Title

Parents' caring practices and coping with schizophrenic offsprings

Author

Chesla, Catherine A

Publication Date

1988

Parents' Caring Practices and Coping With Schizophrenic Offspring, An Interpretive Study

by

Catherine A. Chesla

DISSERTATION

Submitted in partial satisfaction of the requirements for the degree of

DOCTOR OF NURSING SCIENCE

in the

GRADUATE DIVISION

of the

UNIVERSITY OF CALIFORNIA

San Francisco

[redacted]

. . . .

Date MAR 27 1988 University Librarian

Degree Conferred: . . . .

Parents' Caring Practices and Coping with Schizophrenic Offspring, An Interpretive Study

Dedicated to

My parents,

Ann and Joseph Chesla

Acknowledgements

Thanks must go, first and foremost, to the families who opened their homes and their lives to my questions. Home and family life are private places, and yet these families invited me in and trusted me to understand them fairly. Their trust is especially poignant, given the history of how parents of schizophrenics have been misunderstood by mental health professionals. I am deeply grateful for what these families have taught me about schizophrenia, about living with life's painful turns, and about the power of caring practices.

In my doctoral education, Dr. Patricia Benner was an expert teacher and guide. From the initial introduction to interpretive work, to the close of the dissertation, she opened up possibilities for how I might understand, challenged my previous stances and showed concern. In large part, Dr. Benner shaped my research education. Her belief in my project, and in me, was an invaluable gift.

Dr. Catherine Gilliss proved both mentor and friend. My study of family science was encouraged and guided by her. In nursing and interdisciplinary arenas, Dr. Gilliss challenged me to take risks and supported my efforts. She often served as the first reader for my writing on family health and therefore suffered with me through many revisions. I am truly grateful.

Dr. Holly Wilson advised me during the first several years of doctoral study. Her advise and teaching throughout the program were generous, thoughtful and greatly appreciated. She has been for me and example of how one practices the art of nursing in academia.

It was through my work with Dr. Joan Ablon that I found the courage to study families through participant observation. Her research on families and stigmatized groups provide stunning models of quality investigations for a fledgling family scientist. She has been an important model and a trusted advisor.

I have been in the doctoral program long enough, to share the experience with several cohorts of doctoral students. I am grateful to Karen Brykczynski, Harriet Lionberger, Linda McKeever and Erna Schilder for teaching me, through their work, what interpretive nursing research can be. I am equally grateful to Annemarie Kesselring, Vicky Leonard, and Lee Smith for many wonderful, searching and yet satisfying discussions. Additionally, Carol Landis, Merrie Kaas and Brook Randell have been sustaining friends.

For their expert and patient transcribing of the taped interviews I am indebted to Emily Kulenkamp and Catherine Curtis. I thank the Office of Student Affairs for their tangible and intangible support throughout my studies. This research was supported in part by an individual National Research Service Award from the National Center for Nursing Research.

Mom, Dad, Ginny Felice and all my brothers were wonderful family to me in good times and bad. I know intimately from them what family care is all about. Finally, I thank my husband, Jeffry Vanderbilt, for his special brand of humor, for baseball, for dinners, and for unswerving support.

PARENTS' CARING PRACTICES AND COPING WITH SCHIZOPHRENIC OFFSPRING

AN INTERPRETIVE STUDY

Catherine Ann Chesla

Investigations of families of schizophrenics have focused on how families cause or influence the illness course. How the family understands, cares for and copes with a schizophrenic member have been largely overlooked. The aim of this project was to provide an interpretive account of parents' understandings of schizophrenia, the concerns that shaped parents' care, and their caring practices.

An interpretive approach, similar to an ethnography, was employed. Fourteen families who lived with or had regular contact with a schizophrenic member were recruited from family support groups and followed prospectively for three months. Each participating family member (typically father, mother and schizophrenic), was interviewed once a month regarding illness understandings, stressful incidents and the family's attempts to cope with those incidents. In-home care practices were observed for 2-4 hours per week, over three months, with half the families. Joint family history interviews were also conducted.

Parents had diverse and elaborate models of the nature, course and causes of schizophrenia. These illness understandings forcefully influenced parents' caregiving practices. For example, parents who understood the disease as biological, helped the schizophrenic achieve chemical balance, while parents who understood symptoms as breaks in rationality, directed efforts at reconstructing the ill member's thoughts.

Demands of caring for a schizophrenic member were substantial and pervasive. Demands most often named by parents were: breakdowns in meanings shared by schizophrenic and parent, changes in the schizophrenic's person, unclear illness boundaries, and regression in the schizophrenic's abilities to manage life responsibilities.

Parents involved in care by different concerns for the schizophrenic member evidenced 4 distinct forms of care. Parents concerned for the child's self-esteem, skillfully encouraged his development within the bounds of the illness. Parents involved by a concern for the child's functioning, shaped care according to scientifically derived prescriptions. When concern for the child was continually in conflict with the parent's self-concern, care was more burdensome, conflicted, and less satisfying. Care "once removed" was demonstrated by fathers who were only peripherally involved, while their wives were primary caregivers.

Care practiced by parents of schizophrenics can best be understood through a grasp of their background meanings, including illness understandings, and their concerns for the child. Care provided by these parents was an extension of culturally derived parenting practices. Supports and hindrances to parental care of schizophrenia in modern society are highlighted and implications for nursing interventions with these parents are outlined.

Patricia Benner, RN, Ph.D

Table of Contents

Chapter

Appendices

List of Tables

> Canner
> grating nois
> dream. ...
> pimps, gamb
> Had the man
> "Saints and
> meant the sa
>
> ... How
> quality of
> alive? When
> worms so del
> for they bre
> and crawl of
> gently into
> the way to w
> crawl in by

I must have

Saints, angels, a
who, against all
with schizophrenia
loving and unique
light, the tone, t
that is little und

Like the mari
tale. How can the
triumphs in these
drawn? Faced with
courage, their wil
compelled to tell

I am an outsid
Although I have wor
and have known thei
understand this wor

Chapter 1

Introduction

> Cannery Row in Monterey in California is a poem, a stink, a grating noise, a quality of light, a tone, a habit, a nostalgia, a dream. ... Its inhabitants are, as the man once said, "whores, pimps, gamblers, and sons of bitches," by which he meant Everybody. Had the man looked through another peephole he might have said "Saints and angels and martyrs and holy men," and he would have meant the same thing.
>
> ... How can the poem and the stink and the grating noise- the quality of light, the tone, the habit and the dream- be set down alive? When you collect marine animals there are certain flat worms so delicate that they are almost impossible to capture whole, for they break and tatter under the touch. You must let them ooze and crawl of their own will onto a knife blade and then lift them gently into your bottle of sea water. And perhaps that might be the way to write this book- to open the page and to let the stories crawl in by themselves. (John Steinbeck, Cannery Row)

I must have looked through the other peephole for all I saw were Saints, angels, and holy men and women. This is a story about parents who, against all odds, found ways to care for their sons and daughters with schizophrenia. Their care was uncertain, hopeful, responsible, loving and uniquely personal. It was as elusive as the quality of light, the tone, the habit and the dream of Cannery Row. It was care that is little understood and little talked about in our culture.

Like the marine biologist, I strive to capture whole a delicate tale. How can the changeable beauty, the personal pain and the small triumphs in these parents' involvement with their children be fairly drawn? Faced with the task I am humbled. In the presence of their courage, their willingness to risk all for their children, I am compelled to tell their story as best I can.

I am an outsider in the world of families of schizophrenia. Although I have worked and suffered with people who have schizophrenia, and have known their families for all of my professional life, I understand this world only as an outsider gazing in. Happily, the world has been eloquently described from the inside, most recently by Mary Ellen Walsh (1985). Unhappily, stories told from an outside, professional vantage point, have often been jaded, accusatory, and lacking in empathy. Professionals from various schools, in their efforts to contain the horror of schizophrenia, have too often looked upon the family as part of the problem, as the cause, or the precipitant of the disease. They have created new horrors by intensifying the family's guilt and by constructing systems of care that systematically distance families from their ill members.

My aim, in this project, is to respectfully interpret the world of the family who cares for a schizophrenic member, to professionals who work with these families. My central concern, as a nurse, is to provide psychiatric and general practice nurses a different access to these families' worlds. I hope it is an access that allows for understanding, rather than judgement.

The project provides several different points of access to these parents' worlds. The first is the parents' understandings of their offspring's illness. Parents' specific and symbolic descriptions of what is wrong with their sons and how the illness has changed them are presented. A second point of access is a story about the demands that the illness places on the family. Presented here are the concrete, specific demands experienced by parents, as they live with and care for the schizophrenic member. Finally, the ways that parents care for their ill child and the ways in which their concerns for the child set up that care, is detailed.

The story presented here must be situated in relation to the rapidly proliferating body of research on families of schizophrenics.

My interpretive tale evolves from, and is in part a reaction to, this scientific literature. Thus, the proper introduction to the interpretive story is a review of this body of research. This review is found in Chapters 1 and 2. The methods used to construct the tale must also precede a fair understanding of its content. Chapter 3 contains a description of the interpretive methods employed in the project. The story begins with the parent's explanatory models of the illness, in Chapter 4. Next, the demands that parents experienced in their one-to-one relationships with the ill member, in the family at large and in the family's relationship with the community are outlined in Chapter 5. Chapter 6 contains the heart of the story. Here, I describe the specific kinds of concerns that parents expressed and lived in their day to day care with the ill member. Finally, some of the cultural strains that make the parent's task more difficult, and the implications of the project for nursing practice, are outlined in Chapter 7.

A few decisions about how to present the findings deserve mention. First, there were only two families in this study in which the schizophrenic was female. To provide anonymity to these families, all the schizophrenics in the study are referred to as males. Second, the the schizophrenics were 20-35 years of age. Although it is unusual to refer to persons of this age as children, the term correctly represents their relationships with parental caregivers. For ease of reading, the schizophrenic members will therefore be referred to as children, even though a more appropriate term might be 'adult-children'. Finally, I am sensitive to the fact that use of the term 'schizophrenic' rather than 'person with schizophrenia' might offend some. Although I use the less cumbersome expression, schizophrenic, I mean no disrespect for the personhood of those who have this disease.

Background

Interest in and investigation of families of schizophrenics has risen sharply in the last decade for a number of reasons. Attempts to shift care of the mentally ill from the hospital to the community, coupled with the inadequate development of community based programs have established the family as the primary resource for many of the chronically mentally ill (Goldstein & Doane, 1982). Dramatic findings have emerged on the influence of family environment on the course of schizophrenic illness (Brown, Birley & Wing, 1972). Finally, families of schizophrenics have drawn attention to their plight and special needs in increasingly more organized ways (Hatfield, 1979a, 1979b).

Goldman (1982) estimates that 65% of the 1.5 million mental patients discharged to the community each year return to family. Approximately half of these return to spouses and the other half live with parents or relatives. The chronically ill, those with severe and persistent psychiatric disorders which inhibit ability to function in the community, comprise about one forth of the total number of all mentally ill who live with relatives (Goldman, Gattozzi & Taube, 1981).

Family Burden.

Families report significant disruption and disorder in their lives because of caring for a mentally ill member. Disruption in family routine, employment, finances, social and leisure activities and relations with persons outside the family are reported by 70% to 80% of families studied. Most troublesome are upsets in the family routine and financial losses. Feelings of embarrassment, resentment and loss of control resulting from ongoing care of an ill member are reported by 40-50% of the samples studied (Creer Sturt & Wykes, 1982; Hoening & Hamilton, 1966; Thompson & Doll, 1982). Concern about the future is the most frequently mentioned emotional burden.

Families who are "burdened" according to pragmatic measures of financial costs and work loss may in fact experience the care of the schizophrenic member as a drain, or a burden. Alternatively, the adjustments and efforts required may be experienced as rewarding, bonding, satisfying. Two researchers note that the families they studied described the care of their member in terms of concern, rather than in economic, exchange or suffering terms. They note that care motivated by love or from a sense of obligation may not be experienced as a burden (Creer et al, 1982; Hoening & Hamilton, 1966). Little is known about the meaning that caring for an ill member has for the family of a schizophrenic. How the family has absorbed and interpreted the current cultural explanations of schizophrenia and of their role in causing or influencing the disease may impact how the family cares for and copes with the schizophrenic family member.

Family Meanings

Families have their own conceptions of the nature and evolution of the schizophrenic member's problems, and how they might be best treated. These explanatory models of schizophrenia develop from the family's experience with the ill member as well as from models currently available in the mental health community. Additional communities in which families participate, for example support groups for families of the mentally ill also provide models.

Several examples of possible informal explanatory models can be cited. A biological imbalance model is the belief that schizophrenia is physiologically based, and might be corrected by megavitamin therapy. Alternatively, in a trauma model, families hold that childbirth and early life experiences cause childhood behavior problems which evolve into schizophrenic symptoms at adolescence. In a faulty genetics model, families take the stance that the disease is genetically determined, and that social factors play no role in its development. Finally, some may conclude that health professionals are at least partially correct in saying that schizophrenic illness is a signal of family system pathology. Accounts of families' explanatory models of schizophrenia, (Bernheim, Lewin & Beale, 1982; Torrey, 1983; Weschler, 1972; Wilson, 1968) are refined and expanded upon in this study. It is reasonable to assume that these diverse informal ideologies influence treatment preferences and coping practices of families. However, no systematic description of these relationships have been made.

Good and Good (1981) note that the understandings, theories and values that patients and families have about their health determine not only their patterns of care seeking, and evaluations of the care they receive, but the experience of the illness itself. Put simply, the meanings that an experience, such as heart palpitations or low energy, have for the individual or family determines whether they assess it as a health event and guides their responsive action.

Similarly, a family's explanatory model for schizophrenic illness is an important framework from which the family views the ill member's behavior. The family's understanding of the illness, comprises part of the background from which it assesses and deals with the day to day experience of living with and caring for a schizophrenic member. Good and Good (1981) suggest that by ignoring the person's understanding of his illness, health care practitioners offer interventions blindly with little understanding of how these interventions might conflict with the family's beliefs and current practices.

Inquiry About Families of Schizophrenics

Most recent investigations of families of schizophrenics have attempted to identify family factors that influence the development or course of schizophrenia. Two central and productive lines of research focused on specific family interaction patterns that repeatedly correlated with the diagnosis or particular course of schizophrenia. The first was research on the differences in communication patterns that marked families with schizophrenic offspring. The second was a constellation of family affect expression, presented as the construct expressed emotion, which correlated with a worsened course of the illness. The strength of the relationships between these family patterns and schizophrenic outcomes were demonstrated repeatedly and prospectively. (See Chapter 2 for a detailed discussion.)

Intervention programs, aimed at altering family traits thought to be detrimental to the schizophrenic offspring developed out of these two lines of research. Relapse and rehospitalization of the ill member have been significantly decreased in the family treatment programs (Strachan, 1986). Many family intervention programs, modeled after the demonstration programs, have been proposed and implemented. If these achieve similar results, family education and problem solving programs may well become standard care for schizophrenics and their families.

Descriptive and intervention research programs with families of schizophrenics have influenced family care and family inquiry in positive and negative ways. In the positive vein, family qualities and characteristics, rather than individual intrapsychic processes have been examined in great detail. Sophisticated family level constructs have been translated into standardized measures and have been examined in well designed studies. The advances made in this field outstrip those in any other area of family health research (Campbell, 1987). Similarly, sophisticated and ground breaking intervention programs have evolved from this broader focus on family constructs.

Remarkable as the advances have been, drawbacks must be recognized. The elaboration and investigation of family level constructs have been limited to the independent variable in the equation. Dependent variables, or outcomes of the investigations and intervention programs have been measures of the ill member's well being or change. With one notable exception (Falloon, Boyd & McGill, 1984), family level outcomes have been largely ignored. By focusing on change for the ill member rather than the family, scientists reinforce the tradition of blaming the family for the illness. Their omissions lead some to believe that "scientists are out to get the family again", (Strachan, 1986, p 694). This time they are looking for family impacts on illness course rather than as a possible cause of the illness.

Missing from family investigations are inquiries into families' responses to the illness course, and treatment interventions. Major questions about family understandings, concerns and personal responses have not been addressed. Additionally, the impact of care on family members' health and quality of life remains in question.

Interpretive Study of Family Stress and Coping

The study of individual psychological stress and coping has evolved to the current practice of examining persons in context, involved in the process of coping with day to day as well as significant unique events. For Lazarus and his associates (Lazarus & Launier, 1978; Lazarus & Folkman, 1984), Stress has come to be understood as residing not in the person or the situation but in the transaction between them. The process of coping is understood through an in-depth and fine grained study of the meaning that all aspects of the process have for the individual. One must grasp both how the person appraises the significance of the event for his well being, as well as the cognitive, emotional and action strategies s/he employs to cope with the situation (Lazarus & Folkman, 1984; Wrubel, 1985).

Two investigations of the relationship between personal meanings and individual stress appraisals and coping have employed an interpretive approach (Benner, 1984; Wrubel, 1985). The investigators assume Heidegger's view of person-context relations, which is congruent with that employed in the Lazarus paradigm. This philosophical approach suggests that humans experience the world directly rather than as a mental representation. Situations are grasped as meaningful wholes, by individuals who share common background meanings as a result of sharing language, social practices, skills and a common history. The task of the investigator is to uncover and understand the meanings imbedded in the actions and expressions of those they study.

In the two studies cited, the investigators demonstrated how personal meanings shaped both stress appraisals and coping strategies. They studied subject selected stress and coping episodes, as well as episodes of positive and negative emotions. In this study, I use a similar approach to study family meanings and their relation to stress appraisals and coping. The method is adapted to include the study of multiple members of the same family and a search for the meanings they hold in common. In addition, I observe family coping practices in day to day activities in the home, in an attempt to tap practices that are so habitual and transparent that the family member cannot express them verbally.

Problem Statement

Families in the situation of caring for a schizophrenic member have personal understandings of the illness and of the family's role in its etiology and course. An important descriptive task is to outline the families' explanatory models of schizophrenia. The practices of caring for an ill member and coping with the adaptive demands of the illness, evolve over time and are influenced by the the families' background meanings, including their explanatory models of the illness. Detailed study of families' care practices and coping strategies and the influence that family meanings have on these practices can contribute to our understanding of the processes of family level coping. In this study family level constructs are examined from the perspective of the parents who care for the schizophrenic member.

Research Questions

I intend to investigate, from the parents' perspectives, the experience of living with a schizophrenic member over time. Parents' understandings of the disorder, the meaning that caregiving has for parents, adaptive demands of caregiving and the ways parents cope with those demands will be investigated. Specific research questions are:

1. What are the parents' informal explanatory models of schizophrenia? How do these models influence the parents' current stress appraisals and coping?

2. What are the adaptive demands that schizophrenic illness behavior place on the parent and the family unit? Are there recurring themes across families?

3. How do personal background meanings and interpersonal concerns shape parents' day to day stress appraisals and coping with the care of a schizophrenic member?

Significance

This project broadens the focus on families who care for a chronically ill schizophrenic member from discrete variables (affective tone, communication patterns) that are predictive of illness outcomes, to family members' personal meanings, concerns and understandings that shape their responses in this situation of care. The ways in which family members' caregiving practices are set up and shaped by these concerns and meanings are demonstrated. Grasp of the family members' worlds of meaning opens up possibilities for intervening with families, in ways that respect their meanings, concerns and practices. Finally, the project will enhance current understandings of culturally embedded dimensions of family caregiving relationships, that are instantiated by parents in this specific study of care of schizophrenia.

Chapter 2

Current Constructions of Schizophrenia and the Family

Historical Trends

Research on families and mental illness has with time become more sophisticated in terms of method of study and theories that guide the investigations. The conceptual and clinical inquiries of the 1950's led the way to more systematic interaction research of the 1960's. In that decade cross-sectional studies of families in which a member with mental illness had already been identified predominated. The hope was to identify patterns of interaction or family dynamics that were etiologic agents for mental illness. The hope was not realized, in part because the investigations failed to distinguish factors that might antedate and result from, the mental illness of a relative. The inconclusiveness of the interaction research efforts led, in the late 1960's, to investigations of families at risk for mental illness in a member. This research persists, although in a secondary role to new interests (Hahlweg & Goldstein, 1987). The central and pervasive puzzle for family researchers who focus on schizophrenia, and many other mental disorders, are family factors that influence illness course.

Two scientific developments influenced the shift to more sophisticated risk studies and investigations of illness course: the accumulation of evidence suggesting a genetic predisposition for major mental disorders, and advances in psychopharmacology that allowed for the alleviation of symptoms. With these discoveries, theories that implicated the family as an etiologic agent had to be revised. A new organizing framework was needed to guide the next generation of family research.

The framework now guiding research on families of the mentally ill is the "vulnerability-stress" model (Hahlweg & Goldstein, 1987). According to this model certain segments of the population are born with a genetic vulnerability for certain mental disorders, like schizophrenia. Stressors, such as life events or qualities of the family in which one is raised, increase or decrease the likelihood that the disorder will express itself during adulthood. The task of science is to discover which stressors place the vulnerable individual at greatest risk. The model is also applicable after the illness is expressed, when vulnerabilities interact with environmental influences and life events, to produce a better or worsened illness course.

The vulnerability-stress model comprises the background understanding of schizophrenia in two central lines of research on families of schizophrenics that are reviewed here. In the "expressed emotion" research, the potential stressor investigated is the affective quality of the family environment. Reliance on the vulnerability-stress model is seldom made explicit in this research, but it underpins its guiding hypothesis. The second line of research addresses intervention with families of schizophrenics. Psychoeducational programs for families of schizophrenics were explicitly modeled according to the understanding of schizophrenia afforded by the stress-vulnerability model.

Notably absent in the literature, and therefore in this review, are investigations that go beyond the search for factors that influence illness course. Little attention is paid to family responses or family coping with the care of a schizophrenic member. It will be evident in the review of psychoeducational programs that these investigators are beginning to look at the broad scale effects of the interventions on family health and functioning. However, the central focus remains the containment or cure of the disease, rather than on how families cope with the illness over time.

Affective Tone in Families of Schizophrenics

The central question in recent research on families of schizophrenics has been: How do families influence the course of schizophrenia in a member? Research on a construct labeled family expressed emotion evolved from Brown's discovery that schizophrenics with higher relapse rates came from families who were more critical, hostile and overinvolved with the ill member (Brown, Monck, Carstairs and Wing, 1962). The construct was and is defined operationally as a measurement of parents' expressions of hostility, criticism and overinvolvement when discussing the schizophrenic family member with an interviewer. The construct lacks a theoretical and practical/clinical definition, which goes beyond the demonstrated ability of the measure to predict relapse (Kanter, Lamb & Loeper, 1987; Koenigsberg & Handley, 1986).

Evidence in support of the expressed emotion hypothesis is discussed first. Disconfirming evidence is presented next. Concerns about the theoretical validity, practical significance and misuse of the construct are then raised. Finally I discuss aspects of the research on affective tone in families that deserve further consideration.

The Expressed Emotion Hypothesis

The central hypotheses in the expressed emotion research is that three qualities of parents' interactions with schizophrenic offspring influence the course of the disease. In families where parents demonstrate high levels of criticism and hostility or emotional overinvolvement, the schizophrenic offspring is considered at higher risk for recurrence of the positive symptoms of schizophrenia. Conversely, schizophrenics from families who demonstrate low levels of expressed emotion are expected to experience lower rates of relapse.

Four separate investigations have established the predictive validity of family measures of expressed emotion on the course of schizophrenia in a family member. In all these studies, high expressed emotion correlated with relapse. Forty-eight to 60% of the patients from high expressed emotion homes relapsed as compared with 9% to 17% from homes low on this factor, over a period of nine months to two years (Brown et al., 1962; Brown, Birley & Wing, 1972; Vaughn & Leff, 1981; Vaughn, Snyder, Jones, Freeman & Falloon, 1984). Two factors were consistently associated with lowered relapse rates in high expressed emotion homes: regular use of medications and a lower degree of contact (less than 35 hours per week), between the schizophrenic member and the rest of the family. In each of the studies, standard criteria for diagnosis were employed and standardized measures of family affect were used in the three most recent studies, which built upon the earlier works by Brown and associates (1962, 1972).

Two studies (Kottgen, Sonnichsen & Mollenhauer, 1984; MacMillan, Gold, Crow et al., 1986) failed to confirm the association between family expressed emotion and illness course. In the first study, Kottgen and associates failed to find a significant difference in 9 month relapse rates in schizophrenics from families rated high or low on the dimensions of expressed emotion. In this sample, a statistically insignificant, yet greater number of patients in the low expressed emotion group relapsed. The sample was younger and less chronic than schizophrenics studied in prior research, which may be an important key to understanding how expressed emotion works.

MacMillan and associates (1986) examined illness course in 77 first break schizophrenic men and women. They found no significant relationships between family measures of expressed emotion and relapse. Two prognostic factors strongly correlated with increased relapse: longer duration of symptoms prior to admission and neuroleptic treatment (as opposed to placebo) in the post-hospital term. In contrast to prior studies, affective family measures were not predictive of outcome. The authors believe their investigation casts considerable doubt on the interpretation that family environments are important predictors of schizophrenic illness course. They suggest that complex interactions of illness severity, family burden and and family response to the illness, be considered in future research instead of the repetitive search a direct causal relation between family affect and illness course.

In these two studies where younger, first break or less chronic clients were examined, the expressed emotion hypothesis failed. Perhaps parental criticism and overinvolvement are parental responses to living with the disease over time. Levels of criticism and social contact were greater in samples with longer duration of illness. Additional support for this possibility is found in the fact that duration of illness prior to hospitalization correlated with parental criticism in first break schizophrenics (MacMillan et al., 1986)

Theoretical Perspectives

Remarkably few theoretical discussions of the relationship between family affective tone and schizophrenic illness course are evident in the literature. Thus, the conceptual meaning of expressed emotion has yet to be elucidated. Serious reservations about the conceptual clarity of the construct have been raised (Kanter et al., 1987; Koenigsberg & Handley, 1986). A central criticism is that the construct represents two unrelated phenomenon: hostile criticism and emotional overinvolvement.

Evidence does not support the continued combination of three separate interaction variables into a single expressed emotion construct. Hostility and criticism are found in the same families in almost every investigation, and probably reflect the same tendency in the family to respond in harsh or critical fashion under stress (Koenigsberg & Handley, 1986). In contrast, criticism and overinvolvement are seldom found in the same family. For example, in a recent investigation, (Hogarty, Anderson, Reiss et al., 1986) only 10% of the families who had high expressed emotion demonstrated both overinvolvement and criticism. In a separate project, criticism and overinvolvement were significantly related to distinct patient characteristics. This suggests that parental affect might reflect a response to the ill child's particular needs (Miklowitz, Goldstein & Falloon, 1983). Miklowitz and associates found parental overinvolvement when the ill member demonstrated poor premorbid functioning and more residual symptoms after discharge. The investigators believed that these parents may have tried to compensate for the child's vulnerability and inability to function, by taking on a greater degree of care. In contrast, parents who were highly critical cared for schizophrenics with higher premorbid functioning and fewer residual symptoms. These parents may have criticized the ill child in their attempt to get him to function at a higher level (Kanter et al., 1987). The central point, however, was that parents' affective expressions were different in different clinical situations, and may have been appropriate responses to their childrens' particular vulnerabilities.

Critics also charge that expressed emotion is an invalid measure of family environment or interaction, because it is measured in a one on one conversation with an interviewer, rather than in family interaction. Evidence that expressed emotion indicators actually reflect family interaction patterns is available from two studies. Valone and associates (1983) found that parents who demonstrated high expressed emotion in interviews were also highly critical with offspring during an interaction task. The overinvolved component was not evident in the families' interactional patterns. In a second study, significantly more critical and neutral intrusive statements were made by high expressed emotion parents in an interaction task with their schizophrenic offspring than were made by low expressed emotion families (Miklowitz et al., 1983). Critical comments in the interview assessment correlated with criticism in the interaction task. Similarly, overinvolved ratings in the interview correlated with neutral intrusive statements during interaction. Both studies validate expressed emotion measures as reflective of family interaction patterns, at least during laboratory tasks. The second study adds further support for the separation of expressed emotion into two distinct concepts.

Practical Significance of Expressed Emotion

The application of expressed emotion findings to clinical practice deserve cautious attention. Kanter and associates (1987) find the clinical conclusions drawn from the research are incongruent with or overreach the actual content of the findings. They charge that "there is little question that the expressed emotion scales conceal subjective judgments of families behind the objective veneer of a complex scientific methodology" (1987, p 379). Their persuasive argument follows. Emotional overinvolvement is a subjective criticism of parents who invest significant amounts of time and energy in the care of a schizophrenic child. The criticism overlooks entirely the life choices that families must make, between investing their lives in care of the child or abandoning him to public care that is often woefully inadequate. The dilemmas are moral dilemmas which face both families and practitioners who work with families. Scientific attempts to arrive at objective measures of how much or how little involvement is required to produce or avoid relapse, contributes nothing to the moral debate and probably hinders meaningful discussion (Kanter et al., 1987).

In addition, elements of expressed emotion thought to have ill effects on the schizophrenic, may in fact help him to manage more effectively in the world. For example Leff and Vaughn (1985) contend that when parents criticize and expect the ill member to control symptoms, it pathologically affects the child. Kanter and associates (1987) argue that there is good empirical evidence that schizophrenics <u>can</u> control their symptoms. That criticism aimed at specific behaviors and accompanied by effective limits can help the schizophrenic to establish some control.

It appears that suggestions for clinical practice with questionable efficacy have arisen from the expressed emotion research. Parents have been counseled to stop criticizing their ill member, in an attempt to stop one symptom, but the consequences of that action have been incompletely considered. Perhaps more frightening, are the clinical suggestions to families that they maintain greater distance from the ill member. Indiscriminate application of such advice with families of schizophrenics might have disastrous results. Families who strive, against tremendous odds, to maintain human contact with the schizophrenic might be counseled away from this effort. If the families actually take the advice, one wonders what options the ill member will have left.

Very little is known about expressed emotion and how it actually works. Clinical applications of the concept must at this time be tentative. For example, clinicians might include the dimensions of criticism, hostility and overinvolvement in their assessment of families. Variations in how families express these qualities in interactions and how the interactions impact on the ill member should be noted. Broad scale efforts to help families eliminate these kinds of interactions is not warranted.

In summary, the dramatic findings in expressed emotion research deserved and have received serious attention. The research has refocused attention on the family at large, and has advanced the methods by which we study families as whole units. A positive outcome of this research has been the development of psychoeducational programs which help families understand the illness, its treatment and intricacies of working with a schizophrenic in the community. These programs are reviewed in the next section.

The atheoretical nature of the expressed emotion research tradition has limited our understanding of what expressed emotion actually is, and has allowed for some misapplication and misunderstanding of the concept in clinical work with families. It now appears likely that the construct encompasses at least two distinct family responses, which deserve separate conceptual as well as empirical examination. Kanter and associates (1986) suggest that the construct be reconceptualized as three separate family influences: criticism, warmth/hostility and involvement. They conceptualize each as having its own continuum, and so, for example criticism might extend from sadism to firmness to patience to masochism. Similarly, warmth/hostility might include the range of hate, anger irritation, respect/warmth and love. Finally, they conceptualized involvement to include neglect, detachment, concern and overinvolvement. These authors, who are in fact clinicians, offer a re-conceptualization that expands the limits of the expressed emotion construct. Discussions like theirs are urgently needed to shape the next generation of research on families of schizophrenics into one that examines a meaningful diversity of family patterns of relations.

Interventions with Families of Schizophrenics

Advances in treatment programs for families of schizophrenics are undoubtedly the most positive outcome of the expressed emotion research tradition. Family environment appeared to have an impact on illness outcome, so interest in shaping that impact into a positive one increased. Four separate, but similar programs were developed to work with families of schizophrenics at risk because they had high levels of the expressed emotion qualities (Goldstein, Rodnick, Evans, May & Steinberg, 1978; Leff, Kuipers, Berkowitz, Eberlein-Vries & Sturgeon, 1982; Anderson, Hogarty and Reiss, 1981; Falloon, Boyd & McGill, 1984). All four, in varying stages of completion, have demonstrated a positive impact of the family intervention in controlled clinical trials. In this section, the commonalities of the four approaches are highlighted first. Next, the unique nature of each program is described, and the clinical results are reported. Finally, limitations of the research projects and the inferences that can be drawn from their findings are discussed.

Commonalities in Family Treatment Programs

Although each treatment program has a unique emphasis, their commonalities may be the reason for their success in contrast to past treatment approaches (Strachan, 1986). Each program approached families with practical, concrete, present-oriented goals. Dynamic family "therapy", which was intensive, uncovering, or insight-oriented, was avoided. Analytical work with schizophrenics, in individual or group treatment can lead to regression and was therefore not used. The history of mistreatment of schizophrenic families in the analytically based therapies argues against their use with this population (Terkelson, 1983).

Each program had a strong educational focus. In all but one of these programs, education was structured into classes or workshops where groups of families met with experts. In these classes current knowledge about the etiology, course, and treatment of schizophrenia were discussed, as were psychopharmacological and social therapies. One program transmitted information to families individually during the course of crisis intervention meetings (Goldstein et al., 1978)

Families' concerns, special understandings and experiences were treated respectfully and used as the basis of treatment in all of these programs. Practitioners were warm, empathic, and attempted to establish an alliance with the family. Treatment was an attempt to work with families rather than to treat them. Attempts to join with the family were less central in the first two programs (Goldstein et. al., and Leff et. al.) which were aimed at reeducating and changing the family. The last two programs instead attempted to engaged with the family and the ill member by trying to enter their world of understanding and working forward from that point of understanding.

From a scientific standpoint, these four intervention programs were similarly well designed. All employed a randomized experimental design with at least one non-family treatment condition contrasted with the experimental family intervention. Sample selection was carefully limited to populations of schizophrenics that were diagnosed by standard research criteria. All provided treatment in the months immediately following hospitalization for a schizophrenic psychoses and are therefore parallel in the timing of the research attempt. The distinguishing qualities of each program are presented in the following section.

Unique Qualities of Family Treatment Approaches and Outcomes

Crisis Intervention Program. One of the earliest family intervention programs tested variable doses of phenothiazine injections in combination with six weeks of family crisis intervention counseling. Families of 104 schizophrenics were randomly assigned to one of four groups who received high or low doses of prolixin and family or no psychosocial intervention. The goals of family counseling were: recognition of event as psychosis, recognition of precipitants of the event, and planning for future stresses that might precipitate further psychosis (Goldstein et al., 1978).

Significantly lower relapse rates were found in the high dose family treatment group as compared with the low dose no treatment group. Relapse rates were 0% and 50% respectively. Examining the data by type of treatment there was a significant, (high dose), drug effect and a non-significant, but positive effect from family therapy, (Goldstein et al., 1978).

Risk Reduction Program. A British family intervention program addressed the risk factors that had been discovered in expressed emotion research (Leff et al., 1982). The aim was to reduce family expressed emotion and/or decrease the amount of contact between the schizophrenic patient and relatives. The program combined medication for the index patient, with education, multiple family groups and family therapy sessions. Medication was provided through long acting phenothiazine injections. The educational component was a 4 week program, in the family home, that covered illness symptoms, course and treatment. Professionally led parent groups guided discussions of parents' current difficulties and taught alternative coping strategies. Finally, in home family therapy with the parents and the schizophrenic member addressed problems the family was coping with in the home.

Twenty four families of schizophrenics were randomly assigned to the family intervention or to no treatment. All schizophrenic members continued to receive their usual individual care. Participants in the family intervention program had significantly reduced relapse rates at nine months (Leff et al., 1982), and two years (Leff, Kuipers, Berkowitz et al., 1985). Criticism was significantly reduced in the experimental but not the control group and reduction in face to face contact was more successful in the experimental group.

Family Psychoeducation and Social Skills Training. The psychoeducational program designed by Anderson et al. (1981) attempted to decrease the schizophrenic's vulnerability through medications, improved stability in the family environment and increased interpersonal skills. They took a three pronged approach to achieve this end, and tested each approach separately and in combination. Neuroleptic medication management for the schizophrenic comprised the first approach. Intensive social skills training for the schizophrenic, with an individual therapist, was the second condition. This training followed behavioral training principles but was slowed and adjusted to the particular needs of a schizophrenic recovering from a serious psychosis.

Finally family treatment was provided, aimed at increasing the stability of family life by addressing family anxiety, knowledge deficits and management needs. This program differed from others because it focused on broad principles for living with a schizophrenic and on the family's response to this process. Direct training in communication or problem solving skills was minimized. The program was structured into phases. First, the treatment team attempted to connect with the family, learn its interpretation of events and to establish a treatment alliance. Phase two comprised educating families about: 1) the nature of the disorder, 2) the kinds of structure and distancing that are most beneficial to families, 3) communication and 4) how to take care of family as well as the patient needs. In the next phase, families were given the opportunity to apply this information to unique family problems in therapy sessions.

This program was tested with schizophrenics from high risk homes who were randomly assigned to a) family treatment and medication, b) social skills training and medication, c) a combination of a and b, or d) drug treatment only. Relapse rates of the schizophrenic member at one year showed a main effect for family treatment (19% of the participants relapsed), a main effect for social skills training (20% of the participants relapsed), no interaction effects, and additive effect of family and social skills training (0% of the participants in both programs relapsed). Relapse rates in the group that received medication only were 41%.

There were hopeful findings in this study regarding the impact of treatment on changing family atmosphere. There were no relapses in families that changed from high expressed emotion to low during the study period. In the families that remained high, only the combined effect of family treatment and social skills training for the ill member "protected" the ill member from relapse at one year; there were no relapses in this group. Family treatment demonstrated the most substantial impact on lowering family expressed emotion, while social skills training, which specifically tried to help the ill member precipitate fewer criticisms, had no apparent impact.

Problem Solving and Communication Skills Training. In the forth program, Falloon, Boyd and McGill (1984) tried to help families decrease the stress on the schizophrenic member by teaching them new communication skills and problem solving strategies. They specifically did not direct their efforts at reducing the expressed emotion qualities, attempting instead to give families options for expressing emotions in ways that could be tolerated by the schizophrenic member.

Family treatme
according to a
biweekly meeti
last 15 months

Family tr
the schizophre
entire family
solving. The
and was called
experience sch

Evaluatio
superior resul
program (Falloo
treated with fa
substantially l
treatment (40%)
follow-up data (
significant dif
individual care
family treatment
medication noncon
two groups were e
employment, unpar
program patients

The family's
either treatment
reduced in the fa

Family treatment was contrasted with individual treatment administered according to an identical schedule: weekly meetings for three months, biweekly meetings for the next six months and monthly visits for the last 15 months of the study.

Family treatment was a combination of low dose oral medication for the schizophrenic member, two structured educational sessions for the entire family and in home family training in communication and problem solving. The schizophrenic was actively included in all family meetings and was called upon to provide expert advice on how it felt to experience schizophrenic symptoms.

Evaluation of this program with 36 high risk families demonstrated superior results of the family as opposed to the individual treatment program (Falloon et al., 1984). At nine months patients who were treated with family interventions had less symptomatology and substantially lower relapse rates (6%) than those in individual treatment (40%). This difference was stable over time, as the two year follow-up data (Falloon, Boyd, McGill et. al., 1985) showed a highly significant difference in relapse rates from family treatment (17%) and individual care (83%). Patient social adjustment was markedly better in family treatment with significantly fewer cases of behavior disturbance, medication noncompliance and family distress. Employment rates for the two groups were equal (44%) at nine months, but substantial gains in employment, unparalleled by control patients, were made by the family program patients during the second year.

The family's social functioning and health were altered little by either treatment program. Family burden, however, was significantly reduced in the family treatment group. Seventy-eight percent of these

families were
receiving indi
time period (F

Changes i
in the family
Families who p
critical and i
Problem solvin
from a critica
problem solvin

Limitations on

In several
from the expres
been raised (Ko
The critique ce
family environme
demonstrated the
illness course.
preceded the evo
to 2 years. The
that family expre
of the living wit
schizophrenic mig
succeeding time p

Interpretati
intervention stud
decreasing famili

families were burdened at intake and only 17% at nine months. Families receiving individual treatment showed an increase in burden in the same time period (Falloon et al., 1984).

