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# A Grounded Theory of Families Responding to Mental Illness<sup>1</sup>

Linda Rose  
R. Kevin Mallinson  
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*Despite decades of research documenting family burden related to mental illness of a relative, little is known about families' responses over time. A grounded theory study was designed to describe families' responses to these severe mental illnesses. Twenty-nine participants representing 17 families were interviewed 3 times over 2 years. Interviews were analyzed using constant comparison. Living with ambiguity of mental illness was the central concern. The basic social process was pursuing normalcy and included confronting the ambiguity of mental illness, seeking to control impact of the illness, and seeing possibilities for the future. Goals were managing crises, containing and controlling symptoms, and crafting a notion of "normal." Strategies were being vigilant, setting limits on patients, invoking logic, dealing with sense of loss, seeing patients' strengths, and taking on roles. The study revealed that families were profoundly affected by the social contexts of mental illnesses.*

Forty million adult Americans are affected by mental illnesses each year (U.S. Department of Health and Human Services, 2000). Of that number, 2 million have a diagnosis of schizophrenia; affective disorders—the leading cause of disability in the United States—affect 6.5% of all women and 3.3% of men in the country. Characterized as both “severe” and “persistent,” these illnesses remain poorly understood and inconsistently managed and are often unpredictable in terms of outcomes.

Severe mental illnesses (SMI) such as schizophrenia, bipolar disorder, and major depression are often devastating illnesses that extract a significant toll on both patients and their families. Characterized by alterations in thinking, mood, or behavior, these illnesses affect patients' abilities to relate to

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others, to function independently, and to remain in the community without repeated hospitalizations. Family members become caregivers, providing ongoing support and practical assistance while grappling with their lack of understanding of the mental illness itself. Being a caregiver extracts a heavy toll as families question their ability to adjust to the illness and deal with their own reactions to it (Magliano et al., 2000; Maurin & Boyd, 1990).

Inadequate and restricted access to care often means that families find themselves as the primary source of support to patients although they feel they are the least equipped to handle mental illness. They monitor symptoms, help with medication management, and intervene on the patient's behalf to get treatment (Reinhard, 1994). Such a role frequently causes a great deal of psychological strain and a sense of burden. Although some families do cope well, others continue to struggle with anxiety and worry associated with their efforts to help the patient. Our ability to identify and offer assistance to these families has been hampered by a lack of understanding of their cumulative experience with mental illness in the context of changing family life and evolving relationships with the patient. The purposes of this study were to (a) develop a substantive theory that described how families managed the experience of mental illness and how that process was influenced by critical elements of their personal situation, and (b) identify points in the process where families seemed to need help in coping with the illness while also highlighting the characteristics of families who were doing well.

## BACKGROUND

Mental illnesses represent unique experiences for family members, in no small part because of enduring social and cultural climates of secrecy, stigma, and a tendency to perceive mentally ill persons as weak, dangerous, and unpredictable (Crisp, Gelder, Rix, Meltzer, & Rowlands, 2000). The person afflicted with the illness often resists the diagnosis, may not cooperate with treatment, and will often resist the efforts of family members to intervene (Karp & Tanarugsachock, 2000). Families try to make sense of mental illness as a personal experience: They need to deal with problems that occur as a result of the illness, and they must learn to cope with intense emotional responses to the illness (Karp & Tanarugsachock, 2000). Their ability to come to terms with the mental illness and forge a satisfying relationship with the patient greatly affects the degree of burden and stress (Rose, 1998; Scazufca & Kuipers, 1996).

Burden associated with family caregiving of mentally ill persons has been well documented for the past three decades (Bibou-Nakou, Kidaiou, & Bairactaris, 1997; Greenberg, Kim, & Greenley, 1997; Hatfield, 1978; Jones, Roth, & Jones, 1995; Magliano et al., 2000; Maurin & Boyd, 1990; Perlick et al., 1999; Pickett, Cook, Cohler, & Solomon, 1997; Thompson & Doll, 1982) and continues to receive attention (Baronet, 1999; Jenkins & Schumacher, 1999). Burden is commonly defined as the negative consequence to families related to their caregiving roles (Reinhard, 1994) and includes fatigue, worry, restricted activity outside the home, and financial costs and constraints (Jenkins & Schumacher, 1999). Efforts to cope can be highly stressful, particularly in the absence of social or professional support (Reinhard, 1994). Chafetz and Barnes (1989) found that families identified the following as most stressful: the emotional and mental state of the ill relatives, fears about the future, unpredictability of the patient's progress, and relationship problems. Families attempting to prevent a relapse are often afraid they might exacerbate the illness through their own actions (Rose, 1998). The initial diagnosis of a mental disorder can be particularly stressful, resulting in reactions of shock, confusion, and fear (Hatfield, 1978; Hinrichsen & Lieberman, 1999; Rose, 1983; Tennakoon et al., 2000). Families have a sense of loss and grief; the losses can be actual, such as loss of functioning level, or symbolic, such as the loss of hope for the future (Eakes, 1995; Marsh, 1998). Stigma further hampers coping as families are highly selective about seeking support from others, anticipating negative reactions and a lack of understanding (Chafetz & Barnes, 1989; Rose, 1998).

