrum of accuracy in memories of childhood trauma. Topeka, KS: Menninger Clinic. (Reprinted from the *Harvard Review of Psychiatry, 3*(2), 94-95, with permission from Mosby-Year Book, Inc. Copyright, 1995, by Harvard Medical School, Cambridge, MA).

American Psychiatric Association. (1994). *Diagnostic and statistical manual of mental disorders* (4th ed.). Washington, DC: Author.

Anderson, K. N., Anderson, L. E. & Glanze, W. D. (Eds.). (1984). *Mosby's medical, nursing, and allied health dictionary* (4th ed.). St. Louis: Mosby.

Andreasen, N. C. (1996, June). *The broken brain: Clinical implications of recent advances in schizophrenia.* Paper presented at the 2nd Annual Schizophrenia Conference, Riverview Hospital, Port Coquitlam, BC.

Ash, P. (1949). The reliability of psychiatric diagnoses. *Journal of Abnormal Psychology, 44*, 272-276.

Asnis, G .M., Kaplan, M. L., van Praag, H. M., & Sanderson, W. C. (1994). Homicidal behaviors among psychiatric outpatients. *Hospital and Community Psychiatry, 45*(2), 127-132.

Atkinson, S. D. (1994). Grieving and loss in parents with a schizophrenic child. *American Journal of Psychiatry, 151*(8), 1137-1139.

Avison, W. R. & Speechley, K. N. (1987). The discharged psychiatric patient: A review of social, social-psychological, and psychiatric correlates of outcome. *American Journal of Psychiatry, 144*(1), 10-18.

Backlar, P. (1994). *The family face of schizophrenia: Practical counsel from America's leading experts.* New York: G. P. Putnam's Sons.

Bachrach, L .L. (1984). Asylum and chronically ill psychiatric patients. *American Journal of Psychiatry, 141*(8), 975-978.

Bachrach, L. L. (1986a). Deinstitutionalization: What do the numbers mean? *Hospital and Community Psychiatry, 37*(2), 118-121.

Bachrach, L. L. (1986b). Dimensions of disability in the chronic mentally ill. *Hospital and Community Psychiatry, 37*(10), 981-982.

Bachrach, L. L. (1988). Defining Chronic mental illness: A concept paper. *Hospital and Community Psychiatry, 39*, 383-388.

Bartol, G. M., Moon, E., & Linton, M. (1994). Nursing assistance for families of patients. *Journal of Psychosocial Nursing, 32*(12), 27-29.

Bateson, G. D., Jackson, D., Haley, J, & Weakland, J. (1956). Towards a theory of schizophrenia. *Behavioral Science, 1*, 251-264.

Beard, J. H., Propst, R. N. & Malamud, T. J. (1982). The Fountain House model of psychiatric rehabilitation. *Psychosocial Rehabilitation Journal, 5*(1), 47-53.

Becker, H. S. (1973). *Outsiders: Studies in the sociology of deviance.* New York: The Free Press.

Belcher, J. R. (1988). Mothers alone and supporting chronically mentally ill adult children: A greater vulnerability to stress. *Women & Health, 14*(2), 61-80.

Belenky, M. F., Clinchy, M. F., Goldberger, N. R., & Tarule, J. M. (1986). *Women's ways of knowing.* New York: Basic Books.

Beley, T. G. (1991). *The family and chronic mental illness: Boundary ambiguity as a factor influencing family burden.* Miami: Barry University School of Social Work. Dissertation.

Biegel, D. E., Sales, E., & Schulz, R. (1991). Caregiving in Chronic Mental Illness. In *Family Caregiving in Chronic Illness* (pp. 164-198). Newbury Park: Sage.

Biegel, D. E.; Song, L. -Y.; & Chakravarthy, V. (1994). Predictors of caregiver burden among support group members of persons with chronic mental illness. In E. Kahana, D. E. Biegel, & Wykle, M. L. (Eds.), *Family Caregiving Across the Lifespan*. Newbury Park: Sage.

Birenbaum, A. (1970). On managing a courtesy stigma. *Journal of Health and Social Behavior, 11*, 196-206.

Blair, S. M. (1973). Psychiatric diagnosis [Letter to the editor]. *Science, 180,* 362-363.

Bland, R. C. (1988a) Month of birth and schizophrenia in Alberta. *Canadian Journal of Psychiatry, 33*, 705-706.

Bland, R. C. (1988b). Psychiatric epidemiology. *Canadian Journal of Psychiatry, 33*, 618-625.

Bland, R. C., Orn, H. & Newman, S. C. (1988). Lifetime prevalence of psychiatric disorders in Edmonton. *Acta Psychiatrica Scandinavica, 77*(suppl. 338), 24-32.

Bland, R. C., Stebelsky, G, Orn, H., & Newman, S. C. (1988). Psychiatric disorders and unemployment in Edmonton. *Acta Psychiatrica Scandinavica, 77*(suppl. 338), 72-80.

Bleuler, M. (1978). The long-term course of schizophrenic psychosis. In L. Wynne, R. Cromwell, & S. Matthysse (Eds.), *The nature of schizophrenia, new approaches to research and treatment.* New York: John Wiley.

Blumer, H. (1969/1986). *Symbolic interactionism: Perspective and method.* Berkeley: University of California Press.

British Columbia Ministry of Health and Ministry Responsible for Seniors. (1997). *Guide to the Mental Health Act.* Victoria: Province of British Columbia.

British Columbia Ministry of Health and Ministry Responsible for Seniors. (1993). *Families sharing and caring: Summary report of the Task Force of Families of People with Mental Illness* (BC Publication No. 934.MHF.008). Victoria: Province of British Columbia.

British Columbia Royal Commission on Health Care and Costs. (1991). *Closer to home,* Vol. 2. Victoria: Province of British Columbia.

Brown, G. W. (1973). Some thoughts on grounded theory. *Sociology, 7,* 1-16.

Brown, G. W., Birley, J. L., Wing, J. K. (1972). Influence of family life on the course of schizophrenic disorders: A replication. *British Journal of Psychiatry, 121,* 241-258.

Brooker, C. (1990a). The health education needs of families caring for a schizophrenic relative and the potential role for community psychiatric nurses. *Journal of Advanced Nursing, 15,* 1092-1098.

Brooker, C. (1990b). Expressed emotion and psychosocial intervention: A review. *International Journal of Nursing Studies, 27,*(3), 267-276.

Burland, J. (1993). *The journey of hope: Family education and family support* (Education program). Available from the Journey of Hope office, P.O. Box 2547, Baton Rouge, LA, 70821. Baton Rouge, LA: Louisiana Alliance for the Mentally Ill.

Burr, W. A. . (1973). Psychiatric diagnosis [Letter to the editor]. *Science, 180,* 358.

Busfield, J. (1986). *Managing madness: Changing ideas and practice.* London: Unwin Hyman.

Canadian Alliance for Research on Schizophrenia. (1994). A national strategy for research on schizophrenia. *Journal of Psychiatry and Neuroscience, 19*(5, Suppl. 1), 3-49.

Canadian Pharmaceutical Association. (1996). Compendium of pharmaceuticals and specialties (31st edn.). Ottawa, ON: Author.

Careless Britain. (1996, Aug. 14). *The Economist, 340*(7978), 14.

Carpentier, N., Lesage, A., Goulet, J., Lalonde, P. & Renaud, M. (1992). Burden of care of families not living with young schizophrenic relatives. *Hospital and Community Psychiatry, 43*(1), 38-43.

Castenada, C. (1968). *The teachings of Don Juan: A Yaqui way of knowledge.* New York: Pocket Books.

Cavan, R. S. (1962). Self and role in adjustment during old age. In A. M. Rose (Ed.), *Human behaviour and social processes: An interactionist approach* (pp. 20-40). Boston: Houghton Mifflin.

Chafetz, L. & Barnes, L. (1989). Issues in psychiatric caregiving. *Archives in Psychiatric Nursing, 3*(2), 61-68.

Charlesworth, B., Sacks, J., Templer, D. I. & Thackrey, M. (1993). Negative emotion as predictor of relapse in persons with schizophrenia living in board and care homes. *Community Mental Health Journal, 29*(3), 261-268.

Charmaz, K. (1983). The grounded theory method: An explication and interpretation. In R. M. Emerson (Ed.). *Contemporary field research* (pp. 109-126). Boston: Little Brown & Company.

