

Qualitative Health Research

<http://qhr.sagepub.com>

Navigating the Storm of Mental Illness: Phases in the Family's Journey

Susan A. Muhlbauer

Qual Health Res 2002; 12; 1076

DOI: 10.1177/104973202129120458

The online version of this article can be found at:
<http://qhr.sagepub.com/cgi/content/abstract/12/8/1076>

Published by:



<http://www.sagepublications.com>

Additional services and information for *Qualitative Health Research* can be found at:

Email Alerts: <http://qhr.sagepub.com/cgi/alerts>

Subscriptions: <http://qhr.sagepub.com/subscriptions>

Reprints: <http://www.sagepub.com/journalsReprints.nav>

Permissions: <http://www.sagepub.com/journalsPermissions.nav>

Citations <http://qhr.sagepub.com/cgi/content/refs/12/8/1076>

Navigating the Storm of Mental Illness: Phases in the Family's Journey

Susan A. Muhlbauer

About 1.25 million American families live with persistently mentally ill members. Costs, personal and public, are substantial. Research providing holistic understanding of the processes these families experience is needed. This qualitative study's objectives were to (a) examine the process holistically and (b) search for patterns in families' experiences. The author used a framework of symbolic interaction and dramaturgical interviewing. Twenty-six respondents participated in a semistructured interview. Results indicated that families typically experienced six phases: development of awareness, crisis, instability and recurrent crises, movement toward stability, continuum of stability, and growth and advocacy. Needs characteristic of each phase were evident. Additional research is needed to determine if phases are consistent in other groups and to develop interventions appropriate for each phase.

One in five Americans, approximately 60 million people, has a mental illness (U.S. Department of Health and Human Services [DHHS], 1999). For between 4 and 5 million of these individuals, mental illness is severe and persistent (Lefley, 1996; Stuart & Laraia, 1998). At least 25% of this population lives at home with family. At a minimum, 1.25 million families live with members who have a severe and persistent mental illness (Rose, 1996). For these families, the struggle with mental illness can become, metaphorically, an ongoing journey through a storm of hurricane proportions. Families often have difficulty navigating. The storm's topography is ambiguous, experienced guides are rare, and safety beacons are dim or absent. Families can flounder, and mentally ill members can be abandoned (Yarrow, Schwartz, Murphy, & Deasy, 1987).

Although aspects of this journey have been explored, information is dated. The experience has been substantially altered by recent social, political, economic, and technological changes (Rose, 1996). Reexamination of mental illness as a holistic family process has been suggested as a means of expanding understanding (Tuck, du Mont, Evans, & Shupe, 1997).

The purpose of this study was to examine the development and process of severe and persistent mental illness from a family member's/caregiver's perspective.

AUTHOR'S NOTE: Research reported in this paper was part of the author's dissertation through the Sociology Department at the University of Nebraska in Lincoln, Nebraska. I would like to acknowledge the support of my supervisory committee members, J. Allen Williams, Hugh Whit, Tom Calhoun, and Will Spaulding. I also wish to acknowledge and thank the following colleagues for their assistance: Susan Noble Walker, Margaret Wilson, and Betty Craft.

QUALITATIVE HEALTH RESEARCH, Vol. 12 No. 8, October 2002 1076-1092

DOI: 10.1177/104973202236576

© 2002 Sage Publications

Goals were (a) to examine the experience in a holistic manner that explored recent changes and permitted understanding of possible patterns or phases, and (b) to determine family issues or themes characteristic of particular phases. The study was designed as a step in the process of developing needed interventions enhancing family services.

BACKGROUND: ROUTES ALREADY SURVEYED

Severe and Persistent Mental Illness and the Family

Initial research was dominated by belief that families had a powerful etiological role in the mental illness of their member (Maurin & Boyd, 1990). Focus on parenting issues as causative factors for psychotic illness was instrumental in developing the belief among professionals that the etiology of major mental disorders, particularly schizophrenia, was rooted in family dysfunction. Current evidence suggests that professionals acting on that belief added to the trauma experienced by families (Torrey, 1995). Family emotional tone, termed *expressed emotion*, was correlated to relapse by the ill member (Brown, Carstairs, & Topping, 1958).

Researchers, however, reversed perspective and examined the effect of mental illness on the family, and they discovered that the impact reverberated across the entire spectrum of family life (Maurin & Boyd, 1990). Consequences of stigma were noted and addressed (Clausen & Yarrow, 1955; Rose, 1996). Mental illness was recognized as creating a significant burden for caretakers and was explored in increasing depth (Yarrow et al., 1987). Behaviors, typically threats and unrealistic demands, that most distressed caregivers were investigated (Grad & Sainsbury, 1963). Negative feelings experienced by caregivers, including concern for the future, fear, tension, and difficulty sleeping, were explored (Herz, Endicott, & Spitzer, 1976). Connections between a family's burden of care and a mentally ill individual's level of functioning, symptoms, and behavior became increasingly evident (Loukissa, 1995).

Study on the effect of psychiatric illnesses such as schizophrenia and bipolar disorder on the family continued (Miklowitz, 1994). Chronic mental illness and burden of care was examined (Francell, Conn, & Gray, 1988). However, although researchers examined expressed emotion in families with schizophrenic members extensively, minimal investigation of the phenomenon was done in families with other severe and persistent mental illnesses (de Cargas, 1990). Family burden and stress received continued examination (Reinhard & Horwitz, 1995). Focused primarily on the negative aspects of the experience, research indicated that caregiving family members had significant problems with anxiety, depression, and resource issues (Hobbs, 1997). Minimal examination of the experience as a whole occurred.