### **Characteristics of Serious Mental Illnesses**

Symptoms of mental illness are often reported as having the greatest impact on other family members (Perlick et al., 1999), regardless of diagnosis (Jenkins & Schumacher, 1999). Positive symptoms of schizophrenia (hallucinations, delusions) can be perceived by family members as odd or bizarre and sometimes frightening. Negative symptoms of schizophrenia (social withdrawal, apathy, and impaired cognition and decision making) may be even more disturbing and frustrating to family members (Rose, 1996), perhaps because they are so difficult to influence. Affective disturbances of the depressed patient, characterized by apathy, helplessness, and hopelessness; and mood swings of bipolar illness are sources of great frustration, concern, and sadness for family members.

Families of young adults confronted with a diagnosis of mental illness experience shock, confusion, a search for solutions, struggles to acknowledge

permanence of the illness, and finally a search for hope and determination (Badger, 1996; Howard, 1994). The lifetime of responsibility of parental caregiving has been characterized as an experience of disruption, loss (Ryan, 1993), chronic sorrow, and grief (Eakes, 1995). Families of persons with major depression experience "family transformations" as they struggle to adjust to the changes caused by the depressive illness (Badger, 1996).

Burden may be affected by caregiver characteristics, such as age, ethnicity, and gender. Older caregivers may experience more distress than younger caregivers (Cook, Lefley, Pickett, & Cohler, 1994). African American caregivers report less caregiving burden than their Caucasian counterparts (Guarnaccia & Parra, 1996; Horwitz & Reinhard, 1995), although the reasons for this difference are not clear (Stueve, Vine, & Struening, 1997). Experiences of male caregivers, particularly fathers, have not been widely investigated. In a recent study, Johnson (2000) found that males interpreted the mental illness as a lack of motivation rather than a biological illness. Mays and Lund (1999) concluded that male caregivers were strong advocates for mentally ill relatives and were committed to the caregiving role. Family strengths and family competence have been found to play important roles in family coping (Doornbos, 1996). Strong familial bonds and familial commitment may moderate burdens associated with caregiving (Johnson, 2000). Although caregiver burden and stress have been described, these related contextual influences, as well as personal and family values, remain understudied, and cross-sectional, correlational studies have provided mixed results (Baronet, 1999).

The emotional climate of families has been shown to affect the course of the patient's illness. Labeled "expressed emotion," or EE, this construct includes indicators of a hostile family environment, critical remarks toward the patient, and emotional overinvolvement. Numerous studies have shown that the higher the level of EE, the more likely is the chance of a relapse of the illness requiring hospitalization (Falloon et al., 1982; Vaughn & Leff, 1976). More recent studies examined associations of EE to other concepts. For example, Scazufca and Kuipers (1996, 1999) found significant correlations among level of EE, burden, and type of coping strategies used. Family caregivers who use more emotion-focused coping strategies may experience higher levels of burden (Magliano et al., 1998). In a recent study of overall family functioning, psychological distress, social support, and coping, the presence of social support led to more effective family functioning and less psychological distress by family caregivers (Saunders, 1999). The findings of these quantitative studies, while compelling, also indicate that additional research is needed to understand more fully the contextual environments in which the EE and other familial responses to mental illness occur. Questions

remain about how these factors change over time and how families perceive and respond to the personal experience of mental illness.