Chenitz, W. C. & Swanson, J. M. (1986). *From practise to grounded theory: Qualitative research in nursing.* Menlo Park, CA, Addison-Wesley.

Chesla, C. A. (1991). Parents' caring practices with schizophrenic offspring. *Qualitative Health Research, 1*(4), 446-468.

Clark, R. E. (1994). Family costs associated with severe mental illness and substance use. *Hospital and Community Psychiatry, 45*(8), 808-813.

Clark, R. E. & Drake, R. E. (1994). Expenditures of time and money by families of people with severe mental illness and substance use disorders. *Community Mental Health Journal, 30*(2), 145-162.

Cockerham, W. C. (1989). *Medical sociology* (3rd ed.). Englewood Cliffs, Prentice-Hall.

Cockerham, W. C. (1996). *Sociology of mental disorder* (4th ed.). Upper Saddle River, NJ: Prentice-Hall.

Cole, J. D. & Kazarian, S. S. (1993). Predictive validity of the level of expressed emotion (LEE) scale: Readmission follow-up data for 1, 2, and 5 years periods. *Journal of Clinical Psychology, 49*(2), 216-218.

Cook, J. V. (1988). Goffman's legacy: The elimination of the chronic mental patient's community: A review of selected literature. *Research in the Sociology of Health Care, 7*, 249-281.

Cooley, C. H. (1902/1964). *Human nature and the social order.* New York: Charles Scribners.

Copley, J. D. & Bodensteiner, J. B. (1987). Chronic sorrow in families of disabled children. *Journal of Child Neurology, 2*, 67-70.

Creer, C. & Wing, J. (1975). Living with a schizophrenic patient. *British Journal of Hospital Medicine, July*, 73-82.

Curb on drugs sparks protest. (1997). *The Island Adviser: Vancouver Island Mental Health Family Advisory Council Newsletter, 2*(2), 1, 3.

Dahrendorf, R. (1959). *Class and class conflict in industrial society.* Stanford: Stanford University Press, cited in Grabb (1990).

Davis, G. H. (1987). Disability and grief. *Social Casework, June*, 352-357.

Dearth, N., Labenski, B.J., Mott, M. E., & Pellegrini, L. M. (1986). *Families helping families: Living with schizophrenia.* New York: W. W. Norton and Company.

Dickinson, H. D. (1989). *The two psychiatries: The transformation of psychiatric work in Saskatchewan, 1905-1984.* Regina: University of Regina, Canadian Plains Research Center.

Dickinson, H. D. (1994). Mental health policy in Canada: What's the problem? In B.S. Bolaria & H.D. Dickinson (Eds.), *Health, illness, and health care in Canada,* 2nd ed. (pp. 466-481). Toronto: Harcourt Brace.

Dingwall, R. (1976). *Aspects of illness.* London: Martin Robertson and Company.

Doka, K. J. (1989). Disenfranchised grief. In K. J. Doka (Ed.), *Diesnfranchised grief: Recognizing Hidden Sorrow,* (pp. 3-11). Lexington, MA: Lexington Books.

Doka, K. J., & Aber, R. (1989). Psychosocial loss and grief. In K. J. Doka (Ed.), *Diesnfranchised grief: Recognizing Hidden Sorrow,* (pp. 3-11). Lexington, MA: Lexington Books.

Doll, W. (1976). Family coping with the mentally ill: An unanticipated problems. *Hospital & Community Psychiatry, 27*(3), 183-185.

Domic, D. A. (1996). The cost of family caregiving for individuals suffering from schizophrenia. Victoria, BC: University of Victoria. Master's Thesis.

Doubt, K. (1996). *Towards a sociology of schizophrenia: Humanistic reflections.* Toronto: University of Toronto Press.

Earle, K. A.; Forquer, S. L.; Volo, A. M., & McDonnell, P. M. (1994). Characteristics of outpatient suicides. *Hospital & Community Psychiatry, 45*(2), 123-126.

Eisenberg, L. (1977). Disease and illness: Distinctions between professional and popular ideas of sickness. *Culture, Medicine and Psychiatry, 1*, 9-23.

Ellsworth, R. B. (1975). Consumer feedback in measuring the effectiveness of mental health programs. In M. Guttenberg & E. L. Struening (Eds.), *Handbook of evaluation research.* Beverly Hills: Sage.

Estroff, S. E. (1981a). *Making it crazy.* Berkeley: University of California Press.

Estroff, S. E. (1981b). Psychiatric deinstitutionalization: A sociocultural analysis. *Journal of Social Issues, 37*(3), 116-132.

Estroff, S. E., Zimmer, C., Lachicotte, W. S. & Benoit, J. (1994). The influence of social networks and social support on violence by persons with serious mental illness. *Hospital and Community Psychiatry, 45*(7), 669-679.

Falloon, I. & Pederson, J. (1985). Family management in the prevention of morbidity of schizophrenia: The adjustment of the family unit. *British Journal of Psychiatry, 147,* 156-163.

Fischer, B. & Tronto, J. (1990). Toward a feminist theory of caring. In E. K. Abel & M. K. Nelson, (Eds.), *Circles of care: Work and identity in women's lives* (pp. 35-62). Albany: State University of New York Press.

Fleischman, P. R. (1973). Psychiatric diagnosis [Letter to the editor]. *Science, 180, 356.*

Francell, C. G., Conn, V. S., Gray, D. P. (1988). Families' perceptions of burden of care for chronic mentally ill relatives. *Hospital and Community Psychiatry, 39*(12), 1296-1300.

Franks, D. D. (1990). Economic contribution of families caring for persons with severe and persistent mental illness. *Administration and Policy in Mental Health, 18*, 9-18.

French, L. (1987). Victimization of the mentally ill: An unintended consequence of deinstitutionalization. *Social Work, 32*, 502-505.

Freidson, E. (1970). *Profession of medicine.* Chicago: University of Chicago Press.

Fromm-Reichmann, F. (1948). Notes on the development of treatment of schizophrenics by psychoanalytic psychotherapy. *Psychiatry, 11*, 263-273.

Fulton, R. (1978). Death, grief and social recuperation. *Omega, 1*, 23-28.

Gallagher, B. J. (1987). *The sociology of mental illness.* (2nd ed.). Englewood Cliffs: Prentice-Hall.

Geller, J. L. (1992). A historical perspective on the role of state hospitals viewed from the era of the "revolving door." *American Journal of Psychiatry, 149*(11), 1526-1532.

Geller, J. L. (1994). Commentary. In P. Backlar, (Ed.). *The family face of schizophrenia* (pp. 213-223). New York: G.P. Putnam's Sons.

Gerhardt, U. (1989). *Ideas about illness.* New York: New York University Press.

Gilligan, C. (1993). *In a different voice: Psychological theory and women's development.* Cambridge, MA: Harvard University Press.

Glaser, B. G. (1978). *Theoretical Sensitivity.* Mill Valley, CA: The Sociology Press.

Glaser, B. G. (1992). *Basics of Grounded Theory Analysis.* Mill Valley, CA: The Sociology Press.

Glaser, B. G. & Strauss, A. L. (1964). Awareness contexts and social interaction. *American Sociological Review, (29),* 669-679.

Glaser, B. G. & Strauss, A. L. (1965). Temporal aspects of dying as a non-scheduled status passage. *American Journal of Sociology, 30,* 48-59.

Glaser, B. G. & Strauss, A. L. (1967). *The discovery of grounded theory.* Chicago: Aldine.

Glaser, B. G. & Strauss, A. L. (1969). *Mirrors and masks.* San Francisco: The Sociology Press.

Glaser, B. G. & Strauss, A. L. (1971). *Status Passage..* Chicago: Aldine.

Goffman, E. (1959). *The presentation of self in everyday life.* Garden City, NY: Anchor Books.

Goffman, E. (1961). *Asylums.* Garden City, NY: Anchor Books.

Goffman, E. (1963). *Stigma.* Englewood Cliffs, NJ: Prentice-Hall.

Goldman, H. H. (1982). Mental illness and family burden: A public health perspective. *Hospital and Community Psychiatry, 33*(7), 557-560.

Goldstein, M. J. (1987). Psychosocial issues. *Schizophrenia Bulletin, (13)*, 157-171.