Phases in Living With Mental Illness in the Family

Current discussion is primarily anecdotally based and supports the concept of phase- or stage-like development. Tessler, Killian, and Gubman (1987) empirically identified nine stages, from initial awareness of problem without recognition of symptoms through ever-present worry about the future. Terkelsen (1987), noting a

lack of longitudinal investigations, described an empirically based process involving 10 phases. Spaniol and Zippel (1994), acknowledging a lack of information, maintained that general characteristics could be recognized, including recovery as a growth process divided into four phases: discovery/denial, recognition/acceptance, coping, and personal/political advocacy. Tuck et al. (1997), investigating the experience of caring for an adult child with schizophrenia, proposed the following eight-phased process: struggling to frame events as normal, seeking help, transformation of a loved child, living with constantly changing levels of hope, endless caring, gathering personal meaning, preserving identity, and knowing. Although interesting, Tuck's qualitative study was based on interviews with only nine family members and focused solely on the process experienced by families whose members had schizophrenia. Another qualitative study, based on 50 in-depth interviews with relatives of individuals with mood disorders or schizophrenia, identified a four-phased pattern of emotional unfolding: experiencing emotional anomie, getting a diagnosis, perceiving illness permanency, and acceptance (Karp & Tanarugsachock, 2000).

Although researchers have begun to address the process that families experience, studies concentrating on this area are few, the number of respondents is generally small, and the focus is usually on families experiencing schizophrenia. A need exists for research with larger numbers of respondents across a broader spectrum of diagnoses and experiences.

METHOD

I developed a qualitative research design using semistructured interviewing within a framework of symbolic interaction through its paradigm of dramaturgical interviewing. The framework, based on the premise that meaning is handled and modified through an interpretive process derived from social interactions, provided a powerful theoretical foundation for an interview that examined meaning and process in the development of a severe and persistent mental illness (Blumer, 1969; Lofland & Lofland, 1995). Creative and active elements from dramaturgical interviewing were used to provide direction for the interview (Berg, 1998). The design provided a workable, dynamic model for structuring the flexible and in-depth questioning required and created an environment supportive of informational exchange and disclosure.

Data Collection Procedures

Data were obtained from participants' responses to questioning guided by a semistructured interview outline. Adherence to the outline facilitated a systematic exploration of the participant's experience. Interviews of this type produce large amounts of data and tend to create material-management problems that necessitate limiting the numbers of interviews (Lofland & Lofland, 1995). In this study, I interviewed participants until no new themes or phases emerged, and 26 interviews were conducted. Phases in the development of the illnesses were evident at 18 interviews; the additional 8 interviews were used to provide in-depth understanding of themes specific to particular phases.

Sample

Following Institutional Review Board approval, interviewees were recruited by letter from a list of 49 family members who had participated in psychoeducational groups sponsored by the College of Nursing. Twenty-eight individuals responded. Two of the women were eventually unable to participate because of personal or health reasons, and 26 individuals were interviewed. These 18 women and 8 men met the following inclusion criteria: (a) past participation in the 36-hour psychoeducational course, (b) existence of a family member with a severe and persistent mental illness, (c) involvement within the past several years in assisting their family member with management of the mental illness, and (d) willingness to participate in a 1½- to 2-hour audiotaped interview. Individuals with severe and persistent mental illnesses (who did not participate in the interviews) were defined as functionally impaired adults who (a) met the criteria for a mental illness including the schizophrenias, major depressive disorders, bipolar disorders, disabling obsessive compulsive disorders, or others; (b) experienced recurrent relapses and a need for periodic restabilization and possible rehospitalization; and (c) typically had been ill for over a year and were disabled in major areas of living (Lefley, 1996).

The participants, a self-selected and highly motivated group of Midwestern Caucasian individuals, ranged in age between 40 and 76 years, with a mean age of 56. Twenty-one participants, 15 women and 6 men, were parents; 4 couples participated but were interviewed separately. Four participants, 2 male and 2 female, were spouses or significant others. The remaining participant, a female, was a sibling. Twenty participants were in their first marriage, 3 were in a second marriage, 2 were divorced, and 1 was separated. As a whole, the group was well educated. All participants were high school graduates; 21 had additional education. Seven participants had community college or technical training, 8 had baccalaureate degrees, and 6 had graduate degrees. In relationship to occupation, 18 participants were in, or before retirement had held, white-collar jobs, and 6 held blue-collar jobs. Five participants were retired.

Data Collection and Analysis Procedures

Data collected from the audiotaped interviews and from notes recording verbal, contextual, and affective material were combined to create an integrated record of each interview. As advocated by Lofland and Lofland (1995), the written record became an amalgamation of summaries and notes of what the informant said generally, a verbatim transcription of responses, field notes of extra-interview encounters with the informant, the researcher's emotional reactions, methodological difficulties or successes, and ideas or tentative bits of analysis. All materials were entered into computer files and prepared for examination in the computer-based qualitative research program NUD*IST and subjected to hand analysis.

I submitted data to a content analysis process containing both quantitative and qualitative components (Berg, 1998). In the quantitative component, I used tally sheets to measure data frequencies. I organized the sheets into an information matrix that contained the following demographic data about each study participant: age, gender, marital status, family role, education, and occupational background. The matrix also contained the following information about the mentally ill family member: age, sex, age when illness diagnosed, diagnoses, length of illness,

current living situation, work status, insurance, and disability status. The readily accessible quantitative data contained in the information matrix served as base or anchor for the qualitative analysis.