Investigators are beginning to address this gap by using qualitative approaches that focus on families' perspectives of their caregiving experiences. The role of males as caregivers has been explored (Howard, 1998; Mays & Lund, 1999). Families' experiences with the health care system, including involuntary hospitalization (Crisanti, 2000), barriers to help-seeking (Czucta & McCay, 2001), and supportive and nonsupportive interactions with professionals (Doornbos, 2002; Rose, 1998a), have been documented. Cultural differences in families' experiences have not been well studied, although a recent qualitative study that explored the experiences of Thai mothers (Rungreangkulkij & Chesla, 2001) represents an important contribution.

*Meaning* of caregiving has been explored in several qualitative studies. Tuck, du Mont, Evans, and Shupe (1997) found that parents of children with schizophrenia struggled to frame illness-related events as normal while trying to live with the uncertainty of the illness. Chesla (1994) found that parents' caring practices were influenced by their notions of basic parenting concerns and values. Ayres (2000) described the meaning of caregiving as a process of integrating expectations, explanations, and strategies into the caregiving role. Badger (1996) used grounded theory methods to identify stages in the process of family members' responses to depression. Contextual factors identified in that study as influencing the process were family functioning, relationship changes caused by the illness, understanding of symptoms, stigma, and need for self-preservation.

Participants in these studies were most often parents (Chesla, 1994; Crisanti, 2000; Tuck et al., 1997), and participants were interviewed only once (Badger, 1996; Mays & Lund, 1999), thus restricting the investigator's ability to capture changes in family perspectives over time. No studies were found that used a grounded theory approach to investigate processes of coping over time with multiple family members of persons with serious mental illnesses.

## METHOD

Grounded theory methods (Strauss & Corbin, 1990) were used to conduct this study. Derived from a theoretical perspective of symbolic interactionism (Glaser & Strauss, 1967), the grounded theory method was seen as particularly appropriate to this study of families and mentally ill persons, in which

the focus of inquiry is the families' process of dealing with mental illness in the social and interpersonal contexts of their daily lives (Benoliel, 1996). Furthermore, grounded theory posits that meaning for situations, such as mental illness, is constructed through these social interactions. Prior qualitative work focused on the families' processes of creating meaning for caregiving by delineating what they could do that would positively influence the outcome of the illness (Rose, 1998b). Families in that study, however, were interviewed only once, and no attempt was made to capture changes over time. The study reported here extends that work by allowing for more in-depth investigation of contextual factors that affect families' understandings of the illness and their responses to it over 2 years.

### **Participants**

Twenty-nine participants who were family members of 17 patients were recruited. Patients had a diagnosis of schizophrenia, major depression, or bipolar disorder. Nine families included 2 family members; all others included a single family member. Of the 17 families interviewed at Time 1, 12 also participated at Time 2 and Time 3. Families did not continue after the first interview for various reasons. One family stated they did not see how it would help their relative; another elderly woman stated that her general health was poor and that she could not continue. Two families were lost to follow-up (phone disconnected or phone calls not returned), and one family scheduled 3 interviews but did not attend and so was not included in the study.

Following a purposive sampling plan, participants were sought who represented variation in the phenomenon of interest. Family members of both hospitalized and community-based psychiatric patients were sought. Additional variation was sought on the key characteristics of caregivers previously understudied in caregiver research, including gender, ethnicity, socioeconomic status, and length of time since diagnosis. Theoretical sampling was used as the study progressed and concepts emerged from the data as potentially useful in developing the theory. For example, families in which a single caregiver and the patient made up the family unit were included in the study as contrasting cases to families with 3 or more members. Families were recruited for the study if the ill relative had experienced at least 2 hospitalizations or had been in active treatment for at least 2 years. Theoretical sampling (Strauss & Corbin, 1990) was used to refine this category to allow for more variation in length of illness experience.

Permission was obtained from patients to contact their adult relatives. Family participants self-identified or were identified by the patient as a member of the family who had at least one contact per week with the patient. Most patients had a history of at least 3 hospitalizations; several patients had experienced at least 5 hospitalizations, and 2 patients had 10 or more hospitalizations. Time since initial diagnosis ranged from 2 years to more than 10 years. Approximately half of the patients were living with their families.