Changes in family communication and problem solving were also found in the family treated group (Doane, Falloon, Goldstein & Mintz, 1985). Families who participated in family care had significantly lower critical and intrusive comments after three months of treatment. Problem solving statements were more prevalent in families who changed from a critical style. This led the investigators to conclude that problem solving strategies had replaced a critical interaction style.

Limitations on the Inferences Drawn from Intervention Research

In several recent reviews, concerns about the interpretations drawn from the expressed emotion research and the intervention studies have been raised (Koenigsberg & Handley, 1986; Kuipers, 1979; Platman, 1983). The critique centers on the interpretation of a causal relation between family environment and illness course. Recent prospective studies have demonstrated the temporal relation between family expressed emotion and illness course. Clearly, expressed emotion measured at discharge preceded the evolving course of the illness in the subsequent 9 months to 2 years. The descriptive work however could not answer the claim that family expressed emotion was the family's response to the demands of the living with a difficult schizophrenic member. The more difficult schizophrenic might in fact have been at greater risk to relapse in the succeeding time period.

Interpretation of a causal relation could be strengthened by the intervention studies. If the interventions were successful in decreasing families' levels of expressed emotion, and those decreases

were associate
justification f
and illness cou
alterations and
two projects (L
its problems.

Leff and a
and diminished
Unfortunately, t
success in lowe
Since the latte
in high expresse
between expresse
associates (1986
expressed emotio
compromised by t
emotion was take
separate out thos
were experiencing
stress of rehospi
measures of expre
intervention proj

Additional c
that family level
(Koenigsberg and
results. First, t
experimental trea

were associated with improved relapse rates, then there was greater justification for interpreting the relationship between family affect and illness course as causal. Demonstrations of expressed emotion alterations and concomitant reductions in relapse were demonstrated in two projects (Leff et al., 1982; Hogarty et al., 1986). Each study had its problems.

Leff and associates, (1982) demonstrated both lowered relapse rates and diminished levels of expressed emotion in the families they treated. Unfortunately, the findings were contaminated by their additional success in lowering face to face contact between family and ill member. Since the latter has been repeatedly shown to decrease risk of relapse in high expressed emotion families, demonstration of a causal relation between expressed emotion and relapse was not possible. Hogarty and associates (1986) found that in families who changed from high to low expressed emotion the ill member did not relapse. Their findings are compromised by the fact that their follow up measure of expressed emotion was taken at the time of relapse, making it impossible to separate out those families who had lowered their level of emotion and were experiencing a transient increase in response to the increased stress of rehospitalization (Koenigsberg & Handley, 1986). Follow up measures of expressed emotion were not completed in the other two intervention projects.

Additional concerns have been raised regarding the interpretation that family level interventions were superior to alternative treatments (Koenigsberg and Handley, 1986). Several factors may have biased the results. First, two of the programs contrasted home care, in the experimental treatment, with clinic-based care (Leff et al., 1982;

Falloon, et. al., 1984). Superior outcomes may have been due to the attention and respect accorded families by coming into their home, rather than to any specific treatment given those families. Potential biases were also introduced by the use of raters who were were not blind to the treatments that the families and schizophrenics were receiving. In two of the studies, clinicians who treated the families were also responsible for rating the outcomes (Leff et al., 1982; Falloon, et. al., 1984). In other projects it was unclear whether the raters were blind to the treatment condition.

A final concern has been raised over the use of relapse as a measure of illness course (Falloon et al., 1984; Platman, 1983). In most studies relapse was measured by rehospitalization, thus patients who denied symptoms and/or withdrew during symptomatic periods are not counted as relapsed cases. When hospitalization was not the criteria, positive symptoms were. What counted as a treatment failure were 'positive signs' of schizophrenia: hallucinations, active delusions, disorganized or bizarre thoughts (Andreason, 1984). The 'negative signs' of the illness which include low motivation or ability to complete tasks, emotional blunting and social withdrawal, were not used as criteria to determine illness course. Critics charge that in the rush to protect the ill member from over stimulation, these programs may actually set up a situation similar to back ward treatments. The ideal in family care seemed to include little or no stimulation, few demands on the ill member and little motivation to refrain from withdrawing into personal thoughts (Koenigsberg and Handley, 1986; Strachan, 1986). These critics call for the examination of program effects on both the positive and negative symptoms of schizophrenia in future investigations.

Summary

Investigations of families of schizophrenics are firmly lodged within the stress-vulnerability model of the illness. The aim of the expressed emotion research has been to identify stress factors in the family environment which place the vulnerable schizophrenic member at greater risk for repeated relapse. Much has been learned about qualities of the family environment which predict a resurgence of the positive symptoms of the disorder. The ways in which these family qualities bring about the relapse require a different kind of investigation. Assumptions held within the model must be reexamined. The constancy, malleability and impact of affect expressions in face to face interactions between schizophrenics and their families must be examined. Tentative re-conceptualizations of the expressed emotion construct, which separate the multiple qualities that comprise the predictive indicator of expressed emotion, hold promise for a better understanding of these family processes.

Family intervention programs with families of schizophrenics, also build upon the background of the stress-vulnerability model of schizophrenia. The model has allowed clinical investigators to conceptualize and structure "no fault" intervention programs with families. These programs, despite reservations, have demonstrated remarkable success in helping the family and the ill member live and work together to reduce the positive symptoms of the disorder. They have also opened a window on the families' experiences and skills in the caregiving task. Although each of the programs explicitly draws on the family's concerns, understandings and skills in the treatment process, none has formally reported on what they have found. Nonetheless, each approach has furthered the understanding of what is needed and what potentially works with this situation of care. The programs and their critics have also clarified the complexity of the project. These first generation intervention programs successfully focused on reducing positive symptoms of the illness. Undoubtedly the next generation will attempt to expand intervention goals to include impacts on both positive and negative symptoms of the disorder.

In this review of the current research on families of schizophrenics, investigations of family response to the illness and care have been conspicuously absent. The search for objective risk factors that influence illness course has captured the imagination and energy of social scientists who focus on families of the mentally ill. Large scale studies of family coping with this illness have not been done. Some information may be derived from additional analyses of data on family concerns and actions that were gathered in the intervention studies. This more fine-grained information on families' understandings and coping processes is sorely needed.

The metho
is a method tha
families who op
and in the cont
method selected
with the care o

This chapt
research approa
within the trad
and types of me
characteristics
project are des
interpretive res

The interp
understandings o
appropriateness
amply argued (Be
types of underst
of nursing, psyc
Lionberger, 1985

The purpose
evidence the back
study. In this p
parents' backgro

Chapter 3

Methodology

The method used in this study is interpretive or hermeneutical. It is a method that allows one to understand the meanings and practices of families who operate as whole units in the context of their larger world and in the context of their historical cultural tradition. It was the method selected as the most appropriate for the study of family coping with the care of a schizophrenic family member.

This chapter begins with an explanation of the interpretive research approach. Goals of the method, the view of humans encompassed within the tradition, person/context relations as assumed by the method and types of meanings accessed are highlighted. Following this, sample characteristics and specific methodological procedures employed in this project are described. Finally, I discuss the problem of rigor in interpretive research and how this project addresses the problem.

Research Approach

The interpretive method employed is based upon the philosophical understandings of Heidegger as explicated by Dreyfus (1983). The appropriateness of this method for the study of human problems has been amply argued (Benner, 1985; Dreyfus, 1983; Taylor, 1985) and the unique types of understanding that result have been demonstrated in the fields of nursing, psychology and political science (eg. Benner, 1984; Lionberger, 1985; Schilder, 1986; Wrubel, 1985; Taylor, 1979)

The purpose of this method is to illuminate human practices that evidence the background meanings and concerns of the persons under study. In this project, the goal is to give an adequate account of parents' background meanings and concerns so that their caring practices and relations

account, the n

ignored. Rathe

constructs like

worlds of these

account, a more

upon the unders

work.

View of Humans

Interpreti

supports the po

concerns and sh

notion of humans

or shared, under

According t

grasp or underst

learned by parti

raised. For Hei

of reality; the

the world in whi

explicit. They

person elucidates

(Dreyfus, 1983).

Understandi

and most commonly

their background

need or the capac

and relations with the ill member are explained. In giving this account, the normal science explanations of family behavior cannot be ignored. Rather, the task is to illuminate the ways in which central constructs like expressed emotion are inadequate in describing the worlds of these families. The interpretation offered must be a better account, a more complete account which both incorporates and improves upon the understandings that can be derived from the current empirical work.

View of Humans

Interpretive strategies are grounded in a view of humans that supports the possibility of shared understandings of the world, shared concerns and shared practices or activities. It was essential to have a notion of humans that was compatible with the the study of family level, or shared, understandings and practices.

According to Heidegger, humans live in the world directly. They grasp or understand their situations as meaningful wholes, which are learned by participating in the practices of the culture in which they raised. For Heidegger, "background meanings", comprise a human's sense of reality; they are one's implicit ways of discerning anything about the world in which one lives. These meanings cannot be made completely explicit. They can only partially be brought to light by studying how a person elucidates this sense of reality in his actions and expressions (Dreyfus, 1983).

Understandings of one's world need not be cognitive or conscious and most commonly are not. According to Heidegger, humans live through their background meanings, take them for granted and seldom have the need or the capacity to begin to make them conscious and explicit. A

good example of
the notion that
discussed becau
and family deve
fact for most A

One acquir
which has alrea
are different i
Greek, who live
heroes, is a po
potential in te
being a hero do
saint or a sinn
to become a sai
the constraints

The tensio
community, or f
the notion of a
opposition to t
form subjectivel
Heidegger saw t
interpreted mean
insight the prob
knower to the kn
dissolved. Howe
subject perceivi
Heidegger's insi

good example of a pervasive background meaning in American culture is the notion that individuals are self-reliant. This notion need not be discussed because it is threaded through our socialization, educational and family developmental processes. That humans are self reliant is a fact for most Americans.

One acquires background meanings by being raised up in a culture which has already decided what it means to be human. The possibilities are different in varied cultures and times. For example, an ancient Greek, who lived in a culture which understood humans in terms of heroes, is a potential hero. But for a Christian, who understands human potential in terms of becoming a sinner or a saint, the possibility of being a hero does not present itself; rather the Christian will be a saint or a sinner, or as Dreyfus (1983) asserts: a sinner who is trying to become a saint. The culture in which humans are raised, forms both the constraints and possibilities for what it is to be human.

The tension, in Heidegger, is not to understand how something like community, or family, can exist, but to understand how something like the notion of an individual, autonomous being can exist. In direct opposition to the Cartesian view of humans as autonomous subjects who form subjectively unique representations of objects in the world, Heidegger saw that humans, in being human, are in every way comprised of interpreted meanings which are taken up from the culture. With this insight the problems of the mind/body split, the relationship of the knower to the know, the mind to the body and the subject to its object dissolved. However, modern beings live in a world where the private subject perceiving objects is taken for granted, and therefore Heidegger's insight in not readily acceptable.

A second i
humans are esse
the kinds of be
what matters, h
the term "conce
shape human inv
defined by one'
concern is exis
room, but exist
can be spatiall
involved (Dreyf

There is a
qualities or tr
one freely take
concerns are an
appropriate ques
rather than "How
of relations of

Concerns ac
situation as wel
providing care t
might be the saf
outside the home
that concern. I
productivity mig
former might rej
while the latter

A second important insight that flows from the understanding that humans are essentially self-interpreting, is the fact that humans are the kinds of beings for whom things matter. In expressing and acting on what matters, human beings take a stand on who they are. Heidegger uses the term "concern" for what matters to humans. Particular concerns shape human involvement in the world; the way one is in the world is defined by one's concerns. The type of involvement that is shaped by concern is existential, rather than spatial. One is spatially "in" a room, but existentially "in" love or "in" a jam. Objects and persons can be spatially in a situation, but only persons can be existentially involved (Dreyfus, 1983, 1986).

There is a tendency to place concerns in the category of personal qualities or traits. Concerns are <u>not</u> possessions or qualities which one freely takes up or discards as the situation changes. Rather, concerns are an essential part of how humans are in a situation. The appropriate question is: "How are they involved by their concerns?", rather than "How much?". Concerns define the quality, not the quantity of relations of the person in the situation (Wrubel, 1985).

Concerns actually set up what is salient or stressful about a situation as well as ways that the person might cope. For example, in providing care to a family member with schizophrenia, a central concern might be the safety of the ill member. Decisions about his activities outside the home, and the proximity to the caregiver will be shaped by that concern. In contrast, a caregiver's concern for personal productivity might shape these same decisions quite differently. The former might reject day-care programs that provide minimal supervision, while the latter would readily enroll her family member.

Theories of M

Taylor (
understanding
Heideggerian
beings who hav
merely a way
individual sub
one individual
individual.

Through l
articulate our
implicit or ha
constitute a p
finally, we se
discriminations

The first
of representat
our world to on
perceptions. T
and interpretiv
nor is there an
participant. R
of a world in w

Largely in
space of underst
creates a kind o
tempered in a va

Theories of Meanings

Taylor (1985) points out the different possibilities for understanding human expressions which open up when one adopts a Heideggerian view of humans. If one accepts that humans are autonomous beings who have mental representations of their worlds, then language is merely a way of depicting reality. Within the Cartesian constraint of individual subjective reality, language can only be the communication of one individual's mental representation of objective reality to another individual.

Through language, humans perform three distinct functions. We articulate our world to one another, by clarifying what was previously implicit or hazy and try to make it clear and explicit. Second, we constitute a public space, or establish rapport with one another. And finally, we set out for one another particular human concerns and discriminations (Taylor, 1985).

The first function, articulation, most closely matches the function of representation. It is the way that we point out certain aspects of our world to one another, through contrast and refinement of perceptions. The difference is that in Taylor's view, this is a shared and interpretive process. There is no independent reality "out there" nor is there an independent subjective internal reality for each participant. Rather, the articulation brings to clearer focus an aspect of a world in which both participants live and share.

Largely in the expressive dimension, language establishes a public space of understanding between humans. Expressing a perception or idea, creates a kind of rapport, a way of being together. This rapport can be tempered in a variety of ways: conflictual, amiable, conspiratorial and so on. Expressive language need not be denotive or representational. Taylor gives the example of two passengers in a hot train compartment. One exclaims to the other: Whew! It's hot in here! In making the comment the passenger opens up the space between him and his fellow passenger. No information, per se, was exchanged since the other passenger already knew it was hot, and that the exclaimer was hot. The expression served rather to make the condition public and shared; it also served as an opening or invitation to further discussion.

Language has a third dimension which is constitutive. Language sets up what feelings, thoughts and actions are possible. Taylor (1985) suggests that aspects of human experience are constituted by language including our conscious or explicit awareness of things, our feelings and our descriptions of ourselves. Taylor also suggests that the constitutive dimension of language highlights some of our particularly human concerns: our moral sensitivities, for example. I will use an example from the recent press to explain the constitutive role of language.

Recently, at a local high school several members of the football squad physically restrained a teammate who had had a bad day in practice, and roughed him up. The young man shouted for help, and although there were several coaches in earshot they did not interrupt the proceedings. Neither did the other teammates who were not directly involved. Although the young man lost consciousness and had to be taken to the emergency room to be stitched up, the incident was called a "prank" by school officials. They young men involved were asked to give verbal apology and no further action was taken. A few months later, the incident came to the attention of school administrators who were outraged. At this time, the actions of the young men were described as "hazing, physical assault, and potentially criminal". Formal action was taken against the young men involved in the attack as well as the adults who were originally aware of the incident.

Naming the incident an assault rather than a prank, was an articulation, a pointing out distinctions that the administrators thought were lacking. The articulation also constituted the school community in a new way, as one that found physical attack to be morally repugnant. The fact that action was taken against the young men, although these kinds of hazing incidents had passed without consequence in the past, underscored the reconstitution of the community. A particular causal order in the articulation and the constituting is not implied; rather Taylor notes that the two are "essentially linked to one another", they happen at the same time. Constituting the school community in a new way simply accompanied the renaming of the incident.

The expanded understanding of meaning and language dimensions afforded by the Heideggerian view of humans is essential to understand language and expression within families. In order to study the meaningful transactions between members of a family, I believe one must be sensitized to, and aware of, their capacities to create different forms of public space and to raise particular concerns with one another in a variety of ways. To see these in the families' language, one must look for the expressive and constitutive aspects of the interactions.

Human Practices and Practical Knowledge

An important distinction, recognized by Heidegger, (Dreyfus, 1983) can be made between practical knowing and theoretical knowing. Practical knowing is the "know how" needed to operate smoothly in a situation. It allows one to meet the contingencies of a technical or social situation and continue to function. Walking down a crowded street requires practical know how. One must be aware of the proximate distance between oneself and others, maintain the pace allowed by the crowd, avoid obstructions such as parking meters and fire hydrants, follow the prescribed behavior at walk/stop signs and keep one's eye contact and interactional patterns within the bounds of local appropriateness. Heidegger claims that practical knowing, and transparent coping with one's situation are primary ways of knowing.

Secondary to practical knowing is abstract, detached, knowing which arises when we step back from a situation and ask ourselves: What is going on here? It is the conscious, analytical way we attempt to separate aspects of our situation out for examination.

Contrary to what the predominant philosophical and scientific traditions suggest, the practical way of operating in the world precedes and is necessary for analytical operations. One cannot know that a situation is problematic, requiring reflective thought or examination until one has covered a lot of ground, practically. For example, one can't study theory until one has mastered the skill of reading. Reading is a skill that, once mastered, is lived through. It becomes problematic when one encounters new terms or formats, for example, when one attempts to read in a foreign language. But for the most part, reading is a task with which we cope transparently. We do it and don't think about it. In fact, if we do think about it, we falter.

The status accorded theoretical knowing, has led most investigators of human problems to overlook these practices which make up most of human life. From a hermeneutic perspective, I am interested in lived meanings. To access these meanings I must study how families carry on the pragmatic activity of daily life. Practices are not easy to access simply because we live through them and don't often think about them.

In this study I tried to access practices by asking families to describe stories of normal and problematic events in their lives. These stories were provided in first person narrative chronicling actual event sequences, feelings and expectations. The narrative account of actual episodes has the advantage of calling forth few generalizations or hypothetical ideal responses. This description by its very nature, forces the family to recall and imaginatively relive actions that they transparently lived through. It is at least one step removed from their everyday experience. Still, because the stories are about real life problems, carried out in the context of families' actual background meanings and concerns, the stories encompass those concerns and provide an opening for interpretation.

Sample Description

Fourteen families agreed to participate in this project. All were recruited during regular meetings of Bay Area affiliates of the California Alliance for the Mentally Ill. Each had a son or daughter who had been diagnosed with schizophrenia or schizoaffective disorder. In eight of the families the schizophrenic member lived with the parents. In the remaining cases, the ill member lived in board and care, his own apartment, or on the streets.

Parents

Parents who participated were predominantly middle age, married couples. Fifteen of the parents were married, (7 couples and one famliy in which father refused participation), 5 were divorced (2 of these were from the same family), and 2 were widowed. Married couples had been together for an average of 32 years. Single parents were divorced at least 10 years, and in all cases the divorce preceded the illness by many years. Eleven of the 14 families owned their homes and most lived in the same location for 20 or more years.

Parents ages ranged from 50 to 77 with mean age of 56. Almost half of the parents (10/21) were between the ages of 55 and 59. Families who participated belonged to the middle or upper middle classes economically. Educational preparation was quite different for the men and women. Most of the men held bachelors or advanced degrees. Approximately half the women (8/13) had completed high school or some college and the other half (5/13) had bachelor's or advanced degrees.

All of the men, even those who had retired from one career, were employed full time in professions such as teaching, law, engineering, middle management or skilled labor. The women's occupations were more diverse. Five of the women were housewives, while 4 were employed in full time and 4 in part time work. Positions held by the women were predominantly semiskilled such as clerical or secretarial, but a few of the mothers had professional careers in health or education.

Ill Members

The schizophrenic family members were 24 to 35 years old, with an average age of 29 years. To ensure homogeneity in the families studied, those with ill members younger than 17 and older than 35 were not inducted. The ill member had been ill for an average of 8.5 years, with a range of 1-22 years. The majority of the ill members had been ill for 5-10 years. All but two of the schizophrenics in this sample were males. To protect the anonymity of the small number of families with daughters, I will refer to all ill members as males.

Current diagnosis of the ill member was determined by contacting the treating psychiatrist (once permission was obtained for release of information), by consulting parents' copies of medical records and histories, or from the parents' verbal histories of multiple diagnostic evaluations obtained for the child. Twelve of the ill members carried the diagnosis of schizophrenia and the remaining two were diagnosed with schizoaffective disorder.

Educationally, most of the ill members had completed high school (7) or some college (6), but only one child had a college degree. Most of the ill members were involved in some activity outside of their place of residence. Six worked part time in clerical or some type labor position. Usually they attended work sporadically which led to frequent job changes. Two additional children participated in day treatment and one attended school part time. Among the children who did not participate in an activity outside the home, several were actively involved in projects within the home. For example one young man spent his days writing letters to talk show hosts, politicians and newspaper columnists. A lack of socially sanctioned achievement is noteworthy in this group of young adults, because at least half demonstrated above average skills in academia or the arts prior to the illness. They were expected to pursue, if not excel in higher education and employment if the illness had not intervened.

Family Structure

The family structure most frequently represented in this study was a married couple with two children. Most of the ill members in this study had at least one sibling although family size varied from one to six children. As might be evident from the parents' and the childrens' ages, most of the children were grown and out of the home, with the exception of the ill member. In two cases there were younger brothers or sisters still living in the parental home as well. Birth order of the ill member was almost evenly divided between being the first, middle or last child born to the family.

Data Collection Methods

Sample recruitment

Families were invited to join the study during regular meetings of Bay Area affiliates of the National Alliance of the Mentally Ill. The investigator presented a brief overview of the study purposes and procedures and asked families to contact her at the end of the meeting. Monthly meetings of three local organizations were attended for approximately 10 months for recruitment purposes. Families entered the study following this personal presentation, or were referred by families who had attended the meetings or participated in the study. Members of one group were additionally solicited by mail; this effort resulted in one family entering the study.

The first meeting with the family in their home was devoted to explaining the study to all members (since some of the members were not at the initial presentation), and obtaining consents. At that time initial interview and observation times were scheduled. In families where the ill member lived outside the home, the study was explained and informed consent was obtained during the first personal interview.

Three methods of data collection were employed in in this interpretive study: interviews, in-home observations and, with a small sub-sample of families, laboratory testing. The rationale for using multiple methods matches that of rational empiricist researchers who argue for "triangulation" of approaches. Multiple data collection strategies provided multiple opportunities and contexts for observation and family presentation. Returning for a second and third interview provided me with the opportunity to clarify earlier interview material, and provided the families the opportunity to comment on earlier episodes. Observations were essential to this line of inquiry since it allowed me to see practices, skills and interaction patterns that may not have occurred to the participants to discuss.

Interviews

Unlike the empiricists, I assume that family members share meanings that constitute them as a unit and as individuals. While each member can begin to describe the nature of the family meanings, research which engages several members in trying to describe family problems, and make explicit aspects of their lives that are lived through unselfconsciously each day, has a greater chance to open up the understanding for the investigator. For this reason, whenever possible, all members of the family living in the home were interviewed and observed. Multiple interviews were conducted over three months, to access changes in the problems and adjustments made by the family over time. In this method, each additional event or coping episode adds to the overall comprehensiveness of the interpretation. Inconsistencies and anomalies in the member's and the family's responses come to light; the investigators task is to find an interpretation that takes account of the inconsistencies and normalities in the family's pattern.

Three types of interviews were conducted. First, family members were asked to describe the illness in an Explanatory Model Interview. (Interview formats are presented in Appendix A.) Family members' understandings of the etiology, course, process and prognosis of the illness are accessed in this interview. The format for this interview was adapted from the work of Kleinman, Eisenberg and Good (1978).

In the Stress and Coping interview, which was taken from the Berkeley Stress and Coping project, (Benner, 1984, Wrubel, 1985) respondents were asked about the difficulties and positive aspects that arose while living with and caring for a schizophrenic member. The schizophrenic members were similarly asked about stressful or positive events that occurred with the family. Specific "coping episodes", situations of positive or negative impact were elicited from the respondent. Each episode was explored in terms of the precipitants, the flow of the event, the respondent's emotional and cognitive responses throughout the episode, coping strategies considered and tried, and the outcome of the episode. Two to three coping episodes were elicited per interview, although many family members offered more than this number.

The third interview was a Family History in which, ideally, the family was interviewed as a group about its notions of itself, patterns of activities, modes of emotional expression and similarities and dissimilarities of various members. In addition, both parents were asked to briefly describe their families of origin and contrast that family with the one they had created.

Interviews completed. In 11 of the 14 families, complete sets of interviews were obtained from parents engaged in caregiving. Three families had an incomplete number of father interviews because of complete refusal, relocation out of the country (after time 2) and because the father was not the natural father to the ill member and felt only peripherally involved (he was interviewed once). Thirteen mothers who participated in the study completed all interviews. Participation on the part of the schizophrenic family members was less complete. Eight of fourteen schizophrenics agreed to and completed the explanatory model and coping interviews. Amongst those who did not participate, 3 refused directly and 3 were not asked to participate, based on the family's request.

Family research is critiqued for its reliance on a single informant who reports on family level interactions and processes (Miller, Rollins & Thomas, 1982) While this research was designed to tap multiple members of the same family to allow for comparison and interpretation of <u>shared</u> meanings, this was not possible in all families. In two cases only one family member was available or willing to participate. The number of family members participating is listed here. Seven family members who were appropriate for the study refused (or for other reasons) did not participate; six of these were the schizophrenic members of the family, one was a father who refused participation.

Table 1

<u>Number of Members Who Participated from Each Family</u>

Number of Participants	Number Available in Family	Number of Cases
1	2	1
1	3	1
2	2	2
2	3	3
3	3	4
4	4	3
36	42	14

Siblings who lived in the home or had significant contact with the ill member were invited to participate in the interviews. Five siblings agreed to join and completed one or two interviews as requested by the investigator. These interviews provided further information on the family meanings and practices, and were most essential in the single parent families.

In half the families, Family Interviews were completed in the ideal fashion, with mother, father, ill member and sibling (if they participated) responding jointly to questions. In the remaining families, difficulties scheduling time, or resistance on the part of the ill member made this arrangement impossible. Family history was gathered during personal interviews in this instance.

Most interviews were conducted in the family home to decrease the burden on members' schedules. A private room, where the informant could talk freely without being overheard by other family members was used. In two instances (where the schizophrenic refused to participate), family members met with the investigator in a public place, for example a coffee shop, to ensure privacy and to avoid upsetting the ill member. All interviews were audio-taped and later transcribed into a printed form.

Observations

Family practices were observed in the home over a period of three months. Day-to-day interactions among family members demonstrate how they live out their shared meanings and concerns. Observation periods illuminated aspects of the care that parents performed so skillfully or habitually that it was out of their awareness. It also served to validate aspects of care reported on in the interviews. The prospective nature of the study allowed the investigator to reflect back to members of the family, aspects of the observations that were confusing. If the action seemed private, I asked about it during the next private interview with that person. Often, the flow of family activities allowed me to ask individual members questions when others were not present as well as to put questions to the entire family.

Half of the families were appropriate for and agreed to in-home observations. When the schizophrenic member lived outside of the home, observations were not possible. In only one case where the schizophrenic lived at home were observations refused. In one additional case, they were curtailed after three visits, at the request of the ill member.

Families were observed for an average of 25 hours (range= 16-31). The pattern of observations was adapted to fit the family's habitual coming and going, and were scheduled when at least two, but ideally all members of the family were at home. Observations were scheduled to sample different times in the day and days in the week or weekend. Length of each observation varied from 1 1/2 to 6 hours and an average of 8 observation visits were made to the family home.

The role taken by the investigator varied with each family and with the amount of time spent with the family. The initial visits were somewhat strained as the family and I tried to find a comfortable way to relate during the observation times. I attempted to sit quietly, limiting my interactions with the family during the initial visits, communicating by my silence that I was more interested in <u>their</u> interactions than in being treated like a guest who had to be entertained. Their initial offers of dinner were rejected. In the next few visits, as I could feel the family's and my own tension decrease, I attempted to take on a role which fit with the family's expectations and living patterns. In some families, this remained as an outside observer who always sat apart from the family, although in the same or adjacent room. In others, I joined the family for an occasional meal and joined in the conversation. In varying degrees, all family members used their time alone with me for conversation, sometimes about the study topic, often about their interests.

Laboratory testing

I originally proposed to measure all families on the dimensions of the Reiss Family Paradigm. For testing, the family was asked to come to the laboratory in the School of Nursing at the University of California to complete a card-sorting exercise. The family's responses were recorded when they pushed buttons on an event recorder and scored by the investigator who stood behind a one-way mirror and observed their interactions. Three families completed the laboratory testing; the remaining 11 families could not be scheduled to complete this aspect of the study for a variety of reasons including family work schedules, distance from the university and the ill member's paranoia about any form of technical family evaluation. In addition, the laboratory test requires the participation of at least three members so the 7 families with less than three members participating could not be tested.

Data Analysis

Interpretive analysis, or hermeneutics, is an approach to understanding human behavior and meanings through text interpretation. A textual analogue of lived experience serves as the basis for this interpretation (Taylor, 1985). Texts to be analyzed are comprised of transcriptions and notes of interviews and participant observations.

The aim in hermeneutics is to give an historically situated, contextually embedded account of human action (Packer, 1985). The investigator's understanding of the action is derived from texts which include the situation in which action occurred and the aspects of the situation which the actor's actions or statements point out as salient.

Hermeneutical analysis is comprised of the of three interwoven processes: thematic analyses, analysis of exemplars, and a search for paradigmatic cases.

<u>Thematic analyses</u> in this project proceeded through the following steps:

1) Each case was read through as a whole, so that the sense of the person reacting within his context and history could be obtained.
2) After the review of several whole cases (at least 10) an initial interpretive plan or outline was formulated. Lines of inquiry were formed from both the guiding research questions and from categories of interest that consistently emerged in the data. (See Appendix B for the interpretive plan developed for this project.)
3) Each interview from each case was then read through and coded according to the lines of inquiry in the interpretive plan. Examples of categories are: Personal meaning changes, impact of illness on work, social life of caregiver. (See Appendix C for a partial example of an interview interpretation or exegesis.)
4) Additional lines of inquiry emerged as the fine-grained interpretation of smaller portions of the texts proceeded. These were

added to the outline, and cases already analyzed are reread for indications of these newly emerging themes.

5) As the bulk of the interviews are interpreted, the most prominent themes were selected from those recorded and were compiled into general topics which comprise the findings of this dissertation.

6) As these topics were written in more general terms, individual cases, from which the data emerged, were reconsulted, to validate that the grouped data adequately represented the themes expressed within individual cases.

Analyzing exemplars. In addition to a search for general themes, "coping episodes", specific examples of stressful or difficult events elicited from participants in the Stress and Coping Interviews[1] were culled from the interview. All relevant aspects of each coping episode were coded together, including: the caregiver's recollection of what preceded the episode, how the episode unfolded, emotions at the start and throughout the episode, actions considered and taken, direct and indirect clues to what was at "stake" for the caregiver, and the caregiver's retrospective reworking of the situation, for example, would s/he change the action taken. These coping episodes, in their complete form, served as "exemplars" of particular patterns of action that included a rich description of the situation and actions that evidenced the caregiver's intentions, concerns, practices. (See Appendix D for an interpreted coping episode.)

This method of analyzing personal coping is exactly complementary to the phenomenological view of stress and coping put forth by Benner & Wrubel (In press). It allows the investigator to capture all aspects of the appraisal and coping process in one piece for recognition and understanding, as well as for eventual presentation to the reader.

Paradigm cases were recognized as I became more familiar with the patterns in the data. A paradigm is a strong instance of a pattern of things that seem to go together. Kuhn (1962) recognized how paradigms guided science and noticed that scientists could "agree in their identification of a paradigm without agreeing on, or even attempting to produce a full interpretation or rationalization of it" (p 44). Often the patterns evident in a concrete paradigm cannot be reduced to a set of rules, nor are the rules needed. Instead, what are recognized are "family resemblances" between the paradigm case and the case one is trying to identify. Family resemblances are the "network of overlapping and crisscrossing resemblances" between the paradigm case and another case.

Interpretive research in this respect resembles the expert clinician or diagnostician who gains access to complex clinical syndromes through whole paradigm cases, complete with their saliences and nuances. A wonderful example of paradigm recognition is told by Oliver Sacks (1985) who first "saw" Tourettes syndrome in its lived reality, during a clinical consultation. He had read of Tourettes and knew some of the symptoms, but had never seen a case. At the time, 1971, the syndrome was believed to be very rare, perhaps one in a million, and some neurologists believed it to be fictitious. The day after he consulted with the Tourettes patient who provided a particularly vivid example, he "saw" while walking the streets of New York, three more people who seemed to have the syndrome. The day after "without specially looking" he saw two more cases. Sacks' experience powerfully demonstrates how humans can grasp a situation (or syndrome) in its entirety, given a concrete example. It further illustrates how the particular instance can be a paradigmatic form for further recognition.

In this project, paradigm cases of care, or of family relations in relation to care, were of interest. In reading through different case studies, I noticed that certain cases had a "family resemblance", to certain other cases. The paradigms were of particular patterns of concerns, background meanings and illness understandings that set up a particular kind of care. Certainly no two cases were exactly alike. Rather they had overlapping, crisscrossing resemblances of concerns and actions. It was through paradigms, that particular forms of care were recognized and eventually named.

Rigor in Interpretive Methods

It is unfair to judge one form of investigation, based on a particular set of philosophical assumptions by the criteria set out to judge an entirely different form of investigation. Thus, it is inappropriate to apply standards of empirical investigations to interpretive projects. Unfortunately, there has been little discussion of the criteria by which interpretive work might be judged.

Sandelowski (1986) suggests four areas in which the concerns about rigor in empirical works are matched by parallel concerns in interpretive studies: a) truth value, b) applicability, c) consistency and d) neutrality. These concerns are met, in empirical studies, by criteria which assure: a) internal validity, b) external validity, c) reliability and d) objectivity. She suggests that the matching criteria by which these concerns can be evaluated in interpretive research are:

a) credibility, b) fittingness, c) auditability and d) confirmability. Each of these are discussed in detail.

The credibility or truth value in interpretive work lies in achieving an adequate interpretation of the experiences and expressions of the subjects. An interpretation is adequate if the subjects themselves, in reading the account find that the story is right. That is, they recognize themselves in it, and find that aspects of their lives are fairly drawn. Aspects of the situation which are important to them are highlighted and those that are not, are in the background. A second test of credibility is whether an unknowing reader can, on reading of the experience, then recognize it in real life.

Sandelowski suggests that a major threat to credibility is the researcher becoming too enmeshed in the subjects' experience. By getting in too close, and over identifying with the subjects under study, the investigator loses the ability to meaningfully separate the subjects' experience from her own. The investigator can guard against this by keeping a log of her experiences in relation to the subjects, noting how she impacts the subjects and is impacted in turn by the continuing contacts.

I used several strategies to gain an adequate account of family care of schizophrenia, without over identifying or becoming enmeshed. First, I kept a log of my experiences, emotional reactions and developing impressions throughout the data collection period. This log is much more complete for the observational experience than for the interviews, because it was there that I felt my understandings were most challenged. Additionally, I engaged two family theorists and therapists to help me understand clinically and personally, the experiences that I was having with these families. These persons helped me to find a stance with families that was neither enmeshed, nor detached; that allowed me to be personally challenged by their understandings and concerns, but not overwhelmed by their pain and trouble.

Fittingness addresses the second concern for rigor in interpretive work: applicability. Fittingness is established when the the findings make sense when applied to persons of similar situations to those studied, but who were not actually studied. In other words, the findings make sense outside of the immediate, local context of the study itself. Results also are judged for their fittingness when readers can make sense of the findings, in terms of their own experience.

Two threats to fittingness are an "elite bias" and the "holistic fallacy". The first, is the problem of attracting the "most articulate, accessible and high status members" of the group of interest. To protect against this bias, the investigator must demonstrate how the group of respondents fits into and adequately represents the group as a whole. The holistic fallacy applies to data analysis. It occurs when data are condensed to appear more congruent than they are. Conclusions drawn under this flawed analysis are assumed to represent the entire data set, but do not.

Sandelowski names five strategies for ensuring fittingness. These include:

> 1. Checking for the representativeness of the data as a whole and of coding categories and examples used to reduce and present the data;
> 2. Triangulating across data sources and data collection procedures to determine the congruence of findings among them.
> 3. Checking that descriptions...contain the typical and atypical elements of the data;
> 4. Deliberately trying to discount or disprove a conclusion drawn about the data;
> 5. Obtaining validation by the subjects themselves. (p.35)

In this project, the sample may represent an "elite" among families who care for the chronically mentally ill. Parents were members of well organized and sophisticated family support groups. They had read the books, heard numerous speakers, and knew many other families who were living in similar situations of care. In addition, these families had cared for the ill member for a number of years. This sample does not well represent families who are struggling with the demands of the early stages of the disease, or families who are isolated in their care. On the other hand, this is a "community" sample rather than a "clinic" sample. Because the families were recruited from a community based group, rather than a clinic or hospital, they better represent those who have not accessed or have refused care. In four of the fourteen cases, the schizophrenic member was not involved in any form of mental health care.

Several attempts were made to establish fittingness. The interpretive plans developed were continually checked and rechecked across the different cases. Observation notes were contrasted with interview data to arrive at a better grasp of a particular case. Interpretative statements about, for example, illness understandings, were continually "tested" against cases that seemed to fit, and not to fit. Finally, some validation was obtained when I presented of early interpretations to a statewide convention of families of the chronically mentally ill (Chesla, 1987). The response to the paper was extremely positive and numerous requests for the paper, from family members, followed.

To establish auditability, which parallels reliability in empirical work, the investigator must give sufficient information about the decisions made throughout the study so that another researcher can clearly follow and judge those decisions. In addition, auditability implies that using the same data set, a second researcher could condense conclusions which would not contradict those of the first project.

In this project, I have attempted to establish auditability by making the process of data collection and interpretive resolution as accessible as possible to the reader. Early and late stages of the data collection and interpretation process were subjected to evaluation and criticism by my dissertation sponsor. In addition, 8 colleagues participating in an interpretive research seminar, read transcripts of selected aspects of the Explanatory Model interviews, and offered separately derived interpretations. These interpretations were similar to one another, and supported the findings reported in this project.

Confirmability, the fourth criteria suggested by Sandelowski, is supposed to parallel the concern for neutrality in empirical work. She notes that interpretive researchers neither seek nor value the objective stance required for neutrality. She suggests that interpretive investigators seek engagement with rather than detachment from their subjects. She suggests this engagement requires respect for both the investigator's subjectivity and subject's subjectivity.

The problem of confirmability has been discussed more coherently by ethnographers (Agar, 1986; Rabinow, 1977) who recognize that the scientist and the subject live in cultures or worlds of meanings that are partially overlapping. Each comes from a world of meaning that is ongoing, incompletely integrated, and requiring constant interpretation. In meeting, the scientist must translate her world to the subject just as the subject translates her world to the scientist. In reporting on the transaction, the best account sits in neither world, but somewhere in between. The scientist cannot completely enter the world of the subject and tell the story from the inside, because she is constrained by her own cultural possibilities, which only partially overlap with those of the subject. Giving an account, from within her own cultural constraints produces an ethnocentrically biased account.

I have attempted to give an account that is somewhere in between my world of meaning, and the parents' world of meaning. To arrive at this interpretative account, I allowed my understandings of the illness, and of the care that should be provided, to be challenged and tested. My initial understandings of parents in the situation of care, have been reformulated and clarified by many more encounters with similar and different forms of care. It is also informed by my initial discussions with parents, and by mulling over and reconsulting the interview texts. What is presented here is my current grasp of these parent's worlds. The reader must judge whether the account breaks through the theoretical and personal biases that I brought with me to the field of study. Ultimately, the informants must judge whether the account begins to approach a middle ground between my world and theirs and gives an better version of the lived experience of caring for a schizophrenic family member than is currently available in the literature.

Chapter 4

Explanatory Models of Schizophrenia

Introduction

Parents of schizophrenics had diverse and elaborate models of the nature of the schizophrenia. They developed these understandings through personal experience with their ill son over time, through reading and consultations with professionals and through contact with other family caregivers.