Gordon, A. (1997). CPA position statement: Psychiatric bed levels. *Canadian Psychiatric Association Bulletin, 29*(3), insert.

Gosselin, J. -Y. (1992). Preface. *Redefining schizophrenia and its treatment: A multidisciplinary approach.* (Available from the Schizophrenia Society of Canada, 75 The Donway West, Suite 814, Don Mills, Ontario, M3C 2E9)

Gottschalk, L. A. & Keatinge, C. (1993). Influence of patient caregivers on course of patient illness: "Expressed emotion" and alternative measures. *Journal of Clinical Psychology, 49*(6), 898-912.

Gove, W. R. (1970). Societal reaction as an explanation of mental illness: An evaluation. *The American Sociological Review, 35*, 873-884.

Grabb, E. G. (1990). *Theories of social inequality: Classical and contemporary perspectives,* 2nd ed. Toronto: Holt, Rinehart & Winston.

Grad, J., & Sainsbury, P. (1968). The effects that patients have on their families in a community care and a control psychiatric service – A two year follow-up. *British Journal of Psychiatry 114*, 265-278.

Greenberg, J. S., Greenley, J. R., & Benedict, P. (1994). Contributions of persons with serious mental illness to their families. *Hospital and Community Psychiatry, 45*(5), 475-480.

Guba, E. G. & Lincoln, Y. S. (1989). *Fourth generation evaluation.* Newbury Park, CA, Sage.

Gudeman, J. E. & Shore, M. F. (1984). Beyond deinstitutionalization: A new class of facilities for the mentally ill. *The New England Journal of Medicine, 311*(13), 832-836.

Hanley, J. (1973). Psychiatric diagnosis [Letter to the editor]. *Science, 180,* 360.

Hansen, D., & Hill, R. (1964). Families under stress. In H. Christensen (Ed.), *Handbook of marriage and the family,* (pp. 782-819). Chicago: Rand-McNally.

Harding, C. M., Brooks, G. W., Ashikaga, T., Strauss, J. S., & Breier, A. (1987a). The Vermont longitudinal study of persons with severe mental illness, I: Methodology, study sample, and overall status 32 years later. *American Journal of Psychiatry, 144*(6), 718-726.

Harding, C. M., Brooks, G. W., Ashikaga, T., Strauss, J. S., & Breier, A. (1987b). The Vermont longitudinal study of persons with severe mental illness, II: Long-term outcome of subjects who retrospectively met DSM-III criteria for schizophrenia. *American Journal of Psychiatry, 144*(6), 727-735.

Harding, C. M., Zubin, J., & Strauss, J. S. (1987). Chronicity in schizophrenia: Fact, partial fact, or artifact? *Hospital and Community Psychiatry, 38*(5), 477-486.

Harding, C. M. (1988). The outcome of schizophrenia [On-line]. Available: http://www.mentalhealth.com (originally published in *The Harvard Medical School mental health letter).*

Hatfield, A. B. (1978). Psychological costs of schizophrenia to the family. *Social Work, 23*, 355-359.

Hatfield, A. B. (1987). Families as caregivers: A historical perspective. In A.B. Hatfield & H.P. Lefley (Eds.), *Families of the mentally ill: Coping and adaptation* (pp. 3-29). New York: Guilford.

Hatfield, A. B., & Lefley, H. P. (Eds.). (1987). *Families of the mentally ill": Coping and adaptation.* New York: Guilford.

Hatfield, A. B., Spaniol, L. & Zipple, A. M. (1987). Expressed emotion: A family perspective. *Schizophrenia Bulletin, 13*(2), 221-226.

Health Canada. (1994). *Suicide in Canada: Update of the report of the Task Force on Suicide in Canada.* (Catalogue No. H39-107/1995E). Ottawa: Health Programs and Services Branch.

Henry, A. D. & Coster, W. J. (1995). Predictors of functional outcome among adolescents and young adults with psychotic disorders. *The American Journal of Occupational Therapy, 50*(3), 171-181.

Herman, J. L. (1986). Histories of violence in an outpatient populations: An exploratory study. *American Journal of Orthopsychiatry, 56*(1), 137-141.

Hinckley, J. & Hinckley, J. (1985). *Breaking Points.* Grand Rapids: Zondervan.

Hoaken, P. C. S. (1973). Psychiatric diagnosis [Letter to the editor]. *Science, 180,* 358.

Hoenig, J. & Hamilton, M. W. (1969). *The desegregation of the mentally ill.* London: Routledge & Kegan Paul.

Hogarty, (1985). Expressed emotion and schizophrenic relapse: Implications from the Pittsburgh study. In M. Alpert (Ed.), *Controversies in schizophrenia* (pp. 354-365). New York: Guilford Press.

Holmes, T. H. & Rahe, R. H. (1967). The social readjustment rating scale. *Journal of Psychosomatic Research, 11*, 213-218.

Horacek, B. J. (1995). A heurisic model of grieving after high-grief deaths. *Death Studies, 19,* 21-31.

Horowitz, A. V., Reinhard, S. C., Howell-White, S. (1996). Caregiving as reciprocal exchange in families with seriously mentally ill members. *Journal of Health and Social Behaviour, 37*(June), 149-162.

Hoult, T. F. (1977). *Dictionary of modern sociology.* Totowa, NJ: Littlefield, Adams & Company.

Howard, P. B. (1994). Lifelong maternal caregiving for children with schizophrenia. *Archives of Psychiatric Nursing, 8*(2), 107-114.

Hughes, E. C. (1945). Dilemmas and contradictions of status. *American Journal of Sociology, 50*, 353-359.

Hunter, F. M. (1973). Psychiatric diagnosis [Letter to the editor]. *Science, 180,* 361.

Hunter, E. P. & Storat, B. (1994). Psychosocial triggers of relapse in persons with chronic mental illness: A pilot study. *Issues in Mental Health Nursing, 15*, 67-72.

Hutchinson, S. (1986). Grounded theory: The method. In P. L. Munhall & C. J. Oiler (Eds.), *Nursing research: A qualitative perspective* (pp. 111-130). Norwalk: Appleton-Century-Crofts.

Isaac, R. J. & Armat, V. C. (1990). *Madness in the streets: How psychiatry and the law abandoned the mentally ill.* New York: The Free Press.

Israel, J. V. (1973). Psychiatric diagnosis [Letter to the editor]. *Science, 180, 356,* 358.

Jeffries, J. J., Plummer, E., Seeman, M. V. & Thornton, J. F. (1990). *Living and working with schizophrenia.* Toronto: University of Toronto Press.

Jones, B. D. (1992). *Redefining schizophrenia and its treatment: A multidisciplinary approach.* Document produced from a meeting conducted at the Chateau Montebello, Quebec, May 29-31, 1992. Pegasus Healthcare International Publication, endorsed by the Canadian Psychiatric Association and The Schizophrenia Society of Canada.

Kastenbaum, R. J. (1977). *Death, society and human experience.* St. Louis: C.V. Mosby.

Kendall, R. E., Cooper, J. Gourley, A. & Copeland, J. (1971). Diagnostic criteria of American and British psychiatrists. *Archives of General Psychiatry, 25*, 123-30.

Kirby, S. & McKenna, K. (1989). *Experience, research, social change: Methods from the margins.* Toronto: Garamond.

Kramp, P. (1995). Poor treatment = Increased Criminality. *Prelapse Magazine, 2* [On-line]. Available: http://www.mentalhealth.com

Kubler-Ross, E. (1969). *On death and dying.* New York: Macmillan.

Kuhn, M. (1964). Major trends in symbolic interaction theory in the past twenty-five years. *Sociological Quarterly, 5,* 61-84.

Lafond, V. (1994). *Grieving Mental Illness.* Toronto: University of Toronto Press.

Laing, R. (1969). *The divided self.* New York: Pantheon.

Lamb, H. R. & Goertzel, V. (1977). The long-term patient in the era of community treatment. *Archives of General Psychiatry, 34*, 679-682.

Lamb, H. R.; Hoffman, A.; Hoffman, F.; Oliphant, E. (1986). Families of schizophrenics: A movement in Jeopardy. *Hospital and Community Psychiatry, 37*(4), 353-357.