Consistent with the grounded theory goal of achieving theoretical sensitivity by seeking heterogeneity of participants (Glaser, 1978), the families were diverse in regards to relationships to the patient as well as in income and education level. Diversity of race was of particular interest because minorities have been seriously understudied to date. Participants were parents ( $n = 13$ ), spouses ( $n = 4$ ), adult siblings ( $n = 8$ ), or adult children ( $n = 4$ ) ranging in age from 18 to 73 years old. Slightly more than a quarter of the sample had annual incomes of \$20,000 or less, and 30% had no more than a high school education. Of the 29 family members who participated at Time 1, 19 were female and 10 were male. Ethnicity of the participants was Caucasian ( $n = 19$ ), African American ( $n = 8$ ), and Hispanic ( $n = 2$ ).

### Procedure

Approval for informed consent procedures and protection of human subjects was obtained from the Institutional Review Board of the medical institution where the study was conducted. Three interviews were scheduled with each family over a 2-year period. The first interview was conducted as soon as possible after initial contact. The second interview was scheduled approximately 6 months later, and the third interview was completed 1 year later. Letters and postcards were sent to the families throughout the time of the study to enhance retention and to inform them of the progress of the study.

The purpose of the first interview was to elicit the "story" of the illness and to place current concerns in the context of past experiences. The purposes of the second interviews were to extend knowledge of family responses over time, to investigate patients' adjustment to the community, and to identify problems and concerns that might have arisen in the intervening period. Patients were included in the second interview when available, and participant observation of family interactions was done at that time. This provided additional data on interactions between patients and family members that were recorded on audiotape immediately following the sessions. The third interview was used to validate the emerging theory with



participants. They were given a brief description of the analysis to that point and asked to comment on the relevance of the emerging conceptualizations to their situation. All interviews were audiotaped and transcribed verbatim. Length of interviews ranged from 60 to 90 minutes.

Interviews were semistructured and followed a topical outline that focused on the following areas: the family's story of the illness and how it started; elements of the caregiving role, including tasks, responsibilities, and day-to-day management strategies related to patient symptoms and patient stress; social/cultural issues and concerns, including experience getting care and any awareness of stigma; and thoughts about the future, including goals for the patient and problems anticipated. All interviews were conducted in the families' homes with the exception of two interviews that were conducted in the investigator's office at the participants' request.

Each interview was reviewed during regular meetings of the research team to ensure that all topics were consistently covered with each family over the course of the interviews. Consistent with the grounded theory approach of saturating categories (Strauss & Corbin, 1990), data collection continued until nothing new was being heard and all areas that seemed to warrant further investigation had been pursued.

*Data analysis.* The substantive theory was developed within a paradigm of contexts, conditions, strategies, and consequences. This process encourages "density and precision" in the resultant theory (Strauss & Corbin, 1990).

Data analysis was conducted using constant comparative methods described by Strauss and Corbin (1990). Each Time 1 interview was transcribed and read prior to conducting the second interview with each family. The same procedure was used between Time 2 and Time 3. Field notes recorded immediately following the interview noted how the family members talked to each other and to the patient, the degree to which the patient participated in the interview, and indicators of family functioning. Field notes were reviewed along with the transcribed interview data.

Data coding procedures were as follows. *Open coding* involved reading the entire transcript and labeling discrete units (usually several sentences or a paragraph) according to their meaning or importance. Then, *coding for categories* identified relationships among like groupings of these initial codes, and more abstract labels were attached to the categories. *Axial coding* was the process of exploring the variations with a category (Strauss & Corbin, 1990). Contexts, conditions, and strategies were then identified as properties of the process that explained the variations among family

members' responses and how well they managed the illness over time. Critical tasks guiding the analysis included the identification of the basic social problem (BSP) confronting the families and the basic sociopsychological process (BSPP) that explained most of the variation in family coping with mental illness over time.

*Trustworthiness of the data.* Each interview was read and coded by at least two members of the research team. Weekly meetings provided an opportunity to alter, clarify, or create specific codes and were supplemented with periodic group coding sessions. Discrepancies in coding were discussed until consensus was achieved. Code definitions were compiled into a codebook to ensure that all coders were using code words in the same way.

Credibility of the study's findings was addressed by sharing emerging conceptualizations with the families at Time 3. A computer program designed for qualitative analysis was used to maintain chronological written documentation of the iterations and increasing abstractions inherent in the coding process. This program was also used to address validity of the findings because it provided for retrieval of similarly coded passages from any or all interviews simultaneously; it was used to identify conceptual links between codes and categories in a rapid and systematic manner; and it linked the analysis directly to the data. At regular intervals, the research team reviewed the intact participant transcripts for clarification and to ensure that interpretations remained grounded in the data. A case summary was created for each family to ensure links to family context as the coding process became more abstract. An audit trail, consisting of notes and memos compiled during analysis sessions, documented the investigators' responses to the data, "emerging hypotheses, analytical schemes, hunches and abstractions" (Stern, 1980). The memos, developed in conjunction with coding of individual interviews, were regularly reviewed as part of the iterative process of developing the substantive theory.