In this chapter I will outline three central aspects of the parents' explanatory models of schizophrenia. First I detail the causes of the schizophrenia as described by parents. I next describe the parents' models of the illness process. This comprises their personal understandings of how the disease works in their son. Finally, parents' models of treatment or care are described for each model of the illness. For some parents, understandings about the process of the illness substantially structured the model of care they thought was required. In other cases parents' models of the illness and of care were less consistent.

Explanatory Models

The distinction between disease and illness is central to the following discussion (Kleinman, Eisenberg & Good, 1978). Disease is an alteration in the structure or function of the body. Illness is the person's experience of altered function or well-being; it is the phenomenal experience of sickness. The fact that disease and illness are not identical processes has been established repeatedly. Identical disease processes give rise to different illness experiences and complaints of distress. Also, a person can feel ill, and seek health care, in the absence of disease. Factors which influence qualitatively different illness experiences include culture, experience with past disease, and understanding of the body (Kleinman et al., 1978).

Kleinman and associates argue for a "meaning-centered" approach to clinical practice where health care providers address problems at the biological and the phenomenal levels of human experience (1978). Since the personal understandings that patients and families have about disease influence their patterns of expressing symptoms, seeking health care, and compliance with treatment regimens, medical practitioners are handicapped in their attempts to influence health behaviors if they ignore these understandings.

Good and Good (1981) argue that all health care be reconceptualized as a negotiation of illness and treatment models between patient and practitioner. They recommend that health assessments include an interview to ascertain the patient and family's "explanatory model" of the illness which includes their understanding of the etiology, course, process and prognosis of the illness.

Schizophrenia as a disease has been researched and reported on repeatedly (eg. Wynne, Cromwell & Mathysse, 1978). Perhaps because of its complexity, there has been greater attention paid to this disease than any other mental disorder. The phenomenal experience of schizophrenia has been described in personal histories (eg. North, 1987) but systematic study of the illness experience has been extremely limited. The disorganized thoughts, altered perceptions and altered sense of safety often experienced by schizophrenics, make it difficult for them to communicate the illness experience to an outsider.

My interest in the parents' explanatory models of the illness was twofold. First, they have lived closely and continuously with the person who has schizophrenia, and therefore understand the illness trajectory over time. Their understanding of the illness differs from that of the ill member, but close proximity gives them perhaps the best access for documenting the illness. Second, they have special access to the illness in natural contexts. This access is denied practitioners who see the person with schizophrenia only in treatment settings. Oliver Sacks has convincingly argued (1985) that the situation or context impacts enormously how a person functions. <u>Where</u> one sees a person influences <u>what</u> one sees of his capacities and deficits. Families understand their family member's illness experience by noting how they function in the meaningful and varied contexts of daily life.

Causes of Schizophrenia

Parents of schizophrenics believed that numerous factors in combination caused schizophrenia in their child. All believed the ill member started with an inherent vulnerability to the disease. Additional precipitants named by parents fell into three categories: biological, social and stress factors.

Biological

All parents, to a greater or lesser extent, said that their offspring were born with the <u>genetic</u> inheritance for schizophrenia. Parents disagreed on the relative importance of the genetic makeup and the environmental factors. One mother described the strength of the inheritance as a "time bomb, set to go off when my son was 17 years old". Six additional parents echoed her belief that environmental factors had little impact on whether their sons developed the disease.

Most parents (13/21) held the more moderate view that the child inherited a vulnerability or susceptibility to the disease, which was then "triggered" by additional factors in the child's life. In one father's words:

> Cancer may be susceptibility. -Although you don't inherit a cancer, your genetic make up may be such that you are more vulnerable than some other person. And so it's conceivable that mental illness has a genetic makeup and might be touched off by an event.

At the other more extreme end of the spectrum were those parents who believed that environmental factors weighed most significantly among causal factors. The two parents who held this view were in a clear minority.

In searching for evidence of basic biologic explanations of the illness, parents reviewed any special traits their child may have displayed, during the developmental years. In 7 of the 14 cases, parents recalled the schizophrenic son as different from their other children. They now wondered if those traits were in fact, early signs of the disorder, but seldom had definitive answers. Only three of these parents actually sought mental health or medical attention for the behavioral traits that they now questioned as early warning signs. The others had interpreted the child's behavioral differences as extreme personality traits, or developmental phases that they believed the child would outgrow.

Examples of special traits in the ill child were many, but there was no striking pattern of similarity. He was more stubborn than other children, more difficult to discipline, or simply more extreme in his responses to parental demands. When these traits persisted into young adulthood, and seem to be a part of the disease symptomatology, parents were more convinced of their initial relevance. In my analysis, no clear signs, consistent across cases, could have warned these families of the impending illness.

Social Factors

Adolescent developmental tasks. Difficulties of adolescence were seen as the central precipitating social factor in schizophrenia, by 10 of the parents. While the nature of these stresses varied with the child's age and life choices, all were normal tasks of the developmental stage. Specific stresses noted by parents were school pressures, pressures from peers to ignore parents' rules for example, in relation to drugs, or sexual activity, or being away from home for the first time.

Family influences. About half the parents (10) looked to themselves as possible contributors to the expression of schizophrenic symptoms in a vulnerable child. Since most parents believed their ill member had an inborn vulnerability to the disease, they questioned how their efforts at childrearing might have influenced the timing, nature and severity of the disease.

> I don't blame my husband or anyone. But I still think the way he handled our son probably aggravated the situation.

Additionally, parents questioned whether they had treated the ill member differently than offspring who did not develop the illness. Most, like the following father, concluded that they had been even handed and consistent in raising the children.

> There is a tendency to think of the middle child syndrome. At least the folklore is that the middle child doesn't get such a good deal. So we try and think if we did anything different about him than the other children. We don't think so.

Parents also questioned whether the quality of family relations impacted the child's illness. Three parents believed that marital discord and the lack of a "sense of family" were significant factors, in addition to genetics, in the development of their ill member's schizophrenia.

> So how my son has reacted to all these ambivalent strange feelings, that I've had (towards my husband) over the whole years, may have produced some of this. It's a possibility.
>
> *****
>
> I will probably always wonder if he had been raised in a different family, how he would have come out, because I definitely think that you're born with it; but I also think that the family has something to do with it, too.

In two of these families, the marriage had ended in divorce long before the onset of schizophrenic symptoms. Still, the parent who provided care blamed the early years of discord for the illness progression. In only one instance was the family intact. This mother suggested that disruptive marital patterns had caused the illness in two offspring, and she had better start changing the way she and her husband related. However, she took no discernible action to change her relationship with her husband in the course of the study.

Stress Factors

Drug use. Use of drugs was the stress factor most frequently mentioned by parents as causing the expression of schizophrenia in a vulnerable child. In most cases street drugs such as marijuana or speed were used. The use of hallucinogenic drugs like LSD and PCP was questioned but seldom known. In 10 of the 14 cases some drug use was evident and in all these cases parents felt the drugs were a likely precipitant.

Stressful events. Events that distressed the ill member were never mentioned as a unique cause of the illness. Rather, parents thought that stress, in combination with a genetic inheritance and in combination with adolescent tasks, brought on the initial symptoms. Isolated, highly stressful events were frequently named as causes for the first psychotic break by 10 of 21 parents. Examples were: participation in EST training, death of the family pet or an accident involving the ill member or a parent. Parents noted that while one isolated event may have pushed their son over the edge into psychosis, the break was probably inevitable.

In conclusion, parents had a variety of ideas about what may have caused schizophrenia in their offspring. All agreed that the biological basis of the disorder was part of the ill member's makeup from birth. The influence of the environment on the expression of that inborn vulnerability was great to some parents, and almost inconsequential to others.

Illness Models

Parents had a range of understandings about what was wrong with their sons, and what, if anything, must be done to correct the problem. Four central models of the illness were evident in the parents interviews. These models were elicited in the Explanatory Model Interview (See Appendix A), in which they were asked what schizophrenia looked like and how it worked, in their son. Additional clues were found in treatment approaches parents favored as well as their personal responses within specific coping episodes.

What follows is a description of parents' illness models. I begin with a general discussion of the nature of the models, the dimensions on which they differed and the pervasiveness of each of the models in the sample studied. Next I present paradigm cases of each type of model. These cases are the clearest, most consistent examples of the range of understandings evident within each model. Finally, I discuss the type of care that flowed from each particular illness model.

The four models of schizophrenia were:
Strong Biological Model
Rational Control Model
Normalizing Model
Survival through Symptoms Model

Dimensions on which these illness understandings differed are highlighted to aid the reader in distinguishing between the various illness models. These analytic dimensions do not capture the whole nature or meaning of the parents illness understandings. Rather, they are a device to aid the reader in recognizing some of the aspects that distinguished one model from another. The dimensions are: the locus of the pathology or the problem, the locus of change and the potential for improvement.

Each illness model is introduced through a discussion of the three dimensions. Each model represented a particular concern, or tension for the parent, and these tensions were not always parallel across models. For example, there was an intense concern for the ill member's phenomenal experience of suffering in the Survival by Symptoms model. This concern for the ill member's personal "internal" experience of the illness was simply not evident in other models. There was no clear dimension on which to contrast this central concern in one model, with the the rest of the models. For this reason, the reader is encouraged to use the dimensional differentiation as a starting point in understanding the model, but to allow the more complete story, evident in the paradigm case to expand this understanding.

A predominant model was identified for each parent who participated in the study. (See Table 2) Many parents had additional understandings

Table 2

Parents' Explanatory Models of Schizophrenia

Model	Primary Model (# of Parents)	Secondary Model (# of Parents)
Strong Biological Model	1	4
Rational Control Model	1	4
Normalizing Model	8	1
Normalizing Model with Cure	2	
Survival by Symptoms Model	9	1
Total	21	10

of the illness that differed or conflicted with the model they predominantly expressed. Often both models were called into play at different times in the study. The pervasiveness of these "secondary" illness models is also presented in Table 2.

Strong Biological Model

The most straightforward model of how schizophrenia worked was one in which all symptoms were viewed as direct outgrowths of a brain chemical malfunction. The locus of the problem, within this model, was a chemical malfunction within the ill member's brain. Change at any level (biological, cognitive, behavioral) was thought to be possible only through primary changes in the brain chemistry. The model encompassed the possibility for improvement, at the chemical, cognitive and behavioral levels, if the chemical influences at the cell level were appropriately adjusted.

The strong biological model is best exemplified by one mother who had been influenced by orthomolecular and general medical research. Her theory was that schizophrenia was an adrenalin excess. Both sugars and stimulants intensified the adrenalin excess and therefore the schizophrenic should avoid eating foods with sugars and stimulants.

> And adrenalin is the one that starts that process, so you have all the symptoms of adrenalin: the fight and flight, the fear response. And this is why, when they drink a lot of cokes, they become very paranoid. Because the fear response flares right up. And so they use stimulants and use a lot of sugar in their diet, which does the same thing. They exacerbate the symptoms.

According to this mother, vulnerability to the disease began at puberty when "sex hormones", appeared and triggered neurotransmitter excesses. She believed this explained why schizophrenic symptoms diminished in middle age; As male sex hormones diminished, she reasoned, that the symptoms would be less severe.

This mother additionally believed that social stressors influenced schizophrenic functioning, but in the same way that coffee, cokes or sugars did: they overstimulated the neurotransmitters.

> Emotional problems that are due to the illness can be stressful. So if the schizophrenic is not happy that is stressful. And stress is solved by neurotransmitters, which become activated and then cause the schizophrenia.

Only one parent understood the illness primarily within the strong biological model. Four additional parents, however, seemed to secondarily rely on the belief that if they could just get the chemistry "right", then their child might be relieved of symptoms and able to get on with his or her life.

Model of Care. The model of care that resulted from this understanding of schizophrenic processes centered upon biological treatments. In the paradigm case, the mother recommended vitamin therapies, restrictions on dietary intake of sugars and stimulants, psychotropic medications, and exercise, because it decreased neurotransmitter stimulation and stress. She had theories of how each of these therapies worked. For example she believed niacin, in high doses, worked to negate the effects of neurotransmitter overstimulation.

> They have discovered that niacin will take some of the chemical molecule away from this sense distortion agent so it kind of cancels it.

She also believed that medication effects were negated by caffeine consumption.

> My son uses so many stimulants, they cancel the medication. When he doesn't drink the caffeine and I don't give him (so much) medication, he's able to manage.

One example of this mother's interactions with her son demonstrated her adherence to the illness model. The schizophrenic son was fixated on drinking coke. This may well have been because it was prohibited, but the craving had reached delusional proportions. About one third of the interactions between mother and son focused on if and when the son would receive his next bottle of coke.

One day this mother decided to implement a program in which her son had to do five things around the house, or forfeit his day's allotment of cokes. He didn't follow through with his side of the agreement and she withheld cokes for an entire day. She noticed that he was much better the next day, after refraining from caffeine for twenty four hours.

I did not encounter another parent who held a biological model as extreme as this mother's. Many of her understandings of the illness were exaggerations or distortions of what she had read in the medical literature and were erroneous. The treatment she prescribed from these misperceptions closely paralleled what might be prescribed by any practicing therapist. Many therapists would support this mother's prescriptions for adherence to medication regimens, avoidance of caffeine, exercise and stress reduction.

Many families agreed with this mother's basic premise that the illness was biological and the treatment should be as well. Four parents, whose illness models were secondarily biological, placed substantial emphasis on, and hoped for, a biologic cure. Despite parents' illness models, 19 of the 21 parents interviewed supported the use of medications. The three parents who doubted the efficacy of medications did so because their ill member had never received medications and or had experienced ill effects of medication treatments, such as tardive dyskinesia, in the past.

Rational Control Model

In the rational control model, parents recognized that the illness had a biological basis, but they additionally believed that an important part of the pathology centered in the ill member's cognitions. They seemed to believe that improvement in overall symptoms followed from a central change in the ill member's thinking. Importantly, they believed that at least some of the time, the ill member was in control of his thought patterns. In short, these parents believed in "mind over matter", or that their offspring could be trained to think differently, and therefore act differently. They presumed that rational arguments or behavioral techniques could influence the ill member to control or diminish his symptoms. Only one father held this view as his primary illness model, but three others demonstrated an affinity to the model in their interactions with offspring and in illness descriptions.

The degree to which the ill member had control over his thoughts was, at times, in doubt even with the father who is the paradigmatic case for this model. This father indicated that he originally felt his son's illness behaviors were out of control.

> So he went to college with some concern about how he would do--not so much because of the academics, but because of his then obvious inability to have full control over his time and his priorities.

This father believed his son could acquire control over the symptoms. His hope sprang in part from the fact that the young man had gotten somewhat better over time even though the control was viewed as somewhat tenuous.

> I'll tell him that I don't want to hear these noises in the bathroom. And most of the time now, he'll seem to be in reasonable control. But every once in awhile, (the symptoms) break loose.

This father directly expressed his ambivalence about the ill member's ability to control the situation. He finally settled on the belief that, yes, the young man could be held responsible.

> So I keep vacillating back and forth, one side saying: You can never expect these things, right? But on the other side saying, now wait a minute, that's not logical. I mean, look where he is now, compared to where he used to be. We can see that he's doing these things, and some things that are very good. How far can he go? Why can't he do these other things? Like going to bed early?

Another mother argued that her offspring could and should straighten out his thinking about his potential and start acting on that potential.

> I told him, "You know how often you've read about people who've been in a bad accident and they're told they'll never walk again. And through sheer will power, they get up and they walk. If you could try to have a more positive attitude. Never say to yourself that you're never going to be rid of this. Whenever possible, say, 'I'm going to get rid of it. Somehow, I'm going to just throw it off. I'm going to try in every way I can, you know, to get rid of it.'" So, I don't know. I just talk and hope that some of it will get through.

It should be highlighted here that persons with schizophrenia often have delusional beliefs that, while difficult to grasp, guide their actions. For example, in the families who were included within this grouping, the ill member believed "irrational" things like martians were speaking to him or that there was a particular physiologic need to cleanse his sinuses. Each acted on these beliefs by listening intently to sounds on the roof, or spending hours in the bathroom cleansing. Given this context, it is understandable that parents tried to talk their offspring out of these irrational beliefs. The logic is quite clear: since so many of his problems arise because he has these odd beliefs, which are irrational anyway, convince him to give up the odd beliefs, and things will be better.

Model of Care. Within the rational control model, parents encouraged the ill members to pull themselves together and change their thinking. In every interaction, and in each conflictual episode, these parents attempted to train their sons to master symptoms. One father discussed the guiding principle of this form of care.

> The message I'm trying to get through, is, keep him give him shelter, see to it that he has food. But don't provide things that he doesn't absolutely need, or things that he can get on his own. -- Although we can't always know what's the right thing, we should not make it easy for him, not take care of things that he can do, and should do.

This father applied the general principle in the specific repeated instances of his son's tardiness. He believed the young man should be ready for events on time and proposed that he be left behind when late. This father viewed this as an important opportunity to train his son in managing himself in the world.

> I think the important thing to me isn't if we get someplace or don't get someplace on time, but how our son reacts to the idea that he doesn't have to. He thinks he doesn't have to worry about it. Cuz good ole' mom and dad will take care of it, so it doesn't matter, when I get up, when I do this when I do that.

This father deliberately tried to convince his son to change his errant habits.

> To help him, in my own way, it probably doesn't work, is to try to think up the <u>right words</u> to get him to understand that getting up in the morning and going about the things you have to do, doesn't start with when you get up in the morning.

In a similar fashion another mother spent hours trying to think of the best arguments and strategies to influence her son to stop shoplifting.

In summary, within this model of care, parents focused on their interactions with offspring, rather than on dietary intake or environmental influences. Certainly these parents supported the continued use of medications. However, their energy and initiative were directed towards helping their offspring "think right" and therefore "act right". Drawing on their assumption that the ill member could cognitively control their symptoms, parents attempted to train their offspring through rational arguments and rewards, to behave less symptomatically.

Normalizing Model

The central tenet of the normalizing model is that the symptoms of schizophrenia can be reduced and the ill member can function optimally if he or she lives within environments that call for reality based, normal, age-appropiate activities. The ways in which these environments elicit "normal" function in the ill member were not clearly described by parents. Also, most parents did not consider this environmental treatment to be a cure. They had the more limited goal to minimize symptoms and promote functioning. Eight parents held this model and two additional parents held many of the same beliefs but also believed a cure was possible. The two parents will be discussed as a subgroup at the end of this model discussion.

The important locus of pathology in this model is in the schizophrenic/environment interface. These parents did not believe that illness was caused by the environment, holding instead that the illness arose from a genetic predisposition, or a mix of genetics and environmental factors. (Three of the five parents who thought the illness was uniquely genetic, held this illness model). In their theorizing and their actions, these parents demonstrated their belief that normal environments held the key to less symptomatic and higher levels of function in the ill member.

Inherent in the normalizing model was the belief that the symptoms of schizophrenia were largely out of the ill member's control. All parents believed that the illness was biological and that medications were needed. They recognized the nature and severity of the symptoms and were, as a group, the most realistic about the immutability of certain symptoms, like delusions. At the same time, they recognized the ill member's capacities and believed that certain cues in the environment could nurture these capacities. Additionally, parents were highly attuned to aspects of the environment that they feared might exacerbate symptoms or cause the ill member to falter in his role responsibilities.

The locus of responsibility for change also fell at the ill member/environment interface. In other words, these parents assumed that change must emanate from both the ill member and the environment. The parent's role, (which was taken on with differing levels of involvement) was to encourage the ill member to participate in the healthy environments or to actively structure these environments for the child.

One father exemplified this view of the illness. He felt that work organized his son, distracted him from delusional thoughts, and should be a central part the treatment. This father blamed a period when his son was bedridden on the fact that the young man switched from a steady job to temporary work. It's telling that this father believed the disruption was initiated by the change in work. A more common view would be that the son's symptoms increased and led to his inability to function at his steady job. The father's prescription, repeated through three months of interviews, was for his son to acquire and hold a steady, meaningful job.

In contrast to the preceding illness models, the normalizing model of the illness focused most centrally on concern that the ill member fulfill his social roles. These parents believed, as did those who held a strong biological model, that the child needed medications as a base of support, but went one step further to state the child additionally needed access to and involvement in social roles that called for normal functioning. They differed from parents who believed in the rational control model, because they held the ill member less responsible for the change that would lead to higher level functioning. They did not believe that they could argue the ill member out of his elusions, nor did they believe that the ill member could, through sheer will power, change these delusional beliefs. Instead, parents in this group avoided discussions of delusions fearing they might make the child worse. They demonstrated the belief that the change would be more externally, or situationally brought about.

Model of Care. Aspects of the care provided by these parents have been described, in other studies of family care of chronic illness, as "normalizing" (Knafl & Deatrick, 1986). Psychologically, these parents minimized the significance of the illness for the family's function or self-definition. Behavioral aspects of "normalizing" noted in this group of parents were their attempts to limit their ill member's contact with other mentally ill young people, to keep them out of structured mental health work or day treatment programs and to help the ill member maintain an appearance of normality, therefore avoiding the label of mental illness.

Parents' central motivation for maintaining normality was their belief that it was the best way to keep the ill member at a high level of functioning. They believed that if the ill member were expected to act normally, he would do so to a greater extent. For some parents, efforts at maintaining normality were additionally motivated by fears that illness would reflect negatively on the family and ill individual.

A clear example of psychological "normalizing" was a mother who seemed reluctant to categorize her son's difficulties as illness. She reported that his behaviors were "different" but not problematic unless he was going through a particularly bad spell when he couldn't function. She found that his oddness was no more extreme than what she had observed, and tolerated, in many other family members.

> As far as I'm concerned, a lot of people are different in different ways and they're entitled to be different. Gives variety in our society. Probably contributes a lot of artists and musicians and creative writers. And I think it's really only a problem when somebody can't function, when they're so suspicious, they can't lead a day to day life.

This mother emphasized that individual differences should be respected. Her belief was clearly formed in relation to her family of origin where many "characters" with odd behaviors were accommodated.

> M: I always respect the right for people to be different. My parents were characters. My elderly aunts that I go to visit are characters. In our families people are always entitled to do their own thing, so just because somebody doesn't do the run of the mill thing, we don't pay any attention.
> I: The sense I'm getting from you is that your son's illness is not that big a deal.
> M: Well people being unconventional isn't that big a deal.

This mother minimized the differences between her son's and the rest of the families behaviors, by finding comparable eccentricities in other family members. She additionally found that difficulties introduced by the ill member were similar to those introduced by her other, healthy children. She adopted the stance that if it wasn't one thing to cope with, it was another, and the schizophrenic fit right in with the rest.

Other parents did not minimize the severity of the ill member's symptoms in their discussions with me, but attempted to divert attention away from illness symptoms in their interactions with offspring. Parents tried to avoid stimuli or conversation that might "set off" the ill member's delusional thinking or talk. A father kept the shades drawn on one side of the house so that his son wouldn't see the neighbor lady about whom he had delusional fears. A mother screened her conversation for any references to material that might "probe up" the delusions her son had had during his last psychotic break. She often wondered what was on her son's mind, but felt the potential for damage was too great to risk introducing certain questions into their conversation.

> He doesn't tell me what's on his mind. And I don't ask him because I'm afraid I'll probe up something. For instance, when he had the first really terrible break, there were voices screaming at him in every bush. I don't want to stir up past things.

This mother's concern was echoed by 6 of 8 parents who held this model. They feared that a misstatement on their part could harm the ill member.

> M: It's always like I'm walking a tightrope when we're discussing anything personal about the condition that he's in.
> I: Because you don't want to say the wrong thing.
> M: Right. I don't want to make things worse.

These parents interacted carefully to avoid all references to issues that set the ill member off. It's important to highlight that these issues were idiosyncratic and each family had to develop skill in recognizing and screening the particular precipitant of their ill member's increased symptomatology.

Outside of their own direct interactions with their offspring, parents tried to provide supportive day to day environments, to shield the ill member from noxious environments and to protect him from unnecessary stigma. For example, most (6/8) discouraged day treatment attendance and involvement in special work programs designed for the disabled. Their rationale was that the ill member might be brought down to a lower level of functioning if he identified exclusively with mentally ill peers. Additionally parents feared that the ill member would get the wrong idea, if they encouraged him to attend treatment programs rather than normal productive work or school.

> As long as he can work most of the time, that's what he should do. And we should encourage him to do it.
> One of the people we talked to said we could take him down to Social Security Office but I just don't think he's at that point yet. I wouldn't even introduce the idea to him. It would probably make him more dependent than he needs to be.

These parents felt, often quite appropriately, that the family or the work setting could offer more in terms of training and stimulation of interests than could treatment programs.

> M: If he could only get into some (job) that he really liked and that occupied his mind because he has such a good mind. This would be very therapeutic for him I know. But he hasn't stumbled on anything like that yet.
> I: Do you think he should attend day treatment?
> M: I don't think so. Only if it got to the point where he couldn't work, where he couldn't function in a normal situation. I think functioning in a normal situation is better for him.

In their attempts to help the child avoid stigma, parents worried about disclosures and coached the ill member to restrict disclosure of their diagnosis or experience of symptoms.

> Last week his work called and asked if he could work. And he, much to my horror, told the girl on the phone, "I'm feeling paranoid at the moment".

Many parents repeatedly counseled the ill member to limit their discussion of, for example hallucinations, to the immediate family members or to persons who knew of their disorder.

Half of these parents (4/8) also feared that hospitalization might have negative effects on the ill member.

> I have always felt that if he had to go into the hospital, emotionally it would just be very very difficult for him, or anyone. No one has ever been able to assure even a fifty-fifty chance that there would be any lasting improvement on the basis of (a hospitalization). So putting that together with the fact that it's such an unpleasant experience for anyone whose alert or awake enough to know what's going on. Well naturally I have not wanted him to go in if he could possible stay out of there.

For some of these parents, fear arose because their knowledge of inpatient treatment was limited to images they had acquired from movies such as "Snake Pit" and "One Flew Over the Cuckoo's Nest". They feared their offspring would be treated insensitively and impersonally at best and mistreated at worst. Other parents objected to hospitalization because the ill member's incapacities, rather than their abilities would be so highlighted by the treatment staff.

Parents actual involvement in negotiating healthy environments for the ill member was quite varied. Some took an active role in arranging and altering jobs that the ill member could tolerate week by week. For example, a father "insisted" that his son help him fix dinner each night. He gave the young man specific tasks like cutting the vegetables or making the rice and found that "actually he does quite well". The young man's performance was linked to his father's close supervision, because in his father's absence he ate cheese sandwiches or canned frosting.

Others parents took a more passive role of encouraging the ill member to find work for him or herself. One mother, for example, was very happy when her son took new jobs in his own gardening service. She believed the work bolstered his self esteem as well as providing him with pocket money. However, when he stopped work for particular clients, perhaps because of unfounded fears about them, she never interfered. Although she felt the work was essential to his getting better, she took a laissez faire attitude about how often he actually did it.

In summary, care prescribed by parents who believed in the normalizing model focused on providing structure and stimuli that supported the ill member in functional and "normal" activities. In many cases, the parents expectations of their children were realistic and their choices of "treatment" settings seemed to have positive effects. The severity of illness in this group of ill members was less than in the general sample and therefore the illness realities matched the parents' beliefs that their sons could and should live as normally as possible.

Normalizing Model with Hope of Cure

Two parents held a model of the illness that was predominantly the normalizing model, with one important difference: they believed that the environmental stimuli and support they arranged could affect a biologic cure in their sons. They held that the cells could be rejuvenated, the damage repaired, or the disorganized thinking corrected, if the schizophrenic were exposed to the proper stimuli and support. The two parents, from separate families, who held this view derived their beliefs about the possibility of rejuvenating the brain from their knowledge of special education.

This key distinguishing feature, the hope of a biologic cure was evident in the parent's attempts to help their child get the most out of any situation. These two parents were two of the most active in arranging "therapeutic" situations and expressed a great deal of personal responsibility for working with the ill son or to alter the brain processes and therefore the symptoms. They did not hold the ill member personally responsible for responding to the therapeutic situations (as did parents in the rational control model), and rather demonstrated that they believed that the ill member was more a passive recipient of care. In gross terms, they seemed to believe that the "illness" would respond to their care and eventually the ill person would be more and more like himself prior to the illness.

Model of care. The goal of treatment was to replace the disorganized brain process for a more organized one or to train the healthy aspects of the brain to take over for the ill part. One parent felt that a variety of therapies could help organize the brain processes, but started with music therapy.

> My hypothesis was obviously something is going on in his brain that he can't control and we can't control and that is interfering with his thoughts and causing him to think and see and feel and smell things that aren't there. Why not try to interfere with all those things. Why not substitute something else up there? And I felt that sound, regulated sound like you get in music, not rock music or anything like that; but (classical music).

This mother constructed a number of therapies that she believed could interfere with and restructure her son's brain processes.

> So my goal was to interfere with the hallucinations in every way: that would be gustatory, olfactory, stroking, pet therapy, sensory motor, just every possible way. And, that's essentially what I tried to do.

This mother actively structured the ill member's activities so that these stimuli were a continual part of his day. She arranged visits to the zoo, errands to the store, cooking tasks and household chores and insisted that her son participate.

The other parent expressed a similar hope that his interactions with his son could affect a change or improvement in the young man's functioning because of changes at the cell level. He hoped to retrain well cells to take over for the damaged cells.

> All I can hope is that the brain cells will either heal or that he can divert responsibility of the cells in that area to cells that are working. -I know the thousands and millions of cells in the brain can sometimes take over the part of sick cells. So I keep thinking that maybe I can help him do that.

This father used natural events in his son's life to try to retrain the ill cells. He described his cell-retraining efforts as providing monetary incentives to go to the day treatment program each day, encouraging his son's achievements, listening, and trying train the young man to ration his money so that it lasted the whole month. Besides these efforts, this father advocated a program of care where trained professionals would help in the systematic reassignment of brain functions. He believed the treatment program should be "a surrogate parent" which helps the schizophrenic grow up again. He had identified a program in another state which he believed performed this type of reparenting.

Within this model of care parents believed they could improve the ill member's prognosis, if their efforts to effect brain changes were successful. One parent felt the therapies she had provided had already shown results. She described the changes that she saw in her son's potential.

> If we had left him unattended and he lived, I doubt that he would have lived, he would have retreated into a corner, been hebephrenic, sat and giggled the whole time. Not washed. Eaten very little. And he would have paid attention, 24 hours a day, to these strange sounds and voices.

It's clear, that she believed the treatment improved the schizophrenic's ability to function through changes in his brain.

> The CAT scan we had just a few years ago, the brain looked absolutely normal. Whereas I have an idea if we had taken it (at

> the worst point in the illness), it would not have looked normal. But I have no way to prove that.

Survival by Symptoms Model

The final model of the illness described by parents was one in which the parent focused on the pain that the illness caused the ill member. The illness was viewed as a torment for the ill son. In the survival by symptoms model parents recognized the ill member was afflicted with incredible mental "noise and confusion" which made it difficult for him to operate in the world. Other parents were more attuned to the ill member's incapacitating paranoia or suffering brought on by the recognition of one's illness induced limits. Nine of the 21 parents ascribed to this model of the illness.

The locus of the problem, within this model, was the illness itself, which incapacitated the ill member's mental and emotional functioning. There was no clearly identified locus for change or improvement, and the overall potential for improvement was seen as minimal. Parents seemed to view their role more as one of support and attempted to diminish the ill member's pain or discomfort. They additionally tried to help the ill member shape his behavior to be less symptomatic, but these efforts were always tempered by the parent's concern to not add to the child's apparent distress.

The following quotes are a sampling of the parent's sensitivity to their family member's suffering.

> He is suffering from a brain disorder. He is suffering from these neurotransmitters that are constantly giving him messages.

*****

> I guess his mind is whirling around so, that he can't think.

*****

> Pain was the other thing that I saw in my son constantly. His face was changing. Over these years his face had changed (by) what I called pain.

An important feature of this model was that the ill member's symptoms like hallucinations, delusions or ritualistic behaviors, were viewed as a protection against or coping with the confusion. One mother explained her understanding quite eloquently:

> I realize that...that Mark (fictitious name) can't help it, and his brother just can't get over the idea that Mark can't be taught how to do things right, you know. And I point out to him that, you know, Mark used to do things right; now he can't help it because this is the way he keeps himself going.
>
> It's almost like the Aztecs with their superstition about how they kept the world going by sacrifice; or otherwise the world would come to an end. Well, that's the way Mark is with his (rituals) the way he eats and the way he washes and everything. His mind is in such a turmoil, it just seems to him the only way that he can function.

And in another case the mother interpreted some of her son's actions as protection against the internal confusion. She noted that her son's odd gesturing, and patterns of staring at himself in the mirror were part of his pattern of self protection.

> Each person who has schizophrenia has different patterns to protect themselves and to deal with the confusion in their heads.
>
> And he gestures like this, with his fingers ...always doing this with his hands when he's upset. It's like his messages must become heightened at that point and he's taking the stance of protection for himself. He will go in the bathroom and just stand there and look at himself in the mirror. I think part of that is also the confusion. He's just checking himself out to make sure he's there or something.

Model of Care. Parents who believed that the ill members' symptoms were a protection from or coping with internal confusion took a more laissez faire attitude towards their childrens' behaviors. They attempted to decrease the stress in their ill member's environment, because they feared that stress would exacerbate the internal turmoil. They were less likely to directly interrupt the ill member's rituals, or to confront delusional statements, since all of these were his attempts to maintain or survive. Parent's general treatment recommendations began with adequate medication treatment, to calm the internal noise. Second, parents called for supportive environments to help the ill member deal with the mental confusion. They believed the home should be one of those supportive environments.

> I think they need very strong supportive system, very strong. They're very dependent people. They need a backup system to assure them constantly that they're okay because of that confusion going on all the time.

Specific events demonstrated how parents actions were influenced by their operating model. For example, a schizophrenic son came home and told his parents of an altercation he'd had with a woman on the bus. Mother, noting that her son frequently became paranoid in these situations, cautioned him to remove himself from the trouble.

> I've tried to caution him in the past. If your going to get on a bus and you start to get upset or paranoid about somebody, just get off the bus and take another bus, wait for a while.

Note that she asked him to remove himself from the stressful situation rather than to control his "protective" response. She knew that his posturing had gotten him into trouble with the past and wanted him to avoid the critical eye of other passengers in close proximity.

Another mother consistently delayed intervening with her son's ritualistic behaviors, even though they were disruptive and destructive of her house. His rituals were not easily overlooked. He collected huge amounts of trash that he saved in piles in the yard and in his own room. Additionally, he washed the entire kitchen and dining area before eating with copious amounts of water, and then refused to clean it up. These parents coped primarily by avoidance of conflict. They went out to dinner instead of interfering with the young man's rituals. When they did attempt to counteract the effects of the rituals, by taking a load of trash to the dump, they did so when their son was not at home or not aware of their efforts.

Frustration was clearly evident in these families. Their lives were often turned upside down and their households severely disrupted by the ritualistic or delusional behaviors. These parents did, on occasion, express their anger and frustration directly to the ill member. In retrospect, they chastised themselves for these outbursts, reminding themselves that the ill member couldn't help his or her behavior and should not be punished for expressing the symptoms that help him survive the devastation of the disease.

Parents who held this model experienced (or expressed) greater personal distress about their children's illness. They tried to understand the illness from the perspective of the schizophrenic, and in doing so, suffered greater pain themselves. Because they understood symptoms as protective measures, they exhibited extreme tolerance and sympathy with the behavioral manifestations of the illness. They had exquisite sensitivities to the ill member's own suffering which precluded them from expecting external control (through the situation), or internal control (through cognitive restructuring), of the illness.

Summary

Parents who cared for a schizophrenic member held diverse and unique views of the illness process. Their understandings were shaped by what they had learned about the illness from professionals and through reading as well as through interactions with ill offspring, over time. Most of the parents had read similar books (Torrey, 1983; Walsh, 1985) and many had attended the same instructional sessions through the Alliance for the Mentally Ill. Still their understandings varied remarkably. The diversity of models found in this study may have arisen from the fact that schizophrenia as manifested in their ill members, varied remarkably. Also, parent's backgrounds influenced their interpretations of what they heard and saw in their sons and daughters.

Parents' models of the illness significantly shaped the care they believed was required. A strong belief in the biological basis of all symptoms, led parents to focus primarily on their ill member's diet, chemical intake and medicines and secondarily on his social and emotional needs. In contrast, parents who believed the schizophrenic member could control the illness through rational thought, spent considerable energy trying to convince the ill member to alter his thoughts and actions. Control of the environment was the goal for those parents who believed that schizophrenic symptoms were amenable to environmental cues. Finally, parents who believed schizophrenic symptoms were the ill member's way of surviving mental confusion, were extremely tolerant of rituals and delusions.

Parents' models of the illness varied on several dimensions that centrally influenced the kind of care they provided for the ill member. These dimensions included:

1) The locus of change. Change was seen as needed at the biological, cognitive or environmental level, or in some models, change was not anticipated.

2) The locus of responsibility. Certain parents held themselves responsible for shaping the environment, or for finding therapeutic ways to train or heal the ill member. Others believed the ill member was responsible for changing his own thought patterns and his associated behavior.

3) The potential for improvement. Cure was considered possible within one model of the illness, but most parents thought that only symptomatic management was possible. Those who believed that symptoms were a form of survival looked for no cure or substantial change through their efforts.

These and other dimensions of the illness understanding shaped the care that parents believed their ill family member should receive within the home and the mental health treatment system. Care they provided became coherent only when their model of the illness was understood. Without the knowledge of their particular understandings of the illness, their actions might be interpreted as nonsensical or pathological. Consider for example, the father who pulled the blinds on one side of the house to prevent his son from being upset by a neighbor. Or the parents who tolerate the build up of garbage in the yard. Within their illness understandings, the actions made sense. Viewed from outside these understandings, their actions appear odd.

Good and Good's (1978) suggestion that health care be reconceptualized as a negotiation of illness and care models between practitioner and patient is certainly appropriate for interventions with parents who care for schizophrenic members. Many parents recounted past episodes of where they disregarded professionals advice or left various forms of care, because their models and that of the practitioner were at odds.

There is clear information that parents illness models do change over time, in an apparent attempt to reconcile differences. Couples who initially disagreed on the nature of the illness and shared caregiving responsibilities, gradually accommodated each other's illness beliefs and came to understand the illness in similar ways. Couples recounted the adjustments and arguments they made in finding common or complimentary illness models.

The few couples who continued to hold conflicting models of the illness during the study period, found disagreements about the illness and ways to manage the ill member to be a central source of stress in the home. Family relations and care in these homes were the most dysfunctional that I saw in the entire sample. These couples might benefit from outside intervention to aid them in finding a common model to which they could both ascribe and upon which caregiving activities could be based.

Parents' models of the illness were not always pure. A significant number (10/21) held mixed models of the illness, although a predominant model, which fit within one category presented above was evident for each person. An excellent example of operating within a mixed model, was a mother who fairly consistently followed the normalizing model. Her central concerns were finding "normal" work and social environments in which her son could spend the bulk of his time. She chastised the young man for disclosing his illness too quickly and openly in a variety of settings, evidence that she hoped he would pass as normal at least some of the time. She was extremely reluctant to hospitalize the young man, even during severe psychosis, for fear that he would be negatively influenced by the inpatient psychiatric setting, which she considered to be noxious. At the same time, there were a few coping episodes in which she clearly ascribed to a model of rational control. In these episodes she lectured the ill member about pulling himself up by the bootstraps, straightening out his attitude and getting his life together. These two models which clearly involve conflicting notions about the ill member's ability and responsibility for change were alternately acted upon by the same mother.

In the following chapter, the demands that caregiving places on the families are discussed in detail. This chapter provides a fuller picture of the situation that these parents coped with. Then in chapter six parents' coping with care is discussed. The impact that illness understandings have on parents' caregiving practices is further described in that chapter.

Chapter Five

Caregiving Demands of Schizophrenia

This chapter presents the aspects of caring for a schizophrenic son or daughter, that parents found to be stressful or difficult. Stress, as used in this investigation, is "a disruption of meanings, understanding and smooth functioning so that harm, loss or challenge are experienced, and sorrow, interpretation or new skill acquisition is required" (Benner & Wrubel, In press). This definition of stress allows the investigator to inquire about aspects of the situation that involved personal suffering, altered hopes and changed meanings, aspects that may well be central demands for these parents. It does not preclude the investigation of daily hassles and personal inconveniences introduced by the illness, but requires that that these be considered only if the parent introduces them as a demand.