LaRossa, R. & Reitzes, D. C. (1993). Symbolic Interactionism and Family Studies. In P. G. Boss, W. J. Doherty, R. LaRossa, W. R. Schumm, & S. D. Steinmetz (Eds.), *Sourcebook of family theories and methods: A contextual approach* (pp. 135-166). New York: Plenum Press.

Layder, D. (1982). Grounded theory: A constructive critique. *Jounral of Theory in Social Behavior, 12*(1), 103-123.

Lazarus, R. S. (1975). Psychological stress and coping in adaptation and illness. *International Journal of Psychiatry in Medicine, 5*(4), 321-333.

Lefley, H. P. (1987). Aging parents as caregivers of mentally ill adult children: An emerging social problem. *Hospital and Community Psychiatry, 38*(10), 1063-1070.

Lefley, H. P. (1989). Family burden and family stigma in major mental illness. *American Psychologist, 44*(3), 556-560.

Lefley, H. P. (1996). *Family Caregiving in Mental Illness.* Thousand Oaks, CA: Sage.

Lehman, A. F. & Linn. (1984). Crimes against discharged mental patients in board-and-care homes. *American Journal of Psychiatry, 141*(2), 271-274.

Leininger, M. (1992). Current issues, problems, and trends to advance qualitative paradigmatic research methods for the future. *Qualitative Health Research, 2*(4), 392-415.

Lemert, E. (1951). *Social Pathology.* New York: McGraw Hill.

Liddle, P. F. (1996). *The multidimensional nature of schizophrenia.* Paper presented at the 2nd Annual Schizophrenia Conference, Riverview Hospital, Port Coquitlam, BC.

Liddle, P. F. (1997). The promise of early intervention. *Visions: The Journal of BC's Mental Health, 1*(Spring), 2.

Lidz, T., Fleck, S., & Cornelison, A. R. (1965). *Schizophrenia & the family.* New York: International Universities Press.

Lieberman, J., Jody, D., Geisler, S., Vital-Herne, J., Alvir, J. M. J., Walsleben, J. & Woerner, M. G. (1989). Treatment outcome of first episode schizophrenia. *Psychopharmacology Bulletin, 25*(1), 92-96.

Lieberman, L. R. (1973). Psychiatric diagnosis [Letter to the editor]. *Science, 180,* 361.

Lindesmith, A. R., Strauss, A. L., Denzin, N. K. (1975). A statement of position: Symbolic interactionism as perspective and method. In A. R. Lindesmith, A. L. Strauss, & N. K. Denzin (Eds.), *Readings in social psychology* (2nd ed., pp. 5-20). Hinsdale, IL: Dryden Press.

Lindesmith, A. R., Strauss, A. L., Denzin, N. K. (1988). *Social Psychology* (7th ed.). Englewood Cliffs, NJ: Prentice-Hall.

Lurigio, A. J. & Lewis, D. A. (1989). Worlds that fail: A longitudinal study of urban mental patients. *Journal of Social Issues, 45*(3), 79-90.

Martin, K. & Elder, S. (1988). Pathways through grief: A model of the process. In J. D. Morgan, (Ed.). *Personal care in an impersonal world: A multidimensional look at bereavement.* Amityville, NY: Baywood Publishing.

Matarazzo, J. D. (1983). The reliability of psychiatric and psychological diagnosis. *Clinical Psychology Review, 3*, 103-145.

McCann, G. & Clancy, B. (1996). Family matters. *Nursing Times, 92*(7), 46-48.

McElroy, E. M. (1987). The beat of a different drummer. In A. B. Hatfield & H. P. Lefley, *Families of the mentally ill: Coping and adaptation* (pp. 225-243). New York: Guilford.

McGlashan, T. (1996, July 5). Course of schizophrenia can be improved through early identification, intervention. *Psychiatric News, 31*(13), 4.

McPhail, C. (1989). Meadian versus neo-Meadian theories of mind. *Symbolic Interaction, 12*(1) 43-51.

Mead, G. H. (1934/1962). *Mind, self, and society.* Chicago: Charles W. Morris.

Mechanic, D. & Rochefort, D. A. (1990). Deinstitutionalization: An appraisal of reform. *Annual Review of Sociology, 16*, 301-327.

Miller, D. (1981). The meaning of role-taking. *Symbolic Interaction, 4*(2), 167-175.

Minkoff, K. (1987). Beyond deinstitutionalization: A new ideology for the postinstitutional era. *Hospital and Community Psychiatry, 38*(9), 945-950.

Mirowsky, J. & Ross, C. E. (1989). *Social causes of psychological distress.* New York: Aldine de Gruyter.

Model Program Successful. (1996). *Psychiatric News (July 5),* 4.

Morse, J. M. (1994). Designing funded qualitative research. In N. K. Denzin & Y. S. Lincoln, (Eds.). *Handbook of qualitative research.* Thousand Oaks, CA: Sage.

Mueser, K. T. & Gingerich, S. (1994). *Coping with schizophrenia: A guide for families.* Oakland, CA: New Harbinger Publications.

Munhall, P. L. (1994). The transformation of anger into pathology. In P. L. Munhall (Ed.). *In women's experience,* (pp. 295-322). New York: National League for Nursing Press..

National Institute of Mental Health. (1986). *Schizophrenia: Questions and answers.* (D. Shore, Ed.). [On-line]. Available: http://www.mentalhealth.com (also available from Public Inquiries Branch, National Institute of Mental Health, Room 15C-05, 5600 Fischers Lane, Rockville, MD 20857).

Newman, S. C. & Bland, R. C. (1991). Mortality in a cohort of patients with schizophrenia: A record linkage study. *Canadian Journal of Psychiatry, 36*(4), 239-245.

Noh, S. & Avison, W. R. (1988). Spouses of discharged psychiatric patients: Factors associated with their experience of burden. *Journal of Marriage and the Familiy, 50*, 377-389.

Noh, S. & Turner, R. J. (1987). Living with psychiatric patients: Implications for the mental health of family members. *Social Science and Medicine, 25*(3), 263-271.

NUD*IST 4.0 [Computer software]. (1997). Melbourne: Qualitative Solutions & Research.

Olshansky, S. (1962). Chronic sorrow: A response to having a mentally defective child. *Social Casework, 43*, 190-193.

Ombudsman. (1994). *Listening: A review of Riverview Hospital.* Public Report No. 33. Victoria: Province of British Columbia.

Ostow, M. (1973). Psychiatric diagnosis [Letter to the editor]. *Science, 180,* 360-361.

Pai. S. & Kapur, R. L. (1982). Impact of treatment intervention on the relationship between dimensions of clinical psychopathology, social dysfunction and burden on the family of psychiatric patients. *Psychological Medicine, 12*, 651-658.

Palmer, M. (1997). *Yin & Yang.* London: Judith Piaktus (Publishers) Ltd.

Park, R. E. (1928). Human migration and the marginal man. *American Journal of Sociology, 33*, 881-893

Pattison, E. M. (1973). Psychiatric diagnosis [Letter to the editor]. *Science, 180,* 364-365.

Pasamanick, B., Scarpitti, F. R. & Dinitz, S. (1967). *Schizophrenics in the community.* New York: Appleton-Century-Crofts.

Pearlin, L. I., Lieberman, M. A., Menaghan, E. G., & Mullan, J. T. (1981). The stress process. *Journal of Health & Social Behavior, 22*, 337-356.

Pearlson, G. D. & Pulver, A. E. (1994). Sex, schizophrenia and the cerebral cortex. In R. J. Ancill, S. Holliday, & J. Higenbottam (Eds.), *Schizophrenia: Exploring the spectrum of psychosis* (pp. 345-362). New York: John Wiley & Sons.

Pinsker, H. (1973). Psychiatric diagnosis [Letter to the editor]. *Science, 180,* 362,

Platt, S. D. (1985). Measuring the burden of psychiatric illness on the family: An evaluation of some rating scales. *Psychological Medicine, 15*, 383-393.

Premier's Commission on Future Health Care for Albertans. (1989). *The rainbow report: Our vision for health.* Vol. 2. Edmonton: Province of Alberta.

Rando, T. A. (1992). The increasing prevalence of complicated mourning: The onslaught is just beginning. *Omega, 26*(1), 43-59.

Raveis, V. H., Siegel, K. & Sudit, M. (1988). Psychological impact of caregiving on the careprovider: A critical review of extant research. *The Journal of Applied Social Sciences, 13*, 40-79.