## RESULTS

The BSP of living with ambiguity of mental illness was identified as investigations were conducted into other topics, such as the sense of loss and the impact on family relationships. Families tried to see the illness as biologically based while considering notions of healthy and normal behavior.

### **Pursuing Normalcy**

The BSPP was pursuing normalcy for the patient. Whereas definitions of what constituted normal in this context varied to some degree, there was a remarkably consistent and compelling view that being healthy meant functioning as normal adults would function: being happy in an adult relationship, having meaningful employment, being independent, and thinking clearly and logically. Pursuing normalcy was defined in this study as “a perspective or a general attitude characterized by thoughts, actions and emotional responses centered around the patients’ achievement of normative goals in a manner that would be expected if the illness had not occurred.” The intensity of the grief, anger, and frustration family members experienced was related to the degree to which they could: (a) revise their notions of being normal to match the situation, (b) work with the patient to actually conform to preexisting notions of functioning normally, or (c) support the patient to achieve a state of “being happy.”

The components of the process were threefold: (a) confronting ambiguity of illness, (b) seeking control over the illness, and (c) adopting a stance of possibilities and realities. Within each component, there were specific goals that families focused on and strategies they used to achieve them. Just as the overall process was not necessarily a linear one, these strategies could be used in other components as the situation required. For example, families could move from seeing possibilities for the future to reexamining ambiguities about the illness itself, a shift precipitated by the patient’s rehospitalization or a new prognosis from a new physician. Figure 1 shows the substantive theory of family responding to mental illness over time.

### **Confronting Ambiguity**

Families responded to the emergence of symptoms and resulting diagnosis with feelings of unreality and a sense that living a normal and predictable life was threatened. Ambiguities were evidenced by the uncertainty they felt about the effectiveness of their own responses. These responses were grouped into three categories: (a) keeping watch/losing trust, (b) being consumed by the illness, and (c) making sense of behaviors as illness symptoms.

*Keeping watch/losing trust.* Families were consumed by questions of unpredictability: “You don’t know what he’s going to be like from day to day.” They were uncertain about how much they could trust the patient to take care of himself or herself. “He became someone you think you need to look

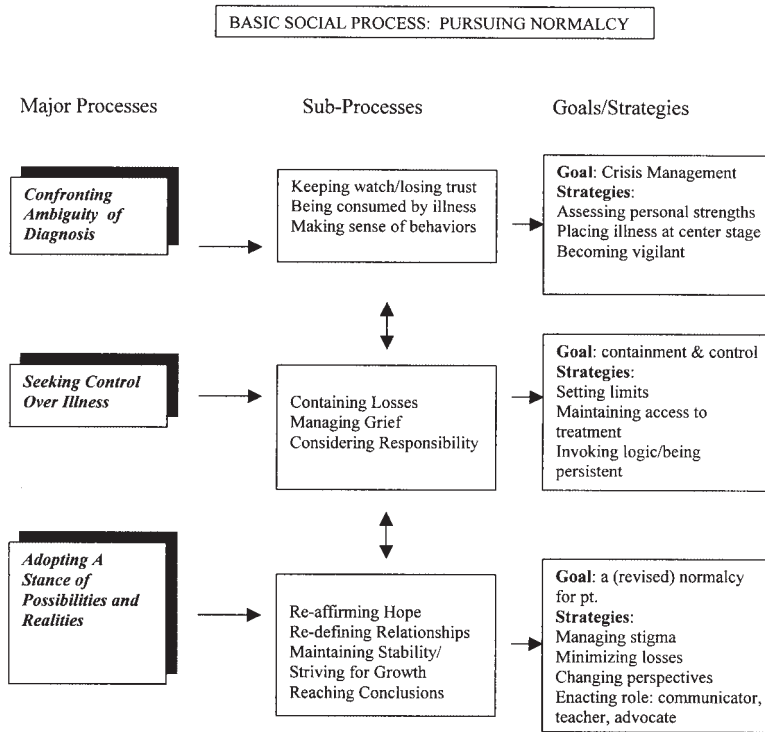


Figure 1: The grounded theory of pursuing normalcy.  
 NOTE: Conditional and contextual factors influenced by age of patient (at onset and at current time), patient employment status, degree of patient's social impairment, family support, system support, treatment access, and family values and goals.

after because you're always checking up on him." The concern was made more intense when erratic patient behavior followed a period of relative calm. Families described an enduring stance of watching and waiting. They worked to figure out the subtleties of symptoms and worried about what they meant.