Aspects of the situation that stressed parents, or disrupted their smooth functioning were elicited in the Stress and Coping Interview. This interview elicited stories of distressing events that arose in the care of the schizophrenic member. Parents were then asked about contextual features, personal expectations, feelings, actions and responses considered. Since it is assumed that stress resided neither in the person, or the situation, but in the transaction between them (Lazarus, 1981; Benner & Wrubel, In Press), these stories provide an excellent vehicle for understanding the aspects of the situation that were salient and gave rise the experience of stress. In other words, the parent introduced the story as an instance of breakdown, or something going awry. In telling the story and answering to probes, the parent demarked situational features that gave rise to this recognition of breakdown.

Coping, within this paradigm, is what one does in response to the breakdown in meanings, understandings or smooth functioning. It encompasses not only direct action to solve the problem, but also the whole array of emotional, cognitive and action responses that the person makes within the situation that gave rise to the breakdown. Coping might take the form of action or purposeful inaction. For example, a mother's efforts to stay silent when her son explodes is coping, as is her husband's effort to set limits on the young man.

Coping has come to connote strategic, goal directed action (Benner & Wrubel, In Press). Some forms of coping are just this, but many forms are not. Humans have many capacities to cope with breakdown in smooth functioning without stepping back from the situation and trying to solve the problem. They shift to another form of action, think about the situation in a new light, or muddle over their feelings about the situation. All of these responses are coping, even though they are not aimed at clarifying or solving a problem.

Parents' coping with the care of an ill member is presented in Chapter 6. Separating the discussion of situational demands, from the discussion of coping was required for adequate presentation of each. Of course they are inextricably linked. My aim in this chapter is to present a rich detailed account of the situation of care as it was described by parents. Hopefully this account will allow the reader to partially enter the parents' worlds and see the dimensions of those worlds that required coping and care.

In this chapter I describe several categories of demands that the parents presented as stressful or difficult in relation to the care of their ill family member. I first describe the demands which were most central to the illness itself, and its effect on the ill member's immediate relationships. These demands included: breakdowns in meanings between parent and child, changes in the schizophrenic's person, illness ambiguity and unpredictability, and regression in the schizophrenic's abilities to care for himself. Next, I discuss the demands that arose for the family as a whole. Disruptions in the parent's or family's patterns of relating as well as their daily routines, and disruptions of more long term rituals, are included here. Finally, difficulties which arose in the relationship between the ill member, the family and the larger community are presented. These included: discrimination and rejection of the schizophrenic in the larger community, the schizophrenic's vulnerability outside the family, and his threats or violence against the community.

This presentation of demands moves from the micro level of immediate relations between parent and ill member, to the level of family relations, and finally to level of family and community relations. Parents were most distressed and most expressive about difficulties at the micro level of the continuum. They were distressed about the changes in their direct relations with the ill member, and with changes in his person. Coping stories about these relationship difficulties far outnumbered those about family or community level difficulties. Certainly this might have been a factor of the interview structure. But as will be illustrated, parents were expressing a core demand of the illness when they discussed the breakdown in the relationship between the child and themselves.

I remind the reader that all the demands presented here are from the parents' points of view. When talking about the demands of the illness on the ill member, parents were reflecting on the stresses that arose for them, when associating closely with the ill member who suffered the disease. Similarly, when demands arose that fit more closely in the parental/ ill member interface, the demands were those felt by the parents. Data were also collected from the schizophrenic members. Demands raised by the ill members were so variable, idiosyncratic and divergent from the parents reports, that a combined account of family and ill member perspectives was not feasible. The schizophrenics' interpretations of their situations will be noted in a separate report.

Demands on Relations Between Parent and Schizophrenic Child

Central Demand: Breakdown of Shared Meanings

A central problem that penetrated all aspects of parents lives was the fact that the ill member failed to share in the family's significant background meanings. The schizophrenic had idiosyncratic, quite irrational and often bizarre beliefs about some aspects of his person or world. Dilemmas that flowed from this core demand were evident in the family's direct relation to the ill member, in their household patterns and in their relations with the larger social world. Every single coping episode related by parents was based, at least in part, on this core demand of persistent and pervasive collision of uncommon worlds.

Strong examples of this breakdown of shared meanings are presented here. Three examples were selected to represent breakdown in the ill member's practice of core family values, and ways of operating in the world. These are obvious examples of breakdown that stood out for the parent who related the story, evidenced by the fact that the parent explicitly discussed how the ill member varied from the family's understandings or practices.

In the first example, the family's moral standing within the community was challenged. The parents learned from their son that he had recently shoplifted several small items, and he thought it was OK because it was "stealing from the rich". Mother in particular was horrified by the deed.

> I: In relation to this shoplifting, what aspect of it is most distressing to you?
> M: Well, that he'd do it at all. It's so foreign to our whole way of looking at things. We just wouldn't think of it.

This mother viewed the family as not only law-abiding but thoughtfully law-abiding. That is, they had discussions about questions of morality and ethics, and confronted these issues together. Mother thought this made her son's actions even more intolerable.

> We think about other people breaking laws and we think about things that we do. This comes up in family situations and we talk about other people and other reasons for doing things.

This mother's basic concern, at the time of the incident was that her son had lost his ability to discriminate right from wrong. Believing this, she had grave concerns about where this might lead her son, as well as her ability to trust him in the future.

> It doesn't seem that he can understand, at this point, because of his illness, the difference between right and wrong, what's ethical and what isn't. And then you think, "Where does <u>that</u> lead to, for heaven's sake." I've said that to him, "A little bit of shoplifting, one minute, can lead to something worse if you don't get a hold of this right now."
>
> The problem is that once somebody has perhaps lied to you, or done something wrong, unfortunately you have an inclination to be

> looking for that again, or possibly misinterpreting something afterwards about it.

This mother doubted her basic relationship with her son because of this incident. In a very real way she saw him as "other", unknowable, perhaps unreachable. The boy's behavior was so far outside of the family's value base (and, she assured me, different from his past behaviors), that her sense of her son was shaken.

The young man's shoplifting caused a breakdown in the mother's trust for her son. She was left in a place of not knowing if and how much she could trust him. The breakdown clearly touched on all aspects of her relationship with her son. It cast into doubt about all that had been "ground" in their prior relationship, because he now seemed to be a different person.

> I: Do you really have a sense that he <u>lost</u> the ability to discriminate right and wrong?
> M: Well, I don't know. I don't know how deep it goes. He's always has been a very concerned person for other people, people who were hurt or ill or whatever. I would hope that he could see, somehow, some dim light of understanding, that it's wrong. If we are able to approach it from the right angle... We try, but, it's all experimental almost. Try to see what, if anything (gets through). And then not knowing whether you've gotten through, is distressing.

It's telling that mother questions how "deep" the lost distinctions between right and wrong go in her son. The young man has already displayed a shocking shift in meanings, which mother attributed to the disorder. Left to discover, were the pervasiveness of his changed meanings and the tenacity with which he held onto and practiced these meanings. This mother felt that the rift between her own and her son's meanings was great, and she had the impression she was moving through a fog in trying to reconnect with him.

The second example of differences in practices induced by the illness, was presented by a mother who found that her son operated in the world much differently than either she or her husband. She attributed the differences to his illness, yet seemed in awe of how different the young man was.

> I feel as though he's deficient in common sense: practical common sense. And I have to repeatedly tell him things in the common sense area. Because my husband is a very practical man and I'm known as being practical where I work; that's one of the strengths I have is that I'm practical. And since he sort of comes from a practical kind of environment, the fact that he sometimes just doesn't show just common sense, ordinary plain common sense (is odd). He does things like eating ice cream five minutes before I'm going to serve dinner, and this goes against common sense.

This mother believed she could affect the differences in her son's practices, by coaching him to behave "practically". Throughout the interviews she remained quite puzzled by his inability to "catch on". Although she maintained a high level of optimism, she made little progress in getting him to demonstrate the practicality that she identified as a strong personal and family trait.

The third example of meaning differences arose in the area of commonly accepted social practices. Father and schizophrenic son were dining at a friend's house. First, the young man ate "voraciously" and then, when all had retired to the living room for an after dinner drink, the young man returned to the kitchen and started going through the woman's cupboards. Father, taking his cue from the hostess, initially laughed off the behavior.

> She's bulletproof; she couldn't be embarrassed, but it was just an imposition, you know.
>
> This sounds terrible. (laughs) It was so outrageous that I really laughed. I mean, it was so ridiculous. Here we were sitting on the sofa having a nice little glass of brandy, the candles were burning, you know, and then crash, bang! It was like some crummy New Yorker cartoon or some Carol Burnett skit. "Just ignore it, it's nothing." (laughs)

The son progressed to the woman's bedroom and began going through her closets. Father asked him to stop and the schizophrenic son insisted on continuing, stating that the hostess "didn't mind at all. People <u>like</u> it", (to have their things inspected). When the young man wouldn't stop, father insisted they go home. This father avoided any further discussion of the young man's behavior, at the time and later, fearing that any confrontation might bring on a "tantrum".

> No, I didn't speak to him. I knew that it was useless. There would be no point in discussing it. It would have caused one of his temper tantrums, I'm sure.

The schizophrenic in this family had a strong behavioral response whenever his idiosyncratic beliefs or actions were questioned. Father was intimidated by the intensity of his son's responses and "avoided them at all cost". This meant that he avoided confronting his son about any delusional material. Father described one of these tantrums as follows.

> D: He occasionally has <u>temper</u> <u>tantrums</u> in which he just becomes... uncontrollable. He's trembling and sweating something awful. Kind of moving around like a boxer sort of. His voice rises and he begins yelling, trembling and moving around the room. It's very irrational talk. And his eyes look very odd indeed; kind of black.
> I: Have you noticed what precipitates these tantrums?
> D: The most frequent thing, I avoid them at all costs, of course (laughs), but what has brought them on the past is any criticism of his activities relating to his letter writing (delusional activity).
>
> Now, you understand, if I say, "Son, you smell bad and you've got to take a bath.", we don't have a temper tantrum. But if I say, "Son, please don't write another letter to this person", that would bring on one of his tantrums, in which he would just go crazy insisting that he has to do it. That aspect of his life, he just won't stand for being crossed.

It's evident that, in this family, the ill member not only lived according to his unique view of reality, or background meanings, but protected himself from arguments about it. It's likely that these tantrums were truly out of his control. They were merely his immediate emotional and physical response to having his views challenged. They caused the father, who was fearful about the effects of the tantrums on the ill member's health, to avoid confrontations.

These examples give an initial sampling of the demands that arose while living closely with a family member who failed to share significant meanings and practices. When the breakdown of shared meanings became apparent, in a variety of situations, parents felt shock, disbelief, distrust, fear. At times they found humor in the situation. Always, they were faced with the dilemma of how to relate to this family member who was somewhat foreign in his basic operating premises.

The situation was similar to living closely with a person from another culture. The culture of the schizophrenic was unknown and had to be discovered in the day to day interactions that arose. Certainly some of the background meanings that formed the basis for the ill member's practices were made explicit. For example, some ill members readily shared their unique beliefs about their hallucinations or their special powers and understandings, with their parents and siblings. But much of what was background for the schizophrenic was not, and could not, be made explicit. Rather, it was discovered when the schizophrenic's practices clashed with or disturbed the parents' own taken for granted meanings.

It's important to emphasize that the ill member wasn't totally "other" or foreign to the family. Instances where the family found no foothold for recognizing commonality or continuity with the ill member, were not represented in this study. I postulate that those families would no longer be intact and would be excluded by the study criteria that called for in-home or at least weekly contact between ill member and family.

Meaning differences are partially captured in the psychiatric definition of a delusion. Delusions are firmly held false beliefs that persist in spite of the facts. Many of the schizophrenic individuals in the study held delusional beliefs. For example, one young man was convinced that he had been Jesus Christ in another lifetime, and that the purpose of his current life was to reveal this to the world. Another young man believed he was regularly visited by aliens from another planet and found evidence in his day to day life of these visits. Many of the schizophrenics, however, operated according to meaning systems that they could not specify and perhaps were unspecifiable. The "oddness" in their practices, readily recognized by the family, hinted that their view of reality was remarkably different from that of other family members. However these differences could not be formalized into a set of "beliefs" false or otherwise.

Central Demand: Changes in the Schizophrenic's Person

Parents saw that the illness robbed their sons of important phases and experiences in life. They grieved over the child's lost potential, internal pain and lack of capacity for satisfaction or joy in life. Some parents believed the illness robbed the child of the possibility of experiences that they felt comprised distinctly human life.

Loss of potential to lead a "normal" life was troublesome for most parents. They were distressed that the schizophrenic seemed to pass over, but not experience the qualities of different phases of life, because they were so engrossed with the illness and its treatment.

> Your heart just goes out to him 'cuz he's missed so much in life. He's never had a teenage life. He's never had a young man life -

> maybe a few moments - but most of it's all been in and out of the hospital, mental problems and troubles. Our one big concern with our son is the fact that he's missed so much of life.

Most parents suffered with the knowledge that their ill son would never experience adult accomplishments of a career, marriage and children. Some held out the hope that if the illness were managed sufficiently in the future, their child might have a reasonable chance of achieving some of these goals but most remained skeptical of this possibility.

Parents who took an "inside" view of the illness, and tried to see the illness from the schizophrenic's perspective, were aware of the ill member's intense pain and isolation. Some parents were denied access to the internal world, because the schizophrenic disclosed so little of what he personally experienced. Other parents were told repeatedly and in fine detail by their children, the terrors and fears that the illness held.

> He has no future. This gets me a little tearful when I think about it in those terms, but he has no goals to look forward to in life. He is very frightened. The main thing is he has no basic future. He's like a lost soul. He has no ability to plan for his life. It's effected his whole being, his whole self image, his whole motivation for living, and he's very frightened.

Additionally, parents who chose to and were allowed an insider's perspective on the illness learned that it was a place of little joy. Clinically, this symptom is described as anhedonia, the inability to experience pleasure. Parents terms are a bit more graphic.

> Unfortunately, schizophrenia means frustration, never any satisfaction of any kind. Torment, you know?
>
> *****
>
> He hasn't learned to laugh, to be happy. We don't think about it, then we realize that, he's not really been what we would call happy. He'll laugh sometimes but it's hard to put your finger on it.
>
> *****
>
> I have seen in his face, pain. Changes I call pain.

Parents felt that schizophrenia had cut their children off, not only from their goals or aspirations, but from human living. They believed that the ill member lived in his own world and could not connect, in a real human way, with persons outside that world. These parents described their children as "playing at" being human.

> It's a tough life. He can't be normal with people, like going up and talking to somebody and socializing, whatever is normal. But, <u>he has his own little life he lives</u> and he wanders around. He's a loner and, I think he's crying out for for something, for companionship especially with his peers his buddies. He doesn't have any.

*****

> He's not able, and never has been, since he was oh, fourteen, to have a total communication between two people as you and I are sitting here talking. I'm listening to what you say, I feel it, I appreciate what you're saying, and then I respond to it. He's not able to do that. Although he tries very hard. It's more of an act with him. It doesn't come from his whole being. He's learned how other people do it and he knows the right words to say but he doesn't really feel it like you or I do. It's very painful for him.

*****

> He's going through the motions of living but he's not really living it. That's the best I can describe it.

These parents saw that the illness cut their children off from normal human relationships. They characterized the ill member as acting human, or going through the motions but not actually living. This distance, which some parents characterized as a perceptual breakdown and others as an emotional breakdown, was thought to be painful for the ill member who recognized his differentness.

Parents themselves were grieved by their childrens' inabilities to connect in a meaningful ways with the family or with others. They believed their children sought companionship, or "buddies" yet lacked the capacity to be friendly with their peers. Parents recognized the pain that the schizophrenic members felt by being cut off from participation in everyday social encounters. They recognized that their children stood, at least partially, outside of shared understandings that comprise human relationships. Lacking this understanding, the ill members, in a very real way, lacked a community. Many parents felt drawn to be that community for their children. They tried to find some ground of common understanding in which they could join with the ill member.

It's clear that parents saw the changes in the ill member's "mind" as central to the changes in his person. In many ways, parents saw that the ill member lived in his "own little world", or in a subjective world. They recognized the schizophrenic's lack of capacity to empathize, to understand the other or the world from a <u>shared</u> perspective. It's striking that the loss of <u>this</u> is what parents defined as the loss, or inability to be human.

Illness Ambiguities

Qualities of the illness that parents found distressing were its ambiguity, and unpredictability, throughout the illness course. Additionally, they were troubled by the apparent "regression" in the ill member's ability to manage his daily life independently, even in basic areas like choosing a diet or selecting clothes that seemed appropriate. Finally, parents worried about the vulnerabilities displayed by the ill member since contracting the illness, and their felt need to protect the ill member, given these vulnerabilities. Each of these illness qualities are detailed in the following discussion.

<u>Ambiguity in the initial definition of illness</u>. The nature of schizophrenia was most ambiguous for parents during the time period before the diagnosis was made, but remained a pressing demand through many years of care. Parents expressed extreme distress and guilt about

their failure, early on, to identify the illness as illness. They feared that they might have spared the schizophrenic some pain if he had received help earlier, and regretted the ways they acted towards the ill member, when they misunderstood symptoms as volitional behavior.

A factor contributing to the ambiguity, was the timing of the illness onset: adolescence. Parents often saw changes in their sons that concerned them, yet were interpreted as adolescent rebellion, testing, or establishing independence.

> You think maybe there's a problem and you think, no that's just somebody growing up, showing that they are different from other people.

Early signs of the illness, in various schizophrenics in the study were not markedly different from changes that might be expected in an adolescent group. Parents noted changes in diet, exercise patterns, performance in school or work, and changes in relationship patterns with the family at large. For example, one young man, took up running long distances prior to his first psychotic break. His dad recalled sadly that the young man was the healthiest he had ever been in his life when he first became psychotic. Several other schizophrenics in the study ascribed to new and often extreme health diets in the year before the illness became more pronounced, causing parents to wonder later, if the diet changes brought on the illness, or if the heightened interest in food was a symptom of the illness.

Changes in relations between ill member and the family were also interpreted as being within the bounds of "normal" adolescent breaking away. One mother told how her family and friends urged just this interpretation when her son failed some courses, had a falling out with roommates and was surly and disagreeable on visits home from college.

> When I said to the kids, "Something is wrong. Something has gone wrong with (son)." (They said) "Aw, mom. He's just doing his thing. Yeah, he's had a little trouble, but don't worry. It's nothing. It's no big deal."

For many of these families (8/14) there was no clear marker when the illness began. These parents recalled a gradual shift from behaviors that seemed quite appropriate, to those that were increasingly odd or bizarre. Somewhere in this process professional help was sought although there was tremendous variation in the timing, nature and source of help sought. Initial diagnosis was a time of relatively greater clarity, which brought relief, but also despair. Most parents wished that the diagnosis had come sooner, and with less struggle.

> If there was enough information out to where somebody when they suspected it, something weird, that they could contact that group, (AMI) without having to go through all the agony that nearly every parent or family member does. It takes so long to find out what it is.
>
> It could have been so different if somebody had enough moxie to just sit me down and say, "I'm pretty sure this is schizophrenia and this is how it's going to react." That didn't happen. And it would have helped if I had a real clear picture of it.

The following father expressed the pain of entering a new and frightening treatment system, a "mental hospital", when he knew little of what was wrong with his son, or what the treatment comprised. In this case the boy's violence forced the parents to rely upon formal systems of care even when the diagnosis had not been established.

> The first time we took him in I was scared to death because I didn't know what was happening. And then you take him in the hospital - a mental hospital. You don't know what they're going to do to him. I guess it's the only time I've ever cried in my life. And I cried that night because they had him in a gurney and he was crying, "Dad, don't let them take me, dad." Boy, it's tough. And he's only fourteen, fifteen then, see. Just a kid. And that's hard to take. It's hard to take. But it was all part of the sickness, you know. Although I didn't have a name for it at the time. We had no idea.
>
> We went a long time before we really found out, really, what it was, schizophrenia. And even then, I didn't know what

> schizophrenia was. (laughs) Even today we're struggling with exactly what it is.

To summarize, the ambiguity during the early phases of the disease was created by its slow, rather insidious onset, (in many cases), and by the fact that many early symptoms were not dissimilar to adolescent and early adult developmental tasks, such as questioning authority, and challenging family rules. Parents felt that little help was available in learning that the child's behavior <u>was</u> a disease, and what that disease comprised. Even after diagnosis, parents suggested that it took them a long time, often years, to learn some of the nuances of the how the disease manifested itself in their son. Although parents recognized that their responses were slowed because of the ill defined nature of the problem, they expressed regret at not seeing the problem, and getting care for the ill member, sooner.

<u>Ambiguity during course of illness</u>. Discriminating actions that reflected the disease, or reflected the ill member's personality posed a considerable dilemma for parents. The dilemma was one of learning the boundaries of the symptomatology in the ill son. Questions indicative of this dilemma were: Why does he act this way, and can we expect it to change? Is his irritability schizophrenia or is he manipulating us? Should we be more strict in this situation or should we be understanding? This questioning of illness boundaries is clear in the following statement.

> He has this bad habit, where he goes through this excessive clearing of his throat, and spitting in the bathroom. The medications do make his mouth dry, and certainly this is a problem, <u>though I don't know if it's all that</u>. He has this excessive way that he does everything. Every time he wants to deal with a problem it has to be dealt with all the way, many times over. (Dad's very annoyed while relating this.) No matter what the problem is. So you don't know how to sort these things out. Does

> he really need to do all of that? Or is it just another one of his obsessions that he's got to be perfect?

Threaded through this father's statement was his suspicion that the young man could stop the obsessive behaviors. This father was frustrated because of the behaviors <u>and</u> the ambiguity of the illness boundaries. The situation was one of questionable interpretations and uncertain action. There was no clear guidance on how to understand, or respond to young man's excessiveness.

This questioning of illness boundaries was a consistent theme in families, even though many of them had cared for the ill member for years. The fact that schizophrenia has such a varied clinical presentation, may have contributed to this confusion. Clinically, schizophrenia is comprised of both "positive" and "negative" symptoms (Andreason, 1985). Positive symptoms, which include hallucinations and delusions, were generally accepted by families as "true" illness. This was not always the case as the father in the above statement demonstrated. Negative symptoms are more frequently questioned as being true illness, or a sign of the ill member's own will. Symptoms such as anhedonia, apathy, social isolation and poor functioning in any productive role are negative symptoms. It's not hard to see why parents questioned the latter group of symptoms as real since they closely match what is considered laziness or lack of drive in our culture. Negative symptoms were particularly hard to understand in a physically healthy young person.

> It would be one thing if he were a paraplegic or an aged person who had to stay in bed, okay then you accept it. But he's a young man and that's not the normal habitat for somebody who is otherwise normally very lively.

Questioning illness boundaries was actually a questioning the ill member's agency. Human agency is defined by Taylor (1985) as follows.

> "To be a full human agent, to be a person or a self in the ordinary meaning, is to exist in a space defined by distinctions of worth. A self is a being for whom certain questions of categoric value have arisen, and received at least partial answers. Perhaps these have been given authoritatively by the culture more than they have been elaborated in the deliberation of the person concerned, but they are *his* in the sense that they are incorporated into his self-understanding, in some degree" (1985, p 104).

Parents believed the schizophrenic had, through the illness, lost "distinctions of worth". The child's actions were seen as illness, rather than personally derived.

> M: It's so hard to know, because I think his personality is different at different times because of his illness. It's just hard to say about our son.
> I: His illness sort of overrides so strongly that it's hard to know what his basic personality is anymore?
> M: Yeah. Like right now, He is stable and he's very sweet and he's very clean.
>
> *****
>
> You know, it's hard to remember, sometimes, that it's not *him* that's doing something; it's his illness. And try to be objective about it. It's kind of hard. Because, he can be very hard to live with.

Parents separated the person that was illness and the person that was "real".

> The experience of taking care of my sick son at home (sigh). It's traumatic. It's draining. Sometimes it's exhausting. It's depressing, and if I didn't see the real (name), sensitive, wonderful sense of humor, if I didn't see that part of him every day, I don't think I could do it.

The ambiguity of the boundary, between person and illness, created many dilemmas in care. Some parents largely resolved the ambiguity by interpreting practically all behavior as illness behavior. These parents seldom raised the boundary issue as a dilemma, because they drew the boundary of the illness broadly, to include almost all of the ill member's behavior. Even these parents, however, set limits on what they would and would not accept. For example, in a family where the ill member's rituals totally disrupted the household, and parents had given up on influencing a change, mother insisted that the young man treat her with respect. In other words, she held her son accountable for his behavior in his relationship with her. All parents held the ill member to be a partially responsible human agent, capable of making distinctions of worth and acting upon them. Deciding when and where to hold them accountable, was the dilemma for many parents.

Unpredictability

Another illness aspect that parents found distressing was its unpredictability. Although schizophrenia is a relapsing disorder, and clinicians attempt to find patterns to individuals' periods of psychosis and periods free from psychosis, there is little predictability about these disease fluctuations. Parents found the uneven and unknowable cycle of relative wellness and illness disruptive.

> It's better now living with him than it has been, in that the medication has more or less stabilized and he's comfortable with it and he takes it most of the time. I'm dealing with him more realistically than I used to when I anticipated that he was always somehow going to come out of it. I'm better today dealing with it on that level. Although sometimes these unexpected turns (psychoses) will still jolt me. As prepared as I may be for them, I'm not. They'll always throw me off. I deal with a low grade depression all the time.

Parents found that even in periods of relative calm, they were reluctant to plan ahead, because they never knew when the ill member might decompensate. With many ill members, factors had been identified that put him at risk for increased symptoms. Anniversaries of distressing events, telephone calls from divorced parents, certain holidays like Christmas, were anticipated by parents as high risk times. What was more distressing were those periods of decompensation that could not be predicted.

> Yesterday was particularly difficult with him. And, you never know whether the next day is going to be worse or better. Whether you're going to be able to do something that you want to do or not.
>
> For example, go on a vacation. Sometimes we start out on our vacation and we wind up not going where we wanted to go and turn around and come home. We can't plan ahead, you know, like get accommodations ahead of time, because we don't know whether we're going to make it to where we want to go.

The unpredictability in the disease was evident in day to day encounters, as well as over the longer course of the disease. Some parents noticed that their ill member fluctuated day by day while others had to give up the notion of a good or bad day, for moment by moment evaluations.

> We go by days, really. (laughs) In fact, sometimes you go by hours, because he does change, his nervousness changes rapidly.
>
> *****
>
> His emotions are very erratic, very erratic. You never know. They can change. He can be very gentle at one moment and he can get very psychotic the next moment. He can suddenly look at his father and start yelling at him because he doesn't like the way he's eating. Or start telling me he's a homosexual or picking his nose, or he calls me a dyke, all these wonderful things.

This unpredictability in the ill member required that the parents remain continually on their guard. They observed the child closely for signs of increasing distress, in an attempt to ward off larger problems. Parents felt they could help manage the situation if they could catch the early signs of trouble, identify possible precipitants and remove the ill member from the stressor.

> You always know the sickness is there and, these dark moods can come up, the unstabilized condition. The potential's always there to come up again. So you're aware of it. But we're more comfortable with it now than we used to be.
>
> We are aware of of <u>him</u> more than we are of the other kids. With them, you can relax and not worry about them. With our son, it's always in the back of your mind.

Illness Related "Regression"

Complexes of symptoms were interpreted by parents to be emotional and behavioral regression in the ill member. Inability to complete age appropriate skills, and loss of former capacities to accomplish even basic daily care, (in some schizophrenics), brought parents to interpret the illness as regression.

> (He looks) young. I feel that I'm dealing with a thirty year old five year old all the time.

The abilities of schizophrenic members to manage their own lives varied across cases, and within the same case across time. At least half the schizophrenics were unable to manage in each of the following areas throughout the study: grooming, dressing appropriately, maintaining a adequate diet, maintaining regular sleep patterns, managing their own money and maintaining even part time work. These areas are discussed in greater detail below.

A central relational strain set up by the ill member's incapacities was the need to negotiate dependence/independence between parent and child. The age of the schizophrenic members, mid-twenties to mid-thirties, meant that these families were struggling with relational issues that were appropriate to an earlier family phase. Normatively, families face negotiation of independence when children are adolescents and young adults. The timing of this strain added to the parents' distress.

> Mary Ellen Walsh (1986) says it's vicious because it comes to you at the time when you expect your son and daughter to go out in the world and make it on their own. Or even if they're living at home, they're doing their thing. And that's when suddenly everything reverts right back again.

*****

> We had anticipated once the kids graduated they would be off on their own. It would be nice to see them quite often but not necessarily to have them under foot. Now we're much more

> concerned, that our son stay with us where we can keep an eye on him as long as his condition is not stable.

For one mother, the ill member's dependence was so burdensome that she compared one period, when her son was acutely ill, to the care of an infant.

> It was like I had more babies at home. -And that was one of my goals, to get him where he wasn't totally dependent on us; particularly on me. For a while there, I thought I was going to crack up because he was with me 24 hours a day and I had absolutely no relief at all. No matter what I tried, it didn't work.

Few parents seemed to be as burdened as was this mother. However, all parents felt the illness represented an extremely bad turn of events for themselves and their schizophrenic offspring. Some specific difficulties raised by the regression, dependency or symptoms of the ill member are discussed next.

Sleep/Wake Cycle Disruptions. Parents were distressed by the disruptions in the ill member's sleep wake cycles because they disrupted the sleep of other family members, made it difficult to monitor the ill member and made it hard for him to participate in "normal" daily life. Eleven of the 14 schizophrenics in the study had sleep cycle disturbances that were of concern to parents. Most demonstrated the pattern of staying up late at night and sleeping in in the morning, and gradually exaggerating this pattern. One schizophrenic merely slept excessively.

The sleep/wake cycle disturbances were found by parents to be immutable. They could influence improvement around the edges of the schedule, but significant shifts toward normal patterns were not achieved. Parents' feelings of distress regarding sleep is evident in the following statements.

> In order to have any kind of normal existence, you have to meet the day and the hours and the people when they are doing all the things that are being done. And very little is being done in the other hours. So, if he's going to have any kind of reasonable coping, he's got to be there when life is going on.
>
> *****
>
> That was very disturbing because he wasn't making anything of him self and if we could get him up, our back would be turned and he would go back. It seemed to be evidence that he didn't have much control over himself and couldn't do much for himself.

Varying concerns raised by the altered sleep patterns were evident in these statements. The first father wanted his son to have the opportunity to live somewhat normally and believed that sleeping days and staying awake nights prevented this. In the second instance, another father was more concerned that the ill son take control of his life and not give into the lethargy induced by the disease. Both parents believed the ill member should actively try to change this symptom and tried various means to persuade him to do so. The sets of parents who persisted in this approach held models of the illness that were classified as Rational Control or Normalizing. (See Chapter 5 p. 83, p. 86) Alternatively, parents who held the Symptoms as Suffering model of schizophrenia (p. 99) were more accepting of the sleep disturbance as inevitable and immutable. Rather than try to change the pattern, they worked around it.

Grooming and Dressing. The schizophrenic member's unusual dress or unconcern for physical appearance and cleanliness was of concern for parents in 8 of the 14 families. Parents were often disbelieving of their children's lack of attention to these basic issues.

> The funniest things happen that the disease causes. Like he was running around in in pants that were the size he wore before he put on all the weight. These pants didn't fit and they tended to go below the belly and look sloppy. And you could see the top end of his tail. And I mentioned it to him a couple of times but I noticed that he didn't really give a damn, or didn't know how to

> fix it. It's the most extraordinary thing that something like that isn't noticed.

Parents feared the schizophrenic might be ridiculed or rejected by others because of their unconventional dress or lack of cleanliness. They also feared personal embarrassment because of their son's appearance.

> It was embarrassing in that you immediately think, if he's going to be around our friends, he's at least got to look a little bit better. There's no excuse for looking like that, sick or not.

Most parents managed to negotiate a mutually acceptable, if not ideal solution to cleanliness. They also were moderately successful in influencing the ill member to wear clean, stylish clothes. There remained a great degree of latitude on the parents part for the ill members' preferences for extra coats, double pairs of pants or outfits that reflected their grandiose or unusual self concepts.

The clothes issue raised quite poignantly the issues of dependence and independence. Parents were often torn between wanting their child avoid public attention and embarrassment and wanting the child to determine their own style. The schizophrenic's response also strongly influenced the parent's willingness to intervene. For example, in the following instance a father avoided any discussion, except to praise his son when he was well groomed.

> We leave it alone because we know it doesn't do any good to offer comments on his dress. He's very touchy about it. He gets defensive. I guess I would too, if somebody criticized the way I dress: that's the way I want to be. --But you don't see young guys running around dressed the way he is.
>
> If I try to explain to him, "People will laugh at you because of the way you're dressed," I get negative results. I kind of leave that alone.

Another mother solved the dilemma by listening closely to her son's preferences for bright, even gaudy clothes. She then purchased many brightly colored shirts at the second hand store and asked him to select the ones he wanted from the batch. She was careful to let him know that while he was the first to choose, his brothers would also be offered the shirts. She sensitively responded to this young man's need for independence, by making it clear that she was treating him no differently than any of the other children.

Maintaining Adequate Diet. In only one case was the ill member's current dietary habits of extreme concern. This young man had bizarre delusions about his food and the rituals that he felt were necessary for eating. These patterns were extremely disruptive to the household and are therefore discussed in greater detail in another section.

Seven additional schizophrenics had eating habits about which parents expressed concern. Parents sighted overeating (2), lack of interest in food (2), odd and non-nutritious diets (1) and rituals at mealtimes that disrupted the family meal (2) as problems in this area.

Managing Money Independently. Money management was an area that forced parents to face directly the dependency issues with their ill children. If the ill member received Social Security Insurance, (SSI), for long term disability, as 9 of the 14 did, they had a monthly income that was fairly substantial. If the parents were not the payee, then the ill member had control over the disbursement of funds. If, however, the parent were the payee, and received the check in the ill member's name, then that parent made primary decisions about how the money should be spent.

Dilemmas that arose in relation to money centered on how much independence to allow the ill member in the use of funds. Parents found that the ill member's judgement was sorely lacking, as he spent excessive amounts in the first week after the check arrived and was without funds for the remainder of the month. In some families the schizophrenic was vulnerable to being robbed, or swindled, and parents were reluctant to give him access to large amounts at one time.

The schizophrenic members demanded independence from parental oversight in money matters, more so than in any other area. They pleaded, cajoled or demanded control of their money. If they received the check directly, they passively resisted any interference by parents on how to spend the money. Not infrequently, during the same month, parents whose advise regarding expenditures was ignored, were turned to for financial assistance.

Summary

Schizophrenia in an adult child placed significant demands on the parents who remained involved in the care of that child. Meaning differences evident in the ill member's practices or statements had to be grasped and negotiated, in order for parent and child to maintain some level of relationship. Meaning differences arose in the ill member's definition of himself or his capacities, in the view of the world and in how he believed he should behave vis-a-vis the family or larger society.

Illness symptoms additionally forced some parents to question the ill member's capacity to participate in real human encounters. Parents grieved over the fact that their child appeared to be cut off from human joy and interpersonal connection.

Illness ambiguities distressed parents particularly at the early stages of the illness. They worried, retrospectively, that diagnosis and treatment were delayed by their early lack of understanding.

Ambiguity of the illness continued a dilemma, because parents were unsure of where the illness left off and their child began. Personal responsibility for actions was questioned in many encounters, which set up situations where there was no clear course of action. Similarly, the unpredictability of the illness kept parents on their guards, since they never knew when the ill member might shift from reality based, to idiosyncratic behavior. Finally, the ill member's inability to manage his own care, in some very basic aspects of living like dressing and eating, led parents into the dilemma of providing for an adult child's needs, while respecting his need for independence and self determination.

Disruptions in Family Patterns and Relations

In contrast to the preceeding demands that centered on the immediate relationship between the ill member and one or another family member, disruptions in family level patterns and interactions are discussed here. Interpersonal difficulties raised by living with or caring closely for the ill member are discussed first. These included conflicts between parents about how to manage care, direct verbal attacks on one or all family members by the ill individual, disrupted holiday and other special family events and strains on relations between the ill member and siblings. Disruptions in household patterns are reported on next.

There were fewer coping episodes and general demands reported that involved family level problems, as opposed to dyadic problems with the ill member. Interviewing individuals separately may have led to an over emphasis of personal dilemmas and demands and a glossing over of family level demands. Although the interview format distinctly addressed both individual and family difficulties, often the parent chose to respond only to the former. The coping episodes presented in the interviews paralleled the dilemmas that I saw during my observations with the families. Minimizing or underspecifying of family problems were not evident when the two forms of data were compared.

Interpersonal Family Disruptions

Family conflicts. Direct family conflicts over how to manage the care of the ill member were limited to three families. In all cases, the conflicts arose because parents interpreted the illness differently and modeled their care according to these different, and conflicting interpretations. In two of the families, conflicts occurred repeatedly, around many aspects of care. In the last family, conflicts arose only in relation to managing the ill member's tardiness. This is not to say that most parents didn't disagree occasionally about how to manage a particular event. The disagreements were resolved peacefully in most families and, more importantly, were not raised as coping episodes by the couple. Also, it should be noted that in almost half the families, (6/14), care was managed by a single parent, who had primary decision making power.

One family's coping episode, reported by both mother and father in separate interviews is used to exemplify these conflicts about care. The event was triggered by the ill member's use of street drugs. When under the influence of marijuana he was verbally abusive to his parents.

> He'll come back having had a couple of puffs on a joint of marijuana and he starts to freak out here. He'll get hostile with us, his usual symptoms of being schizophrenic. He gets mad at us. He can't stand high volumes on the t.v. or the radio. He accuses us of being satanic. He'll start using obscenities toward either one of us. Motherfucker, or whatever enters his mind.

The mother in this family did not tolerate her son's abusiveness and began to shout back at him, telling him to stop and to go to his room. Mother's anger made the young man more excited and even more verbally abusive. Father, believing that the young man needed additional medications and time alone, attempted to separate his wife and son, but with difficulty because the son was drawn to the fight "like a magnet". Father was primarily distressed by his wife's response.

> Sometimes it's very hard because my wife will lose her coolness. And she feels very righteous about being angry at him when he gets hostile with her because she doesn't see him as being sick. At that moment she just sees him as being her son shouting at her and being hostile. She gets hostile with him.

Father, in contrast, saw the son's abusiveness as an exaggeration of the illness. He believed the young man could "get a hold of" his hostility, if he were given a little time and comfort.

> I try to get him to go downstairs for a while. She has to have time because she has all this energy and she needs time to settle herself down. -If I'm very calm and repeat over and over something soothing (to the son), after a little bit he'll get hold of himself.

Later, the parents argued about whether they had handled the incident appropriately. Mother agreed with her husband, to a degree, that shouting didn't help the matter, but she continued to believe that the young man's "manipulativeness" should be stopped. Father, on the other hand, was more concerned that the young man have someone in alliance with him at all times.

> D: And she would ask me why I wouldn't be stronger. And I said I can be strong too but I don't want you to be tough on him and me to be tough on him at the same time. I don't think that would be good.
> I: But that made her mad sometimes.
> D: Sometimes, but she would see what I'm talking about.

Parents were acutely aware of times when their conflicts in care were approaching. At times they "gave in" to the wishes of the other parent, at others they demanded that their approach be followed, and the third outcome was a "blow up" in which the parents actively fought about their choices in the midst of the incident. These parents may well have fought over other incidents if they had not fought over the care of the ill member. The point of here is that the ill member's care served as a focal point for the fights in many instances in these three families, adding to the family strain.

Verbal Attacks on Family. Not infrequently, the schizophrenics' feelings of paranoia or anger were directed at family members themselves. These verbal attacks, which often came on unexpectedly and with no clear precipitant, posed dilemmas for parents who were trying to provide supportive care. They attempted to dismiss the outbursts as actions of the disease, not the ill member, but found it hard to overlook the hurts inflicted by the comments.