Development of the qualitative analysis required additional structure. Analysis was developed from questions on process and human agency (Lofland & Lofland, 1995). I examined data through parameters specific to three process types: cycles, spirals, and sequences.

- *Cycles* are events that reoccur in a repeating pattern when the last act in one series precedes the recurrence of the first in a new series.
- *Spirals* are less stable patterns involving escalation and de-escalation intervals.
- *Sequences* are time-ordered series of steps or phases that differ from cycles or spirals in that the sequences show neither the connection of the first and last steps as in cycles nor the accelerated movement from a stronger to a weaker level, as in spirals.

In the analysis of human agency, I emphasized the view of humans as creatures actively trying to influence their environment through maneuvering, striving, and struggling. Analysis focused on strategies—the means by which an individual interacts with a situation—that participants used as they struggled to deal with mental illness in a family member.

Analysis of data involved recording, coding, organizing, and synthesizing (Lofland & Lofland, 1995). I used the following codings in this study: housekeeping, analytic (initial and focused), elemental, sorting, and integrating.

Housekeeping coding involved obtaining transcripts for each interview, validating the accuracy of each transcript, and making needed corrections. It also involved combining observations in chronological order and integrating these files with transcription material. All chronologically organized transcripts, field notes, and ongoing self-assessments were combined into both a computerized and a hard copy set, thus allowing for easy access to any aspect of the collected data.

Initial analytic coding involved careful reading of each page with concurrent decision making about how to code each piece of emerging data. Both deductive codings based on a theoretical perspective and inductive codings developed directly from data were used (Berg, 1998). As initial codings were evaluated, some categories within selected codes were elaborated, others were collapsed, and still others were dropped. Some codes became increasingly prominent or focused. As these focused codes were developed, I wrote memos about patterns, meanings, ideas, or thoughts related to choices made and data observed. From these focused analytic memos, three additional types of memos were developed: elemental, sorting, and integrating.

Elemental memos, detailed analytic rendering of some relatively specific matter, were written on each deductively chosen category as well as each specific (sometimes collapsed) inductive category. I used these elemental memos as the basis for the development of sorting memos, which took all (or many) of the elemental memos (and codings not yet developed as memos) as topics for analysis. The discoveries made in this sorting were then described. Sorting memos, which are literally an analysis on an analysis, achieve a higher level of abstraction and generalizability than seen in elemental memoing (Lofland & Lofland, 1995). The final type of memo used in this project was the integrating memo, which is an explanation of connections and relationships among the sorting memos. Integrating

memos were used as a means of organizing project information into logical themes and interconnecting relationships, thus providing both structure and substance of the analysis.

Criteria for Rigor

I followed the criteria for rigor advocated by Leininger (1991): credibility, confirmability, recurrent patterning, and saturation.

- *Credibility* refers to the truth, accuracy, or believability of findings and the accuracy, credibility, and believability of informants. Credibility was supported by repetition of similar experiences by a majority of participants.
- *Confirmability* refers to the existence of repeated, direct, and documented evidence with repeated explanations from informants about particular phenomena. Confirmability was evidenced by frequently cited experiences—for example, interactions with insurance companies—that were so consistent the interviewer became able to accurately predict participant responses, including initial cost for crisis management and patterns typical of insurance loss.
- *Recurrent patterning* refers to repeated instances, sequences, or experiences that recur over time in designated ways and contexts. This became readily evident as predictable phases of family processes became apparent.
- *Saturation* means that the researcher has conducted an exhaustive study and no further data or insights are coming forth. I used documentation of data redundancy to substantiate the saturation criteria.

FINDINGS

Characteristics of the Mentally Ill Population

Participants provided the following data about family members. Mentally ill individuals ranged in age from 18 to 73 years, with a mean of 33 years. Seventeen were adult children, four were spouses or significant others, and one (a female) was a sibling. Thirteen had never married, three were currently married, and five were divorced or separated. A majority had some education beyond high school, but most had been unable to complete their education. The typical individual was diagnosed in late teens (19.5 years), had been ill for nearly a decade, had a minimum of two or three diagnoses, a history of multiple hospitalizations, and had a positive family history for mental illness. I was surprised to discover that many had part-time involvement in either work or school. Some lived, with family support, in their own apartments.

To understand the experience, it was essential to understand the problems and behaviors involved. Per participant description, most mentally ill family members had substantial difficulty with memory and concentration. Many had problems with hallucinations, delusions, and violent behaviors. Other significant issues were substance abuse, social skills, social relationship problems, and difficulty managing money, coupled with difficulty in coping with stress and change. Other less frequently reported problem areas included self-care deficits, fatigue, and grandiose behaviors. The majority had substantial problems in multiple areas.

Phases of Experience in Navigating the Storm

Analysis of data revealed a spiraling and cycling of events, consistent with previous reports, that eventually developed into a sequential progression of phases through which the majority of participants journeyed (Spaniol & Zipple, 1994; Terkelsen, 1987; Tessler et al., 1987; Tuck et al., 1997). Movement was reported through the following phases: (a) development of awareness, (b) crisis, (c) cycle of instability and recurrent crises, (d) movement toward stability, (e) continuum of stability, and (f) growth and advocacy. Each phase had specific characteristics.

Phase 1—Development of Awareness: Storm Warnings

Phase 1 of the journey, the awareness spiral, was characterized by (a) recognition of a problem coupled with increasing concern and (b) escalating but ineffective efforts to seek assistance. Duration varied from days to years, depending on the progression of symptoms and problems. Participants readily recalled early concerns, help-seeking behaviors, and frustration with health care providers. The comments of one elderly woman whose daughter had a psychotic disorder demonstrated themes reported by a majority of participants.