*Being consumed by the illness.* Families in the initial stages of the illness described closing themselves off from other family experiences in order to tend to the ill relative. Intense feelings of anger at the health care system for poor treatment, the lack of clear information, and a sense of helplessness also characterized this phase of their response to the illness. Family life was characterized by an atmosphere of heightened vigilance in which a family concluded that the patient could not be left alone for any period of time.

*Making sense of behavior as illness-based.* Families had many questions and a sense of confusion. They asked themselves, "How bad is it? How permanent is it? What caused it? How long will it last? How disruptive will it be?" The experience was seen as unique, like nothing else they had encountered. As one parent stated, "As many times as you tell people, they don't understand until they live it. Even counselors, doctors, I don't think they really understand how it tears a family apart. Oh, God, it tears a family apart." In the early stages and during many repeated hospitalizations, family members described a sense of crisis and an urgent need to find answers to help them to manage the crisis.

### **Seeking Control Over the Illness**

As families' experiences with mental illness continued, they began to seek ways to regain control over the illness, to lessen the impact on the patient, and to influence its course. The following subcategories of seeking control were identified: containing losses/managing grief, navigating the system/becoming savvy, and questioning responsibility for illness management.

*Containing losses/managing grief.* The extent of the losses that families identified for the patient as a result of the illness and the permanence of those losses determined the depth of the grieving that families experienced. The full extent of this aspect of the experience is complex and occurred on many levels: individual, family, and societal. They managed grief by using a variety of strategies, mainly to protect themselves from the intense pain. A father described his reaction to his daughter's severe bipolar illness and suicide attempt:

It is recently that I have learned to cope by tucking this problem in a little compartment inside of me, so that I can function the rest of the day with the pain. The pain goes away into some corner and sits there and waits.

Loss of preillness family relationships was a key focus of families in this stage. A 19-year-old son explained his reactions to his father's depression: "I didn't feel like dealing with him. I didn't want him to be my father anymore." He went on to describe how he sought out another person as a father figure.

*Questioning responsibility for symptom management.* There were clear disagreements across families regarding who is responsible for managing the illness and what aspects could be managed. Many families wondered if it

should be up to the patient. For some, this concern was primarily in the area of medication, for others, it was daily functioning, such as getting a job or being social. A mother stated:

The only thing we can do is encourage him. We can't take him and put a pill down his throat. That's something he has to want to do. I don't care what you say or how you say it. He's got to do it. That's the biggest thing. He's got to do it.

Relationship patterns shifted at this stage as families experienced the ebb and flow of waning and resurging hopes from periods of calm and episodes of crisis and acute exacerbations of the illness. Families considered shutting the patient out, sometimes physically, as one mother did by locking her ill son out of the house. Families reached breaking points in their tolerance of patients' behaviors, such as when the patient became physically threatening or began drinking alcohol to excess.

They tried to reason with the patient, in effect to talk them out of symptoms. They felt the patient could be reached with reason and logic. It was as if they refused to allow the illness to take over the patient's mind in this way. They asked the patient, "Why do you do it?" and, "Don't you see that what you're saying doesn't make any sense?" Learning to "navigate the system" was necessary because all the families had experienced patients' treatment in more than one facility and with more than one therapist, requiring a new learning process each time with regards to how that system worked. Some families were clearly exhausted by the efforts and decided to settle for a peaceful environment rather than risk agitating the patient by pushing him or her to do more.

### **Adopting a Stance of Possibilities and Realities**

Initial shock, fear, frustration, and anger gave way to intense sadness and grief for what was lost and might never be regained, but for some families it led to a feeling of a cautious optimism for the future. For families who maintained or regained some hope, they were able to balance ambiguities associated with the illness with possibilities of marked improvement, recovery, and even cure. The degree of hope felt was a fluid and fluctuating experience that involved compromise: a compromise between a life without mental illness and a life where the illness is present but not all-consuming. The subcategories of contemplating the future were reaffirming hope for the future, redefining relationships, maintaining stability while striving for growth, and reaching conclusions.