> For me it's impossible not to take a lot of this stuff personally. But that would be my advice (to other parents), don't take it personally. Because they're really not attacking you; they're just attacking. Because of their illness, they're just frustrated and they're out of control and they're not responsible.

Consistently, parents were more understanding and tolerant of the outburst when it were directed at themselves, rather than at a spouse or another sibling. They became angry, and intervened swiftly in defense of the other family member. For this reason, single parents were at greater risk. Not only were they the central focus of the attack, they had no one close at hand to either stand up for them, or to reassure them that the attack wasn't personal.

> I know, one time, I really reacted very (strongly), was when he cussed his mother out. I always figure, "You don't talk to your mother like that. I just don't like it. And she doesn't deserve it. You ought to know what a wonderful person she is." And I know how much she loves him and how much it hurts her when he does that to her.

The strains on families in which this pattern of verbal attack was fairly persistent (8/14), were substantial. Any meal, evening at home or family outing could be instantly turned sour by the ill member's statements. Even if he desisted quickly, the tension rose and parents were on their guard for further outbursts. Some parents admitted they <u>never</u> let down their guard, and were always on the alert for topics they should avoid for fear of setting the ill member off.

> Sometimes, no matter how you respond, it's the wrong way. If I were to agree with him, then he would say that I was patronizing him. And if I would disagree with him, then that would upset him even more. And so I might nod my head you know, just to acknowledge that I'm there.
>
> *****
>
> I think I can relate to the other children easier than I can with my son. I don't have to be on my guard. I don't want to upset him, and I don't want <u>him</u> to become upset or unhappy. I feel like he's got enough and so I try to keep things with no controversy. And so I think I'm more guarded.

Continually monitoring one's responses became the rule of the day for many of these families. There were periods of respite for some families, because the ill member attacked only when he became more psychotic. These parents were forewarned of times that they should be more careful in their approach. Also, some ill members gave nonverbal indicators, in their posture and facial expressions, that they were in the mood for an argument. Some parents became quite skilled at tracking these early warning signals, and attempted to ward off the attacks using greater care with or distance from the ill member.

<u>Disrupted Family Events and Holidays</u>.

> All our holidays are ruined. If my son comes, it's so uncomfortable. He's miserable, and always the bad times for him are on birthdays. I <u>dread</u> birthdays and special occasions now, instead of looking forward to them. I <u>dread</u> them.

Holidays and special family occasions, such as birthdays were extremely stressful times for some schizophrenics in the study. They manifested their difficulties by becoming more aggressive with the family, by withdrawing from contact, or in the case represented above, by the becoming self-destructive. Half the families complained that family events had become difficult to plan and carry off, because of the schizophrenic's apparent pain.

Several factors added to the complexity of this situation. Parents had conflicted feelings about depriving the other children, and themselves of family times, in order to diminish the stress for the ill member. Particularly in the instance of annual holidays, parents deliberated over how to plan the celebration in such a way that the ill member was neither excluded or put on the spot. Children's birthdays were tricky because the ill member might feel jealous of the honored guest, and cause a disruption.

Beyond the immediate family, there was the problem of whom to invite and not invite into the home. Work associates may have known the situation in the home, yet never have met the ill member or seen his or her unusual social appearance or behavior. Additionally, parents may have restricted the family's socializing to groups that were well acquainted with the ill member's condition.

To summarize, the mother's statement above represents the negative extreme of parents' reactions to holidays and family events. All parents felt that the illness placed restrictions on their celebrating, made planning difficult, and had at least one disastrous event in their history of care of the disease, that they wished to avoid in future celebrations.

Disrupted Sibling Relations. All but two of the schizophrenics in this study had one or more siblings. In half these families, siblings maintained congenial and supportive relations with the ill member. Parents in these families reported that the schizophrenic was more open with siblings than with the parents, willing to try "frightening" things, when encouraged or accompanied by siblings, and relied on them for emotional support.

At the same time, there was a recognition on the part of parents that their other children were short changed because of the illness. One mother recognized that she never made it to her daughters' houses on the holidays, for fear of traveling too far from her ill son, in case he needed assistance. Other parents saw that throughout the early phases of the illness, most of their attention and concern had to be focused on the schizophrenic member, to the detriment of the other children.

Conflicted or strained relations were evident in the other half of the families where the schizophrenic had siblings. These siblings expressed resentment towards the ill member's special needs that had deprived them of their parent's positive attention for years. They also found the ill member difficult to relate to, embarrassing them and limiting their social options in the home. The most offensive symptom to the siblings was the ill member's "self-centeredness". Additionally, they objected to the ill member's disrespect for their parents. In three of these families, sibling and schizophrenic relations were extremely conflicted or completely severed. Two brothers maintained substantial distance from their ill brothers, and fought verbally and physically with them when contact was made. In a third instance, a woman cut off contact with her brother completely, and asked her parents to not disclose her address or phone number to the brother.

Disrupted Household Patterns

This demand arose in only three families, but was such a severe disruption that it bears discussion. The dilemma was introduced by a schizophrenic who practiced rituals that seriously impacted on the family's shared living space. These rituals were practiced daily, were time consuming and largely uninterpretable. Attempts by parents to diminish the rituals resulted in intense resistance by the ill member. Consequently, parents learned to live around them.

In one family, the ill member's practices involved both cleansing and eating rituals. This case is discussed in some detail in the following, to demonstrate the severity of the disruptions to the household.

> M: He will wait until everybody's gone to bed before he'll go in the bathroom. He can't eat until he's gone in there and gone through all this purification and what not. He comes out and it takes him hours to eat. So that's a good share of what he does all day is get ready to eat, and eat.
>
> There was one case in that book by Mary Ellen Walsh, that was a lot like my son. The one that washes himself all the time and uses all the paper towels. For instance, in one day, he will use at least one roll of paper towels and almost a whole package of toilet paper. Because he uses that in the bathroom, I think he wets it down and goes over everything and cleans up the bathroom (with alcohol) every time he goes in.
>
> -The whole scene of the way he eats, (makes me angry,) because it's so disruptive to the whole household and it's not good for him, either.

This mother had attempted to intervene, fearing for her son's health, but had met with strong resistance and over the years and had never influenced him to change.

> I tell him, "That's too much at one sitting." And remind him how big his stomach is and that the doctor warned him.
> He says, "That doctor's a big liar. That's not what was wrong at all." He says, "It was my blind gut.", whatever that is.

> And I said, "Son, all those tests." And he starts shouting at me before I can even get that out of my mouth. He doesn't listen to what I'm saying and he just sets up a continual barrage of, "Leave me alone! Leave me alone!", you know, in a loud voice, so he can't hear what I'm saying. I just give up.
>
> One way we know he's going to eat is he lines up some cans on the table: usually a can of peas, a can of corn, a small can of tuna fish or maybe two, and a can of pineapple, usually a small can. If he stopped there, it wouldn't be so bad but he eats also one raw potato, maybe one apple, and a green pepper and any other fruit we've got around.
>
> He washes all the tin cans. And when he's washing them, then he washes his hands and he washes his hands all the way up to his elbows and the water runs off his elbows on to the floor. He washes a lot more than he used to because he gets his clothes wet at the same time. He wets his shirt and his pants and everything.

The young man's daily practices of washing have caused mildew in the kitchen, as well as rot in the floorboards and cabinets. In addition, he denied the family access to the kitchen and dining room during his rituals. If his parents came near, he began screaming at them to get out. To avoid this aversive interaction, they often left the house for dinner.

> Sometimes we just leave the house. I might have plans for supper, have things all made up in my head, of what I'm going to do about supper and then I see my son getting ready to eat about three o'clock in the afternoon. I know there's no way we're going to eat here... (laughs) because he'll be busy for several hours. And, so we just go out and eat. Or if I can get as far as the stove, at least, we'll have soup and eat in front of the TV.

The ill member's rituals in this family, and the other two families, were often bizarre and illogical. At times, as in the example above, they represented risks to the ill members' health. The ritualistic practices persistently disrupted the families' abilities to use the public space for day to day household activities and parents' protests, arguments and threats aimed at reestablishing shared household space went unheeded.

Summary

Living with and caring for a schizophrenic family member introduced many demands that required family negotiation or pattern adjustment. Care decisions that were shared by parents who held incompatible guidelines for care introduced the repetitive potential for conflict. The ill member himself introduced considerable family strain by being verbally abusive, self destructive, or generally hard to be around. Day to day family patterns as well as more long term family holiday rituals were altered to accommodate the ill members' needs or tolerances.

Demands in Community Relations

Families named three central demands that arose regarding the ill member's relations to the community at large: the potential for discrimination and rejection, fears about the ill member's vulnerability outside of the immediate family and fears that he might harm himself or another in the community. Episodes that parents related which evidenced these fears ran the gamut from events that were simply embarrassing to those that involved physical violence.

All three demands were different aspects of the same dilemma. Persons with schizophrenia, operating according to their own meaning systems and concerns, did not always observe social norms and practices. Parents, living in close proximity to the ill member, saw the disjunctures in their child's relations in various groups and settings. The general dilemma for parents was to close the juncture, if possible, or diminish the discomfort or vulnerability for the ill member, the family, and those outside the family who were involved.

Discrimination and Rejection

Parents recognized that mental illness remained a stigmatizing condition in their current worlds. They saw the reactions of fear, embarrassment and distrust in encounters with extended family, some friends and co-workers.

> You can just tell, the way people react sometimes, when your son has a mental illness, that it's back to the dark ages type of attitude, you know. Why? I guess they're afraid of it. I think anybody's afraid of something they don't understand.
>
> *****
>
> The family didn't know what to do and they were embarrassed by the way he looked. I was too.

Parents questioned, and sometimes knew of ways in which the ill member, or family was discriminated against because of the illness. Parents wondered about both their own jobs as well as the ill member's efforts to maintain work.

> As far as promotions within the company, that I'll never know. I don't know what's running through the other guy's mind. I doubt it (but) I sometimes think about it. Maybe somebody back there says, "Well, we better leave him alone. He's got this son that's crazy."

Parents were distressed by how much and how the ill member disclosed the condition. They often served as mediators between the ill member and the community trying to influence the the schizophrenic to behave and appear more normal, so that negative attention was diminished. Their efforts often went unheeded, which was some evidence that the ill member was less affected by the attention he aroused than the parents anticipated.

> We felt that he was talking to everybody, not so much about the fact that he had mental illness but about his voices. And we suggested that he maybe could be a little tactful. We were encouraging him not to be quite so open. In fact he was even doing that to strangers on the bus and also in work situations. --Certainly in a new work situation one should be a little bit tactful instead of getting the reputation of being the wierdo right off the bat.

Parents were concerned that their children not be seen as different or odd. They feared that friends and co-workers might distance themselves from the ill member, who would be left without companions. Often this concern was based upon past experiences.

> This thing I think we find most disturbing, he's had various friends (who) probably reacted to his bizarreness and decided, I gather, to drop him.

In addition to coaxing the ill member to shape his behavior, parents took on the responsibility of mediating the relations between the ill member and family friends. Different approaches were employed in avoiding uncomfortable incidents. Some warned friends and family, in advance of gatherings, of the ill member's condition so that inappropriate behavior might be overlooked by the 'informed' guests. Another tactic was to limit social contacts between the ill member and persons outside of the family, at least in the context of family entertaining.

Vulnerability

Every parent in this study feared that the schizophrenic was vulnerable and needed some protection in the commerce of daily life. They saw the ill member as vulnerable because of repeated incidents of loss or robbery of valuable clothes, bicycles, guitars, stereo equipment and so on. They additionally witnessed the ill member forming relationships with street people whom parents feared were on the make, or that they might taken in by trendy religious movements. Parents were particularly concerned because their child seldom learned from his mistakes. That is, after losing a valuable possession, he took no greater care in protecting what remained. In trying to protect their sons from being taken advantage of, parents again faced the dilemma of monitoring and/or setting limits on an adult child. They were forced to grapple with the fact that their son was both independent, yet vulnerable. They often coped by watching nervously as he carried on relatively independently.

> I still feel that he is susceptible. He could get swallowed up by one of these cult groups if we don't watch carefully.
>
> *****
>
> The times when he's downtown. We don't know where he is. We could do nothing but wring our hands and see him go and worry while he was gone.
>
> Here is this grown up person with a mind of a little child. Cannot fend for himself. Will he live through the night again, or won't he? Do you know what kind of a drain this is to have to go through this?

The mediator role, between ill member and community was thought to be an essential family task. Without exception, parents named care of the schizophrenic member after their deaths as the number one concern for the future. They did not believe that public systems of care could take up where the parents left off and wondered who might take on the responsibility. Some siblings of the schizophrenics were pressed into the future planning, but often this was an unsolved, and worrisome dilemma.

Threats or Violence Against the Community

Threats or actual incidents of violence always arose out of the schizophrenic's paranoia about, and therefore vulnerability to the community. At the same time, these acts posed real dangers for the safety of the family or others. Lack of community response, from either the police or the mental health system, prior to an actual incident or a directly stated threat of violence, frustrated and frightened parents. They found the provisions of the law for detaining the mentally ill to be excessively restrictive, in that they could not get professional help at times that they felt very threatened themselves, or were frightened for the safety of others.

Five of the schizophrenic sons posed some level of physical threat to the family and community. Two had tried to take the life of another person, during a past, untreated psychosis. The other cases involved incidents of verbal threats that were never acted upon, or minor striking out at the family. Even in the instances where physical violence had never been acted upon, parents were on their guard against personal injury.

Parents' consistent hope, or "prayer" was that the ill member would obtain help through his threats of violence, and before anyone was physically hurt. Parents found themselves in the odd position of demonstrating care by calling on the authorities to take action against their sons. The interpretation of the action as care was not shared by the schizophrenic, who often railed against the parent for turning on him. In the following instance, a father talks about his response to an incident in which he had to call the police to intervene because his son was physically threatening his wife.

> So I had to handle the situation. Immediately I called the police. I saw no other way to do it other than just go there myself and wait for the police and take them in. You know, somebody has to let them in the house. Although the other alternative was just to stay away from the house and call them and just tell them to start banging on the doors. I felt that I was less of a threat to my son than it would be just the officers coming in. --
>
> It's a very unpleasant situation to have them come and they haul him off in the police car and they act as a taxi service. And the neighbors are all used to it. -- When finally they put the cuffs on him, which is assault-based standard operating procedure, that's kind of traumatic, too. To watch your son being led off in handcuffs. Your stomach is in in tension all the time; very nervous, It's just an unpleasant situation.

Considerable strain was reported by parents because they formed the first line of defense against the ill son acting out. They were frequently in the position of monitoring the young man's deterioration, and watching for the time when it was appropriate to call upon the authorities. They were personally vulnerable, because if they called the authorities too quickly, and the ill member was not at that time detained, there was the threat that he might turn his anger on the family. Also, parents feared that their son might be held for the shortest amount of time, 72 hours, and then be released by an unskilled clinician who could be "conned" by the ill member. Again, if the ill member were released to the community before he were adequately treated, parents were at personal risk for having turned him over to the authorities.

Exemplary incidents of threats experienced by parents, follow.

a) A young man had an obsession with knives. He owned several and insisted on wearing a large one in a holder on his belt. His parents lived in fear that he would be harmed when he pulled the knife and threatened someone who could harm him. On more than one occasion, the young man did pull out the knife in situations where a security guard may have jumped him, or even shot at him, for threatening a shopkeeper or clerk.

b) A father received a telephone call from his son who was upset because he had been contacted by the mental health authorities. The young man threatened to come and beat his father with a metal pipe, if he had called the authorities, or did so in the future.

c) The parents of a young man who had previously struck a roommate over the head, and injured him to an extent requiring hospitalization, watched their son diligently for any signs of decompensation. Although they realized that he had been psychotically afraid during the first incident, and that he was now well controlled on his current medications, they monitored for any sign of a downhill slide.

The violence potential in the ill member was quite unpredictable. In an overwhelming number of incidents raised by parents, the son made verbal threats but was talked out of it, or lost interest in the action. A dilemma introduced by this unpredictability was the parents' feelings of responsibility if the ill members' signals were misread. They felt responsible for providing the first line of defense, even though they were operating in a huge sea of unknowns.

Summary

This chapter has been a presentation of the dilemmas and problems that were noted by parents who lived with or provided substantial care for a chronically ill schizophrenic son. Most distressing to parents were the changes in the young person himself, because of the illness, and the resulting changes in the immediate relations between the ill member and the parent. Parents grieved over their son's loss of potential, loss of ability to relate directly and humanly to others, and their idiosyncratic, or subjective experience of the world. Although they did not call it such, parents recognized the breakdown in meanings between themselves and their adult child, and related numerous incidents where this breakdown of meanings brought disruptions in the life of the ill member and therefore for the family.

Parents were often confused by the boundaries of the illness in their son's life. The ambiguity of schizophrenic symptoms, in both their positive and negative forms, raised questions for parents of where the illness left off and the person began. The illness was so pervasive and powerful in the child's life that parents questioned whether personal agency were even possible. They feared that the illness had destroyed or distorted many of the distinctions that had previously guided the ill member's action. Some parents actually believed that the illness destroyed the child's capacity to live a fully human life.

Regression of the ill member's ability to care for himself was also noted by families to be quite distressing. At an age when many parents had looked forward to be being free of childrearing responsibilities, they were again called upon to provide for many of the basic human needs that the ill member could not organize himself to provide.

Family level disruptions were reported less often than those that related more directly to the ill member and dyadic relations. Significant family level disruptions included family conflicts, verbal attacks on various family members by the schizophrenic and disruptions in day to day household patterns as well as more long term family rituals.

Finally, parents felt the demands of trying to mediate between the ill member and the community beyond the immediate family. These demands were focused in three areas, the potential for discrimination against the ill member and family, the ill member's vulnerability, and the threat that the ill member might pose to the community when he himself felt threatened.

Chapter Six

Coping With Caregiving

Introduction

In the two preceding chapters I discussed the parents' personal understandings of the illness, and the demands that they experienced in situations of care. These two chapters answered the question: Coping with what? In this chapter I present interpretations that answer the question: What does coping look like? I propose that parents' interpersonal concerns substantially shape what coping looks like in these families. Therefore, varieties of interpersonal concerns are presented first, and the patterns of care that flow from those concerns are then described.

Parent's illness understandings are both shaped by and shape interpersonal concerns. For example, the mother who believes that the illness is biologically driven, has a different capacity to be involved directly and uninhibitedly in the child's care than does the mother who feels at least partially responsible for the illness course. Conversely, the mother who is directly and uninhibitedly involved in care, has a different possibilities for gaining new insights into the nature and course of the disease, than does a mother who remains distant, or uninvolved in direct care. The ways in which illness understandings, threaded through interpersonal concerns, influence care, are also presented in this chapter.

Four forms of interpersonal concerns are presented. These are: engaged care; self-care in tension with the care of the other; concern as specialized management; and care from a distance. Each of these instantiate different ways of being involved in the caregiving situation and relationship. I will attempt to describe the qualities of each form of of concern, as well as give numerous exemplars of what the particular form of concern "looks like". Similarly, the care and coping which flow from each particular form of involvement is discussed through a thematic discussion of the parents' coping episodes and through presentation of exemplars.

The four forms of interpersonal concerns discussed here represent the predominant forms evident in the 21 parental caregivers studied. In the interest of depth, the breadth of the concerns and caregiving practices evident in these families is not covered. The purpose of the chapter is to demonstrate how interpersonal concerns shape caregiving practices. The four predominant modes of concern are used to demonstrate this relationship. The discussion of interpersonal concerns evident in parental caregivers is preceeded by a general discussion of how care and coping are conceptualized in this project.

Care and Coping

This discussion of caregiving must begin with a discussion of care. Care, or what matters to people is the basis of coping, because only things that matter to people call up coping. Care establishes those things that are significant in one's life. When significant things, events or persons are threatened, or lost, one is stressed. Without significance, there can be no stress, for the experience of harm, loss, threat and challenge are grounded in significance. It follows that coping too, rests the significations that care sets up. Without stress, or threat to significant things people or events, there is no need for coping (Benner & Wrubel, In press).

The goal of a phenomenological account of stress and coping is "to provide an adequate account of human possibility and experience while providing an account that enhances the possibilities for caring for others and for feeling cared for" (Benner & Wrubel, In press). Parental coping with the care of schizophrenic offspring is presented in this chapter. It is my interpretive account of the possibility and experience of parents who actively cared for their ill sons or daughters. If this project succeeds, it will bear witness to the care these parents gave, and open up, for other parents possibilities for how care might be worked out.

The possibilities for care are not equivalent in all cases. First, because the demands are not equivalent in all cases. Situational demands vary with the child's illness severity, response to medications, symptom complex and functional abilities. These variations cannot be entirely denied or willed away, if the parent stays in the situation of care. They must be dealt with in some manner.

Second, and more importantly, parents' personal background experiences and meanings set up certain possibilities for the kinds of care they can give, and preclude other kinds of care. Their history with the illness, history with the child and, their personal life history all set up a particular set of distinctions from which they see what is needed in the situation and respond. Their engagement in the situation is set up by these distinctions of worth.

Parents' background meanings, history, illness understandings and concerns comprise their 'world' (Dreyfus, 1983, 1986). Parents' coping is set up by this world and can only be made intelligible when aspects of this world are at least partially understood. This is no small task.

Although parents live in worlds, and derive their possibilities from their worlds, it's an active, involved process. They cannot describe their worlds, because, for the most part they are transparent. On way to begin to understand the possibilities and constraints experienced by these parental caregivers is to ask about real life events that solicit their care. The events they name as problematic or stressful evidence their significant concerns. Learning the coping strategies they employ opens up the possibility for understanding the meanings and concerns that guide that care.

The stance taken in this research is that there is no omniscient or omni-competent coping stance. Particular patterns of concern open up certain possibilities for coping and close down other options. Since concerns are a part of the world in which one is raised, and are not freely chosen, the possibilities for coping that arise from those concerns are not without limits. An additional stance taken here is that of situated freedom. Worlds are never completely closed and deterministic. They are not limited to single possibilities but neither are they completely and equally open to all possibilities.

In this chapter, involvement in the situation of care is discussed most centrally in terms of particular background meanings called interpersonal concerns. Parents are involved in the situation of care through their concerns. Concerns are the qualitatively unique ways that these parents existentially (rather than spatially), live in relation to their ill child. Concern is a transactional term that draws on Heidegger's notion of being-in-the-world (Dreyfus, 1983, 1986). It describes the way in which humans inhabit their relations with other human beings, because people <u>matter</u> to them (or because they <u>care</u> about them). These parents inhabit, or dwell in the relationship with their child in ways that define and constitute them.

Wrubel (1985) demonstrated that interpersonal concerns dramatically constituted the individual's coping capacities and limits with regard to day to day problems of living.[2] In this chapter, I demonstrate that personal concerns dramatically shaped the kinds of care that parents even considered to be possible in the in caring for a member with schizophrenia.

Interpersonal Concern: Engaged Care

Wrubel defined engaged care as the form of concern where "there is an inward pull to respond to (other's) needs when they are troubled or in trouble. Likewise, the giver is open to and feels other's support when he needs it" (1985, p.174). Wrubel noted that in this form of concern there is not a sense of a personal loss in the giving and therefore, the reciprocity of relations are not viewed as balance of giving and receiving. Rather, there is a sense of being personally drawn to the care of others and the response to that pull is fulfilling in itself. Care for the other is evident in both difficult and positive events, so the "stories" told by parents involved in caregiving in this way reflected these positive and negative forms of involvement.

Involvement in the form of engaged care is well expressed, in personal terms by the following mother, M4, who is presented as a paradigm case of engaged care.

> I think (caregiving) is like motherhood you know? You just do these things without even thinking about them. I always have watched my children. And I think I know them quite well, even though sometimes they think I don't. (laughs) I think it's because we have been so interested in the kids. They've been the most important things in our life. And anything else really was secondary.

> I have loved being a a mother and a homemaker. And I've always felt good about that. Because I felt that's a very honorable job and that it's a a difficult job and it's a full-time job; and it was for me. And I wouldn't want it any other way.

It's evident in this mother's statement that she feels drawn to the care that she provides for her son. Caring for her son, now in his 30's is an extension of motherhood. It an inward pull rather than an external demand to provide him support and protection. M4 also expresses her satisfaction with the way she lives out her care. She feels it's honorable, difficult and _for her_; she feels called to this kind of involvement with her son and satisfied with living out the call.

Another mother actually described caregiving using the term 'calling'.

> I just love him so much that I want him to have the best life that he can have. If he can't get encouragement and patience and understanding from _me_, who else is he going to get it from? It's what I'm _called_ to do right now.

In the current culture, which idealizes self-reliance and self-determination, one might be tempted to suspect these mothers' motives or to dismiss their statements as too good to be true. An exemplar of the working out of this interpersonal concern can begin to dispel this suspicion.

M4's son, who has been ill for at least 15 years, has a penchant for knives. He collects them, often carries them in plain sight on his person and uses them threateningly when he becomes paranoid. In a particular instance, the young man had become, over several weeks, increasingly nervous and paranoid. M4 admitted that she and her husband locked their bedroom door for the first time in their married life because they feared his unpredictability. One night, M4 heard a loud noise, investigated and saw her husband and son in a physical struggle.

She called the police, and she and her husband (who were alone in the house with the young man), locked themselves in their bedroom. When the police arrived, the son ran out the back door and was not discovered. M4 and her husband spent the remainder of the night at a relative's house and returned in the morning to find that their son had returned and torn his room apart. Pictures were thrown on the floor, clothes strewn about and he had run a knife all the way through his door.

> You can see daylight through the cut. We tried to decide if we should replace the door, but decided to leave it up, as a sort of reminder to him that he has to maintain some control or this is what can happen.

M4 was primarily concerned that her son get care before he hurt someone. To this end, she and her husband went to search for him, not to pick him up, as they truly feared for their own safety, but to locate him for the police before he caused any problems. In this and several other coping episodes M4's hope was that the boy would be detained on a legal hold before he harmed someone. In every instance over the years, her hope had been realized.

M4 was additionally worried about removing the traces of her son's destructiveness before he returned and had to face the damage he had done.

> (I coped by) just putting the room back in order and getting the things so that when he did come back, it would be a livable room again and he wouldn't even have to look at what he had done. I think that was part of my motive of getting it cleaned up so that he wouldn't be embarrassed about it.

There was no question that M4's primary concern was for her son's welfare. She was confident that she could provide for her son's welfare, despite any adversity, because she had years of successful experience. Her confidence was also bolstered by her faith, which she believed would see her through any difficulty that might arise because of the schizophrenia.

> I also feel that whatever happens, it's going to be okay...because the Lord is going to see us through. Every time that our son has been taken to the hospital, the prayer has been answered that no one is really hurt. He is able to go into the hospital and get help without anyone being injured.

This mother had no allusions that her caregiving task would change or even diminish before she died. This realization was presented in terms acceptance rather than loss. M4 clearly accepted her task, hoped for the best, but accepted the worst. For example, at the time of the study, the ill son was living in board and care. He still visited home several times a week or even daily. He had a room of his own, which his parents left undisturbed, because they felt he needed a place of sanctuary. Both parents felt tremendous relief at this living arrangement because it diminished the impact of the son's unpredictable behavior on their daily lives. Still, M4 expected that her son would inevitably return.

> He'll get tired of this and that (at board and care) and be out on the street. And if he doesn't have anyplace to go, I'm not going to tell him he can't come home, so he'll be back here.
> I: How is that for you, to think that this is the way things will be?
> M: I just expect it. If it doesn't work out that way, and he stays in the extended care home, I'll be grateful. But if it does turn out that way and he comes home, I'll just say, well that's what I expected.

Engaged care, implies that both positive and negative experiences arise in the involvement with the ill person (Wrubel, 1985). M4 presented almost equal numbers of situations that were difficult, and situations that elicited positive emotions. Despite her son's very difficult and sometimes threatening symptoms, she found times of enjoyment with him. For example, she recalled a simple event when she and her son were able to chat easily with one another about the past; M4 clearly held this experience very dear, because it was so seldom possible.

> Often, when my son is in the car, he feels comfortable in talking. And he will open up. The other day I told him that we drove by our old house and that it looked really nice. He started talking about when he was little, remembering how he was able to close off the hall and make it real dark, and he and the other children would play in that dark hall. How much fun they had. I had forgotten all about it. So that was fun, when we were reminiscing that.
>
> I think it pleased him that he had brought up a subject that I had completely forgotten about. And then we were able to discuss it. Because there's so many times that there's nothing that we can talk about. You know, there are just times when everything just seems dry, that there's nothing to talk about.

M4's form of care for her son allowed her derive pleasure from his pleasure. Her realization that the illness often made easy shared communication impossible, made her remember this period shared ease as special, something that she can reminisce about with the interviewer.

To summarize, engaged care was a form of involvement where parents responded to the claim that the situation made on them in a way that was self defining. They actively sought to be what their son needed in each particular instance of care. These parents were not selfless, but found a way to be involved in the care of the child that constituted them, enriched them, that they accepted and at times savored. None of these parents diminished the problems that the disease had brought to their child or themselves. Many cautioned that I not misunderstand their current acceptance and ease with care as an ideal state. The ideal, having their child free of schizophrenia, was held out as the contrast with their current situation. Acceptance to them did not mean that they were satisfied or happy with their son's fate. Rather, they found possibility in their own particular child, and their own particular situation.

These parents exhibited a level of acceptance with the situation as it stood. They found possibilities for living within the bounds and limits placed on their lives and relationships with their schizophrenic child.

> I've missed a lot with him that I would like to have had with a son. But you learn to realize that he's sick and you live within the parameters of the sickness.

Acceptance, in these parents meant coming to terms with the illness over time. They did not achieve a "state" of acceptance that was fixed once and for all. Rather, they engaged in the continual process of <u>accepting</u> what the disease turned out to be. What was fixed, was their engagement in the process.

These parents can thus be characterized as having a deeper grasp of the illness as they lived with it over time. They learned the parameters within which they could move. In the following example, M4 described how she reads her son's capacity to interact each day. She knows that there are times that he can, and cannot tolerate conversation. She has learned to read the cues to his mood and ability, but characterizes herself as "still learning".

> M: I can tell by the expression on his face, most of the time, how he's feeling. I can tell by even his body language, what how he's feeling. If I can see that he is more relaxed, then I might say, "Have you had your medication?". Or if I see that he's kind if uptight, I won't ask it.
> I: Did it take you a long while to learn all those cues?
> M: Yeah, it did. Probably I'm still learning.

It's clear in this mother's statement that her acceptance is not a state, but commitment to staying engaged with her son. In what follows, care practices of parents involved by engaged care are outlined. In this discussion and the sections that follow, care practices are presented, as responses to the six categorical demands outlined in the last chapter: meaning differences introduced by the illness, ambiguity, unpredictability, regression of the ill member's capabilities, family conflicts and problems, and problems with the family's relationship to the larger community.

Engaged Care Practices

All of the parents who demonstrated the form of interpersonal concern called engaged care, understood the illness as survival through symptoms. The care they practiced was informed by their attempts to enter the child's world of meaning. Grasp of, or respect for the child's idiosyncratic beliefs allowed these parents to understand, tolerate, and appreciate broader ranges of behavior in the ill child. On the whole, ambiguities in the child's interactions and behaviors were interpreted as illness related, and therefore the child was not held responsible for injury or harm. These actions were interpreted as unintended or out of his control. Illness related regressions were managed supportively although relatively few expectations for improvement or change were evident in the parents actions. These parents had difficulty setting limits on the ill child and therefore suffered greater disruption in their households and personal lives, than did other parents in the study. Finally, the ill members' relations with the community at large were monitored, buffered and negotiated by the parents. Specific care examples that demonstrate these general caregiving stances are presented here.

Coping with Meaning Breakdowns. These parents placed considerable value on understanding the ill member's thoughts and rationale for action. They sought out ways to learn what was on the ill member's mind, and what he was worried about.

> I poured a concrete wall for a walkway in the yard. He comes down and sits and talks to me. It's good (to be) in an association like

> that that we can talk and relate a little bit, and that always helps. Then whenever I can, I ask his opinion on things. I like to have him come to me and have him try to help me. Otherwise I'm shutting him out. To me, it would be devastating to shut him out. He gets enough of that all day long people shutting him out. He's difficult to talk to.

Note the tone of responsiveness in this father, to any opportunity that opens up to connect with his son. He recalled and was pleased about an incident when he was working in the yard, and his son came out to chat. He asked the young man's advice and relished the opportunity to be "in association" or connected with his son. There is not a hint of falseness or condescension in this father's story. Rather he appeared to grab a hold of, perhaps cherish, the opportunity that arose. He recognizes that he would be personally <u>devastated</u> if he closed the young man out, in these instances of meeting. What a powerful statement of personal engagement this is.

Other parents sought ways to access the child's world, and to engage them as much as possible in the real world. One mother purposefully searched the television channels for programs on animals, knowing that her son loved these programs and that they could watch and discuss them together. Other parents watched carefully for signs that the ill member was in an emotional state to interact, and then proceeded. In all these cases, parents felt hurt by the rejection that the ill member experienced in public settings, and tried to diminish the the child's experience of being closed out, within the family.

In the following, a father described his increasing skill in listening with a third ear, waiting for his son to tell the real problem, and "going softly". The episode began when the ill member became angry and "dark" about the people from a town nearby his home. This father was concerned to learn why the son was angry, so that he could ward off any negative actions that might get his son in trouble in that community.

> I: So is that why you pursue it, because you think it might help him solve the problem?
> F: Yeah. To help him solve his own problem and also educate me on what his problem is. I would like to find out. Because I'm curious when he says things, I like to know why he feels that way.
>
> I ask him "Why?", and I try to keep him talking and sometimes, I'll sympathize with him but I don't want (laughs) (to do that too much.) I've told him a million times you know that people are the same everywhere. "Why do they react the way they react?". I try to get him to try to think it out.
>
> Sometimes that gets him defensive if I keep coming on, "Why? Why do they do this? Why do they laugh at you?" But it worked fairly well, this time. I just kind of took it very softly and didn't push too hard. And pretty soon it came out that these kids were making fun of him and that sort of thing. I'm sure it's either the way he dressed or acted that they did this.
> I: Where did you learn that?
> D: To go softly? Just from past experience I guess. Back in the beginning, I used to come on pretty strong, I suppose. More direct approach (had) very negative results.

This father had several agendas in the conversation. First to learn what was making his son feel "dark" about the community. Second, to help his son think it through, and see how his own behavior contributed to the interactions he had with others. Third, to challenge the young man's negativity about the incident in hopes of warding off full blown paranoia about the community in which it occurred. Father also described how he had to adapt his approach to be able to talk reasonably with his son.

Other parents expressed similar interest in learning and understanding the ill member's day by day problems and worries, so that they could prevent the ill member undue stress.

> I: Why is it important that you do what you call "snooping"? What makes that important?
> M: Because if too many things build up on him it becomes a burden to him. I think that's what set him off when he got so sick, was he had the burden of the bills that he couldn't pay and stuff. You know, if those things are taken care of as they come up, there's not going to be any problem. But all of a sudden, if they're all

> built on top of him, then he starts to thinking about the problems and can't handle it. So that's why I want to stay with it, you know.

This mother felt guilty, because she felt she had to notice things that her son left out on his desk, and attend to messages that he received at the house, in order to stay "with it" and be able to prompt him when the appointments or requirements arose.

Finally, parents tuned in to the ill member's idiosyncratic meanings as a way of staying connected to him. Although they did not want to validate delusional beliefs, they did want to track them and respond to them.

> I: I've wondered what's going through your head and what you're trying to do when he's talking rapidly about things I can't make sense of, you know? Do you try and follow what he's saying most of the time? And make sense of it?
> M: Yeah, I do. Um hmm. Sometimes I can. Sometimes I can't. But sometimes, he's referring to something that I can relate to. But sometimes he's just talking about something that's in his head.
> I: So when it's something that you can relate to, you'll try and respond to him and pick on up and engage him in a conversation?
> M: Um hmm. - I guess I've been around him so much (laughs) that I can sort of sense it when something's wrong or something is important.

This mother demonstrated exquisite skill in selectively attending to the young man's nonstop chatter. To an outsider, very few of his statements made any sense. But mother, who had cared for the young man at home for years, knew the consistent themes in his ramblings, and knew, by his tone of voice, or manner of speaking when there was a new thread, or greater level of anxiety to attend to. She would then stop what she was doing and speak with him directly, ask him if he were fearful, or clarify what he was talking about.

In summary, these parents regarded listening and understanding the ill member's inner world to be central to their task of staying connected to the ill member, as well as an important way that they negotiated the differences between the ill member and the larger world. At times they would try to alter the ill member's perceptions, and at other times the listening was merely monitoring. Parents seldom knew how the ill member responded to this intervention, but the schizophrenic members expressed great satisfaction (in their private interviews) when the parent heard them out.

One son, whose mother heard him out, and whose father did not, illustrates how different it felt to him, to relate to a mother who was engaged in care, and to a father whose care was taken on amidst conflicting concerns. In the following, the schizophrenic member discusses his experience and feelings in discussing his delusions with each parent.

> P: I've talked to my mom a lot about it and my dad a little bit about it. My dad's not very receptive about talking about it. --
> I: How is that for you?
> P: Well, my mom's a very loving, caring and understanding person and I get along with her very well. And my dad and I get along as long as we don't talk about my beliefs. He's very touchy about the subject for some reason. I don't know why, but he is.
> I: So you just don't bring it up with him and he doesn't bring it up with you?
> P: Uh... usually, yeah. I have hope that he'll come to believe and I'll say something and he'll usually put it down, whatever it is.
> I: Do you talk about it with your mom?
> P: Yes.
> I: Uh huh. And what kinds of conversations do you have?
> P: Well, I share with her the spiritual experiences that I've had that I've told you about earlier. And, I tell her.... She responds with understanding. I tell her where I'm at in, uh..., in everything. She asks questions and I give the best answer I can.
> I: How is that for you to talk that stuff over with your mom?
> P: Well, I think it's pretty healthy to talk about it.

It's important to understand that the young man's beliefs were delusionally religious. He believed he had religious powers and special understandings. The difference in his relations with his father and mother, based upon their response and openness to his delusional beliefs is palpable. He feels closed off from his dad, in regard to his beliefs, even though his religious beliefs guided much of how this young man structured his day to day decisions. In contrast, he felt that his mother heard him out, and therefore, he disclosed his thoughts to her, about everything. Her willingness to hear him out about his odd beliefs formed the basis of a different level of disclosure and connection.

Coping with Illness Ambiguity. In contrast to parents whose involvement in care was shaped by different concerns, parents who demonstrated engaged care interpreted ambiguous patterns of the schizophrenic's behavior as reflecting the illness. The ill member was blameless in his transgression of publicly acceptable behavior, family norms or habits. Therefore there was a high level of acceptance of these transgressions. These parents suffered public embarrassment and personal discomfort because of the ill members' actions, but were not troubled by the additional discomfort of wondering if the ill member acted with the intent of embarrassing or hurting them.

> One time, I really reacted very (strongly), not violently when he cussed his mother out. "Don't don't talk to your mother like that you know. I just don't like it." And we both know now that this is his sickness that is doing this. It sure wasn't really him. It's the way the thing affects him.
>
> *****
>
> He sat there and he'd bounce. Now that used to bug me. I'd say, "Son, you're bouncing." Then he would stop. It was embarrassing to him. And he would stop it, for maybe a second, and the next thing I knew, he was bouncing again. He just couldn't help it. Finally, we just let him bounce. We were educated to let him bounce away. That this is part of the sickness.
>
> *****
>
> Sometimes it's hard to remember that it's not him that's doing something, it's his illness. And try to be objective about it. It's kind of hard because... he can be very hard.

It's clear, particularly in the last statement, that these parents occasionally slipped into doubt about the ill member's responsibility. Consistently these parents assured themselves (sometimes after the heat of the moment had passed), and the interviewer, that they could not blame the ill member for his symptoms.

Coping with Illness Regression. In general, parents who were involved in care in an engaged way, found possibilities within the situation for managing the problems introduced by the illness. Their general coping stance was one of finding a way to make things work. It's striking that many of these parents explicitly described their background understanding as: one can find good in any situation. Remarkably difficult situations were named for their "positive" results. For example, one couple, in retrospect, believed that the trial and hospitalization that resulted from their son's physical assault on a roommate was a "blessing in disguise" because he was placed on a medication regime and was required to have long term care. (They hastened to add that victim was not seriously injured.) Another mother found a degree of comfort in the fact that the ill member's siblings grew up learning that they weren't "the center of the universe". Several mothers recounted positive changes in themselves and in their relations with their husbands because of the illness difficulties. These women found that they had become more forceful, self-assured, and certain of their positions because they had to be in representing the interests of the child.