From the time she was in preschool, we began to feel that there were things that were more than just unique to her. Perhaps there were some abnormalities. She cried so many times, "Don't leave me! You won't die before I do, will you?" We discussed it with the pediatrician, he said, "Mothers worry too much." We talked to our rabbi. . . . We took her to two counselors and a psychiatric social worker. We took her to a psychiatrist. . . . We were told, "You are overprotective. Let her be more independent."

In contrast to denial, which research generally portrays as a fairly common response to the emergence of a family member's mental illness, the majority of participants reported a pattern of recognizing a problem, seeking assistance, and having concerns negated (Yarrow et al., 1987).

Whether problem behaviors increased slowly or happened within hours or days, most participants acknowledged knowing that something was wrong, but they were unable to define that "wrongness." One mother said, "We knew something was terribly wrong, we didn't have a name for it." Families typically and unsuccessfully tried to manage increasing difficulties until their inability to control the situation became evident in the form of a crisis precipitated by their family member's bizarre behavior. That crisis marked the beginning of phase 2.

Phase 2—Crisis: Confronting the Storm

Phase 2 of the journey was the crisis culmination of the awareness spiral. It was characterized by (a) an exacerbation of problems beyond the family's ability to control; (b) an abrupt confrontation with the mental health care system, usually via an emergency room admission resulting in a mental illness diagnosis; (c) tremendous emotional distress; (d) problems communicating with health care providers; and (e) financial concerns.

The participants consistently reported confronting their family members' psychotic and relatively frequent violent behavior during the crisis phase. One participant shared the following:

It was totally out of reality. It was very frightening. I watched him change from the kid that you saw, the normal child, to a totally different child, a child you couldn't recognize. His total body, his facial affect, everything was gone. It was like he had disappeared. It was very frightening. . . . I didn't have a clue what to do.

Crisis episodes, even nonviolent ones, were terrifying and traumatic. Consistent with earlier research, the crisis usually resulted in formal entrance of the ill family member into the mental health system with a concurrent mental illness diagnosis. Participant reaction to the labeling of the relative as mentally ill alternated between concern over the long-term consequences and relief over having an explanation for previously inexplicable behavior (Karp & Tanarugsachock, 2000). Participants reported that learning their family member had a mental illness offered them a way to deal with negative feelings toward the person. One participant said, "Information made me hold her less accountable. She wasn't a horrible, evil person, this woman I was so afraid of, she was ill." Participants reported feeling that having a diagnosis offered the potential for a means of treatment.

In relationship to interactions with mental health care providers, the majority of participants stated that they had problems communicating and noted that providers often did not listen or provide important information. This theme intensified over time. Regarding financial and insurance issues, participants focused on difficulty paying for needed mental health services. They reported either substantial or complete depletion of their mental health insurance coverage during the initial crisis. One participant, a husband, displayed both themes as he described trying to tell the unit social worker about the effect of his wife's severe depression on their children.

She said, "I cannot talk to you without a release of information from your wife." Then she walked away and left me standing, embarrassed, in the hallway. . . . I'm still frustrated at not being able, at least, to express myself. . . . I had to pay a \$28,000 hospital bill [his insurance had only covered about \$25,000 of the \$50,000-plus bill] but nobody would talk to me.

As time went on, problems intensified. Resolutions were poor, and the family's initial relief and optimism declined.

Phase 3—Cycle of Instability and Recurrent Crises: Adrift on Perilous Seas

The journey continued in a third phase. Typically years in length, it was characterized by the following themes: (a) instability and recurrent crises; (b) anger, grief, and loss; (c) searching for explanations, treatment, and increased knowledge; (d) intensifying financial concerns and problems with insurance; (e) occasional acknowledgment of assistance from newer treatments and technologies; (f) frequently expressed dissatisfaction with mental health care services and providers; and (g) issues related to stigma.

Participants described becoming painfully aware of the chronic trajectory of the journey. Relapses or exacerbations were the norm. The mother of a young woman with bipolar disorder stated, "Once we knew what was wrong and the medications started to work, I thought 'We can handle this. All she has to do is take her lithium.' I never dreamed she wouldn't." The daughter's inability to comply with treatment resulted in years of crisis, turbulence, and tremendous strain for her family. Another participant recalled her feelings.

The anger was just in every direction. The anger was at myself, at not being able to just get up and get going with some kind of a plan. It was at the rest of the family, because I thought they should be doing more to help. I didn't know what, but I felt everybody should be doing something. And very angry at him. (son with paranoid schizophrenia)

This mother's intense anger was a fairly representative response, as was her sense of helplessness. Participants also described their sense of grief and loss. The father of a middle-aged man with schizophrenia poignantly articulated his loss and grief.

Essentially you lost a child and all the hopes and dreams you had for that child. I've thought about this at various times, if Justin had been well, I would have had grandchildren. I would have him helping me instead of me helping him. He would have a family. That won't happen. It's a long-term loss, a future loss. It's like having a child die, but the difference is that when the child dies, you mourn that child and then move on. With this, the mentally ill child, that mourning never really quits.

The sense of loss and grieving, previously documented in research describing parental grief in response to mental illness in a child (Karp & Tanarugsachock, 2000; MacGregor, 1994), was a clearly articulated theme that consistently ran through participant interviews.

As phase 3 progressed, participants searched for explanations for the constant or recurring symptoms. Explanations typically involved either family deficits or physiological abnormalities. One mother reported that her other son blamed his brother's illness (paranoid schizophrenia) on the family's inability "to love him enough." Searching for information, families reported becoming disillusioned by the difficulties encountered with the mental health care system. Unhappy with responses and concerned about adequacy of information, participants then reported seeking knowledge from self-help groups.