*Reaffirming hope.* Families were hopeful if they had experienced specific pivotal events, such as the patient's getting a job, or had come to realize that a hopeful stance was more helpful to the patient. Other factors affecting a sense of hope were identifying patient strengths, seeing that their efforts at relating to the patient were making a difference, and/or seeing a positive patient response to new medications or a new therapist. The absence of improved functioning over time, rather than deterioration per se was enough to dash the families' hopes for the future. Having options was necessary for families to feel competent to effect some change. A daughter described her evolving response to her depressed father: "Now I think, 'What can I do to make it better?' instead of, 'How do I get out of this situation?'"

*Resolving questions of responsibility.* Families reached a stage where they made important decisions about who was ultimately responsible for managing the illness. Families either communicated an expectation of self-responsibility to the patient or continued to accept it for themselves. Families at this stage were less willing to excuse behaviors as illness based and attributed a degree of manipulation and innate intelligence to the patient, who, in their view, was deciding to behave in certain ways. A mother put it this way: "He [patient] can use his illness as an excuse." Another family member concluded, "It's just the way he has chosen to be. Everybody knows it, and he knows it too."

For families who did not feel the illness had been contained (no aspect of the patient had been unaffected), they attributed no responsibility to the patient for its management and decided the patient could not be normal. One family member illustrated this concept by saying, "She couldn't hold a job. She is no where near being a normal person from the standpoint of taking and holding responsibility."

Families accepted limitations on what they could do. They were aware that "we can't and shouldn't do it all" but struggled with the sense that the patient was "like a 2-year-old." Several families emphasized the age of the patient as a critical factor. The patients in these cases were males who were 30 to 40 years of age and therefore were seen as adults who had the right and the responsibility to take care of themselves. For others, they viewed the damage of the illness to be so great (it had occurred at such a young age and had gone on so long) that the patient's ability to be responsible was permanently limited, and families took over. A father explained, "You can't really bury that stuff. It's your unfulfilled expectations that serve the frustrations and the frustrations that serve the anger." He went on to explain his final stance: "I realized that she has to live her life. I can't live it

for her.” Conclusions were reached in the context of a stance of cautious optimism for the future, as exemplified by this mother’s statement: “So many things I would like to see him do . . . He’s 90% better than he was. I’m hoping and praying.”

*Redefining relationships.* Families were engaged in either maintaining the status quo in relationships with patients or pushing for change in those relationships. This process was particularly affected by the nature of relationships prior to the illness. Males were as involved and as invested in defining relationships with patients as females were. As one father noted, “I’m the one who had my son committed three times.” Fathers and daughters had unique relationships that in many cases were intense. “We have a history of conflict,” a father said. Adult children took on a supporter role for the primary caregiver (usually a spouse). In each of these cases, relationships were adjusted to take into account the limitations they saw for the relationships as a result of the illness.

*Maintaining stability while striving for growth.* Several families had experienced violent behavior by the patient in the past or had been involved in numerous committal processes involving the police. It was harder for these families to consider pushing for growth and goal achievement. For them, their goal was to maintain calm and avoid the chaos associated with disruptive patient behavior. A father whose son had a history of throwing furniture describes his view: “It would be nice if he had some ambitions, but we’re not going to rock the boat and take a chance on him coming in and [becoming belligerent].” Another family concurred: “I am very comfortable with the way things are going, outside of one or two things. I just wish he would go out more.”

*Reaching conclusions.* This component of the process was characterized by unambiguous statements of priorities, decisions, and evaluations of situations. Families achieved this in part by looking back and seeing what they had endured, appreciating how far they had come from the initial days of the illness, and seeing how much they had learned. For example, families set priorities in relation to what they wanted for their relatives: medication, employment, and meaningful social relationships. They made decisions about how hard to push or how much to “back off” because, they concluded, pushing the patient would do no good.

Families revised their notions of what it meant to be normal to include their wish that the patient be happy. This conclusion took several forms. For



example, a wife was firm in her conviction that for her depressed husband, "Nobody can make him happy except him." A brother decided that his sister's happiness was a quality of life concern for them both:

It's going to be there, and I know she going to have times when she's going to need help; she may have a breakdown . . . but try to make it easier, try to make it better for her. Somewhere in her life that she can be more happier and then at least if it means 8 months out of a year she is happy, four months out of the year she isn't, at least some part of her life is she will be happy. If that is all that it is, that would make me happy.