> It was really hard for me to express myself to my husband. He's a very strong, powerful man, and I always would look to him for the answers. And this illness has brought me out a whole bunch because I was very introverted. And I could hardly stand up to what my husband's decisions were. Now I can say, "I don't think that's a good decision. Let's do it some other way."

Later this mother clearly stated that her love for her son and concern that she give him something better, allowed her to state a conflicting opinion. Other women expressed similar personal changes in which they felt the demands of the situation simply required them to be different, to change in a way that had formerly been frightening. One mother recalled that her metamorphosis was so complete, that even the IRS, from whom she had always felt a great threat, didn't scare her. She would even stand up to them.

Some parents also noted positive changes in the family because of illness demands. The positives were viewed as a good outcome to a horrible situation.

> It's been devastating, on the whole family. It's a terrible thing; I wouldn't want anybody to have to go through with an illness like that... if there was any way to avoid it.
> But it's done some wonderful things in our lives, too.
>
> It's brought out a love that maybe just would have been more buried. We've become a more giving, loving family, who's not afraid to show it, and a more caring family, rather than our son going off in his own direction, living his life on his own and my husband and I going our separate ways, and that could have happened. I can see that we were headed in that direction.

Central demands that arose for families because of the ill member's inability to manage age-appropriate tasks centered on issues of dependence/independence and distance/closeness between parent and child. Both the practical and emotional aspects of these issues faced parents. This group of parents demonstrated finely tuned capacities to negotiate distance/closeness and dependence/independence in ways that respected an adult child's capacities. A drawback to this stance was that these parents had few expectations for the ill member to change, and therefore structured fewer opportunities to help the child become more functional.

In the following statement, one mother described her philosophy for managing social distance or closeness with her son. She spoke as if she were coaching other parents.

> You're the well person and you're the one that has the strength of both mental health and physical health so it is up to the family to

> help the sick one and try to relieve as much pressure as possible from that sick one.
>
> To, include them in all the activities, but not be upset if they don't want to accept it. This is something that we had to learn. We would always invite our son to do things but sometimes he would and sometimes he wouldn't. And, at the most critical times, when you think that you want him the most, that's when he doesn't want to go. So accept that. And say, "Okay, he's not well. It's as if he had an upset stomach.", you know. "He can't do it because he's sick to his stomach."

This mother and family accepted the ill member's variable tolerance for participation or nonparticipation. They invited him to numerous and frequent family gatherings, accepted his refusal of an invitation, and tolerated without comment his coming and going from the room where the activities were centered. The parents maintained a room for their son, (although he did not live at home) where he could make a hasty retreat if the social stress were too great. There, he he could listen to his own music, or merely close the door on the activity and noise.

Regulation of distance and closeness required effort. Arranging social situations in a way that allowed the ill member to engage at the level he could tolerate at the moment took forethought, and a sympathetic, understanding stance during the event. Some parents tried to prevent problems by only inviting friends who understood the illness demands. Others invited groups of people broadly, but warned them in advance of the ill member's needs. Parents also planned different kinds of gatherings, around the holidays for example, where just immediate family would be present, or family and close friends, or large gatherings. They then allowed the ill member to attend only those events that he could tolerate.

Parents who were involved in care in this engaged way also demonstrated great flexibility in arranging the distance between the ill member and themselves that matched the parent's tolerance. The best example was a couple who insisted that their son live outside of the home, yet allowed him to visit as often as he wished. Their care for their son allowed them to claim, honestly, that they could not tolerate his unpredictability in their moment to moment lives. They recognized that he needed a place that he could be unpredictable, and found a community residential service to meet this need. Tones of guilt or self-reproach for this living arrangement were simply not present in the parents' interviews. They were satisfied that it was the best for both the family and the ill member because they had the capacity to provide the young man with strong emotional support, while the board and care operator provided the tangible support of meals and a place to sleep.

Negotiating care in a way that respected the independence of a 25 to 35 year old adult, and at the same time responded to the ill member's vulnerability also required skill. These parents admitted they made mistakes, but their care for their child called on them grapple with the issue, rather than overlook it. The following incident highlights humorously, the struggle.

> It's hard for me to go down to his little apartment and see that it needs vacuuming; that the bed should be changed; and it's hard not to do it. I could do it so easily and get it done in a half hour. Last night I went in to return something and there's three sacks of garbage sitting there. (laughs) Today's garbage day. I thought, I should put that garbage out. I took one bag out; I didn't take all three. (laughs) But I thought I should take them all. Then I thought, I shouldn't take any; I'll take one. (laughs)
>
> But it's hard not do that kind of stuff. But what I keep telling myself and my husband too: that's his apartment; if he wants to live with it.... that's his choice.

This mother resisted the temptation to leap in and take over for the child. Distancing from her son was not an option. This mother's stance, which is characteristic of the engaged parents, is one of moving in, and then stepping back, in response to the ill member's fluctuating capabilities. The metaphor of a dance, between parent and child fits here. The adult child was given the lead. His intimations of personal capacity and independence were closely followed, adapted to and fostered by the parent.

Concerns about preparing the ill member for long term functioning was a secondary concern in one family but not evident in most families with engaged care practices. These parents worried more about the ill member's self esteem. They wanted him to have a response to the query: What have you been doing? They wanted him to be able to respond with pride. Unlike parents with other concerns, they did not work on training the ill member to live independently, or take on self management once the parents were gone. According to their understanding of the illness, the child would never function without multifaceted support. The following incident demonstrates the parent's concern for the ill member's self esteem, over other possible interests.

> We have one of these instant hot water taps for the kitchen sink. The darn thing sticks. My wife says: "He is fixing the hot water faucet." (laughs), like it's going to be a disaster. We had a feeling he was going to really screw this up. He didn't fix it. But rather than telling him, "Leave it alone." to me it is worth even buying a new hot water faucet than to discourage him.

In this and many instances like it, parents looked for ways to give the child support and encouragement. Their goal was to find positive aspects in the young person's behavior and "give him the positives", no matter what they were.

These parents maintained a supportive stance by lowering their expectations to the level at which the child could perform. Lowered expectations were how these parents found the possibility within the situation. Rather than staying angry, resentful or mournful for what had been lost in their child's life, the parent found some possibility for satisfaction, joy or "high notes".

> He bought me a nice Father's Day card. And, that's a high note, when he does little things like that. That was a high moment. (pause) That's about it as far as the high moments go. Just the fact that there's been no problems is a high moment right there. There have been no problems. We're real happy about that. (pause) Doesn't take much of a good thing to be called a high moment, with our son.

This father's statement is bittersweet. It reflects his sad acceptance of what is possible in his son's world. Many of these parents were thankful that the ill member could join the family for some occasions, rather than being in the hospital, or too symptomatic to join in. Others were thankful for quiet moments when they could simply <u>talk</u> with the ill son, without interference from hallucinations or delusions.

<u>Coping with Community Relations</u>. Parents who were involved in care in an engaged way invested considerable effort in buffering the ill member from stigma, standing up for him, and negotiating roles for the ill member in the community outside the family. The tension to allow the ill member independent functioning remained, but parents did not hesitate to get involved if it were clear that he was misreading a situation or being taken advantage of.

> My son saw some guys that he went to school with over in the store. They drew him out, talked to him but they were probably making fun behind his back. They told him that this girl liked him and would like to hear from him. I think they even had some female call him up. This went on for a couple weeks until one time I happened to answer the phone when one of these people called up. They sent him on several wild goose chases.
>
> I said, "Haven't you done enough to (name)? You get fun out of this?". I really told them. I said, "You made his life miserable when he was in school and now you want to make fun of him. Well, you just better stop or you're going to be in some trouble."

In addition to protecting the ill member from ridicule and from being taken advantage of, parents tried to help him to manage in the real world. Parents all related incidents of helping the ill member get to appointments, work, day treatment or any event in the real world on time. Some approaches to this have been described: attending to the ill member's calendar and providing minimal prompts and reminders. Several mothers tried to coax their sons to manage the responsibilities by leaving written reminders. Apparently they felt that the distance of the written note allowed the ill member to accept the prompt with greater ease. In other cases, the situation called up meticulous hands-on management. Here parents coached the ill member step by step to get up, dressed, fed and out the door in time to meet commitments.

Care Difficulties Arising from Engaged Care

Parents engaged in care had difficulty setting limits and asking the ill member to change noxious behaviors. Consequently their lives were disrupted by the ill member's symptoms to a greater extent than were other families. For example, one young man collected garbage and stored it in large visible piles around the parents' home. Although the parents were distressed by this practice, embarrassed with the neighbors, and fearful that people coming to the house didn't take them seriously because of the yard, they could not limit their son's collecting. They surreptitiously removed objects from the bottom of the piles when their son was not around. They never directly forced the removal of all the trash, for fear of making the young man upset and perhaps self destructive.

Explicit expectations for change were not often expressed by these parents. Their illness understandings as well as the way they were involved in the child's care meant that they accepted, for the most part, the child's disabilities.

> I don't know whether it's right or wrong with making demands. I haven't figured that one out, (laughs) whether you should demand anything. It hasn't worked with us.

These parents directed their energies towards supporting the ill member, making him feel loved, safe, accepted. They were much less concerned that they improve the child's level of functioning, or capacity to manage independently in the world. They did not pass up opportunities to do this if they arose, but they did not actively set up activities and or treatment to effect this change. Consequently, these parents did not sharpen the child's capacities in a way that might have been possible if they had focused their efforts on trying to diminish his deficits. The success that can be achieved in deficit reduction, when this is the focus of care is graphically depicted in by parents who were involved as specialized managers. They contrast nicely with parents engaged in care, because the concerns that involve them in the care are so distinctly different, and the care that results is also distinct.

Parents who were engaged in care did not consciously choose to overlook the child's deficits. Rather, their background understandings, their understandings of the illness and way of being in the world, brought into focus the child's pain and need for support. It would violate these parents' relationships with their children, and their way of caring for their child, to set up a behavioral program aimed at improving their son's functioning. Doing this would not occur to them and if it were suggested, it would seem nonsensical.

M4 gave a stunning example of how mental health care can conflict with families' personal concerns. She recalled for the interviewer family therapy sessions that they had attended in years past. The therapist suggested that she and her husband contract with their son to take his medications. She retrospectively found the suggestion "stupid" because "you can't make someone do something that they don't want to do". Any good behaviorist knows that you can make someone do something if you make the stakes high enough. What made this suggestion "stupid" in this mother's world of meaning, was the unstated understanding that she would never punish or coerce her son in a way that would cause him further pain. The family therapist might have pushed the couple to evict the son if he didn't follow through on his part of the contract. Such contingency management was simply not possible for this couple.

In summary, parents engaged in care attempted to enter the ill child's world of meaning. They suspended disbelief and attempted to understand the ill member's world from his perspective. These parents were pulled to understand and accept a variety of odd, and difficult behaviors because of their involvement with their adult child.

Involvement in the form of engaged care gave rise to many skilled practices in supporting the ill member during symptomatic and painful times, in negotiating roles for the ill member in the community, in coaching more appropriate interactions. These parents found possibilities for their children within the parameters of the illness. Learning these parameters and working within them gave these parents an access to work with the illness in a way that no other parent group exhibited. Engaged parents were involved in a way that opened up understanding between them and their child. This fine-grained understanding of the child made possible fine tuned, responsive interventions that fostered the child's personal agency and potential.

One area of difficulty in this form of involvement was setting limits, or asking the ill member for positive changes. Although this was possible in this form of care, parents seldom were able to ask the child to contribute, or to control his symptoms. This was a sort of blind spot for this form of involvement. Making demands on the ill member, or asking him to control his symptoms, really didn't show up as an option for these parents. Their concerns directed their attention and energies towards supporting the capacities that they saw in the child, rather that towards shaping the child towards a more external goal.

Interpersonal Concern:
Self Care in Tension with Care for the Other

This form of care was characterized by the parent who attended to their adult child's needs but was always dissatisfied disgruntled and angry at the situation in which he or she found himself. The anger arose from the thwarting of hopes and dreams, for the self and for the child. What characterized these parents was involvement in the situation which placed their own needs, hopes, desires in conflict or in tension with the needs of the child.

These parents lived in the unhappy place of losing past possibilities, for themselves and their child, that were available before the schizophrenia, and yet not finding new possibilities that they could accept. For these parents there was some aspect of schizophrenia, or the situation of care, that they struggled with daily. The situation of care called upon them, engaged them to respond to and care for their child, while at the same time it called up particular concerns for their own well being.

It would be wrong to understand these parents as uncaring or uninvolved. They were intimately, emotionally and practically involved. If they were uninvolved, then the dual pulls of concerns that arose for them in the situation could be easily resolved. They might simply pull away from the care of the child in the interest of their personal stakes. Rather, the conflicting pulls that the situation held for them were so intense, and pervasive, that their caregiving was a struggle.

In a generic sense, these parents were unaccepting of the fact that their child was not "normal". They had a fairly sophisticated understanding of the disease, and of the symptoms that accompanied the disease, but were troubled by the symptoms in day to day interactions with the ill member. They accepted the illness abstractly and intellectually, but that acceptance broke down in day to day encounters with the ill member.

The tension, and lack of acceptance of non-normalcy is apparent in the following statements:

> Because I still want to try to deal with him as much as I can on a normal basis and I still struggle for that. I guess I'm always fighting his schizophrenia. Not really accepting it. Accepting it but not accepting it. I'm constantly dealing with both parts of me in dealing with it. Because it's a hard thing for a parent to have to accept really. Or for anybody part of a family to accept.
>
> *****
>
> And those kinds of problems are all the kinds of problems that keep hurting me, I notice. It's like sandpaper; it's ways of reinforcing that there's something different here; there's something wrong: It's not normal for two people to go together and sit in the same building and not sit together, that kind of thing.

The Nature of the Concerns in Tension.

The pull between the parent's own concerns and the concern for the child are evident in the following exemplar. One father tried to give the interviewer the "big picture" of the family situation. He was distressed both because he and his wife would never have a life free of parenting responsibilities, and because his son would never have the quality of life that he had hoped for his son.

> One of the things that's sort of ongoing, it sort of filters in through the whole situation... I guess I'm resolved in a sense - you never totally resolve yourself to it - that he's not really going anywhere; not geographically but otherwise. So that's one part of it.

"One part of it" is one side of this father's conflicting concern. He resents the loss of his own independence from parenting. This is evident in his direct statements as well as in his coping episodes.

> You know if you raise your children, one of the things you anticipate, you don't normally express, but it's there and it's normal, (is) that certainly by the early 20's, you expect them to be out of the house. And you expect that you and your wife, will be able to live a little bit more the way that you want to live. Do what you want to do. And have a little more privacy, finally, and all the rest of it. But of course we don't have that.

Episodes that this father presented as difficult, represented multiple concerns, but present in all 9 episodes was a concern for his own freedom from the direct responsibility of care or from interference in his daily life by the young man's personal habits. The coping episodes all focused on minor day to day events, like the way the ill member washed the car, his tardiness in coming to dinner, his sleep pattern disturbances and nonparticipation in preparing for family gatherings. In many of these episodes father's fears of "how long can this go on?" and his frustration with the "eternal nature of it" were expressed. Daily instances that stressed this father did so to a greater extent because each instance reminded him that the situation would never end.

The second central concern, that pulled this father in a conflicting direction, was the concern that his son have a "decent life". This father empathetically recognized and responded to his son's diminished possibilities. He worried about the young man's quality of life, and about his survival once father and mother were no longer alive.

> He's not going to have a full life; at least it doesn't appear that that's going to happen. And a full life doesn't mean the same thing to everybody but his potential was obviously very great... And it isn't just that he's not going to go any place, but how is he even going to cope with things without help? And will he have help? (After he and his wife are gone.)

This pull for his son's quality of life was centrally directed towards helping his son function at the highest possible level <u>now</u>, so that "fall" would be lessened when his parents were no longer available to support him. This concern, expressed directly as a wish for his son's betterment, or indirectly as a concern for the young man's self reliance, showed up in 8 of the father's 9 coping episodes.

The tension set up by these two concerns is evident if one imagines what this father's life would look like if one were absent. If, for example, the father were solely concerned for his son's quality of life and prevention of future suffering, then he might allow the young man to keep his own schedule, sleep late, work only when he felt able, and father would prepare for his future well being by arranging some system of care for after the parents were gone. Conversely, if this father were pulled only by his concern that he be free from the constraints of care, he might well evict his son, or distance himself from interaction with the young man, leaving the care to his wife or the psychiatrist. This father's way of being in the situation of care allowed for neither of these possibilities. He could not ignore his concern for his son's present and future survival any more than he could dismiss his own loss of independence. Both concerns were called up for him in this situation of care, and both impinged on every interaction that he had with the young man day by day.

Other parents were similarly involved in care, in that their concerns for themselves were constantly in tension with concerns for the ill member. The content of these concerns was quite different in these alternate cases. For example one mother's concern that she provide a supportive environment for her son who "suffered tremendously from all the noise and confusion in his head" was continually in tension with her concern that she be understood, cared for, and supported in her difficult life. Another father was pulled in the two directions by his wish for an easy, joyful, hassle free retirement, and his wish to prevent his son, who was extremely dear to him, from becoming "goofy" again.

Care Practiced by Parents with Self Concerns in Tension With Care for the Other

Care given by these parents was not entirely different from that practiced by parents who demonstrate different kinds of involvement. What differed was the way in which they carried out this care. The emotional tone of their interviews was one of frustration, anger, feeling depleted and even disgusted with what they were called to do.

> It's kind of a pain in the ass because even though you want life to continue as normal, and you still have a tendency to try, it definitely changes your life in that respect.
>
> I had always dreamed of just being able to - at this point in life - just pick up and go wherever I felt like and I made sure that I had enough money to do that. And now this thing has been put upon us and sure, you feel a little bit cheated. Because you did everything you could to make your life go smoothly and then this comes along and puts a crimp on it. So it's just another thing you've got to learn to work around and it's still annoying as hell, but you've got to do it.
>
> *****
>
> I'm just angry at the fact that we have to deal with this and cope with all this crap of our son's antics. He is really paranoid.

Several forms of caregiving were enabled and precluded by this form of parental involvement. These are discussed in detail in the following sections.

Coping with Breakdowns in Meaning. Parents involved in this form of care did not enter their child's alternative world of meaning. Rather, there seemed to be a sense of competition between the parent's and the child's take on various situations. These parents recognized that the ill member operated according to a different or altered set of meanings, but expressed no sense of what it would be like to live in the child's world. This is in sharp contrast to parents, in engaged involvement, who did suspend disbelief, for periods of time, and try imagine what it might be like to live in the world set up by the ill member's idiosyncratic meanings.

Depending on their view of the illness, these parents tried instead to convince the ill member to think differently, to act according to the parent's understandings of the world, or they tolerated but refused to traverse the difference between theirs and their child's understanding of the situation. One father understood the illness as a failure of rational control and tried to convince his son to think differently, to view things more like the father. Another father, who believed he would never convince his son to give up his irrational beliefs, tried to ignore the young man's delusions. When his son began a delusional discussion, he would cut him off, or merely state that "you and I believe differently". This father's illness model was 'normalizing' and he invested considerable effort in helping his son to act normal by setting up work and social opportunities to do just this.

The fact that these parents never imagined the world according to the child's altered meanings, had consequences for the care they provided. This was, in a sense, a rejection of the child's world which set up degree of intolerance of the child's behaviors that reflected that world. The following exemplar demonstrates how one father felt that his interpretation of the event was in <u>conflict</u> with his son's interpretation. The father obviously felt it important that he not "give in" or give any indication that he condoned the young man's perspective.

This father described an episode in which the ill member offered to do a favor for his parents. Pleased, they asked him to wash one of the family cars. He did so in his idiosyncratic fashion. For example, he didn't begin the task until mid- afternoon, because he took several hours to prepare himself for the task (getting dressed, donning goggles and so on.) Then, with the car parked in a neighbor's parking slot, he spent the next five hours meticulously vacuuming and washing the car. Father was disturbed by the young man's timing of the project, his over attention to detail and with his apparent disregard for the neighbor's right to use their own parking space, (although the neighbor had not returned during the time the space was occupied). When the young man finally finished the task, father was annoyed and angry, but particularly concerned that his son <u>not</u> be praised for his efforts.

> It's another thing where I feel he should not get a sense of satisfaction out of having washed the car under those conditions, because that's not helping him. In other words, if he gets a sense of satisfaction out of it, then he thinks the only thing that's important is that he washed the car. And I don't think that's the only thing that's important.
>
> I think what's important is the <u>way</u> that you do anything, whether you're washing the car or any other activity. If you're going to do it under those conditions, you don't begin to deserve congratulations.

This father's annoyance is apparent in his tone. He was most focused on denying his son any satisfaction from completing the job because father feared any sign of approval would validate they young man's approach to the job. According to the father, the young man's approach was warped by his illness related beliefs. To accept the son's way would have felt like a capitulation to the illness and a lessening of father's concern to help the son be normal. This father had to fight the son's way of operating in the situation, for it was in direct opposition to the father's concern that the young man behave normally.

Note that a benign disregard for the ill member's approach to the situation was not available to this father, both because it conflicted with his concerns about the neighbor's (theoretical) rights, and because it conflicted with his sense of the "right" way to do things. This father could not pass up the opportunity to influence his son in a positive direction.

Coping with Illness Ambiguity. A second area of illness demand that these parents responded to in unique ways, was the ambiguity of the illness. These were the only parents in the study who interpreted the ill member's behavior in the family context as manipulation. The behaviors to which they applied this interpretation included, for example, the ill member's persistent efforts to get money from the parent, his requests for the family car, cursing the parents and purposefully performing below capacity. It should be emphasized that all the schizophrenics in this study behaved in ways that might have been interpreted as manipulation. What stands out in these cases was the fact that ambiguous facets of the young person's behavior, even those that might well be symptoms of the disease, were often viewed as an attempt to "pressure" or manipulate the parent. Two examples follow.

The first example is a father's response to his son's suggestion that he contributes to the household by taking out the garbage.

> I: Do you think he's capable of a lot more?
> D: Oh yeah. Yeah, I think he is. I think he is, only because he has progressed. I know he is capable of being a better participator in the house. Or being less of a user, more of a contributor in one way or another. I not talking necessarily about materially, although that can be improved too. But in things that need to be done.

This father interpreted his son's sleep pattern disturbance and low motivation to work in and out of the home as willed behaviors rather than illness symptoms. In another interview, the same father admitted that, although he didn't say it aloud, he still thought his son was "freeloading". The apparent contradiction between this, and the father's equally prevalent stance that his son needed to be trained to "survive" without his parent's protection and support was not evident to the father. What the contradiction demonstrates is the conflicting concerns that were threaded through the father's care. Concern for the self gave rise to feelings of being taken advantage of, while concern for his son led him to work diligently at helping the young man improve his skills.

In a second example a mother interpreted many of her son's behaviors as out and out manipulation.

> He's very manipulative mind-wise, very manipulative. Very self centered. You have to remind him sometimes that he's not being considerate of other people. Sometimes he can be and sometimes he can't.
>
> I feel there are times when he needs to know his limits even though he is crazy. That there are times when you've got to either shake him into reality by yelling at him, "Stop that" or something, to make him wake up to cut into that.

One episode in which this mother felt that her son needed this kind of shaking up was at her birthday celebration. The entire family had gone to dinner in a restaurant, and the ill son became increasingly suspicious and nervous. He stood up whenever the wait help came to the table, moved to an empty table during part of the meal and stared intently at a young woman at an adjoining table. Also he asked that the family not talk, because the noise made him too nervous. At first, everyone including mother complied, but then she lost her patience.

> M: We had a conflict, all sitting a booth, we're trying to communicate, we're celebrating my birthday, we're having a delicious meal and we're enjoying the ambience of the place. And here is this son. I was getting angry with him.
>
> I did (keep quiet) for a few minutes and then I got mad. I said, "I can't keep quiet now. If you don't like it just get up and walk out." It was very difficult.
>
> I: Did it seem like his request was unreasonable?
>
> M: Yes. And here again I was looking at him as a normal person and suddenly he was making these demands upon me like a spoiled brat.
>
> I could have said nicely to him, "Why don't you just get up and walk out for a while and then come back when you're feeling better", or something nicer. But I was too angry at the moment to deal with it that way. And I said, "I'm going to tell the Share and Care group how you spoiled my birthday"

The dual pull in this situation was evident in the mother's statements. She knew, at least retrospectively, that her ill son needed reassurance and relief from stimuli. The personal pull to celebrate her birthday in a reasonable fashion, and her anger at her son for preventing this, stopped her from caring for him in the way she knew was best. Rather than trying to calm her son by nicely suggesting actions that might soothe him, she angrily told him to stop his demands. She additionally threatened to reveal his odd behavior to a meaningful peer group. She regretted her actions later, but admitted to the interviewer, that her remorse never moved her to change. Her admission, along with repeated episodes of this kind of explosion evidences her dual concern to meet personal concerns while at the same time caring for her son.

Coping with Regression. A third demand, regression, was managed primarily as a challenge by the parents who were conflictually involved. The patterns of care that they provided for the ill member were strongly influenced by their illness model. For example, two fathers understood the illness in such a way that improvement in functioning was a possibility. Their illness model allowed for the possibility of meaningful action on the part of the ill member which would meet both of their conflicting concerns. For example, one father who held a rational control model of the illness, attempted to rationally convince his son to get up at the same time each day. He was engaged in the task by his concern for his own liberation from responsibility and for his son's long-term quality of life. (His efforts were never successful.) Another father's multiple efforts to keep his son involved in some form of work, were made possible by his illness understanding that "normal" expectations brought forth normal responses in the ill member. He took his son to work with him and gave the young man manageable tasks that served the family business. Both his concern for his own future ease of living and his concern for his son's nonsymptomatic behavior were addressed by this action because he was training his son for future self-sufficiency and placing him in a normalizing environment. His optimism about making a positive impact is evident in the following.

> In one way or another, I think I've had some positive influence in the past. And I don't know in what ways I can influence him now. I'm constantly, in some form or another, searching for ways to influence him. But it's not that I don't think I can; it's just that I don't <u>know</u> how I can and I'm hoping that somehow I can figure it out.

These fathers had a the capacity to experiment, try new ways of managing the regressed behavior and make mistakes, (that may or may not have been harmful to the ill member), because of their form of involvement. They were, as a group, less fearful of doing harm and therefore less constricted in their care options than were parents, for example who were involved in engaged care. Perhaps this was because they were pulled by their own needs as well as their concerns for the general well being of the ill member. Their coping with regression had a flexibility that was not evident in the care of other groups of parents. This was most evident in the fathers who had models of the illness that implied that meaningful change resulting from their efforts was possible.

A different illness understanding set up different possibilities for care, in another case. This mother understood schizophrenia as survival through symptoms. Her coping options were limited because she did not believe her actions could affect change in her son's behavior. Unlike the fathers discussed above, she did not believe that rational argument, or structured interventions would change her son's symptoms.

This mother was involved in care by her concern to support her son in his suffering. She was pulled, at the same time, by her concern that the young man reciprocate her care. Clearly, in event after event, she saw that he did not reciprocate in any meaningful way. Additionally, she believed there was nothing she could do to make him understand her position, and give her something back. Her angry, at times rageful, responses to situations that demanded her nonreciprocal care are made comprehensible in this light. She was drawn to care for her son by these two concerns, but believed that the situation provided the possibility of meeting only her concern for her son. An example highlights this mother's dilemma.

The background to this incident is that the ill member has a history of borrowing money from his parents and not repaying it. In this episode, he asked Mother persistently for money that they previously agreed he couldn't have. She was annoyed by his repetitive request, and further annoyed because he was ignoring an agreements that they had worked out.

> I can't "let it go at that". Only if he accepts it calmly. But if he keeps after me and at me and at me then I'm going to lose my cool. I can't keep saying no, no, no calmly.

In this episode, Mother's requirement is that her son give up the request calmly. It's not a huge reciprocation that she seeks. However, when she doesn't feel that he is respecting her wishes in the situation, she explodes.

> I'm angry but I've got to get it out of me. Because at that moment my emotions are so worked up, it's like my own inner explosion.

She feels that she has few options for changing her son's behavior which has been remarkably consistent over the years on the issue of money. She feels he wears her down, and knows how to do it. Since she has no way of changing his illness behavior, she explodes and claims her own rights in the situation.

Care Difficulties Arising from Concerns in Tension

A form of coping with caregiving that was not available to these parents was letting things run their own course. These parents lacked the capacity to remain emotionally at ease with non-action, or benign neglect. The tension that arose between their own concerns or the concern for the ill member prevented them from watching from a emotional or physical distance, and letting the ill member live out his delusions, react to his hallucinations, or just be. The parent's concerns with the ill member's non-normalcy called them to act. Occasionally, when they coached themselves to inhibit action, they remained emotionally cued into the progression of events, and were clearly invested in the outcome even if they did not get directly involved in the action. Each time the ending turned out differently from their ideal, they felt frustrated, disappointed, angry, or despairing. Parents who were involved in care in this fashion had the most difficult time of any group of parents in the study.

Parents whose involvement in care demonstrated personal concerns in tension with concern for the child, were often distressed. By standing outside the child's meaning system, or intellectually fighting with his idiosyncratic beliefs, these parents experienced greater difficulties understanding and accepting odd behaviors. Often they interpreted these behaviors as willful attempts to manipulate or aggravate the parent. For parents with certain illness understandings, conflicting concerns were aligned when they tried to help the child cope with illness regression. Two fathers were fully, nonconflictually engaged in care directed at helping the child improve his functioning. Of course, if these attempts failed, they were doubly disappointed. One mother who believed the she could not alter the schizophrenia through personal effort felt caught, because her world offered no possibility for meeting her personal concern. She wanted her son to reciprocate her concern, saw that he didn't do that, and saw no way to make him reciprocate. Her dual response was to angrily review her hardships, and explode at the young man when she could no longer tolerate his unresponsiveness.

Interpersonal Concern: Specialized Management

Specialized management was a form of involvement in care of a schizophrenic member in which parents demonstrated objectivity, clear plans for how they hoped the child might change and improve, and a relatively unambiguous end goal for care. Parents who were involved in this way thought of themselves as managers, with specialized knowledge about how to help their sons function at a higher level or achieve a better biochemical balance. They remained objective, even in presence of serious symptoms and distress on the part of the ill member, because they believed that care was best administered with an eye to long term goals.

> So each year, I'd try to sort of set new priorities. The first year was just to kind of civilize him again so we could take him in public: Get him to dress up, get him clean. The second year was just more of the same. More activity so he would know the weekend from the weekday. Okay. So let's see. We sort of looked at it all in stages.

Parents who were involved as specialized managers were similar to those involved in engaged care because they found possibilities within the situation that provided them with guidance for care they could provide. Although the nature of the goals and care was quite different in the two instances, these parents were actively involved, and took on the caregiving task in a way that actualized their personal concerns as well as their concerns for the ill member. Both groups therefore differed from parents who found their personal concerns in conflict with their caregiving concerns.

Parents involved as managers drew their possibilities for care from external ideals, or from the scientific literature rather than from the ill member's demonstrated capabilities. They were not overly concerned about understanding the illness from the ill member's perspective, because that perspective was tainted by the disease. Instead, they relied on their own analysis of available information, (including the information gained from watching the ill member's behavior) to map out a course of action and direction for improvement.

These parents characterized the care they gave as treatment. Their self identity was linked to some profession that cared for the chronically mentally ill: a therapist, social worker, nurse or technician.

> I explained to (shopkeepers) that this was part of his therapy and I said, "I'm his physician and I'm trying this." I didn't say "I'm his mother.", (laughs) because that never worked. I always said "I'm his therapist" or "his physician" or "his psychologist" or "his social worker". I've been all those roles. And "I'm sending him over." Would they please cooperate?
>
> *****
>
> If I hired a psychiatric nurse, the nurse would have to have a certain number of hours off and since I really consider that the role I'm playing now is that of a psychiatric technician, I have to have a certain number of hours off to be able to have enough ability and strength to go back.
>
> *****
>
> The Red Cross Nurse is somebody who sort of volunteers to help people who are sick. The person likes to do it and and enjoys it and feels that they're doing a service. So my friend calls me the Red Cross Nurse. (laughs) I used to think of myself more as the social worker. I guess I just... like helping people and trying to make things better. I don't know.

Contrast this self identification with that of parents engaged in care. The latter group most frequently expressed caregiving as an extension of parenting; responsibilities for care were not bounded by time or role definition. For the engaged care parents the involvement was all encompassing. In contrast, parents who managed, viewed caregiving as a role with specified responsibilities and boundaries. This is evident in one preceding quote, where the mother discusses her need for time off. When involvement in care was managing, parents viewed their care as work, from which they sought relief through distractions or distance from the ill member. Similarly, the satisfactions from the work came from the observed improvements. Improvements in the child were a signal of success in the parents' caregiving efforts. They therefore served to validate and reward the work.

Care Practices

Two mothers, with different illness models, practiced as managers of care of their ill member. The first had a strongly biochemical understanding of the illness and its treatment and focused her care on achieving a balance in her son's chemistry. The second structured her care according to her understanding that the illness would respond to normalizing environments and stimuli. Each mother used scientific authority, as much as possible, to design and explain care. The first mother studied orthomolecular journals, attended workshops, had her son see several orthomolecular therapists, and was even writing her own essay on the cures she had seen affected by this treatment. The second mother relied on her own reading of the psychiatric literature and her consultations with physicians and mental health workers in time of need, to establish the scientific base for her practices.

> We tried a lot harder than lots of families we saw. We explored every avenue possible, with the exception that we were not faddists at all. If we read the literature and it looked like it was iffy, we didn't even attempt that. If we didn't attempt something, it was simply on the basis of our judgment that there wasn't enough to sustain it in the literature.

Of course, there were many gaps in the information that these womens' sources provided to guide their care. Empirical studies have not been adequate to address the contingencies that arise in care of schizophrenia. These mothers, however, found ways to interpret problems, so that they believed their actions were largely directed by established knowledge. It is probably more the case that their practical experience with the ill member over the years actually guided their care, but they failed to highlight their experience as rationale or authority for their decisions.

Care as management was a form of involvement in which the caregiver stepped in and took over the the care of the ill member. These mothers, under the authority of one or another form of scientific knowledge, defined the goals for the care of the ill member, and did not swerve from those goals. There was a kind of single-mindedness in this form of care. It was as though the problem were clearly spelled out and although the short range goals may have changed, the overall plan remained largely unaltered.

The unfortunate aspect of the stability in the mother's understandings was that they missed subtle changes in the ill member's personal well being and interpretations of events. These mothers were not particularly interested in, or sensitive to, the ill member's personal meanings and shifts in meanings except when these shifts influenced progress towards the mother's goals. Absent from these interviews were indications that these mothers understood what the disease felt like to their sons.

For example, one mother did not notice the fluctuations in the ill member's symptoms, which the interviewer noticed during the in-home observations. When I asked her about this, she attributed the changes to his boredom in spite of the fact that he had been quite verbal about feeling greater emotional pain on that day.

> I: I thought (name) was having a rougher day than he has had any of the other times that I've observed, and I was wondering if you felt that way.
> M: You said that, but I didn't notice it. Didn't he go upstairs and lie down?
> I: Um hmm. He spent most of the afternoon and evening lying down.
> M: Well, he's been doing that a lot more lately. He was getting so bored.
> I: So do you see that as a sign of anything? Does it concern you?
> M: No.

This mother retrospectively assessed the change in her son's pattern as boredom. On the day of the observation, and again during the interview, she expressed little interest in exploring with her son what the problem actually was. Instead, she interpreted the shift in events in a positive light, in terms of her overriding treatment goal, chemical balance.

> If he really does sleep... Actually it's better. He's a smoker and if he smokes he always comes downstairs. He always has a coke and a cigarette. And so when he's upstairs sleeping, he's not getting them, so I think that's better.

That this mother preferred her to son sleep rather than be up during the day, simply because it reduced the amount of chemicals he ingested, speaks to the intensity of her concern for her treatment goal. It seems she hoped to achieve chemical balance at any cost. In fairness, she believed that limiting her son's intake of chemicals, would allow for complete withdrawal from therapeutic medications, and a more satisfactory life.

This mother took over additional aspects of the ill member's care in ways that addressed her treatment objective. For example, she insisted that he eat three meals a day, prepared a tray of vitamins for him to take in the morning, along with booster doses throughout the day. Additionally, she used any means she could to diminish his intake of caffeine, including arguments, cajoling, joking, medical arguments, and the most effective approach, locking up the soda and doling it out one bottle at a time. When he objected to any of her treatments, she insisted verbally that he comply. He did eventually follow her wishes.

Coping with Meaning Differences. These parents fully recognized that their children had an altered view of reality. They did not try to understand the child's altered meanings from the inside (as the engaged parents did), or dismiss the child's view as odd but untouchable. Rather, they attempted to show the ill member the right way to look at things.

For example, one mother knew that her son was quite open to other's points of view and therefore vulnerable to influence. She was confident, however, that her ideas would prevail over outside influences on the young man.

> M: He's also very swayed by what people say, too. He's a very believing person, so when people tell him things, he will believe it, you know, for a while.
> I: Does that concern you?
> M: Oh no, I straighten him out.

The relation between this mother and son was such that she could have this kind of confidence in her influence over his thinking. Both had grown accustomed to the mutual dependence which accorded the mother management of the ill member's environment, and direction of his responses to his environment. They both seemed quite comfortable with the relationship.

These mothers leapt in and took over for the child in managing meaning differences. They tried to create a world of meaning for the child, from the ground up. One is awed by the enormity of the task that they took upon themselves. They believed their sons could not adequately interpret the world and therefore, in their caring, they had to step in and mediate meanings. The stance carried with it enormous responsibility to try to take over and structure the son's world.

M11, for example, always tried to help her son see things according to a real perspective. She suggested to the interviewer that she was "quite direct" in telling him what she thought. She was unsure, but generally believed that giving him her take on reality was better than ignoring his misperceptions.

> I'm not sure about this myself. I'm trying to feed back to him what reality is and do it consistently on certain issues. I'm not sure if this is productive or not but I'm pretty sure that the way other people do - which is to completely ignore all this and just let it go by and accept anything he does - isn't helpful either.

This form of leaping in can be contrasted with the parents in the preceding group, (self-care in tension with care for the other) who presented a competing view of reality to the ill member. The parents whose concerns were in tension, "fought" with the ill member, but mothers who were managers didn't have to fight. Neither of these mothers doubted that her take on the situation would prevail over the ill member's perceptions.

M11, for example, did not hesitate to misrepresent her true opinion or feelings to her son, in hopes of influencing his understandings or behavior.

> I have blown up theatrically, loudly, verbosely, histrionically. I mean, I've really made a big scene of it, but when I did that, it was very calculated. I thought it out ahead and I did it. And it was highly effective. It frightened him; it stopped what I wanted to be stopped. And it brought a lot of really important improvement.

M11 was willing to try anything that worked, to clear up meaning differences, that arose between her and her son. She did not limit her efforts to her one-to-one relationship with him. Rather, she actively worked with others in the community to respond to her son's breakdowns in meanings. For example, once when the schizophrenic visited a neighbor at work, the neighbor complained to mother about the interruption. He asked that M11 reprimand the young man. M11 resisted the request, suggesting instead that the neighbor speak with her son directly about his concerns. In many ways, it would have been easier for M11 to discuss the event with her son and set him straight. However, she believed that her son would get the message more clearly if it came from the offended party. Consequently, she spent considerable effort coaching and coaxing the neighbor to speak up. The neighbor let the incident pass, and the schizophrenic never repeated his visit, so the situation resolved of its own accord. This was a good example of how M11 effortfully tried to shape her son's world, beyond the immediate family, so that others would "feed back to him what reality is".