Regan, T. G. (1988). Negotiating an innovative mental health service: The question of limits to negotiated orders. In D. Coburn, C. D'Arcy, G. M. Torrance, & P. New (Eds.).

Health and Canadian society: Sociological perspectives (pp. 501-514). Markham, ON: Fitzhenry & Whiteside.

Reich, W. (1973). Psychiatric diagnosis [Letter to the editor]. *Science, 180,* 363.

Reinhard, S. C. (1991). *Living with mental illness: Effects of professional contacts and personal control on caregiver burden.* New Brunswick, NJ: Rutgers, Dissertation.

Remington, G. J. (1995). The long-term treatment of schizophrenia. *Canadian Journal of Psychiatry, 40*(suppl. 1), S3-S4.

Remington, G. (1997, June 6). *Schizophrenia: New theories and novel antipsychotics.* Paper presented at the Victoria Schizophrenia '97 Conference.

Remington, G. J. & Adams, M. E. (1995). Depot neuroleptic therapy: Clinical considerations. *Canadian Journal of Psychiatry, 40*(suppl. 1), S5-S11.

Reynolds, I. & Hoult, J. E. (1984). The relatives of the mentally ill: A comparative trial of community-oriented and hospital-oriented psychiatric care. *The Journal of Nervous and Mental Disease, 172*(8), 480-489.

Richards, L. & Richards, T. (1994). Using computers in qualitative analysis. In N. K. Denzin & Y. S. Lincoln (Eds.). *Handbook of qualitative research* (pp. 445-462). Thousand Oaks, CA: Sage.

Richards, L. & Richards, T. (1991). Computing in Qualitative Analysis: A Healthy Development? *Qualitative Health Research, 1*(3), 234-262.

Richardson, L. (1994). Writing: A method of inquiry. In N.K. Denzin & Y.S. Lincoln (Eds.), *Handbook of qualitative research,* (pp. 516-529). New York: Wiley & Sons.

Rigney, E. G. & Smith, R. L. (1991). A behavioral examination of Mead's role-taking. *Symbolic Interaction, 14*(1), 71-81.

Ritzer, G. (1988). *Contemporary social theory.* New York: Alfred A. Knopf.

Rose, A. M. (1962). A systematic summary of symbolic interaction theory. In A. M. Rose, *Human behavior and social processes* (pp. 3-19). Boston: Houghton Mifflin.

Rosenberg, M. (1984). A symbolic interactionist view of psychosis. *Journal of Health and Social Behavior, 25*, 289-302.

Rosenberg, M. (1992). *The unread mind.* New York: Lexington Books.

Rosenblatt, A. (1984). Concepts of the asylum in the care of the mentally ill. *Hospital and Community Psychiatry, 35*(3), 244-250.

Rosenhan, D. L. (1973a). On being sane in insane places. *Science, 179*, 250-258.

Rosenhan, D.L. (1973b). Psychiatric diagnosis [Letter to the editor]. *Science, 180,* 365-369.

Rosenfarb, I. S., Goldstein, M. J., Mintz, J. & Nuechterlein, K. H. (1995). Expressed emotion and subclinical psychopathology observable within the transactions between schizophrenic patients and their family members. *Journal of Abnormal Psychology, 104*(2), 259-267.

Rotter, J. B. (1966). Generalized expectancies for internal vs. external control of reinforcements. *Psychological Monographs, 80*(609), 1-28.

Rubin, S. S. (1990). Death of the future?: An outcome study of bereaved parents in Israel. *Omega, 20*(4), 323-339.

Rutman, I. (1997, June 6). Psychiatric rehabilitation: emerging principles, methods and research. Paper presented at the Victoria Schizophrenia '97 Conference.

Sandelowski, M. (1986). The problem of rigor in qualitative research. *Advances in Nursing Science, 8*(3), 27-37.

Sartorius, N. & de Girolamo, G. (1991). Preface. *Schizophrenia Bulletin, 17*(3), 371-373.

Scheff, T. (1966/1984). *Being mentally ill.* Chicago: Aldine.

Scheff, T. J. (1975). *Labeling madness.* Englewood Cliffs, NJ: Prentice-Hall.

Scheyette, A. (1990). The oppression of caring: Women caregivers of relatives of the mentally ill. *Affilia, 5*(1), 32-48.

Schooler, N. R. (1995). Integration of family and drug treatment strategies in the treatment of schizophrenia: A select review. *International Clinical Psychopharmacology, 10*(Suppl. 3), 73-80.

Schreiber, R. (1995). *(Re)defining my self: Women's process of recovery from depression.* Buffalo, NY: State University of New York. Dissertation.

Scull, A. T. (1976). The decarceration of the mentally ill: A critical view. *Politics and Society, 6*(2), 417-437.

Seeman, M. & Seeman, T. E. (1983). Health behavior and personal autonomy: A longitudinal study of the sense of control in illness. *Journal of Health and Social Control, 24*(June), 144-160.

Selye, H. (1976). *The stress of life.* New York: McGraw-Hill.

Sherif, M. (1948). *An outline of social psychology.* New York: Harper.

Shibutani, T. (1962). Reference groups and social control. In A. M. Rose (Ed.), *Human behavior and social processes* (pp. 128-147).

Shibutani, T. (1991). On the empirical investigation of self-concepts. In D. R. Maines (Ed.), *Social organization and social process: Essays in honor of Anselm Strauss* (pp. 59-69). New York: Aldine de Gruyter.

Slovenko, R. & Luby, E. D. (1974). From moral treatment to railroading out of the mental hospital. *Bulletin of the American Academy of Psychiatry and the Law, 2*, 223-236.

Spaniol, L., Jung, H., Zipple, A. M. & Fitzgerald, S. (1987). Families as a resource in the rehabilitation of the severely psychiatrically disabled. In A. B. Hatfield & H. P. Lefley, *Families of the mentally ill: Coping and adaptation.* New York: Guildford.

Splane, S., Monahan, J., Prestholt, D, Friedlander, H. D. (1982). Patients' perceptions of the family's role in involuntary commitment. *Hospital and Community Psychiatry, 33*(7), 569-572.

Statistics Canada. (1997). A national overview. *1996 Census of Canada.* Catalogue number 93-357-XPB. Table 17. Ottawa: Industry Canada.

Stein, L. I. & Test, M. A. (1980). Alternative to mental hospital treatment: I. Conceptual model, treatment program, and clinical evaluation. *Archives of General Psychiatry, 37*, 392-397.

Stephenson, J. S. (1985). *Death, grief, and mourning: Individual and social realities.* New York: The Free Press.

Stephenson, J. S. & Murphy, D. (1986). Existential grief: The special case of the chronically ill and disabled. *Death Studies, 10*, 135-145.

Stern, P. N. (1980). Grounded theory methodology: Its uses and processes. *Image, 12*(1), 20-23.

Stern, P. N. (1985). Using grounded theory in nursing research. In M. M. Leininger (Ed.). *Qualitative research methods in nursing* (pp. 149-160). New York: Grune & Stratton.

Strauss, A. L. (1969). *Mirrors & Masks.* San Francisco: The Sociology Press.

Strauss, A. L. (1987).*Qualitative analysis for social scientists.* Cambridge: Cambridge University Press.

Strauss, A. & Corbin, J. (1990). *Basics of qualitative research.* Newbury Park: Sage.

Strauss, A., Schatzman, L., Ehrlich, D., Bucher, R., & Sabshin, M. (1963). The hospital in its negotiated order. In E. Friedson (Ed.), *The hospital in modern society* (pp. 147-169). New York: Free Press.

Stryker, S. (1980). *Symbolic interactionism: A social structural version.* London: Benjamin/Cummings.

Stryker, S. & Statham, A. (1985). Symbolic interaction and role theory. In G. Lindsey & E. Aronson (Eds.), *The handbook of social psychology* (Vol. 1, pp. 311-378). New York: Random House.

Sundram, C. J. (1986). Mental illness and health care policy. *Journal of Public Health Policy,* Summer.

Szasz, T. S. (1974. *The myth of mental illness.* New York: Harper and Row.

Terkelsen, K. G. (1987). The meaning of mental illness to the family. In A. B. Hatfield & H. P. Lefley, *Families of the mentally ill: Coping and adaptation* (pp. 128-150). New York: Guilford.