## DISCUSSION

The emergence of normalcy as a central concept in the families' process of managing mental illness is important for several reasons. The families' stories illustrated the complex and difficult process of accepting the social implications of mental illness. Families were most concerned about understanding the behavior they were seeing—and helping others to see the behavior—as illness based. They were engaged in a complex process of accepting the illness as personal experiences. To date, normalizing has been investigated primarily as a coping response of parents with a chronically ill child (Anderson, 1981; Deatrck, Knafl, & Walsh, 1988; Knafl & Deatrck, 1986). Strauss and Glaser (1975), in their seminal work on chronic illness and quality of life, discussed normalizing as a strategy that involved concealing the illness by acting as if life were normal. This study adds to that body of work by conceptualizing pursuing normalcy as goal-oriented, used by family members of adult relatives with serious mental illnesses to make sense of their experience. The families' accounts strongly suggest they were engaged in an effort to help the patient be normal. Achievement of that goal required them to consider and revise their own notions of what it means to be normal. As Rehm and Franck (2000) noted in their study of families of children with HIV/AIDS, normalization in chronic illness is emerging as an important focus for chronic illness research. This study provides further evidence that families of persons with stigmatizing conditions, such as mental illness and HIV, carefully choose specific strategies to reach that goal (Rehm & Franck, 2000), often in a context of great uncertainty about the illness and its trajectory (Brown & Powell-Cope, 1991).

The onset of severe mental illness challenged these families to reconsider their notions of normal and what the principles of behavior were to be

normal. Their accounts clearly indicated that achieving a revised sense of normalcy was an evolving and difficult process. Deatrick, Knafl, and Murphy-Moore (1999) proposed that such a process might be impeded by sustained experiences of uncertainty and grief associated with chronic illness. Johnson (2000) further noted that families of persons with mental illness, whose lives are punctuated by periods of normal and abnormal behavior by the patient, have difficulty sustaining their efforts to accommodate the illness over time. The findings of this study support those conclusions and highlight further the enormity of that struggle.

Family members described major disruptions of expectations for the future, disruptions in the relationships with the ill relative, and challenges to their own taken-for-granted assumptions about mental illness. Karp and Tanarugsachock (2000) described families' responses as "emotion management." They reported that families achieved either a "resigned acceptance" or an "affirmative acceptance" of the mental illness. The findings of this study concur with that distinction. Experiences over time helped some family members find new ways to relate to the patient, whereas others became resigned to the loss and were satisfied that the illness had become no worse.

Families' questions about assigning responsibility were pervasive and recurring, and many family decisions about responding to patients revolved around these concerns. The most distressed family members in this study saw their adult ill relative as a child who was unpredictable, not responsible, and who would not significantly improve in the future. Similar to the findings of Badger (1996), families in this study that seemed to do well were able to find reasons for hope and were able to redefine the relationship with the patient.

Over time, many of these families developed skills in crisis management and illness containment, or stability and growth. Similar to other caregivers (Schumacher, Stewart, Archbold, Dodd, & Dibble, 2000), these family members became skilled at interpreting a situation and deciding upon a response. Ayres (2000) described a process of "making meaning" for caregiving that included expectations, explanations and strategies. Caregivers in her study made sense of their situation by considering the past, reviewing personal philosophies, and carefully considering the future. Families in this study were similarly engaged in a task of making sense of mental illness, using age-based expectations and knowledge of the person prior to the illness as the reference point for interpretation.

Some families were able to achieve a goal of being positive about the future for themselves and their relative. The enormity of the impact of the mental illness on some families cannot be overemphasized. The devastation

that some families described of ruined lives and permanently altered relationships cannot be dismissed or ignored. All family members, regardless of where they were in the illness experience, acknowledged that they continued to need help to reconcile societal goals of independence and productivity with the behaviors of young adult or even middle-aged mentally ill relatives. As Chesla (1994) pointed out, understanding families' experiences cannot be captured by focusing narrowly on concepts of burden or expressed emotion. Diversity and complexity of family experience, including a focus on what families do well, should be investigated. Further research is needed to identify ways that health professionals can assist families in their struggles to achieve a sense of normalcy for themselves and the family member who has a serious mental illness.

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