Phase 3, consistent with research emphasizing the cost of mental illness (Clark & Drake, 1994), was also characterized by a continuing theme of financial concern. Most participants reported losing access to insurance coverage either through disqualification or depletion of lifetime limits for mental health services. Families turned to governmental entitlement programs. These programs were often difficult to access, and their use created additional issues. Positive results from the use of new treatments occasionally further complicated financial issues and resulted in ethical dilemmas involving work and entitlement systems. The mother of a young man with schizophrenia described her experience.

After three times and hiring a lawyer [was able to get approved for SSI and Medicaid]. The lawyer didn't say anything I hadn't said in the last appeal, but they don't get serious until you are on your third appeal and have someone representing

you. It was very frustrating. But if he didn't get Medicaid, how could he have medication [costs between \$500 and \$800 per month]? There's no way he could start working now and lose his Medicaid or he would not have his medication [and would not be able to work because he would again become psychotic].

The majority of participants reported confronting similar issues and indicated plainly that management of financial concerns was a tremendous stressor and burden.

Significant problems in interactions with the mental health care system also continued. Concerns reported in earlier phases intensified. One participant, after describing his unsuccessful attempts to communicate with his wife's psychiatrist, stated, "I have to accept that. I know he is good. If everyone respects him, I guess I'd better too [pause] . . . I don't think the good man knows how to listen." Another man stated, "I've felt like an outcast at the hospital . . . just a necessary evil." Participants described learning to "work the system." One mother described her technique in a matter-of-fact manner: "Of course they wouldn't tell me anything. I learned to work the system, I called the social worker and said, 'Just give me information about schizophrenia.' Well, inadvertently they would tell me about him." Needing to learn methods to get desperately needed information was a prominent theme in this phase.

Although concerns related to stigma had been apparent earlier, the theme now intensified. Participants reported having to share at least some information with others. Several reported traumatic encounters with negative stereotypes, but the majority acknowledged being surprised by how well they were treated when involved in face-to-face interactions. One mother said, "If someone would ask me, I'm not going to say, 'No, she isn't. I would say, 'Yeah.' But, you know, people don't come around and ask you either, don't even pay much attention to it anymore." Although unexpected, this response was consistent with earlier research that also denied direct, face-to-face stigma experiences (Wahl & Harman, 1989).

Participants did report confronting an institutionalized type of stigma, comparable to institutionalized racism, embedded in governmental and corporate regulations that was more problematic and profound than any face-to-face encounter (Murphy & Choi, 1997). One father, whose daughter was doing well in treatment, explained:

Where the problem comes is the employment and insurance. If she gets there [able to be employed full-time], then she will face it. I'm sure it will be difficult for her to get a good job or full coverage insurance [because of discriminatory employment and insurance regulations]. . . . This is where the stigma part will be hard for her.

Eventually, participants reported, a measure of control was painfully gained. This control correlated with changes in expectations and interactions. As changes coalesced, families progressed into the fourth phase, movement toward stability.

Phase 4—Movement Toward Stability: Realigning the Internal Compass

Substantial alterations in participant thoughts, values, and behaviors were the hallmarks of the journey in the fourth phase. Themes included (a) finding ways to

regain control, (b) managing feelings of guilt and helplessness, (c) changing perceptions and expectations, (d) struggling with ethical and limit-setting issues related to control, and (e) developing workable symptom management techniques. Participants described struggling to regain control of their lives while accepting limits in managing the lives of their ill relatives. One woman, the wife of a man who experienced recurrent severe depressions, described her experience as a "sorting through" process that allowed her to make choices. She noted, "You can make a decision to continue on doing the same thing over and over again or stop it." With this statement, she acknowledged her ability to control her response to her husband's behavior even though she was unable to control his behavior.

Another participant talked about how he dealt with similar issues and the comfort and support he found in his religious and spiritual beliefs.

That [belief] helps my peace of mind, if you will, a little bit. It doesn't take it [the feelings] away. It just alleviates it to the extent that we know we can no longer really control this, and that's the big thing, really . . . I can't control the situation, there's not a cure for the situation, and I didn't cause it. And this helps me a lot.

Participants, acknowledging increased understanding, reported changes in their perception of behaviors initially perceived as selfish, indulgent, provocative, or willful. Many participants, for example, considered excessive sleeping an indication of laziness. The husband of a middle-aged woman with severe depression shared his experience: "I just thought she wouldn't work. I thought she was lazy. I didn't know it was a symptom of depression." Objectionable actions were reframed as symptoms of an illness, thus providing a feasible and acceptable explanation for behavior that was often bizarre and occasionally threatening. The result was usually decreased anger, increased tolerance, and clearer understanding. This shift in emotions lessened the tension and hostility in the home. The resulting drop in ambient anxiety made it easier for the mentally ill individual to function. Modifying expectations to make them realistic was cited as helpful by a majority of participants. Knowledge that allowed participants to make interactional changes also led to a decrease in feelings of self-blame and guilt. Energy could then be directed into more useful responses.

Participants discussed struggling with ethical dilemmas related to control, autonomy, independence, privacy, and freedom. Issues focused on balancing those rights against their relative's intermittent inability to comprehend the consequences—often the danger—of their behavior. The mother of a man with paranoid schizophrenia shared her family's experience when faced with the potentially violent behavior of a son returning home after hospitalization.