Tessler, R. C., Killian, L. M., & Gubman, G. D. (1987). Stages in family response to mental illness: An ideal type. *Psychosocial Rehabilitation Journal, 10*(4), 3-16.

Test, M. A., Wallisch, L. S., Allness, D. J. & Ripp, K. (1989). Substance use in young adults with schizophrenic disorders. *Schizophrenia Bulletin, 15*(3), 465-476.

Thaler, O. F. (1973). Psychiatric diagnosis [Letter to the editor]. *Science, 180,* 358.

The compact edition of the Oxford English dictionary (Xth ed.). Glasgow: Oxford University Press.

Thornton, J. F. & Seeman, M. V. (1991). *Schizophrenia Simplified.* Toronto: Hogrefe & Huber.

Torrey, E. F. (1983). *Surviving schizophrenia.* New York: HarperCollins.

Torrey, E. F. (1988). *Nowhere to go.* New York: Harper and Row.

Torrey, E. F. (1994). Violent behavior by individuals with serious mental illness. *Hospital and Community Psychiatry, 45*(7), 653-662.

Torrey, E.F. (1995). *Surviving schizophrenia* (3rd ed.). New York: Harper Collins.

Torrey, E.F. (1997). *Out of the shadows: Confronting America's mental health crisis.* New York: John Wiley & Sons.

Torrey, E. F., Bowler, A. E., Taylor, E. H., & Gottesman, I. I. (1996). *Schizophrenia & manic-depressive disorder.* New York: Basic Books.

Trolley, B. C. (1994). A bridge between traumatic life events and losses by death. *Omega, 28*, 285-300.

Townsend, M. C. (1993). Psychiatric/Mental Health Nursing: Concepts of care. Philadelphia, F. A. Davis Company.

Turner, R. H. (1962). Role-taking: Process versus conformity. In A. M. Rose (Ed.). *Human behavior and social processes* (pp. 20-40). Boston: Houghton Mifflin.

Van Hammond, T. & Deans, C. (1995). A phenomenological study of families and psychoeducation support groups. *Journal of Psychosocial Nursing, 33*(10), 7-12.

Varcarolis, E. M. (1994). Schizophrenic disorders. In E. M. Varcarolis (Ed.), *Foundations of psychiatric mental health nursing* (2nd ed., pp. 491-543). Philadelphia: W.B. Saunders.

Vaughn, C. E. & Leff, J. P. (1981). Patterns of emotional response in relatives of schizophrenic patients. *Schizophrenia Bulletin, 7*, 43-44.

Wahl, O. F., Borostovik, L., & Reippi, R. (1995). Schizophrenia in popular periodicals. *Community Mental Health Journal, 31*(3), 239-248.

Wallace, R. A. & Wolf, A. (1986). *Contemporary social theory: Continuing the classical tradition.* Englewood Cliffs: Prentice-Hall.

Walsh, M. (1985). *Schizophrenia: Straight talk for family and friends.* New York: William Morrow.

Weber, M. (1922). *Economy and society.* New York: Bedminster Press, cited in Grabb (1990).

Weideman, G. H. (1973). Psychiatric diagnosis [Letter to the editor]. *Science, 180,* 363-364.

Williams, R. (1997, June 6). *Assessment, diagnosis and early intervention in schizophrenia.* Paper presented at the Victoria Schizophrenia '97 Conference, Victoria, BC.

Wing, J. K. (1988). Comments on the long-term outcome of schizophrenia. *Schizophrenia Bulletin, 14*(4), 669-673.

V , J. K. (1990). The functions of asylum. *British Journal of Psychiatry, 157,* 822-827.

Wolff, K. H. (1979). *Emile Durkheim.* New York: Arno Press

Wright, E. R. (1994). *Caring for those who "can't", Gender, network structure, and the burden of caring for people with mental illness.* Bloomington: Indiana University, Dissertation.

Zola, I. K. (1973). Pathways to the doctor – From person to patient. *Social Science and Medicine 7,* 677-689.

Zucker, H. D. (1973). Psychiatric diagnosis [Letter to the editor]. *Science, 180,* 358, 360.

APPENDIX I INITIAL INTERVIEW SCHEDULE

I am interested in learning about your own experience in caring for your son (daughter) who has schizophrenia. Take your time and tell me in as much detail as possible and in your own words.

DESCRIBE FOR ME WHAT (NAME) WAS LIKE BEFORE HE (SHE) BECAME ILL.
Probes: Interests?
Talents?
What did he (she) want to be when grown up?
Relationships with parents? Siblings? Friends? Teachers?

NOW, CAN YOU DESCRIBE YOUR SON (DAUGHTER) TODAY?
Probes: Same as above, replacing 3rd probe with: What are his (her) present goals?

LOOKING BACK, HOW HAS HE (SHE) CHANGED AS THE ILLNESS DEVELOPED?
Probes: Initially, how did you deal with changes in his (her) behavior?
What first made you suspect a psychiatric problem?
Tell me how that made you feel?

OVERALL, HOW HAS HIS (HER) HAVING SCHIZOPHRENIA CHANGED YOUR OWN LIFE?
Probes: Family? Friends? Social and recreational activities? Work?
How do you help your son (daughter)?
What do you do if he (she) doesn't want your help?
Who helps you deal with your son (daughter)? Family? Friends? Professionals?
What is the worst thing that has happened since he (she) became ill?
Tell me about any good things that have happened since he (she) became ill.

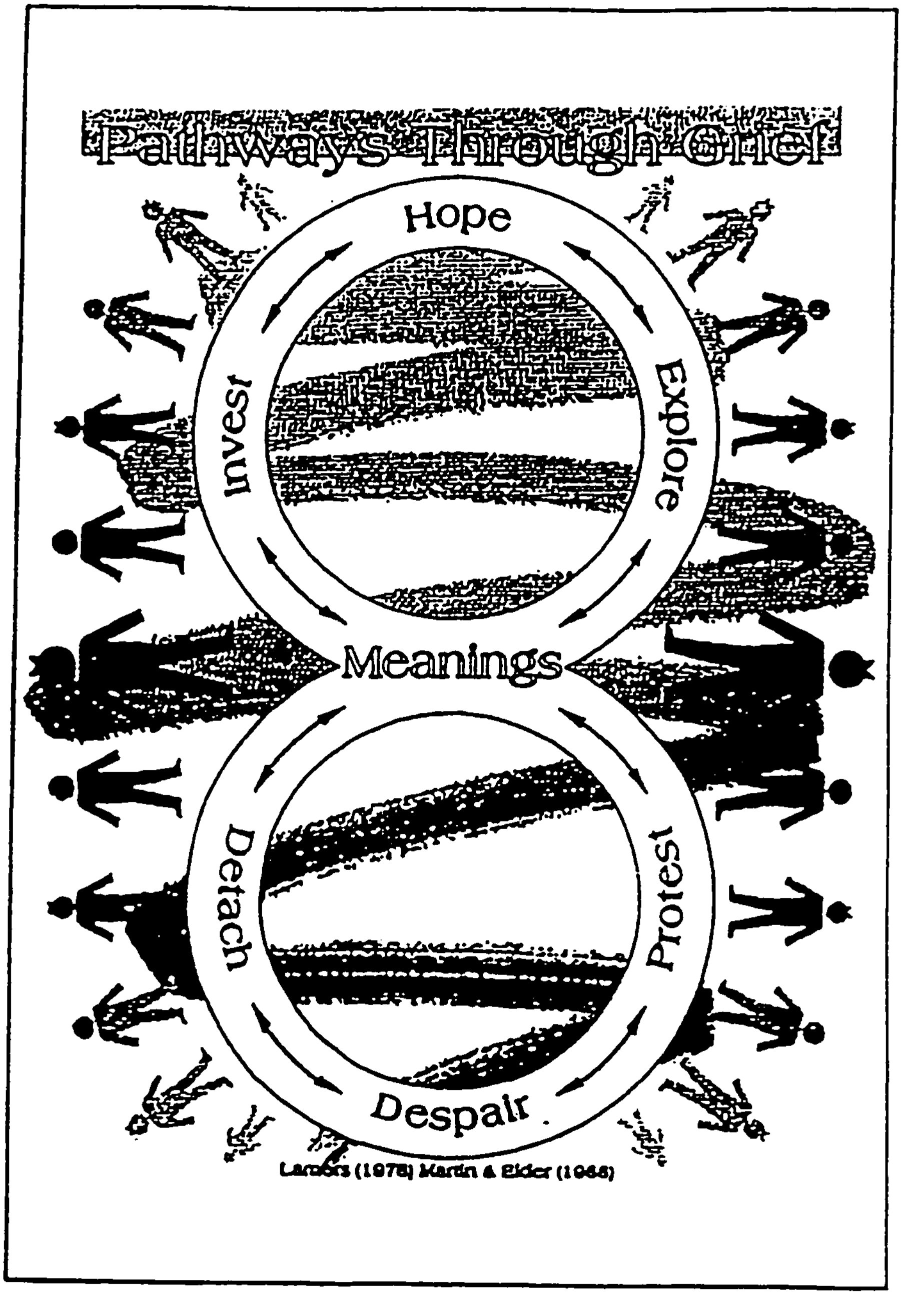
WHAT DO YOU THINK THE FUTURE HOLDS FOR YOUR SON (DAUGHTER)?
YOURSELF?