Care of Illness Regression. In both cases where parents were involved in specialized management, the impact on actual caregiving was most evident in management of the illness regression. M11's central objective was to improve her son's functioning. Hers is an exemplary case of how care shows up in this form of involvement. Her treatment goal most centrally addressed the demands of illness regression. Only two demands showed up in her coping episodes: illness regression and problematic relations with the community. She was not troubled as were other parents, by illness ambiguities, or unpredictability, or by the pain the the illness caused her son.

In several interviews M11 expressed the intensity of her feeling about the young man's inability to complete developmental tasks. Recognition of his deficits initially caused her tremendous distress, until she found a reasonable course of action.

> One of the things that was killing me was that the years were going by and my child was becoming an adult and functioning like a two year old. And this was actually just killing me inside. It was so... wounding and painful to me to see this big person, who functioned on a three year old level, that I thought I had to do something that would help us pass the time. I saw that the years were going to go very slowly with him.
>
> And I began to try to figure out all the ways that I could maybe... work with him with all of those disabilities, which are rather enormous disabilities, and still do something that would be

> creative and that he wouldn't realize was therapy, and nobody else would realize was therapy, and would also help <u>me</u> to pass the time.

To address her son's deficits, M11 marshalled all of her resources and directed them towards the goal of improving her son's functioning. She was clear thinking, skilled and tireless in her pursuit of this goal. Over the years, she devoted much of her personal time to setting up and managing a personalized treatment program for her son.

> My goal in all of these therapies is to institute them, stick with him, pattern him, use behavior modification and modeling. My end goal is to institute these things and then taper off my involvement in them more and more and more and more, which I've actually been able to do with some things.

There are many many examples of various forms of therapies that she creatively constructed to help her son. She named, for example, music therapy, cooking therapy, shopping therapy, pet therapy and so on. Each of these therapies required effortful involvement on M11's part as is evident in the following example.

> I worked with him on a little checking account. I've reinstituted his checking account this month and he's supposed to take out \$5 or \$10 for gasoline and put a balance in. I have to constantly check it and sit him down and do it with him.

M11 understood clearly that she was working against the nature of schizophrenia in trying to help her son to function. She sought ways motivate her son, so that he could overcome the lethargy produced by the illness. She explicitly identified herself as a behaviorist, and consistent with that theoretical approach she searched for motivating rewards. One reward was the use of a new car that she purchased for his use. She allowed him to use the car, contingent upon his efforts at school work, and on his limiting his (often pervasive) demands on her. Other graduated incentives were built into the son's life, like going out to dinner, or going to a more expensive restaurant, which he especially enjoyed, and so on.

Both of the mothers who provided care to their schizophrenic offspring through specialized management, had relative success in achieving their goals. The first mother successfully limited her son's intake of chemicals that she considered harmful although her long term goal of maintaining him free of psychotropic medications was not achieved. The second mother, M11, achieved remarkable success in terms of her son's functioning. He had successfully completed college level courses and continued to work towards an AA degree. Both mothers were satisfied that their efforts were the reason for their son's current level of relative wellness, and intended to further pursue this form of care.

In specialized management, mothers leapt in and took over for the ill member in terms of his functional deficits, as well as in terms of his meaning differences. These mothers believed the schizophrenia distorted or removed the ill member's capacity to live a fully human life. They felt called to structure that world for their son, so that he could reasonably carry on. Consequently, they leapt in and interpreted the world for their sons and actively structured experiences that would improve his functioning.

There is a way in which this taking care of schizophrenia was more of a project than a form of care. These mothers' concerns were aroused by illness deficits, and a concern for their resolution, rather than by the ill members' personal experience of the illness or of treatment.

Specialized management was a form of care that objectified the situation, and the ill member within it. These parents evaluated their sons in a way that was external to the sons' concerns and meanings. In a way, the mothers' position had to be external, because they believed the illness made their sons' internal impressions, judgements, understandings and meanings insignificant.

A few instances of how this taking over for the ill member objectified the care might illuminate the point. One instance arose because the schizophrenic was having difficulties at school. He was dangerously close to failing a course, in which he had invested considerable time and effort. M11, in an effort to learn what was going on with her son, wrote to the instructor and asked his assessment.

> M: I wrote a letter to the instructor at the college in which he got an F and I wrote out a whole behavioral checklist and asked him, from "frequently to never", to check all the items. So I would have an idea what's going on.
> I: You mean how he's performing in class?
> M: Um hmm. I sent the instructor a letter explaining something about his history and sent him a self-addressed envelope so he could send it back to me. So we'll see what's happening.

One must be a little in awe of this mother's capacity to get the world to join her in the struggle to get her son functioning again. At the same time, it gives one pause to think of how her son might feel about his mother sending this sort of letter to his college instructor. Although his behavior in class might have hinted at his difficulties, there is no doubt that he always tried to pass as normal. Unfortunately, this young man refused participation in the study so his response to his mother's therapies is not accessible.

Another instance arose when the ill member in another family was feeling particularly depressed. He complained to his mother that he needed more medications, for he felt extremely sick. He went on at length about the horrible nature of schizophrenia, how inscrutable it was that God could allow such a disease, where one could never be happy.

Especially confusing was the fact that he could feel so horrible, and yet never feel any pleasure. M7 interjected that he should stop this "ain't it awful talk" and go out for a bike ride. She confided to the interviewer that whenever he got into a conversation like that he made himself feel worse, so she cut him off. It's not clear whether M7 recognized that her son was actually in pain, and simply refused to acknowledge it, for fear of making him more depressed or if she really denied his pain. In either case, her caregiving stance was external to her son's concerns, and aimed at influencing him to see things from her perspective, which was more positive.

Care Difficulties Arising From Specialized Management

Both mothers felt the need to escape from the ill member for periods of time during the day, and yearned for extended time away from the caregiving task. Their care was work, and they needed leisure time away from that work. Both mothers found this respite in their own rooms. One did her writing there, and enjoyed herself by listening to the television and radio, while she knew that her son was content by himself downstairs. The other mother had a "do not disturb" sign that signalled her unavailability; She found it was effective most of the time.

One mother was quite expressive of how clearly the care she gave was work and burdensome.

> I felt like somebody who had a twenty ton weight on their shoulder that they had to carry around for ten years. Which is sometimes the feeling I have with this responsibility; that I'm not very big and this is a big heavy weight.

She worried, as did most parents, about who would care for her son after her death. Her concern in the matter focused on burdening another friend or family member with the difficult task.

> I don't want my other child to feel that her brother is a burden to her and that her whole life has to be monitored by this problem. I really feel pretty keenly about that. I have thought, "Look, one life is ruined; we shouldn't ruin two."

This mother had made arrangements with the mental health services in the area, and with friends, to monitor her son's well-being and provide for him after her death. The intensity of her feeling about burdening someone else with the task was evident in her language; She feared the new caregiver would be "a prisoner of the disease". Although she never stated that she felt imprisoned by her responsibilities, the suggestion is clearly there.

In summary, specialized management was a form of interpersonal involvement characterized by an objective assessment of the ill member's situation and clearly defined goal for the outcome of care. Involvement encompassed many aspects of the ill member's life, because the parent effortfully, often creatively and skillfully attempted to help the ill member achieve the goal of care. While these parents achieved relative success in helping their sons progress toward their treatment goals, they were tired. Their care was work and they coped by seeking respite from the work, which meant seeking some distance from the ill member.

Interpersonal Concern: Care from a Distance

All parents who were involved in care from a distance were fathers who relied on their wives to carry out the hands-on direct care of the ill member. These fathers were interested in the ill member's well being, concerned that his needs were met, yet were not personally involved in discovering or providing the care required. This was a form of care 'once removed'.

These fathers were involved in caregiving by a concern that distanced them from the adult child. They were not solicited by the child's difficulties in a way that called up their moment by moment concern or attention. Rather, they were happy to hear the periodic reports that their wives, the primary caregivers, provided them on changes in the ill member's status, treatment needs or care requirements. Their awareness of the problems in care were global, rather than specific. Similarly, their understandings of illness fluctuations were in gross terms rather than finely tuned distinctions. Interviews with these fathers revealed their acceptance, and satisfaction with the relative distance that they maintained from care, which they saw as fairly clear-cut division of labor in the family.

> She's doing a very, very hard job because she is doing the bulk of the work with him. Because of (living closer to him) and being involved in the mental health thing there, she's the one who's always on the firing line taking care of the dirty work. "Where's the SSI check? or What's happening with the medication?"
>
> It seems like the job that has fallen to me until recently is that my son worked with me one day a week. And my job, I felt, was to build him up in the area of feeling good about having a job and doing it well. And hanging out with him, going out to eat and social things.

In two of the families, the wives were equally satisfied, but in contrast, another mother found that primary responsibility for care unnecessarily burdensome and complained bitterly about her divorced husband's lack of participation.

Evidence of the fathers' relative disengagement in the caregiving came in their lack of knowledge about what was currently problematic. They continually referred the interviewer to their wives for the information.

> I'm not around him nearly as much as his mother is and when I'm away from home ten hours a day and sleeping eight hours a day there isn't that much time and our son is out often too so I am not in a position to follow him hour by hour.
>
> *****
>
> I think again that my wife is in a much better situation to recall these things because she was witnessing them first hand...

Additionally, these fathers noticed their emotions were less affected by the illness events, than were their wives' emotions.

> I seem to have been somewhat, immune, or somewhat on the periphery of the stress. My wife suffered most from it, when our son was in this overintrusiveness. -There were times when my wife was under great strain. Much of the time, <u>I wasn't even around or even aware of it</u>. And, of course, then I would hear about it later.
>
> *****
>
> I think an 'inattitude' is the best attitude to take. Just take it: You're here, look at today, see how he's feeling. What do you have to do to get through today? Next week, next month, you know, my whole sense of that is gone.

These fathers believed their role was to support their wives in the role as caregiver. Some seemed quite aware of their wives' emotional and practical involvement, but others did not seem to understand what direct, involved care entailed for their wives.

<u>Care Practices</u>

Fathers who were not directly engaged in giving care to the schizophrenic member, nonetheless provided assistance in other forms. These fathers, who worked full time and were quite committed to their work, implied they contributed to family care through financial support. Indeed, in two of these families, the mothers were not involved in gainful employment, although both were substantially involved in community and personal projects.

It was clear in all cases, however, that for these fathers, work came first. Their schedules revolved around work, and their energies were primarily placed there as well.

> Although I try to stay involved in that, it's very difficult to do. -I'm operating on about six different levels all the time, from running a business, running a family, you know; I'm keeping my truck working. There's a lot of details involved in what I do. I have a very detail filled life and there's a lot to do every single day.

Work was an understandable draw away from direct care. In contrast to these fathers, however, there were fathers in the study who worked full time and were involved in care more directly and intimately. An excellent example is a father who was described in detail in the section on engaged care. This father was committed to his work, yet interrupted his schedule at any time when he was needed at home. In addition, he used his free time to try to engage his son in activities and hobbies where they could participate together and share similar interests.

A second form of care that the fathers provided was backup support when their wives could no longer manage a problem alone, or simply needed a break. For example, in one family where the son had significant sleep pattern disturbances and slept progressively later and later into the day, mother grew tired of the daily battle to get him out of bed. Occasionally on weekends, when his wife had "thrown up her hands in despair", this father would take on the responsibility of getting the son up and involved in some activity by midday. He reminded, cajoled and finally humored the young man out of bed. In a second, fairly dramatic example, the husband took over primary care of the son for two weeks, while his wife took a personal vacation to visit her own family.

More commonly, however, these fathers were uninvolved in the day to day care. They learned about difficult episodes when they were a "fait accompli", after the immediate problem had been handled. One example was an episode where the son was hospitalized for the first time, during the study period. Both parents were aware that the young man had become increasingly ill, because of his withdrawal and altered sleep patterns. His disorganization reached serious proportions during a visit to his psychiatrist, who suggested immediate hospitalization for restabilization. Mother was extremely fearful and concerned that hospitalization might be detrimental to the young man because he was so sensitive to his environment. She nonetheless took him to the inpatient unit, waited fearfully alone while the young man was evaluated and admitted, and finally called her husband when she returned home. She had considered calling him earlier, but did not. Consequently, father was not aware of the entire incident until he returned from work that evening, and his wife related the details. Understandably, he was less emotionally distraught than his wife had been, hearing the story after the fact and once the young man was safely admitted to a care unit.

> I noticed the hospitalization seems to be really no very big deal. When one usually thinks of hospitalization you think of Snakepit or One Flew Over the Cuckoo's Nest. And so many people in very bad condition. Some question of the capacity or the quality and the quantity of staff for taking care of the patients. But at the (local hospital), obviously they were mental wards but they seemed to be rather pleasant places to be.
>
> -I don't know if I feel stresses as much as... I certainly don't feel it as much as my wife, who was in tears when she was discussing the hospitalization.

A second example also involves a hospitalization. In this family the schizophrenic son was chronically suicidal. He had made several attempts on his own life in the past, but was stable for several months prior to this episode. The ill member stopped taking his medications, decompensated rapidly and tried to kill himself by slitting his wrists. This father learned of the episode after the fact, and after the young man was hospitalized at the local crisis center. He took the news calmly, recognizing that he was much more detached now, and "burned out" on the frequency of the attempts.

> And then all of a sudden I get the call from his mother that he's cut his wrists and is in the crisis center. -I think I'm drained at some level from overreacting to these things anymore. Short of

> out and out death, I don't think my reactions are ever going to be as deep again. Some part of me is dead to this. I've been through it for too long. I'm burned out.
>
> I have developed some kind of protective armor, I think, to ward off getting too seriously involved in it. I mean, I know what part is mine and what part has to be taken care of by someone else.

This father suggests that he wasn't always disengaged, but now finds he must be. Instead of getting emotionally overwrought with his son's highs and lows, he stands apart from the situation and allows others to manage.

Care Difficulties Arising from Caring from a Distance

In many ways involvement as care from a distance set up care that was the most facile, least trouble for the parent. These fathers were certainly not embroiled in the day by day, minute by minute demands of working with the ill member. Their distance from hands on care spared them the daily hassles and disappointments of caregiving. At the same time, their distance precluded them from enjoying the small advances, the moments of lucidity and the kind of closeness that other caregivers had with the ill member. They could not possibly develop the finely tuned skills that others had at reading the ill member's moods and cognitive states, or at knowing when to interact, and when to hold back. These fathers could not be attentive and receptive to the ill member, in their distance.

At the same time, their distance did not prevent these fathers from suffering all together. In fact, they may have been more vulnerable than any of the other 3 parent groups, because they lacked that direct access to, and connection with, the ill member that might buffer the pain. Two cases give evidence of the father's vulnerability. In the first, the father felt "burned out". He felt that he had been through so many suicide attempts with his son, that he could no longer feel the pain that the threat of the young man's death used to cause. He felt numbed. There is no doubt that he lived in dread that the young man might actually succeed in his attempts, but father felt that he could not be emotionally invested in the possibility. In contrast, his wife, who was closely involved in her son's day by day fluctuations, saw the minute, positive changes in her son. She continued to be devastated by his less frequent attempts on his life, but she also saw signs for hope. Father, in his numbed state, and in his distant involvement, had no way to track these minor, hopeful signs.

The second case demonstrates a similar contrast between mother and father who were closely and distantly involved in care. The father in this family worked full time, was in close physical proximity to his son, because they lived in a small home, but had very few interactions with the young man. The son contributed to the distance by refusing to eat if his father were in the room, and by severely limiting his conversations in the presence of the father. It was impossible to discern where the distancing began, and mother, who commented on it to the interviewer suggested that it was a mutual process.

This father lived in fear that his son would harm himself. Although the young man had never made a suicide attempt, he had talked about it years ago. Father believed it was a current and consistent threat.

> F: One thing that I have in mind right now is that he could very well run off and do something to himself. I'm very leery of that.
> I: You mean he might harm himself in some way?
> F: Yeah. I think, even to the extent of committing suicide.

The fear threaded through this father's daily interactions with his son. For example, Father wouldn't cross his son about his rituals, because he feared that the young man might run into the street. When the young man, who had a habit of taking long walks in the community, did not return by the time father went to bed, he couldn't sleep, worrying that some harm might come to him or that "he might harm himself."

Conversations with this man's wife gave one a different sense of the situation. She doubted that her son was self destructive.

> I never worry about him jumping off the bridge or anything like that, that other people worry about.

This mother, was very in tune with her son's internal musings and concerns. She listened to his ramblings, and knew cues to the young man's increasing anxiety or fearfulness. There is no doubt that this mother felt that she had an early warning system of trouble. If he were to become self-destructive, she would know that trouble were afoot long before the young man took off, or ran into the street. This mother's level of understanding with her son made her much more comfortable in her dealings with her son, and gave her much greater flexibility in interacting with him, speaking her mind, and asking him for things.

In summary, care from a distance was an emotionally "cool", practically unencumbered way to relate to a son or daughter with schizophrenia. It is impossible to know how these fathers would have taken on care, had their wives not been available, or willing to assume primary caregiving responsibilities. In two of the families, fathers involved in this way seemed more vulnerable to the fears about potential loss of the child, because they lacked attunement to the child's day by day progress and emotional state. In all the families where this arrangement was observed, the fathers were satisfied with the relative distance that they had from the intricacies of care. In only one of these families was the mother <u>not</u> equally satisfied with the relative division of responsibilities.

Summary

This chapter began with the promise of describing what care "looked like" in the families who cared for a schizophrenic member in the community. Interpersonal concerns, the existential ways that parents were in the situation of care served as an organizing framework, because these concerns shaped the care that was given. Four qualitatively distinct forms of interpersonal involvement were presented: engaged care, care for self in tension with care of the other, specialized management and care from a distance.

Parents' experience of care was tangibly different when their involvement was set up by these different concerns. Parents who had concerns in tension were predominantly angry, disgruntled, unsatisfied with themselves, their adult child and the outcomes of their caregiving efforts. They always wanted more for themselves and more for their child, but found no way to attain those ends. Parents engaged in care were much more satisfied, having found ways to stay in contact, support and protect the ill member, yet not be drained, or burned out. The care they gave fulfilled the child's needs and defined and fulfilled the parent as well. Involvement that took the form of specialized management was energetic, hopeful, goal-directed. These parents were challenged by the problems that the illness presented, and enthused by their own, creative responses. They viewed their care as an important piece of work, but since the demands of the work lasted 24-hours a day, they felt drained. Finally, disengaged caregivers were cool, relatively unencumbered providers who were satisfied with the distant stance they took towards understanding the intricacies of demand and of the care required. At least two of these parents appeared more vulnerable to fears about the ill member, because of their distance their because unlike their wives, they lacked fine tuned ways of knowing the ill member's status.

Each of these groups of parents represent forms of involvement that are familiar and recognizable. Their dilemmas and efforts to grapple with those dilemmas have evidenced forms of interpersonal concern that we recognize in ourselves and in others around us. Of course this must be so. These parents don't live on another planet. Rather they share with us and with each other, a culture, a set of common meanings and understandings. Because we share with these parents a common culture, we are able to inch into their particular worlds and begin to grasp the particular concerns that guide their care.

Although the patterns evident in these parents are familiar, they are particularly theirs. The particular qualities of their situations, as well as their unique background meanings, understandings and histories, (their worlds) set up the kinds of responses that they made to their children's illness. Some of these responses feel easier, more comfortable, more acceptable than others. Different readers might identify with one or another of the parents whose story has been told. If any of the parents seemed unintelligible, or their actions seemed unacceptable to the reader than the project has missed the mark. These parents <u>were</u> intelligible, and their actions made some kind of sense, in terms of their worlds of understanding and experience. If the reader cannot access that intelligibility, it is the fault of the writing, in inadequately presenting the parents' worlds.

None of these parents were able to completely consciously, or strategically choose how to relate to their child, how to define the problem or how to cope. That would have required the super human capacity to climb outside their world, to look in on it and choose how to be. An outside-in vantage point was not available to these parents. At the same time, they were not locked into one way of being. Rather, they had a scope of options that their involvement and background provided them. The strongest evidence of flexibility and change in coping and care come from parents who note how they have changed over years. Change over time was not the focus of this presentation, but there were threads of it in many of the stories.

In the following chapter, some common cultural threads that gave rise to the various forms of care evidenced by these parents will be discussed. The aim of this chapter is make more explicit how the care these parents provided fits with our cultural understandings and practices of family care and care of the chronically mentally ill. In addition, the way in which this account of parental care of a schizophrenic member fits with, and conflicts with the current constructions of family care of schizophrenia will be discussed.

Chapter 7

Implications

What are the implications of this interpretive account of family care of schizophrenia? In this chapter I contrast the different possibilities for understanding family care that were evident in this interpretive project and in the current theoretical constructions of family care of schizophrenia. In chapter three, I noted that the aim of an interpretive account is to provide a story that includes and extends the understandings derived from empirical work. In what follows, I outline the ways in which this story differs from and improves upon the understandings that might be derived from the expressed emotion literature.

Next, parental care of schizophrenic offspring is discussed as a particular instance of parenting practices in our culture. Core parenting practices are illuminated by parents who extend those practices to include a child with a severe illness. The breakdown in expectations for the child and for the parenting task introduced by schizophrenia, provides an instructive example of how those practices can be adaptive, resilient, and persistent.

Modern cultural ideals, about ways of being in the world, about work, and about family relations, seriously challenge the realities of family life that includes a schizophrenic member. Parents of schizophrenics somehow manage to continue to provide concerned care to their children who will never approach these modern ideals. Their capacity to stand between and negotiate differences in the distinct worlds of the schizophrenic and larger society is a a dramatic example of the power of caring practices.

Finally, the ways in which this work might inform nursing practice with families of schizophrenics is outlined. Practice begins with respectful attempts to understand families' worlds, including their illness understandings, their personal concerns and their caring practices. If care is the core of nursing practice, then an essential element of that practice must be the recognition, valuing and support of caring practices evident in the lives of patients and families that nurses serve.

Interpretive Understandings vrs. Theoretical Models

How can we understand, theoretically, the care that parents gave to their schizophrenic children? I believe that we cannot. We are particularly disabled if the we must look at the situation through a theory that currently guides research on families of the chronically mentally ill: the stress-vulnerability model of the disease which specifies family affect as a stressor causing relapse.

The limits of the stress-vulnerability model become all too evident if we examine the families described here through the model. What elements of their lives come into focus and what elements are excluded from view within the stress vulnerability model? Further, is their care comprehensible within the model and would understanding them in this way give us guidance in caring for these families?

The parents most likely to be identified as being "at risk" or high on the critical dimension of expressed emotion are those that have personal concerns in tension with the concern for the schizophrenic member. Their disgruntlement with the ill member and with the outcomes of their caregiving efforts make them likely candidates for the expressed emotion label. They probably would make more than six critical comments about the ill member in a research interview. Unfortunately, the only thing that the expressed emotion analysis would reveal about these parents is their criticism. The concerns that drive their criticism would not be examined, nor would the counterbalancing concerns that keep them involved in the day to day care of the ill child.

It is plausible that mental health intervention with these parents would take the form of encouragement to stop criticizing the ill member. They would be educated about the ill member's vulnerability to hostile or negative emotional environments and would be trained to decrease, if not eliminate their critical attitude toward the child and their situation. Two problems must be named with this approach. First, the approach might not work, and second, the approach might work, with disastrous results.

At least one of the parents explicitly described the "ideal" approach to her caring for her son when he was psychotic. She recognized that a quiet, noncritical intervention caused much less distress in the ill member. She also recognized that she could not be quiet and noncritical when she was angry with her son. Her angry responses made sense in light of her conflicting concerns for herself and her son, and the illness understanding that disallowed satisfaction of her personal concerns. It's hard to imagine that a psychoeducational approach would have much impact on this mother. She already knew the information that the program had to impart. It's unlikely that any form of intervention that did not begin with her concerns for both her son and herself, would fail in changing her form of care. It's unlikely that interventions, which were comprised of education directed towards changing the parents' behaviors, would be successful with any of the parents whose care was constituted by concerns that were in tension.

What if the intervention were successful? What if parents could be trained to stop criticizing the ill member when he did things that disturbed the parent? It seems that the only way that parents whose self concerns were in conflict with their concerns for the child could stop their criticism, is if they gave up one of their concerns. Take the specific example the father who was dually concerned that he prepare his son for independent living, and that he, father, be freed from the burden of living with a schizophrenic son. Which concern should he relinquish? His concern for his son's independence or his concern for his personal freedom from responsibility for parenting an adult child? The former concern led him to engage with his son, to try to train him and to spend countless hours thinking of ways to convince the young man to live a more normal life. Should he be counseled to give this up? If he could give it up, what would be the basis of his connection with his son? It might be a flimsy, non-meaningful 'sense' of obligation, or 'feeling' of responsibility. If interventions successfully severed the basis of the father's connection with his son, that arose from within his world of meaning and concerns, all he would have left to practice that connection might be a trait or quality that he chose to demonstrate. Perhaps this would be a trait that the the mental health program espoused as "healthful" for the child. Notice, however that the trait would be chosen, not constitutive and therefore vulnerable to breakdown. Even if it were possible to get this father to give up his concern for his son's normality, the outcome might be a much more devastating distancing from his son.

This father's second concern for his own freedom from parenting responsibility, led him to fight the ill member's illness, and to try to get the ill member to limit his symptoms. Should this father be counseled to give himself over to the disease? Would it be a good thing to ask this father to give up his personal concerns and live selflessly for his son? Talking about the father in this way reveals the arrogance in the expectation that he change in this external, or outside in manner. If we understand the father as involved by his concerns, even if these concerns cause him great distress, any attempt to work with him must start with the professional's attempt to understand those concerns.

The emptiness of the expressed emotion model for examining parental care is even more apparent when the notion of overinvolvement is considered. Overinvolvement was defined as "a tendency to overprotect, to over dramatize incidents, go into excessive and inordinate detail, and show emotional distress in the interview" (Kuipers, 1979, p 240). The definition cannot parallel the actual criteria for rating the parent as overinvolved, since such a low percentage of families actually acquire this label. In one study as few as 5% of the high expressed emotion families were overinvolved. With the definition provided, I believe that <u>all</u> the parents in this project might be rated overinvolved, particularly when one considers that the rating is made at the time of hospitalization. I cannot imagine a parent in this project not being emotionally distressed at that time. Thus, the actual meaning of overinvolvement remains elusive.

Mothers who were involved in care as specialized managers were the group most likely to be classified as overinvolved, using the broad definition provided above. These mothers were the most attentive to detail because they had clear cut goals for care. Also, they often leapt in and took over care for the schizophrenic member, out of their concern that the illness disturbed his ability to understand and operate optimally within the world. These mothers might therefore be called overprotective.

Understanding these mothers who were involved as specialized managers, solely in terms of their overinvolvement would miss much of what was important in their care. Their intense concern for the schizophrenic member's improvement, and the energy and creativity that they invested in structuring environments so that he could improve, are totally lost in the negative labeling. We might be offended by these mothers' tendencies to leap in and take over for their children, but we must also be respectful of their remarkable capacity to maintain the fight. Their efforts to achieve the goals of high level functioning or biochemical balance might never be reached. Still, there is little doubt that they will ever give up the struggle and abandon their children, or their goals for their children.

At its core, the model which guides the expressed emotion research, looks at families from a perspective of deficits. It offers no positive model to guide family involvement with a schizophrenic member. Rather, the model suggests only the possibilities of how not to be: noncritical, nonhostile, or not overinvolved. Guided by this deficit model, research on family care has failed to consider the positive ways that families relate, acquire sensitive understanding and skill in managing the care of a schizophrenic member.

The stress-vulnerability model, and the expressed emotion research assume a view of humans that involves technological self understanding and strategic pursuit of goals (Benner & Wrubel, In Press; Dreyfus, 1983; Taylor, 1985). Within these theories, humans are assumed to live subjectively within their own representations of their objective worlds. The best understanding that humans can have of their worlds is to get the most truthful, or clear picture of the objective world. This truth then allows them to see a situation clearly, form a decision based upon the factual qualities of the situation, and act on that informed decision; it means the acting out of man's strategic capacity.

The working out of these assumptions are most apparent in the expressed emotion intervention programs. If humans pursue goals strategically, based upon their instrumental reasoning about their sense of the situation, then the best way to influence parents in a (presumed) positive direction is to help them get the right grasp of the situation. Teach them which elements, out of a host of elements, that they should attend to, and show them the right relation to aspire to with those situational elements, to achieve the desired end. This is precisely what the psychoeducational programs strive to do. They attempt to teach parents the vulnerability factors central to their children's illness course, and the relation that the parent should get into with the child so that minimal stress is placed on the his vulnerable character. The right relation is one that involves little criticism and little involvement.

What is wrong with this view of humans, or specifically of these parents, and with the interventions that are structured upon it? First, it assumes that these parents live outside their worlds, or at least outside the situations that they are involved in in their worlds. It assumes that parents think about these situations in abstract, uninvolved ways and strategically structure their action according to rationally considered goals. In an odd way, parents are assumed to be spatially but not existentially involved in their children's world. Involvement is only in the form that they choose.

Care, in this model, is a personal possession, that one can distribute, withhold, and shape in a manner that is also calculated. Any notion of parents being involved by concern that outstrips or overrides their rational approach to the situation is absent or a focus of concern. Perhaps this is just what "overinvolvement" in the situation is: nonrational giving oneself over to the situation and its demands.

This project has demonstrated, hopefully in convincing ways, that parents of schizophrenics do not stand outside their situations, and think rationally and unemotionally about how they should relate. Rather, their relations and their care evidence their involvement _in_ the situation, or their concerns. Certainly for some parents involvement with the child set up problems that required coping by standing back and thinking about what to do, how to move next, how to get through to their child. This calculation was not about how to get involved, but how to work with the child given the kind of involvement (or concern) they already had. The kinds of care they gave the child was inextricably bound up with the way they were involved with the child. Because of this, disowning, reshaping, or withholding the care they gave, even on the advice of a knowledgeable therapist, would be impossible. Their care was so bound up with their connectedness with their child, that trying to change the care, without first understanding the connection, would be nonsensical.

Parenting Practices, the Basis of Schizophrenia Care

Parents of schizophrenics found possible ways to care for their children in a modern world. Their caring practices were derived from current cultural constructions, (both theoretical and practical) of what care is. Their care might best be understood as an extension of those practices that comprise parenting in our culture. That these parents were able to extend and adapt their parenting to respond to the special needs of a schizophrenic son or daughter, is remarkable. Their efforts deserve careful examination, for they may have much to teach others about care of an injured, chronically ill or "normal" child.

Hauerwas (1986) similarly suggests that being a parent of a mentally retarded child is an extension of the tradition of being a parent. He believes that parents with retarded children learn quickly and perhaps more thoroughly, because of the breakdown of expectations for the child, what it means to be a parent. These parents learn the moral pull, the claim, that their children have on them, even though their children turned out different than expected.

> Our problem is that we have no philosophy of public morality through which we are able to articulate the kind of commitment we find witnessed in the lives of parents who have learned through their (retarded) children to be parents. I do not think there is any easy solution to this problem. Rather, I think what we must do is let the witness of such parents guide our way, as they stand as a beacon to remind us what it means to be a parent no matter what our child may be like.
>
> But that they are witnesses only indicates the tenuousness of our situation. How long can we expect to be graced with such presence when we even lack the moral language to express the commitments their lives display? Perhaps, in the interim the best thing we can do is make public these remarkable, but no less ordinary, families. (Hauerwas, 1986, p. 208)

Perhaps there is no language to adequately describe practices of parents involved in care of their schizophrenic offspring. If this is the case, then Hauerwas' example must be followed, and the parents' stories must be left standing as remarkable examples of interpersonal concern (or commitment in his terms) in a modern world. The best tack may be to simply give instances of various forms of care which demonstrate the reality and the quality of that care.

There are hazards in talking about care in abstract or theoretical terms. Every move that one makes away from the concrete instances of care, is a move that might distort the complex relations of parents who lived that care in real, meaningful situations. Additionally, abstract descriptions may be inappropriately interpreted as formulas or prescriptions for how care "should" be. Mindful of these hazards, I cautiously proceed with a discussion of how parental care of schizophrenia is an illuminating instance of parenting practices in our culture.

Several aspects of care that were centrally important to the parents in this project, simply belong to parenting today. These parents, like all parents strove to demonstrate to their children that they were valued and loved. They tried to provide for their children's autonomy and personal capacity to operate successfully in the world. Additionally they attempted, often against tremendous odds, to assist their children to develop these personal capacities, for gainful employment, or art, or some form of activity that would provide them pleasure, satisfaction, or improved self esteem (Kagan, 1980).

At the base of all practices evident in these families, and a core essential of parenting practices in general, is care for the child. Children matter to parents, and thus parents are involved and connected to their children in ways that are strong, resilient, flexible, persistent. The different forms of interpersonal concern that were evident in these parents of schizophrenics, shows the variety of ways that parents' involvement can be elicited by a child. In what follows, I elaborate on the key parenting practices listed above, and show how certain forms of parental involvement centrally addressed these practices. In addition, I present some of the cultural strains that make these parents' task exceedingly difficult with a schizophrenic child.

Central Parenting Practices

Parents' care sets up the child's world of meaning. It is through his parents that a child learns what it is to be a person. He learns certain possibilities for being human, through an intimate sharing in his parents' world of meaning and practice. Parents, in the flow and engagement of raising the child, foster and shape the child's grasp of the world (background meanings), they point out distinctions of worth (concerns) in their actions and words, and they foster the child's personal agency (Benner & Wrubel, In Press; Taylor, 1985). One of the distinctions of worth evident to the child in concerned parental care, is that he is valued and loved.

Parents demonstrate to their children that they are valued and loved through their day to day care. Through their acceptance of the child's personal idiosyncrasies and problems, and their attention to his changing needs, parents express, (and create) their love for the child. The child is, in a very real way constituted by this affection. He is the kind of child he is, because of his parents' constitutive love. This is a two way street, however. Parents are equally constituted by their relations with their children. They become certain kinds of parents, based upon the kind of child theirs turns out to be. Parents of schizophrenics and parents of the mentally retarded are two good examples. They are called upon to be a special kind of parent, one who can practice parenting through the enormous breakdowns in expectations for a normal, achieving, healthy, happy child.

Fostering the child's independence is a second important parenting task in this culture (Kagan, 1980). The difference between parents in this and other cultures is well documented. Most striking are the contrasts between Japanese parenting, which attempts to socialize the child into the network of family and institutional interdependent relations, and American parenting, which from day one strives to constitute the child as an independent being.

Although independence training occurs at all stages of the child's life, it becomes most acute in adolescence. Here, parents and children recognize the necessity of an ideological rebellion if emancipation is to be successful. The child must make a good effort to establish his own autonomously constructed way of operating in the world, that is distinctly different from his parents' way of operating. Of course this is impossible, but the effort is considered an essential task in the transition to independent adulthood. Parents foster this striving for autonomy by encouraging self-sufficient decision making and by tolerating the child's distinctly rebellious distancing from what they have heretofore offered him.

A third central aspect of parenting in our culture is helping the child to develop his skills and capacities. Since personal worth is measured by personal competency (Kagan, 1980), it is expected that parents help their children develop talents and skills that will ensure their being valued outside the family. Accomplishments in school are particularly valued in adolescence while young adults are expected to develop competencies in some line of work.

Modern Expectations and Parents' Predicaments

Parents' practices are set up by their care for the child, by the child's own possibilities and constraints, and by the prevailing cultural valuing of certain kinds of adults. Increasingly, parents have assistance in carring out their practices, from parenting "technologies" that have evolved in recent decades. These technologies include parent training programs, books on "how to parent" and advise and assistance in the popular media that run the gamut from educational television programs on parenting to magazine columnists' advice.

Success of these parenting technologies derive from a deep acceptance of a scientific basis for structuring one's life choices. Over time, scientific knowledge about childhood development, parenting skills, disciplinary strategies and so on, has accrued. This scientific knowledge base provides the authority, and substance for the various techniques set up to help parents parent.

There is a way in which these technologies, or prescriptions for parenting, undermine practices that are set up by parent's care for, and involvement with, a child. For example, directives for parents, that may emanate from the latest Dr. Spock or the new Dear Abby cannot encompass the particular needs of the child, concerns of the parent or the particular qualities of their relations. Rather, directives are merely that. They are abstract rules or prescriptions, modeled to fit a generalized parent, but no particular parent. To the extent that a particular parent follows directives or rules and allows these rules to override his concerns for, and understandings of the child, he objectifies the child. To the extent that technologies are accepted, parenting becomes acting on, rather than involvement with the child's person.

The influence of science on modern day living is, of course, not limited to the realm of parenting. Scientific advancements have dramatically influenced the modern American's life. Obviously this is true in terms of the possibilities that have opened up in our physical world because of scientific, technological advancements. We now make telephone calls on fiber-optic lines that perceptually cut the distance of thousands of miles, to a few feet. For many, writing has been moved from the realm of papers and pencils to keyboards and computer screens. Examples are abundant. Beyond these physical examples, however, the contributions of the human sciences are perhaps more significant.

The influence of advancements in human sciences like psychology, sociology, anthropology on modern life is substantial. Living in a world informed by these sciences, the modern's self concept is inevitably altered. Take for example, the influence of behaviorism. No matter how wrong-headed this theory of human behavior may be, it's impact on human relations is enormous. How can anyone who has studied operant conditioning, not be at least peripherally aware of it's premises when they discipline a child or reward a student? As much as one might like to purge one's consciousness of behaviorist notions, they are there, and to a certain extent must be reacted to, (accepted or rejected) in our day to day lives. Another way of saying this is that our scientifically constructed notions of the the self are so centrally a part of our culture, that they at least partially constitute the selves that participate in that culture.

Additional aspects of modern living within the American culture present particular predicaments for parents who care for schizophrenic offspring. These include the emphasis on organizing one's life according to external time constraints, the general acceptance that self worth is defined by one's accomplishments, or by one's efforts to achieve, and that social and economic independence of children from their parents is a sought for ideal. Each of these are discussed briefly here.

Time is predominantly understood in this culture as linear, moving in a line from past through present to the future, and segmental, or divided into units of hours, minutes and seconds. This grasp of time is central to how we operate in our worlds. Time is experienced as a container to be filled up, with work, social engagements, and other experiences. If time is not maximized, the day may end with the container half full. That is, a person may not fill his time optimally with productivity or with play and in this, there a sense of time being wasted. Thus, much of American life is ruled by the clock. Particularly in the realm of public life, in businesses, schools, and in social relations, schedules and appointments dominate (Helman, 1987).

This conception of time, and pressure to make optimal use of time, is clearly problematic for the schizophrenic. Persons with schizophrenia seem ill attuned to external time constraints. The most dramatic example is in their sleep cycle disruptions. Many schizophrenics have difficulty adhering to "normal" cycles of sleep and wakefulness. Another persistent example, is their inability to monitor and meet the time structure of appointments, meetings and so on. Missed appointments occurred in relation to both positively and negatively valued meetings. For example, one mother noted that her son simply could not get up, dressed and out the door in time for his appointments with a counselor that he clearly liked.

The mismatch between the schizophrenic's understanding of time and the understanding that guides cultural practices, often put the parent in the position of trying to negotiate differences. Their efforts were directed at both the schizophrenic, and the agencies and persons in the time constrained social world. They coached the schizophrenic to move a bit closer to world time, at the same time that they asked for leniency and understanding from doctors, dentists, treatment programs and so on, for the child's tardiness.

Another dilemma for schizophrenics and their parents is that self worth is often equated with personal accomplishment. This valuing of the person as achiever derives from the tradition of the Protestant work ethic. Within this tradition, work is valued for more than its financial benefits. It is the basis of one's self identity and self-esteem. A person is judged by what they do, more so than by who they are. Involvement in some activity, regardless of its social or financial benefits is better than idleness. If a person's worth is determined by his work, and he does no work, he is potentially shamed. (Bellah et al., 1985; Benner, 1984)

A variant on the work ethic, which is also pervasive in modern life has been labeled "duty to duty" (Benner, 1984). In this ethic, value is found in doing any job well, regardless of the content, interest or worth of that job. In this view, work might be drudgery, but if done right, or according to the highest possible standards, it is satisfying.

Schizophrenics fit poorly into a society that values achievement or efforts to achieve because the illness drains the individual of motivation to accomplish these valued goals. The negative symptoms of the illness read like a list of vices in our culture: apathy, social withdrawal, anhedonia, amotivation (Andreason, 1976). Matters are made worse by the fact that these symptoms are present in physically healthy young adults, who appear able to work.