We all talked among ourselves that if he was totally out of control and made an attempt to hit us, to hurt us, we'd just have to call 911. And, if necessary, literally run out of the door . . . or lock him in his room . . . I reversed the locks before he came home so that it could not be locked from the inside [so he couldn't lock himself in the bedroom but they could lock him in if needed]. I know that's against human rights and dignity, but sometimes you do what you have to do. That did not last long. Eventually we took the lock off, no lock at all. And we try to respect that privacy. You knock on the door before you just barge in because that is his space.

Concerns about ethical issues and limits of responsibility were consistent themes in this phase. Arriving at some manner of resolution allowed participants to progress in their ability to cope.

With changes in perspective, decreased guilt feelings, and clarification of concerns about independence and autonomy, participants reported increased decision-making ability. They noted recognizing the need to provide clear limits on problem behaviors, particularly noncompliance with treatment and substance abuse, which magnified psychotic or violent activities. One participant described an episode with her son.

He was still self-medicating with drugs and alcohol. There was one experience where he hallucinated, evidently visually, along with what he was hearing. We just more or less told him he would have to leave the house [after he had hit his father]. He would just have to go. You know, if he wouldn't seek help and if he was going to continue to use alcohol and drugs, then he could not live in our house.

As indicated, this phase occasionally saw the exodus of the ill family member, a fairly common finding in research literature (Karp & Tanarugsachock, 2000; Yarrow et al., 1987). In this circumstance, it was typically the choice of the mentally ill relative in response to limits set by participants on behaviors perceived as being under the relative's control. In variance with previous reports, this exodus typically was temporary, with some contact, often erratic, being maintained. The primary focus of this phase was the beginning of restabilization of family life through a process by which the participant became able to act rather than simply react to inappropriate behaviors. Actions resulted from a struggle to balance the needs of their families and themselves with the needs of the ill member.

Participants also discussed their increasing ability, typically from integrating information and experience, to assist with symptom management. One mother recalled aids she used to help her severely depressed adolescent son concentrate and organize his thoughts.

He always loved art and painting. We'd get paint-by-number sets [to help him organize his thoughts]. He was really into that for about a month. The puzzles helped when he was having trouble putting his thinking together . . . he knew he had to focus on this 50- or that 500-piece puzzle. I'd see him many times downstairs working, I'd say, "Oh, you're working on . . ." He'd say, "Yeah, this helps me think because I know I've got to think to find all of the blue pieces together for the sky."

Participants noted that over time, they became more skilled at techniques that helped family members manage symptoms and make decisions. Elaboration of these skills resulted in the development of care patterns.

Phase 5—Continuum of Stability: Mastering Navigational Skills

As a majority of participants discussed increasing successes with symptom management and decision making, a fifth phase of the journey, the continuum of stability, became evident. Themes of this phase included (a) further development of the participant's expertise in managing symptoms and creating workable care patterns;

and (b) the use of a variety of support systems, including the mental health care system/professionals, friends, and support/psychoeducational groups.

Participant symptom management expertise tended to develop in the areas of cognitive deficits and anxiety. One participant described a fairly typical pattern of assisting a family member to manage cognitive deficits that distorted decision making:

When a decision comes up, I do not say, "You need to do this." I will very carefully lay out paths that she could take and the consequences. I will ask her, and I don't just lay it out, I ask her. . . . So I lay out her different options and the consequences, or I help her discover them.

The participant was aware that the relative dealt more capably with information that was laid out concretely and explained how that knowledge was incorporated into problem solving.

We talk about it; we write it down. It has gotten to the point where we draw pictures out or like a chart . . . a flow chart. This is where the goal you want is. This is how.

Demonstrating in a concrete way how the relative could be successfully involved in the intricacies of a complex and abstract decision-making process, the participant also discussed learning to deal concretely with abstract difficulties in the area of boundary management.

She had a hard time with that [managing boundaries] until I came up with the image that you are blue and I am red. And sometimes you need to make blue decisions and I need to make red decisions. And in our relationship and our house, we make purple decisions . . . I don't know what it was about the terminology that wasn't clicking. But as soon as I put it in color [she understood]. . . . I tell her that her mother is yellow and her relationship with her mother is green. And my relationship with her mother is orange, and we shouldn't get the green in with the orange. And, by God, we don't want any of that yellow in with our purple. And as soon as I made those color analogies, this light bulb came on.

As this participant indicated, many consumers were able to process abstract ideas if those ideas could be introduced and interpreted concretely. Visualization was often helpful.

Participants consistently described how they attempt to provide aid by sharing their own experiences. Through self-disclosure, they offered ideas about how others would perceive and respond to the situation their family member found perplexing and difficult. One mother noted, "I tell him how I'd feel about it so he has some idea what normal feelings would be."

Management of anxiety was also an important issue. Participants varied in awareness of their relative's vulnerability, but many noted its crippling effect. A primary goal for these families became rapid management of escalating anxiety.

Because increases in anxiety often occurred around episodes of overstimulation, participants worked to maintain control as a containment measure. One woman discussed helping her son contain anxiety and psychotic symptoms in the overstimulation of a holiday family gathering. Anxiety escalating, he began hearing voices calling him names. Inaccurately attributing the name-calling to his brother, he became

convinced that he was being insulted. His agitation increasing, he incorporated a visitor into his delusional system and prepared to attack. At that point, the mother, preoccupied with food preparation, realized what was occurring and intervened.

I went out there and said, "No, you cannot do this." And he says, "I don't care. That is [individual from his delusional system], and I am going to get him." And I said, "No, you're not." "You know," I says "I've really got a lot to do here. I've got to get dinner on and by you doing this, it really hurts me. It really hurts me by your doing this." And he says, "Okay, Mom."