* Once loss, bereavement, grief of mourning is mentioned by the informant, other questions may be asked, such as:

TELL ME WHAT IT IS LIKE TO GRIEVE FOR THE WAY YOUR SON (DAUGHTER) USED TO BE?
Probes: Is the grief constant or does it vary in intensity?
What makes it worse? Better?
How does your grief affect you relationship with your son (daughter)?
Other family members?
Friends?
Professionals?
Who do you talk to about your loss?
What would help others to understand your grief?

IS THERE ANYTHING ELSE YOU THINK THAT I SHOULD KNOW ABOUT WHAT IS LIKE TO CARE FOR SOMEONE WHO HAS SCHIZOPHRENIA?

APPENDIX 2 PATHWAYS THROUGH GRIEF MODEL



Pathways through Grief Model

Source:

Martin, K. & Elder, S. (1988). Pathways through grief: A model of the process. In J. D. Morgan, (Ed.), *Personal care in an impersonal world: A multidimensional look at bereavement*, p. 78. Amityville, NY: Baywood Publishing. Used with permission of the publisher (Appendix 9.)

APPENDIX 3-a SUBMISSION TO SUPPORT GROUP NEWSLETTERS

The request included three forms of the research announcement - various lengths depending on how much room the group was willing to give me in their newsletter.

Long Form:

Research on Caregiving and Schizophrenia Needs Volunteers

Jane Milliken is interviewing parents of persons diagnosed with schizophrenia and is looking for more participants on Vancouver Island. Mrs. Milliken is a registered nurse, presently teaching at the University of Victoria. This study will complete her Ph.D. in medical sociology from the University of Alberta.

Mrs. Milliken wants to interview a broad range of caregivers: those who are and are not connected with a support group, those with the ill relative living at home or elsewhere, and those who's relatives are ill, recovering or recovered schizophrenics. Knowing the challenges and how people deal with them will assist other parent caregivers, mental health professionals, researchers, and those people who developing health care policy.

When both parents agree to participate, they are interviewed separately. Interviews should last about one to one and a half hours. To ensure accuracy, interviews are tape recorded but, when typed, the transcripts contain no real names or identifying features. Complete confidentiality is assured.

If you agree to participate, please fill in the enclosed form or **phone Jane Milliken at (250) 721-6465.** Leave a message on the voice-mail, if no one answers.

I would like to participate in the study of parents caring for persons who have been diagnosed with schizophrenia, conducted by Mrs. Jane Milliken.

Name:______________________________
Address:_____________________________
____
Telephone number:______________________
The best time to contact me is:______________

Mail to:

Mrs. Jane Milliken
School of Nursing
P.O. Box 1700
University of Victoria
Victoria, B. C. V8W 2Y2

APPENDIX 3 - b SUBMISSION TO SUPPORT GROUP NEWSLETTERS

Middle-length Form:

Research Project on Caregiving Needs Volunteers

Parent caregivers of persons diagnosed with schizophrenia are needed for a research project examining their experience. A broad range of caregivers from Vancouver Island is wanted, including:

- those who are and are not connected with a support group,
- those with the ill relative living at home or elsewhere, and
- those who's relatives are presently ill, recovering or recovered schizophrenics.

Parents will be interviewed separately for about one to one and a half hours. Complete confidentiality is assured.

Phone Jane Milliken at (250) 721-6465 or fill in the enclosed form and mail to:

Mrs. Jane Milliken
School of Nursing
P.O. Box 1700
University of Victoria
Victoria, B. C. V8W 2Y2

I would like to participate in the study of parents caring for persons who have been diagnosed with schizophrenia, conducted by Mrs. Jane Milliken.

Name:____

Address:____

____

Telephone number:____________________________________

The best time to contact me is:____________________________

APPENDIX 3 - c SUBMISSION TO SUPPORT GROUP NEWSLETTERS

Short Form:

Research Project on Caregiving Needs Volunteers

Parent caregivers of persons diagnosed with schizophrenia are needed for a research project examining their experience. A broad range of caregivers from Vancouver Island is wanted, including:

- those who are and are not connected with a support group,
- those with the ill relative living at home or elsewhere, and
- those who's relatives are ill, recovering or recovered schizophrenics.

Parents will be interviewed separately for about one to one and a half hours. Complete confidentiality is assured.

Phone Jane Milliken at (250) 721-6465 or write to:

Mrs. Jane Milliken
School of Nursing
P.O. Box 1700
University of Victoria
Victoria, B. C. V8W 2Y2

APPENDIX 4 LETTER TO VOLUNTEER PARTICIPANTS

(DATE)

Dear (NAME):

Thank you for indicating an interest in participating in my research project, to investigate the caregiving experience of parents of persons diagnosed with schizophrenia. As most people with schizophrenia are being treated in the community and not spending extensive periods in hospital, family members are required, more and more, to become involved with both direct care and also the ill persons' contacts with professional caregivers and social agencies.

Anyone who is involved with caregiving is familiar with the term "caregiver burden." Much of the research into this phenomenon has focused on caregivers of the elderly and, often, the assumption is made that the experience is similar for family caregivers of those with any severe illness. I believe that those who care for someone with a severe psychiatric illness, in this case schizophrenia, have different challenges with which to deal than do those who care for an elderly person with Alzheimer's disease. What those different challenges are and how caregivers deal with them is what I am hoping you will be able to tell me. A better understanding of caregiving for those with schizophrenia will be helpful to other parent caregivers, to mental health professionals, to researchers, and to those responsible for health care policy decisions.

The interview should last about one to one and a half hours. If more time is required, you will be given the choice whether to participate further or not. To ensure accuracy, I intend to tape record the interview but, when typed, the transcript will contain no actual names or identifying features. I will also assure you of complete confidentiality in the dissertation and any subsequent published articles or presentations.

I am a registered nurse, presently teaching at the University of Victoria and studying medical sociology at the University of Alberta. This research will complete the requirements for a Doctor of Philosophy degree. If you have any questions to ask me before agreeing to participate, please phone me at my office, (604) 721-6465. If I am not in, please leave a message on the voice-mail and I will return your call promptly. My academic supervisor is Dr. Herbert C. Northcott, Department of Sociology, University of Alberta. He may be contacted at (403) 492-2204.

If you agree to participate, please write your name and telephone number on the enclosed form and return it to me in the self-addressed envelope. I will then call you to arrange a time for the interview, to take place in your home or my office, whichever you prefer. Thank you for considering this research project. I look forward to hearing from you.

Yours truly,

Jane Milliken, RN, MA

APPENDIX 5 FORM FOR PROSPECTIVE PARTICIPANTS

Please return this form in the self-addressed, stamped envelope provided.

I would like to participate in the study of parents caring for persons who have been diagnosed with schizophrenia, conducted by Mrs. Jane Millken.

Name: ______________________________

Telephone number: ______________________________

The best time to contact me is: ______________________________

APPENDIX 6 INTERVIEW CONSENT

The focus of this study is to gain a better understanding of what it is like to care for a family member who has been diagnosed with schizophrenia.