Finally, there is a cultural tension for families to spring their children from the nest during young adulthood. The transition to adulthood is most clearly marked by the child's social and economic independence from his parents. Failure to complete this transition potentially brings negative judgements upon both parents and children. It is an unfortunate fact, that the illness seriously disables the schizophrenic from ever achieving any semblance of social or economic independence. It is also a fact that parents who support the child by allowing him to stay in their homes, or by providing him substantial emotional, social and financial aid, are misjudged as overprotective, and overinvolved.

How Concerns Guided Parents Through Predicaments

All the parents in this study understood the caring practices embedded in the parental role. Their understandings were illustrated in their concerned care for their children over time. These parents were also cognizant of and concerned about the cultural expectations that impinged upon their children. They knew that their children lived in a world that operated on clock time, where personal worth was judged by personal accomplishments, and where adult emancipation was valued over family ties and bondedness. Each of these parents grappled with the disjunctures between societal ideals for adulthood and their own child's possibilities. Parents involved by various forms of concern approached the disjunctures with different emphases and different forms of care. Their involvement with the child, brought certain aspects of basic parenting practices to the fore. In what follows, I highlight how each form of interpersonal concern structured the emphasis of parenting practices.

Parenting by engaged care parents was centrally focused upon the task of making the child feel valued and loved. These parents were engaged by their continuing efforts to accept the child, as he was, in his schizophrenia. They were deeply concerned that they stay bonded to the child, that they be a source of support and comfort, and that they be a link between the child and the larger world.

Engaged care parents had particular skill in sharing in the ill child's world of meaning. This sharing took the form of listening to the son's delusions, or trying to understand his perception of his environment. Care was evident in the parent's willingness to suspend disbelief, and imagine living in a world from the child's standpoint.

These parents, more so than any other group, found possibilities for the child, within the immutable bounds of the illness. As their understanding of the illness grew, so did their possibilities for staying in tune with the child. These parents found a kind of situated freedom in the realities of schizophrenia, that gave rise to finely tuned, skillful, empathic care. Of secondary concern to these parents was helping the ill member measure up to modern ideals of adult relations and functioning. These parents relinquished their hopes that their children would be productive, economically self-sufficient members of society. They continued to hope that their children might find a form of work that would suit their capabilities, and from which they might garner wider praise. The nature of their hopes reflected their lowered expectations. They wished, for example, for a year without psychosis, or that the child might find a volunteer job in which he could find satisfaction.

Parents who were involved with their ill child's care by concerns that were in tension, demonstrated particular sensitivity to the cultural ideals arising from the Protestant work ethic. Illness demands and coping episodes named by the parents in this group revolved around their sons' incapacities to function in age-appropriate tasks. These parents were intensely concerned that their sons work, or be involved in activity, to the greatest extent possible. Toward this end, they tried to argue their sons into daily habits that supported the possibility of work. Additionally they structured the young mens' lives in ways that allowed for some meaningful employment.

Parents whose concerns were in tension, urged their sons to work in an effort to build their self esteem, and to ward off potential shame. They were acutely aware that the young men lived in a culture that rewards achievement above all. One father, for example, said that he understood his son's unwillingness to work for minimum wage job, when he could earn no more than he currently earned on SSI. At the same time, this father was troubled by the young man's penchant for sleeping in, sitting around the house doing nothing all day except visiting and drinking a few beers with his friends. The illness induced lethargy gravely challenged this father because he loved his son and wished to protect him from being stigmatized in a culture where work is considered a virtue.

The tension in these parents arose (at least in part), from the conviction that they stood alone in supporting their children. They recognized that they lived in communities in which families were separate units, set apart and private, rather than embedded in a network of supportive relations. They felt the onus of care was upon them and felt the moral weight of maintaining this responsibility in relative isolation. They suffered under the myth of the self-sufficient, protected and protective family (Keniston, 1980). Just as they believed that they must prepare their sons for an unsympathetic, unsupportive world, they too felt that they must brace themselves to manage the struggle of care alone, in community which would judge them wanting if they could not manage self sufficiently.

Parents who were involved in care as specialized managers demonstrated a concern for the child's functioning that paralleled that of the previous group of parents. They seemed centrally concerned that the child achieve a level of functioning that might be valued beyond the bounds of the family. What uniquely characterized this care was a greater reliance on parenting technologies. In their concern to help their children function, or achieve greater levels of biologic balance, these mothers relied on scientific authorities and articles in setting up their care. The potential hazard in objectifying the child by a reliance on rules or prescriptives rather than moving from understanding derived from personal involvement, was outlined above. At times these mothers' care had this quality of acting on the child rather than involvement with his personhood. Another way of saying this is that in their attempts to help their sons fit into a world that poorly accepts the disabilities of schizophrenia, these mothers relied on the authority of science rather than the power of their care. Their reliance on technologies at times eroded their basic caring practices.

Care from a distance can best be understood as a reflection of a time in which mens' and womens' work were divided into distinct spheres. In its pure form, the woman's sphere was the home, while the man's sphere was the world of work, and the larger society. Certainly spheres of womens' and mens' work are no longer so cleanly divided. However, recent studies of American life suggest that the melding of spheres has not been complete. The way that Americans organize their lives is still influenced by the distinction of the spheres of family and work, or private and public (Bellah et al., 1985).

The acceptance of a division of spheres of influence and responsibility was clearly evident in the families where the fathers cared from a distance. These couples had negotiated, at least in their practices, separate forms of involvement and concern in family life. The women were primarily engaged in managing the home, and the care of the ill child (although one divorced mother also worked). The men were primarily engaged in their careers. It is noteworthy that in the families in this study who demonstrated this more traditional division of labor, the mother's care was always in the form of engaged care.

In summary, there are serious differences between societal expectations and the capacities of young adults with schizophrenia to meet those expectations. Parents, in their care for these children, grappled with ways to help the schizophrenic deal with the differences. Some parents were engaged by the task of helping the child feel valued and loved, in a society that ill supported or understood his illness. Other parents were equally involved by their efforts to help the child minimally address societal expectations for work and self sufficiency. All parents were called to the task by their concerns for their children, and responded to the task with variations on, and extensions of basic parenting practices.

Implications for Nursing Practice

Nursing care of families of schizophrenics can be informed by several findings of this study. First, parents had unique, yet richly elaborated understandings of their child's illness. They derived their understandings from watching their child in the meaningful contexts of daily life. Over time, parents developed working models of what was wrong with their child, how the illness strengthened aspects of his being, and incapacitated other aspects. They additionally developed deep understandings of what their child needed to manage in the world. Their care practices with the schizophrenic child made sense only in light of their illness understandings.

It is reasonable to conceptualize nursing interventions with parents of schizophrenics as a negotiation of illness models. Parents illness models are a good indication of their enduring concerns for the child, and are therefore an excellent access to the parents' worlds of meanings. Nuances of parents' illness understandings are influential in how they structure their care. Their grasp of their child, and his needs, deserves respectful attention, for it can far exceed the clinicians grasp. Parents know the illness over time and across contexts, but most importantly, they understand the illness in a way that only concerned involvement can open up.

Second, parents who care for a schizophrenic child in the community live lives that are fraught with difficulties. The illness creates breakdowns in meanings, changes in the ill member's person, illness ambiguities, and illness regressions. Parents who care for their children, must cope with these illness induced difficulties. The problems can neither be ignored or willed away. They are simply a part of parents' day to day lives.

Third, this project demonstrated that parents' care was structured by their background meanings and concerns. The various forms of care evident in the families studied, were best understood in light of the interpersonal concerns that involved them in the care of that child. Different aspects of the illness distressed parents who were involved in the child's care in different ways. Similarly, parent's care responses were significantly different, depending on how they were involved in their child's care.

Nursing practice with families of schizophrenics must begin with attempts to understand the caregiver's concerns and meanings. Ways to access parents concerns are first, to learn their illness understandings. A second access to a particular parent's world of meaning and concern is careful inquiry about what the parent does with the child, what troubles him, and how he responds. Care practices evidence concerns, and are therefore an excellent entree to the parent's world.

Nurses, in their attempts to understand, both recognize, and bear witness to the care that parents provide. Interventions that fail to begin here, are disrespectful of parents ongoing efforts. Extending parents' care is also possible. Nurses can help parents see new possibilities for ways of being involved with their children, that are at the same time respectful of their current forms of involvement. Like parents who find situated possibilities for their schizophrenic children, nurses, can find situated possibilities for parents in their caregiving practices.

Bibliography

Agar, M. H. (1986) Speaking of Ethnography. Sage University Paper series on Qualitative Research Methods, Volume 2. Beverly Hills, CA: Sage.

Anderson, C. M., Hogarty, G., & Reiss, D. J. (1981) A psychoeducational program for families. In M. Goldstein (Ed.), New directions for mental health services: New developments in interventions with families of schizophrenics. San Francisco: Jossey Bass.

Andreason, N. C. (1984) The Broken Brain. The Biological Revolution in Psychiatry. New York: Harper & Row.

Bellah, R.N., Madsen, R., Sullivan, W.M., Swindler, A. & Tipton, S.M. (1985) Habits of the Heart. Individualism and Commitment in American Life. Berkeley: University of California Press.

Benner, P. E. (1984) Stress and Satisfaction on the Job, Work Meanings and Coping of Mid-Career Men. New York: Praeger.

Benner, P. E. (1985) Quality of life: Explanation, prediction and understanding in Nursing Science, Advances in Nursing Science, 8, 1-14.

Benner, P. & Wrubel, J. (In Press) The Primacy of Caring, Stress and Coping in Health and Illness. Menlo Park: Addison Wesley.

Bernheim, K. F., Lewine, R. J. & Beale, C. T. (1982) The caring family. Living with mental illness. New York: Random House.

Brown, G. W., Birley, J. T. L., & Wing, J. K. (1972) Influence of family life on the course of schizophrenic disorders: A replication. British Journal of Psychiatry, 121, 241-258.

Brown, G. W., Monck, E. M., Carstairs, G. M., & Wing, J. K. (1962) Influence of family life on the course of schizophrenic illness. British Journal of Preventive and Social Medicine, 16, 55-68.

Campbell, T. L. (1987) Family's Impact on Health: A critical Review. National Institute of Mental Health, Series DN No. 6, Washington, D.C.: U.S. Government Printing Office.

Chesla, C. A. (1987) Parents' understanding of, and skill in, living with schizophrenic offspring. Paper presentation. California Alliance for the Mentally Ill, Annual Conference, April, 1987.

Creer, C., Sturt, E., & Wykes, T. (1982) The role of relatives. In S. K. Wing (Ed.), Long term community care: experience in a London borough. Psychological Medicine, Monograph Supplement, 2, 41-54.

Doane, J. A., Falloon, I. R. H., Goldstein, M. J. & Minz, J. (1985) Parental affective style and treatment of schizophrenia. Archives of General Psychiatry, 42, 34-42.

Dreyfus, H. L. (1983) Being-in-the-World: A Commentary on Heidegger's Being and Time, Division I. Manuscript. Philosophy Department, University of California, Berkeley.

Dreyfus, H. L. (1986) Being-in-the-World: A Commentary on Heidegger's Being and Time, Division I. (Chapters V and VI) Manuscript. Philosophy Department, University of California, Berkeley.

Falloon, I. R. H., Boyd, J. L. & McGill, C. W. (1984) Family Care of Schizophrenia. New York: Guilford Press.

Falloon, I. R. H., Boyd, J. L., McGill, C. W., Williamson, M., Razani, J., Moss, H. B., Gilderman, A. M. & Simpson, G. M. (1985) Family management in the prevention of morbidity in schizophrenia. Archives of General Psychiatry, 42: 887-896.

Goldman, H. H. (1982) Mental illness and family burden: A public health perspective. Hospital and Community Psychiatry, 33, 557-560.

Goldman, H. H., Gattozzi, A. A. & Taube, C. A. (1981) Defining and counting the chronically mentally ill. Hospital & Community Psychiatry, 32, 22-27.

Goldstein, M. J. & Doane, J. A. (1982) Family factors in the onset, course and treatment of schizophrenic disorders. An update on current research. The Journal of Nervous and Mental Disease, 170, 692-700.

Goldstein, M. J., Rodnick, E. H., Evans, J. R., May, P. & Steinberg, M. R. (1978) Drug and family therapy in the aftercare of acute schizophrenics. Archives of General Psychiatry, 35, 1169-1177.

Good, B. J. & Good, M. D. (1981) The meaning of symptoms: A cultural hermeneutic model for clinical practice. In L. Eisenberg & A. Kleinman (eds.), The Relevance of Social Science for Medicine. Boston: Reidel.

Hahlweg, K. & Goldstein, M. J. (Eds.) (1987) Understanding Major Mental Disorder: The Contribution of Family Interaction Research. New York: Family Process Press.

Hauerwas, S. (1986) Suffering Presence. Theological Reflections on Medicine, the Mentally Handicapped and the Church. Notre Dame: University of Notre Dame Press.

Hatfield, A. B. (1979a) The family as partner in the treatment of mental illness. Hospital and Community Psychiatry, 30(5), 338-340.

Hatfield, A. B. (1979b) Help-seeking behavior in families of schizophrenics. American Journal of Community Psychology, 7, 563-569.

Helman, C. G. (1987) Heart disease and the cultural construction of time: The Type A behavioral pattern as a western culture-bound syndrome. Social Science and Medicine. 25, 969-979.

Hoening, J. & Hamilton, M. W. (1966) The schizophrenic patient in the community and his effect on the household. International Journal of Social Psychiatry, 12(3), 165-176.

Hogarty, G. E., Anderson, C. M., Reiss, D. J., Kornblith, S., Greenwald, D., Javna, C., Madonia, M. & Environmental/Personal Indicators in the course of Schizophrenia Research Group. (1986) Family psychoeducation, social skills training and maintenance chemotherapy in the aftercare treatment of schizophrenia. Archives of General Psychiatry, 43, 633-642.

Kagan, J. (1980) The psychological requirements for human development. In A. Skolnick & J. H. Skolnick, (Eds.) Family in Transition, 3rd Edition. Boston: Little-Brown.

Kanter, J., Lamb, R., Loeper, C. (1987) Expressed emotion in families: A critical review. Hospital & Community Psychiatry, 38, 374-380, 1987.

Keniston, K. (1980) Children and families. In A. Skolnick & J. H. Skolnick, (Eds.) Family in Transition, 3rd Edition Boston: Little-Brown.

Kleinman, A., Eisenberg, L. & Good, B. (1978) Culture, illness and care. Clinical lessons from anthropologic and cross cultural research. Annals of Internal Medicine, 88: 251-258.

Knafl, K. A. & Deatrick, J. A. (1986) How families manage chronic conditions: An analysis of the concept of normalization. Research in Nursing and Health, 9, 215-222.

Koenigsberg, H. W. & Handley, R. (1986) Expressed emotion: From predictive index to clinical construct. American Journal of Psychiatry, 143, 1361-1373.

Kottgen, C., Sonnichsen, I., Mollenhauer, K. (1984) Families' high expressed emotion and relapses in young schizophrenic patients: Results of the Hamburg-Camberwell family intervention study, II. International Journal of Family Psychiatry, 5, 71-82.

Kuhn, T. S. (1970) The Structure of Scientific Revolutions. Chicago: University of Chicago Press.

Kuipers, L. (1979) Expressed emotion: A review. British Journal of Social Clinical Psychology, 18, 237-243.

Lazarus, R. (1981) The stress and coping paradigm. In C. Eisdorfer (Ed.) Models for Clinical Psychopathology. New York: Medical and Scientific Books.

Lazarus, R. & Folkman, S. (1984) Stress, Appraisal and Coping. New York: Springer.

Leff, J. P., Kuipers, L., Berkowitz, R. & Sturgeon, D. A. (1985) A controlled trial of social intervention in families of schizophrenic patients: Two year follow-up. British Journal of Psychiatry, 146, 594-600.

Leff, J., Kuipers, L., Berkowitz, R., Eberlein-Vries, R. & Sturgeon, D. (1982) A controlled trial in the social intervention in the families of schizophrenic patients. British Journal of Psychiatry, 141, 121-134.

Leff, J. & Vaughn, C. (1985) Expressed Emotion in Families: Its Significance for Mental Illness. New York: Guilford.

Lionberger, H. J. (1985) An Interpretive Study of Nurses' Practice of Therapeutic Touch. Doctoral Dissertation. University of California, San Francisco.

MacMillan, J. F., Gold, A., Crow, T. J., Johnson, A. L. & Johnstone, E. (1986) Northwick park study of first episodes of schizophrenia, Part IV. Expressed emotion and relapse. British Journal of Psychiatry, 148, 133-143.

Miller, B. C., Rollins, B. C. & Thomas, D. L. (1982) On methods of studying marriages and families. Journal of Marriage and the Family, 44, 851-873.

Miklowitz, D., Goldstein, J. Falloon, I. (1983) Premorbid and symptomatic characteristics of schizophrenics from families with high and low levels of expressed emotion. Journal of Abnormal Psychology, 92, 359-367.

North, C. (1987) Welcome, Silence. My Triumph Over Schizophrenia. New York: Simon and Schuster.

Packer, M. J. (1985) Hermeneutic inquiry in the study of human conduct. American Psychologist, 40(10): 1081-1093.

Platman, S. R. (1983) Family caretaking and expressed emotion: An evaluation. Hospital and Community Psychiatry, 34, 921-925.

Rabinow, P. (1977) Reflections on Fieldwork in Morocco. Berkeley: University of California Press.

Rose, L. E. (1983) Understanding mental illness: The experience of families and psychiatric patients. Journal of Advanced Nursing, 8, 507-511.

Sacks, O. (1985) The Man Who Mistook His Wife for a Hat, and Other Clinical Tales. New York: Summit Books.

Sandelowski, M. (1986) The problem of rigor in qualitative research. Advances in Nursing Science, 8(3), 27-37.

Schilder, E. J. (1986) The Use of Physical Restraints in an Acute Care Medical Ward. Doctoral Dissertation. University of California, San Francisco.

Schwartz, B. (1986) The Battle for Human Nature. Science Morality, and Modern Life. New York: W. W. Norton.

Strachan, A. M. (1986) Family intervention for the rehabilitation of schizophrenia: Toward protection and coping. Schizophrenia Bulletin, 12, 678-698.

Taylor, C. (1979) Hegel and Modern Society. Cambridge: Cambridge University Press.

Taylor, C. (1985) Human Agency and Language: Philosophical Papers, Volume I. New York: Cambridge University Press.

Terkelson, K.G. (1984) Response. Family Process, 23, 425-428.

Thompson, E. H. & Doll, W. (1982) The burden of families coping with the mentally ill: An invisible crisis. Family Relations, 31, 379-388.

Torrey, E. F. (1983) Surviving schizophrenia. A family manual. New York: Harper & Row.

Valone, K., Norton, J. P., Goldstein, M. J. & Doane, J. A. (1983) Parental expressed emotion and affective style in an adolescent sample at risk for schizophrenia spectrum disorders. Journal of Abnormal Psychology, 92(4), 399-407.

Vaughn, C. E. & Leff, J. P. (1981) Patterns of emotional response in relatives of schizophrenic patients. Schizophrenia Bulletin, 7, 43-44.

Vaughn, C. E., Snyder, K. S., Jones, S., Freeman, W. B., & Falloon, I. R. H. (1984). Family factors in schizophrenic relapse: A California replication of British research on expressed emotion. Archives of General Psychiatry, 41, 1169-1177.

Walsh, M. E. (1985) Schizophrenia, Straight Talk for Families and Friends. New York: Warner Books.

Weschler, J. A. (1972). In a darkness. New York: W. W. Norton.

Wilson, L. (1968). This stranger, my son. A mother's story. New York: G. P. Putnam & Sons.

Wrubel, J. (1985) Personal Meanings and Coping Processes. Doctoral Dissertation, University of California, San Francisco.

Footnotes

1. The Stress and Coping interview protocol and guideline for interpretive analysis were developed in the Berkeley Stress and Coping Project by Richard Lazarus and his associates.

2. Dr. Judith Wrubel (1985) discussed various forms of interpersonal concerns demonstrated by healthy middle aged men and women in relation to their family, friends and work in her dissertation entitled Personal Meanings and Coping Processes. Her insights allowed me to identify similar and dissimilar concerns in parents of schizophrenics.

APPENDIX A
INTERVIEW SCHEDULES

Explanatory Model Interview

1. Can you tell me how you understand your/your family member's illness? What led up to it and how did it develop?
2. You know there are many different explanations for what schizophrenia is all about. I'm interested in your understanding of the illness.
    a. Could you describe the first things you noticed about yourself/your family member that made you suspect there was something different or that there was a problem? Why do you think it started when it did?
    b. What do you think might have caused these problems or differences?
    c. Could you describe, in your own words, what you think schizophrenia really is? How does it work?
    Probes: What does schizophrenia look like in you/your family member?
        Is there something different about the way your/your family member's body, mind or emotions work?
    d. How severe is your/your family member's sickness? What do you think the course of the illness will be?
    e. What kind of treatment should you/your family member receive?
    Probes: Medications
        Other chemical treatments, ie megavitamin therapies
        Behavioral therapies, (Get them to be specific.)
        Family interventions
        No treatment helpful? Any options?
    f. What are the most important results you hope you/your family member will receive from this treatment?

3. What are the chief problems that schizophrenia has caused for you/ your family member?

4. What do you fear most about your/your family member's illness?

5. What are your hopes and desires for your/your family member's future?

*Adapted from Kleinman, A., Eisenberg, L. And Good, B. (1978) Culture illness and care. Clinical lessons from anthropologic and cross cultural research. Annals of Internal Medicine, 88, 251-258.

Family Coping Interview (Family Form)**

1. You are now in a position to care for your family member who has schizophrenia. I wonder if you can talk briefly about what the experience has been like for you?

2. I am interested in the kinds of stressful things that happen to people in relation to the care or behavior of their family member who has schizophrenia. Please think of an incident that occurred in the last year that stands out for you as being particularly difficult or stressful in relation to your family member with schizophrenia.

   a. In general, tell me what happened.
   b. How did it make you feel?
   c. What led up to this situation?
   d. What did you do?
   e. How did what you did change the situation?
      How did what you did impact the family?
      Did your action change the way you felt about the situation?
   f. What else did you consider doing?
   g. Looking back on it now, is there anything you would have done differently?
   h. Is there anything about this situation that you think I should know about, something that my questions haven't covered?

2. Could you think of another situation that stands out for you as being particularly stressful or meaningful for your <u>family</u> in relation to the care or behavior of your schizophrenic family member?

   a. In general, tell me what happened.
   b. How did you and the other members of the family react?
      (How did the respondent feel? How does s/he think the other family member's felt?)
   c. What did the family do?
      (Did they seem to take one unified course of action or were there many courses of action taken?)
   d. Did family members agree on what should be done? How was this resolved? Who made the decision? How do you feel about the decision?
   e. How did the family's action change the situation? Change how you felt about the situation? Did the experience change the family in any way?
   f. What do you think led up to this situation? Does it remind you of anything that happened in the past? Do you think the family responded in the same way that it responded to similar situations in the past?
   g. Looking back on it now, is there anything that you would have done differently?

3. Could you now think of a situation that was particularly warm, meaningful, or satisfying in relation to living with or caring for your family member with schizophrenia?

   a. In general, tell me what happened.
   b. Did this incident seem to impact the whole family or primarily one individual?

c. What led up to this situation?
d. How did you feel?
   How did the rest of the family involved seem to feel?
e. How did you and the rest of the family express your feelings, in response to this situation?
f. Was this different from the way you <u>had</u> been feeling about the patient or your situation? In what ways?
f. Did you want to <u>change</u> the way you felt in this situation?
g. Was any action taken?
h. Is there anything else about this situation that you think I should know about, something my questions haven't covered?

** Adapted from the Coping Interview, Stress and Coping Project, R. S. Lazarus and J. B. Cohen, 1977.

****

FAMILY SELF ASSESSMENT

1. GENERAL INTRODUCTION If I am going to understand your family, what things should I know about it?
What's important to your family?
What are you like?

2. ACTIVITIES What sorts of things do you do together?
In the home? Outside of the home?
What kinds of things does the family do together on weekends?
Describe one of your typical days.
Are you pretty satisfied with the amount and kinds of time you spend together with your family?

3. RESPONSIBILITIES How are the responsibilities divided in this family? Who takes care of: providing an income; housework; laundry; meals; shopping; child-care; special family responsibilities for care of the schizophrenic member?

Who is involved in responsibilities outside of the family: school relations; church; neighborhood relations; civic responsibilities?

How satisfied are you with the way the responsibilities are divided?

4. HISTORY What was your childhood home like?
Ask both wife and husband.

In what ways is this family like the family you grew up in? How is it different? Consider the following.
Values: religion; education; money; occupations.
Behaviors: decision making; affection; recreation; problem negotiation

What are your feelings about the way this family is in comparison to the family you grew up in?

What are your aims for your family?

What are you particularly proud of?

Have you regrets or disappointments about your family?

5. INTERACTION/RELATIONS

How do you express affection for one another?

How do you disagree with one another?

Briefly describe the most recent incident that comes to mind in which two or more family members disagreed. What happened? How was the situation resolved? Is this typical?

In what ways are you like other members of this family? In what ways are you different? (Who is like whom and why?)

What do you like about each member of this family?

What would you like each member to change about him or herself?

APPENDIX B
ANALYTIC PLAN FOR SCHIZOPHRENIA DATA

I. UNDERSTANDING OF SCHIZOPHRENIA

IA. GENERAL UNDERSTANDING
  1. BIOCHEMICAL EXPLANATIONS
  2. BIOCHEMICAL EXPLANATIONS (IDIOSYNCRATIC)
  3. SOCIAL EXPLANATIONS (NON FAMILY)
  4. FAMILY EXPLANATIONS
  5. STRESS EXPLANATIONS

IB. EARLY SIGNS IN FAMILY MEMBER
  1. Early/First Signs
  2. Pre Diagnosis
    (What went on before sought medical help?
    What led up to seeking help?)
  3. The diagnosis
    a. The process of diagnosis.
    b. What difference did the diagnosis make for the caregiver? (Ambiguity generates stress or hope.)

IC. CAUSES OF ILLNESS

ID. EXPLANATIONS OF THE PROCESS OF SCHIZOPHRENIA
  1. BODY
  2. MIND
  3. EMOTIONS
  4. PARTICULAR VULNERABILITIES
  5. PARTICULAR ABILITIES
  6. WHAT IT LOOKS LIKE IN THEIR CHILD
  7. OTHER
IE. SEVERITY AND COURSE OF ILLNESS
IF. TREATMENT NEEDED
  1. TRADITIONAL CARE
  2. NONTRADITIONAL, ALTERNATIVE CARE
  3. BEST OF ALL WORLDS CARE
IG. LIFE PROBLEMS FOR THE ILL MEMBER, CAUSED BY ILLNESS
IH. GREATEST FEARS
IJ. HOPES AND DESIRES FOR FUTURE
IK. INTERACTIONS WITH MENTAL HEALTH SYSTEM
  1. HELPFUL TO PATIENT
  2. UNHELPFUL TO PATIENT
  3. HELPFUL TO PARENT
  4. UNHELPFUL TO PARENT

II. The experience of caring for a person with SCHIZOPHRENIA.

III. PARENTS RELATIONSHIP TO THE CHILD
  A. CHARACTERIZE GENERAL RELATIONS
  B. INTERPERSONAL CONCERNS
  C. TURNING POINTS (Meaning changes)

IV. GENERAL SITUATIONAL DEMANDS

A. DEMANDS FROM THE SCHIZOPHRENIC MEMBER
B. DEMANDS FROM OTHER SOURCES

V. GENERAL COPING

VI. RESOURCES (Caregiver's intrapersonal resources)

A. What's available
B. What's unavailable
C. SPECIAL SKILLS ACQUIRED IN CAREGIVING

VII. SOCIAL SUPPORT

A. Who's available for what kind of support
B. Who makes demands for support
C. Self Help groups

VIII. COSTS TO CAREGIVER IN THE REST OF LIFE.

A. FAMILY LIFE
B. WORK
C. SOCIAL LIFE
D HEALTH

****

IX. OPEN CODE

X. COPING EPISODE

A. SITUATION
    1. Description of the event
    2. Other situational features
B. STAKES FOR CAREGIVER
C. COPING
D. EMOTIONS
E. EFFECTIVENESS OF COPING

****

X. COPING EPISODE

A. SITUATION
    1. Description of the event
    2. Other situational features
B. STAKES FOR CAREGIVER
C. COPING
D. EMOTIONS
E. EFFECTIVENESS OF COPING

****

XI. SITUATION OF POSITIVE EMOTION

APPENDIX C
EXAMPLE OF A CODED INTERVIEW

II. <u>The experience of caring for a person with SCHIZOPHRENIA</u>.

ADAPTATION TO CAREGIVING

"It's better now than it has been. It's better now living with him than it has been, in that the medication has more or less stabilized and he's comfortable with it and he takes it most of the time.

But we have...we're back to monitoring him now because we got these calls from Day Care so we decided he wasn't doing it properly. And it's better right now since (hsb) has been handling the money. Part of that burden has been off me because I've been dealing with that for a long time and the medication. And (hsb) been dealing more with the medication too because he went to Tough Love and they encouraged him to do that.

<u>I'm dealing with him more realistically than I used to. When I dealt with him with the anticipation that he was always somehow going to come out of it, so I'm better today with dealing with it on that level</u>. Today, although sometimes these unexpected turns will still jolt me. As prepared as I may be for them, I'm not. They'll always throw me off and I deal with a low grade depression all the time.

EARLY AND CURRENT NIGHTMARE

It's like living in a nightmare that you never wake up from.

I: Is it still?

C: Yes, yes it is but it is not as heightened...the trauma is not as heightened as it was because <u>you get used to the trauma and you live with it</u>. But it is basically a low depression that's there all the time, all the time. I'm always dealing with it. We...sure we laugh during the day. We do the things we have to do but it's there. And when I think about our son, if I have to think of him head-on I get...I don't try to think of what he couldn't have been or anything else anymore.

EARLY DAYS: ATTENDED TO OWN FEELINGS THAN TO Mental Health ADVISE

I hurt. A lot of hurt and pain and anger, and anger because I wasn't...I heard this (accusations that she was at fault) and I still was angry enough. I was looking for answers and I wasn't getting answers and I said, well maybe they have the answers, you know.

So she made...my own strong maternal need to protect our son overpowered everything they had to say. So I wasn't paying that much attention to them in that sense.

I: So in other words, they hurt you but they didn't dissuade you from the action that your own maternal kinds of feelings were.

C: Right.

TRIED TO SOLVE THE PROBLEM

First I tried very hard to think...overworking my brains to figure out how I'm going to get him out of this. Constantly figuring out different programs, different thoughts, different ideas.

CHANGES OVER TIME - THINGS ARE BETTER

But dealing with him is better and only because we're more apprised of his condition. We have that small support system, (at the day treatment center)

III. PARENTS RELATIONSHIP TO THE CHILD

A. CHARACTERIZE GENERAL RELATIONS

From this reading of interview #1 M sounds quite sympathetic to her son's condition. She mourns the loss of his capacities, believes that he's in pain, and is just living out his life, "faking it." She also finds comfort in the fact that he DOES seem capable of experiencing pleasure.

B. INTERPERSONAL CONCERNS

CONCERN FOR SON'S INDEPENDENCE

We went to see him (counselor at day treatment) just recently. We tried to stay away from there a long time. We wanted it to be our son's thing.

CONCERN FOR S`S COMFORT

We want to make sure they don't over do it. Because once he came home and he didn't tell us that they gave him...and then we gave him some and so he got over-medicated and he tells us that so it's not so bad. I can see he's miserable when he's like that.

CONCERN FOR S IN HIS ISOLATION

When he first got sick he was very...he was afraid to go out for a while, very isolated downstairs. He was very secluded here for a number of months. He loved Alexander Demoui so we bought him a forty volume set of Demoui. It cost me 75 bucks at an old book store. And Sherlock Holmes, which he loved so I thought at least he'll get into...well he started to. It did help him a little bit.

And when he was suicidal we would go to restaurants a lot. He liked that. Made him feel special.

C. TURNING POINTS (Meaning changes)

IV. GENERAL SITUATIONAL DEMANDS

A. DEMANDS FROM THE SCHIZOPHRENIC MEMBER

ATTEMPTS TO MANIPULATE MOM (HER PERCEPTION)

It would drive me insane because he was constantly manipulating me (RE:MONEY). He knows me to be the softer touch between the two of us.

I: And you are?

C: Yeah. And I'm the more emotional one. I'm the one who screams more but I'm also the softer touch. I give in more.

TIMING OF ILLNESS MAKES A DEMAND--THWARTS EXPECTATIONS

Mary Ellen Walsh says it's vicious because it comes to you at the time when you expect your son and daughter to go out in the world and make it on their own or even if their living at home, they're doing their thing. And that's when suddenly everything reverts right back again.

SSI IS SUPPORT PLUS A STRESS BECAUSE SON WANTS MONEY FOR DRUGS

I had to work hard to get SSI and I'm grateful we have it but it's also... the first of the month comes around and he's right on us for a bit check of money to go downtown. We know what it means.

(He wants to go buy drugs.) And there definitely a change in our son, when he comes home and he's had some drugs. There's no question about it. And he never learns. Always says he's learned but he never does.

"ESCAPE" OF MOVIES NOT WIDELY AVAILABLE WITH SON

We have taken our son to the movies with us and it's been disastrous. He gets very restless and there's not...we can only go where there's smoking and if there's no smoking then he's out in the lobby more than he's in watching the movie with us. Or he doesn't like the movie or something usually happens. We've gone with him a few times but we prefer not going with him when we can help it, unless it's something he can enjoy with us.

B. DEMANDS FROM OTHER SOURCES

DEVELOPING A TRUST RELATION WITH S'S TREATERS

Even his recent psychiatrist, who he's had for a number of years now. First...when he first spoke to me he said, "Your son has to make his own decisions you know". After a while he's come to learn and realize that our son doesn't make very good decisions. He's come to realize...

MALTREATMENT BY SON'S DAY TREATMENT COUNSELOR

I decided we got to go down there and see how we can unravel some of this so they can maybe heighten their understanding of what's going on, you know (laughter). He wouldn't look at me. This guy was sitting here like this and I talked to him and he wouldn't look at me, he'd look down, or he'd look at (hsb) while I was talking to him. (Hsb) couldn't stand it either.

V. GENERAL COPING

EXPRESSES ANGER DIRECTLY AT SON

There have been times when I've been mad at my son and say I wish you were dead and I wish somebody would just beat you up or something cause when he gets psychotic and screams the way he does...I go...(laughter) I get psychotic myself.

But I have my own temper. I don't scream at him as much anymore as I used to but I do get angry. I don't get angry in the same degree, but that anger is there. ...Just tell him, "I'm angry with you now for what you've done".

COLLECTS THINGS-- NOW OUT OF CONTROL

"Of course my clutter is worse than ever, as you can well witness. And that is bugging me to some degree because I've always been more or less a collector and a pack rat, but it's just gotten out of hand in the many years of dealing with my son.

ESCAPES THROUGH MOVIES (LESS SO NOW)

"It's (going to the movies) is a good escape, better than just watching the t.v. The t.v. is still...you're focused in all around on your environment. But that takes your mind away. It's like taking it to the laundry for a little while. And you need that.

VI. RESOURCES (Caregiver's intrapersonal resources)

A. What's available

B. What's unavailable

C. SPECIAL SKILLS ACQUIRED IN CAREGIVING

MONITORING AND ADJUSTING MEDICATIONS

He gets very uncomfortable if we give him more than he should take. Sometimes we'll give him more when he needs it. But he's most comfortable with twelve, in fact the Center calls us at times. "your son is acting up and we have to give him more medication", and stuff like that.

I: Do they have more medication for him there?

C: They do and we want to make sure they don't over do it.

ADVOCACY WITH MENTAL HEALTH SYSTEM

I'm always (upset?) with the Day Care Center when they say feel he's acting out of sorts and they want to give him extra...how much extra are you giving him? I want to make sure that their not treating him...over-medicating him.

SKILLED OBSERVATION: SEES EARLY BODY SIGNS OF PSYCHOSIS

You can almost see it coming on him when it does come on. He starts...his position...his arms start moving like he was a muscle bound guy and he's (laughter) not a muscle bound guy. You know, like a big tough guy and it's funny to watch it if you didn't realize...if it weren't also so tragic.

SKILLED OBSERVATION: RE LAUGHTER AS SIGN OF PSYCHOSIS

They (bowling partners) just scream because they threw a strike, "Wow" and some of them get their jollies just getting that stuff out. It effects him. Yet he likes being part of them and they'll be laughing together. He's not laughing with them. He doesn't know what he's laughing about.

He starts getting this heightened giggle and then he gets...when he gets like that then we know he's off some where. And he'll say, "I'm telling myself some jokes." We try to bring him back to reality.

COACHING APPROPRIATE BEHAVIOR

We try to bring him back to reality. Saying "Son, what are you laughing about?", or "come on, we got to win this game", you know. This kind of stuff. But then we've got to say, "Hey son, not that. Look at the arrows, look at the arrows." Because he can start bowling in the wrong alley, you know.

APPENDIX D
EXAMPLES OF CODED CODING EPISODES

COPING EPISODE # 1 Use of drugs/ Family Conflict

A. SITUATION

1. Description of the event

> "When he gets twenty or twenty-five dollars he goes downtown. I'm trying to tell him no drugs because sometimes he'll come back having had a couple of puffs on a joint of marijuana and he starts to freak out here. He'll start to get hostile with us his usual symptoms of being schizophrenic. He gets mad at us. He can't stand high volumes from the t.v. or the radio. He accuses us of being satanic. He'll start using obscenities toward either one of us. Motherfucker, or whatever enters his mind.

Mother gets really upset and starts a row with Son. Dad tries to keep them distant from one another, to give Son his Trilafon and keep some peace. Dad also tries to intervene in his fashion, as described below.

Dad recognizes that Son is attracted to the fight. Dad believes because it represents love to Son.

> "It's like a magnet, he's pulled back up (to the living room from his bedroom). Because in a sense all that shouting, even though it's a verbal hostility and profanity it's still...it's still like a room splashed in brilliant...in gaudy colors, but the word "love" is written across it. Because nobody who didn't love him would tolerate it.

2. Other situational features

Repetitive event for the family.

B. STAKES FOR CAREGIVER

CONCERN THAT GIVE HIS SON'S "TRUE CHARACTER" A CHANCE

> "After a little bit he'll get hold of himself, apologize and then the sweetness of his real character takes over for a while.

CONCERN THAT WIFE'S RESPONSE IS NOT THERAPEUTIC

> "Sometimes it's very hard because (wife) will lose her coolness. And she feels very righteous about being angry at him when he gets hostile with her because she doesn't seem him as being sick. At that moment she just sees him as being her son shouting at her and hostile and she gets hostile with him.

CONCERN RE: ATTEMPT TO PREVENT DRUG USE/ SYMPTOMS

> I'm trying to tell him no drugs because he'll come back having had a couple of puffs and he starts to freak out here.

CONCERN FOR WIFE'S SELF CONTROL

> She has to have time because she has all this energy and she needs time to settle herself down.

C. COPING

DIRECT ACTION TO LIMIT SYMPTOMS - MEDICATIONS

> If we notice that he's come back from downtown that way, we remind him that the drugs will neutralize his medicine and he needs to take some more or Trilafon

DIRECT ACTION- PERSONALLY TRIES TO CALM SON

> "If I'm very calm and repeat over and over something soothing, after a little bit he'll get hold of himself.

LIMITS CONFLICT BY SEPARATING SON AND WIFE

Generally if I'm here I try to get him to go downstairs for a while. She has to have time because she has all this energy and she needs time to settle herself down.

COMFORTING COGNITION: CONFLICT REPRESENTS LOVE TO S

"But somehow he knows that when she's mad at him and shouts and she gets obscene that it's his mother, because he's lived with her all his life. He knows she loves him.

D. EMOTIONS

Not really explored

E. EFFECTIVENESS OF COPING

Separating son and wife will sometimes work, if he can also get some Trilafon into Son.

Sometimes Dad's soothing approach works to calm son down.

Dad does seem comforted that the conflict represents affection to son.

****