She then directed him to go to a quiet place in the house where he could calm down. She knew if the overstimulation was stopped, his symptoms would subside. She had learned that her son could not tolerate extended periods in a stimulating environment, even an environment with his brothers and sisters, and had created a quiet room in the basement to which he could retreat. Knowing her son had lost awareness and insight, she quietly intervened and gave needed direction that permitted him the quiet time needed to regain control. As this example indicates, participants found that managing the environment through choices limiting exposure to overstimulation helped to prevent or de-escalate erratic responses.

Consistent with information derived from research on expressed emotion, participants talked about the need to keep their home atmosphere calm and quiet, noting their relative was more functional in that environment (Lefley, 1996). They offered reassurance and calm messages. One mother summarized succinctly: "I try to give him positive thoughts."

A final anxiety-producing concern involved accessing and using complex social service systems. Anxiety on receiving a letter from a social service agency was so overwhelming that recipients were often unable to open the envelope. Participants reported that, anxious and unable to manage, relatives depended on them for help. One stated, "I have to navigate the system for her. I am the gateway for her."

Despite the positive effect of continual and unconditional support, participants admitted to eventually recognizing their limitations. Several reported becoming depressed and seeking therapy. Acknowledging the need for assistance, many emphasized the value of support from families dealing with similar issues; community self-help groups and psychoeducational groups provided access to others with similar experiences. One participant, the father of a young woman with multiple psychotic symptoms, noted,

It was helpful to listen to people that have the diseases and had it under control. . . . I can't emphasize enough, learning about is so very helpful . . . don't worry about where it came from, whether it is hereditary in your family. Learn to accept it. Don't be ashamed because it is nothing you did.

As the family's expertise grew, longer interludes of respite resulted, although chaos could recur with illness exacerbation. Families developed strategies to help their mentally ill members manage symptoms, handle money, control anxiety, and adapt to change. Insisting that ill members comply with treatment became an increasingly effective strategy, as was access to new treatments and medications, which usually became available because of successful enrollment in Medicaid.

Phase 6—Growth and Advocacy: Sailing Existential Seas

As participants recalled experiences and talked about personal change, a number described development of their journey into a sixth phase characterized by subjective awareness of personal growth and substantial fears about their loved one's future. The sense of personal growth developed, at times, into a sense of empowerment with concurrent advocacy behaviors. Although apprehensive about relapses, participants described deriving meaning, value, and personal growth from their experiences. One man considered his experience a source of value clarification.

I can look back and I can see that my attitude has changed. I think it's probably made my wife's relationship and mine much stronger. It causes you to take a look at yourself and see what changes you need to make. . . . When something like this happens, it brings you back down to square one in reality. In that respect, it hasn't been all bad. I think I've grown because of it . . . little things don't upset me as much as they used to. Should everybody go through this? [laughs] No!

Some, obviously not all, participants talked about their increasing ability to effect change. One man talked about a growing sense of competency and capability: "One of the things that has come out of this is self-empowerment. You find out that you can do stuff that you never thought you would be able to do previously." Active in his community, this participant had been able to provide a voice for the needs of his son and others who could not speak as clearly. Despite the burdens experienced, participants were able to articulate areas of strength and growth. A number reported finding meaning and purpose that reshaped their perceptions and values. In essence, they described satisfaction and comfort in the development of meaning from an existential nightmare and validated research that emphasized the health and strength of families functioning successfully in overwhelming circumstances (Doornbos, 1996).

Despite growth, however, tremendous issues and problems remained. All participants expressed concern about the future centered on how their relative would survive after they were unable to provide care. One mother asked,

But what happens when we are gone and when we can't monitor her? Are people like her supposed to be just thrown to the wolves? Which right now is what I see happening. And, somehow, the general public does not seem to be interested enough and the politicians in making some kind of provisions for people like this.

Consistent with earlier research (Tuck et al., 1997), some participants acknowledged feeling helpless. The elderly mother of a middle-aged man with paranoid schizophrenia stated clearly, "I can't plan for the future." All participants expressed concern about their relative's future. Most participants identified this as their greatest worry.

CONCLUSIONS AND RESEARCH IMPLICATIONS

Consistent with past anecdotal and research information, data from the study supported a sequential progression of phases inherent in the process of mental illness.

The following six phases were identified: (a) cycle of awareness, (b) crisis, (c) cycle of instability and recurrent crisis, (d) movement toward stability, (e) continuum of stability, and (f) growth and advocacy. Although each phase was characterized by a number of specific and important themes, the following topics were consistent across phases: (a) significant problems communicating with providers within the mental health care system; (b) substantial financial/resource issues, including the effect of institutionalized stigma, which limited resources; (c) strongly felt needs on the part of the participants for access to information; and (d) the use of knowledge as the basis of the participant's development of symptom management care patterns. In contrast to abandonment reported in earlier research, data from this study acknowledged the exodus of some mentally ill members from the family system but also indicated eventual reintegration of the mentally ill family member in later phases of the process.

Information from this study must be considered within the scope of its generalizability and limitations. Data were drawn from a stable, well educated, self-selected and highly motivated group of middle-aged to elderly Caucasian Midwesterners. Information can probably be extrapolated to similar groups, but obvious limitations exist in further generalization.

Results suggest the need for replication of this study in other ethnic and socio-economic groups and in groups who have not experienced a similar psycho-educational intervention. If additional research supports the existence of similar phases in a variety of groups, the possibility exists to further define specific phases and determine concurrent family needs, thus allowing for the development of more specifically and appropriately tailored interventions.