In consenting to help with this study, I understand and agree with the following statements:

1. I give permission to be interviewed and for this interview to be tape-recorded.
2. I understand that I am free to refuse to answer any specific question or questions and that I may withdraw my consent, ending the interview at any time, without penalty.
3. I have been given the opportunity to ask any questions I wish about the study, and these questions have been answered to my satisfaction.
4. I give permission to Mrs. Jane Milliken to quote from and refer to the content of this interview in academic talks and professional writing, subject to any requests or limitations that I may make on the tape itself, concerning specific topics or statements.
5. I also understand that Mrs. Jane Milliken will ensure my privacy and anonymity when citing any material from this interview.
6. The interview is expected to last approximately one to one and a half hours. In the event that a follow-up interview is requested, it will be my choice whether or not to participate.

Interviewee

____

Dated and signed on

____

Interviewer

____

Dated and signed on

____

APPENDIX 7 FACE SHEET DATA

INTERVIEW NUMBER ____________________

DATE OF INTERVIEW____________________

CAREGIVER'S PSEUDONYM____________________

AGE____________________

MARITAL STATUS____________________

OCCUPATION____________________

OCCUPATION PRIOR TO CHILD'S ILLNESS____________________

SPOUSE'S OCCUPATION____________________

ILL CHILD'S GENDER____________________

AGE AT DIAGNOSIS____________________

PRESENT AGE____________________

MARITAL STATUS____________________

PLACE OF RESIDENCE____________________

OTHER CHILDREN: AGE AND GENDER____________________

____

____

SIGNIFICANT FEATURES OF INTERVIEW:

APPENDIX 8 LIST OF GRIEF COUNSELORS

Some Grief Counselors in the **Victoria** Area.

These names were given to me when I telephoned the B.C. Psychological Association. You could also phone them. They will tell you the names of 3 psychologists if you tell them the geographical area and the area of specialty.

Harry Craver	658-1519	1060 Gatewood Court
Madeleine Ingimundson	658-5188	4731 Sunnymead Way
Judy Schonfeld	598-2017	Oak Bay area

B.C. Psychological Association 1-800-730-0522

From the telephone book, I have taken these names of people who advertise that they can help people to deal with grief and loss.

Sandra Elder	651-4142	Brentwood Bay area
Patricia Manning	360-2306	3112 Glasgow
Pacific Centre Family Service Association	478-8357	offices in Victoria, Colwood and Sooke

Some Grief Counselors in the **Lower Mainland** of B.C.

Rosemarie Alvero	736-4378
Leslie Murill	734-8172
Danielle Savasta	733-5924

* This does not constitute a recommendation or a referral, just some possible resources for you.

APPENDIX 9 COPYRIGHT PERMISSION TO USE THE PATHWAYS THROUGH GRIEF MODEL

baywood
PUBLISHING COMPANY, INCORPORATED
26 Austin Avenue • P.O. Box 337 • Amityville, New York 11701 • (516) 691-1270 • Fax (516) 691-1770
e-mail: baywood@baywood.com • web site: http://baywood.com

March 9, 1998

Ms. P. Jane Milliken
Visiting Lecturer
University of Victoria, School of Nursing
P.O. Box 1700,
Victoria, BC, Canada V8W 2Y2

Dear Ms. Milliken:

Thank you for your request for permission to use material from the publication(s) of the Baywood **Publishing Company, Incorporated.** Permission is granted for use as stated below:

1. On each copy of the selection, full credit must be given to the Book or Journal, to the Author (as well as to the Series, Editor, or Translator, if any), and the **Baywood Publishing Co., Inc.** as Publisher. In addition, the acknowledgement must include the identical copyright notice as it appears in our publication.

2. This permission does not apply to any part of the selection which is independently copyrighted or bears a separate source notation. The responsibility for determining the source of
the material rests with the prospective publisher of the quoted material.

3. _X__ Permission is granted. GRATIS
____ One copy of the published work should be sent to each living author included in your request.

Sincerely,
Julie Krempa
Julie Krempa
Permissions Department

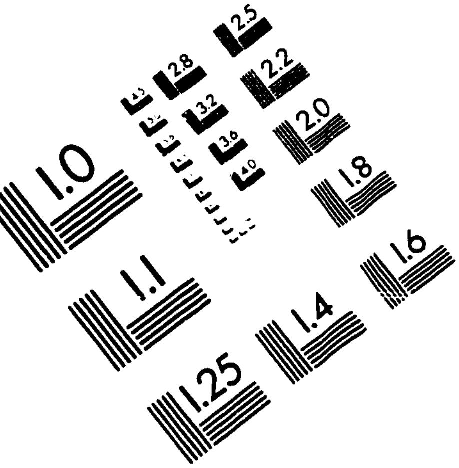
MATERIAL REQUESTED

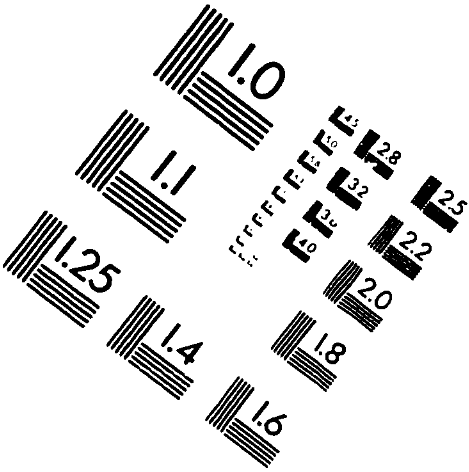
Reference:
Request Date: 2/14/98

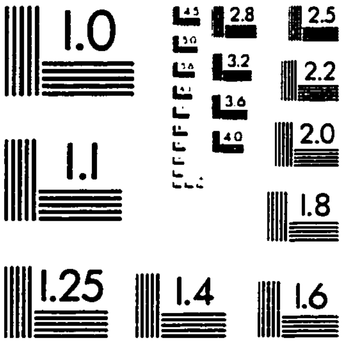
Book: *Personal Care in an Impersonal World: A Multidimensional Look at Bereavement*

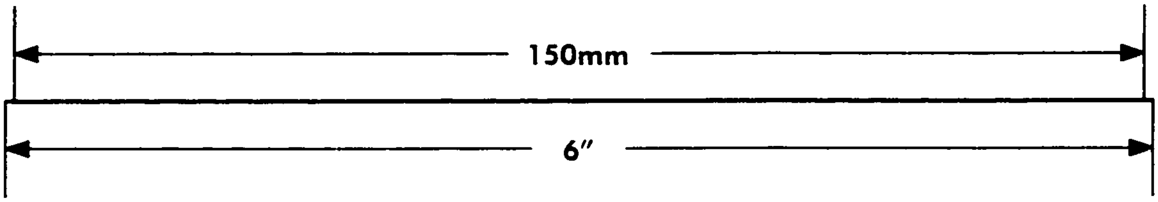
Article: The Model printed on page 78 of above book
Author: John D. Morgan

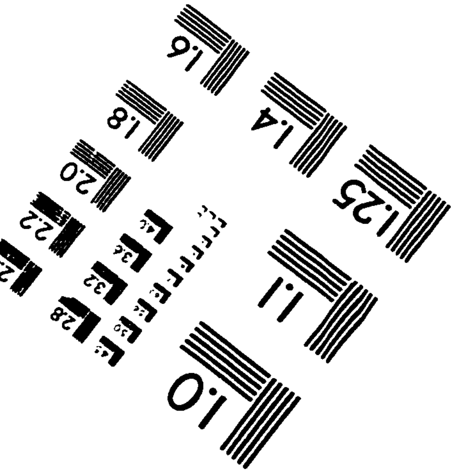
IMAGE EVALUATION
TEST TARGET (QA-3)

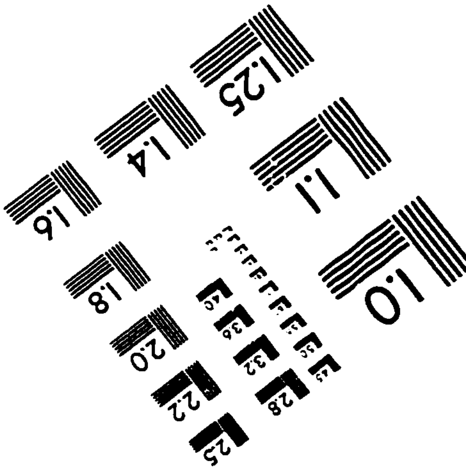












APPLIED IMAGE . Inc
1653 East Main Street
Rochester, NY 14609 USA
Phone: 716/482-0300
Fax: 716/288-5989