REFERENCES

- Berg, B. L. (1998). *Qualitative research methods for the social sciences* (3rd ed.). Boston: Allyn & Bacon.
- Blumer, H. (1969). *Symbolic interactionism*. Englewood Cliffs, NJ: Prentice Hall.
- Brown, G. W., Carstairs G. M., & Topping, G. (1958). Post hospital adjustment of chronic mental patients. *The Lancet*, 2, 685-689.
- Clark, E., & Drake, R. (1994). Expenditures of time and money by families of people with severe mental illness and substance use disorders. *Community Mental Health Journal*, 30, 145-163.
- Clausen, J., & Yarrow M. R. (1955). The impact of mental illness on the family. *Journal of Social Sciences*, 11, 4.
- de Cangas, J. (1990). Exploring expressed emotion: Does it contribute to chronic mental illness? *Journal of Psychosocial Nursing*, 28(2), 31-34.
- Doornbos, M. (1996). The strengths of families coping with serious mental illness. *Archives of Psychiatric Nursing*, 10, 214-220.
- Fadden, G., Bebbington, P., & Kuipers, L. (1987). Caring and its burdens. *British Journal of Psychiatry*, 151, 660-667.
- Francell, C. G., Conn V. S., & Gray, P. D. (1988). Families' perceptions of burden of care for chronically mentally ill relatives. *Hospital and Community Psychiatry*, 39, 296-300.
- Grad, J., & Sainsbury, P. (1963). Mental illness and the family. *The Lancet*, 1, 544-547.
- Herz, M. I., Endicott J., & Spitzer R. L. (1976). Brief versus standard hospitalization: The families. *American Journal of Psychiatry*, 133, 795-801.
- Hobbs, T. (1997). Depression in the caregiving mothers of adult schizophrenics: A test of the resource deterioration model. *Community Mental Health Journal*, 33, 387-399.
- Karp, D., & Tanarugsachock, V., (2000). Mental illness, caregiving, and emotional management. *Qualitative Health Research* 10(1), 6-25.
- Lefley, H. (1996). *Family caregiving in mental illness*. Thousand Oaks, CA: Sage.

- Leininger, M. (1991). Ethnonursing: A research method with enablers to study the theory of culture care. In M. Leininger (Ed.), *Culture care, diversity and universality: A theory of nursing* (pp. 73-117). New York: National League for Nursing.
- Lofland, J., & Lofland, L. (1995). *Analyzing social settings: A guide to qualitative observation and analysis* (3rd ed.). Boston: Wadsworth.
- Loukissa, D. (1995). Family burden in chronic mental illness: A review of research studies. *Journal of Advanced Nursing*, 21, 248-255.
- MacGregor, P. (1994). Grief: The unrecognized parental response to mental illness in a child. *Social Work*, 39, 160-166.
- Maurin, J. T., & Boyd, C.B. (1990). Burden of mental illness on the family: A critical review. *Archives of Psychiatric Nursing*, 4(2), 99-107.
- Miklowitz, D. J. (1994). Family risk indicators in schizophrenia. *Schizophrenia Bulletin*, 20, 137-149.
- Murphy, J. W., & Choi, J. M. (1997). *Postmodernism, unraveling racism and democratic institutions*. Westport, CT: Praeger.
- Reinhard, S., & Horwitz, A. (1995). Caregiver burden: Differentiating the content and consequence of family caregiving. *Journal of Marriage and the Family*, 57, 741-750.
- Rose, L. (1996). Families of psychiatric patients: A critical review and future research directions. *Archives of Psychiatric Nursing*, 10(2), 67-76.
- Spaniol, L., & Zipple, A. (1994). Coping strategies for families of people who have a mental illness. In H. Lefley & M. Wasow (Eds.), *Helping Families Cope With Mental Illness* (pp. 131-146). New York: Harwood Academic.
- Stuart, G. W., & Laraia, M. T. (1998). *Principles and practices of psychiatric nursing* (6th ed.). New York: Mosby.
- Terkelsen, K. (1987). The evolution of family responses to mental illness through time. In A. B. Hatfield & H. Lefley (Eds.), *Families of the mentally ill: Coping and adaptation* (pp. 151-166). New York: Guilford.
- Tessler, R. C., Killian, L. M., & Gubman, G. D. (1987). Stages in family response to mental illness: An ideal type. *Psychosocial Rehabilitation Journal*, 10, 3-16.
- Torrey, E. F. (1995). *Surviving schizophrenia* (3rd ed.). New York: HarperCollins.
- Tuck, I., du Mont, P., Evans G., & Shupe, J. (1997). The experience of caring for an adult child with schizophrenia. *Archives of Psychiatric Nursing*, 11, 118-125.
- U.S. Department of Health and Human Services. (1999). *Mental health: A report of the surgeon general-executive summary*. Rockville, MD: U.S. Department of Health and Human Services Administration, Center for Mental Health Services, National Institutes of Health, National Institute of Mental Health.
- Wahl, O. & Harman, C.R. (1989). Family views of stigma. *Schizophrenia Bulletin*, 15(1), 131-139.
- Yarrow, M., Schwartz, C., Murphy, H., and Deasy, L. (1987). The psychological meaning of mental illness in the family. In E. Rubington & M. Weinberg (Eds.) *Deviance: The interactionist perspective* (5th ed.) (pp. 25-32). New York: Macmillan.

Susan Muhlbauer, a psychiatric nurse practitioner and certified specialist in Adult Mental Health and Psychiatric Nursing, is an assistant professor at the University of Nebraska College of Nursing.