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What is This?
The 24-7-52 Job: Family Caregiving for Young Adults With Serious and Persistent Mental Illness

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Few of the studies focusing on family caregiving have dealt with families caring for a young adult member with a serious and persistent mental illness. This qualitative study expands our understanding of the caregiving processes in these families. The narrative responses of 76 family caregivers from National Alliance for the Mentally Ill chapters across the United States were analyzed using content analysis. Five caregiving processes were identified including monitoring, managing the illness, maintaining the home, supporting/encouraging, and socializing. Family caregivers cited a need for information about the illness and available resources with which to prepare themselves for their caregiving responsibilities. Multiple client outcomes were used by the caregivers to evaluate the effectiveness of their efforts. Comparisons are made between these results and the findings of empirical studies in the broader caregiving literature.

The National Institute of Mental Health (NIMH) (1994) has estimated that there are approximately 5 million Americans with serious and persistent mental illnesses (SPMIs). Between 40% and 60% of these persons either reside with or receive care from their families (Cook, Cohler, Pickett, & Beeler, 1997; NIMH, 1994). This is due to the fact

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that the SPMIs often follow an unpredictable course that includes relapses and frequent hospitalizations, and the current mental health care system has failed to adequately address the service needs of those challenged with these devastating illnesses. Thus, of necessity, a substantial number of family members have assumed the multifaceted role of caregiver to their loved ones who struggle with mental illnesses.

BACKGROUND

The caregiving experiences of families with an SPMI member have rarely been mentioned in the caregiving literature, and thus, this category of caregiver has essentially been ignored (Lefley, 1996). Many of the studies that do exist have focused primarily on the burden associated with the families’ caregiving responsibilities (Cook, Lefley, Pickett, & Cohler, 1994; Jones, Roth, & Jones, 1995; Reinhard, 1994; Ricard, Bonin, & Ezer, 1999). Therefore, little is known about the complexities of the caregiving processes in SPMI families.

Several researchers have expanded our understanding of the context of family caregiving processes. An early study by Chafetz and Barnes (1989) explored issues surrounding psychiatric caregiving by conducting focused interviews with 20 family caregivers recruited from community organizations and clinical services. This research documented problems associated with caregiving, issues related to protracted parenting, and critical sources of support for caregivers. Although these caregivers acknowledged the stressful nature of caregiving, a warmth and concern for their ill relatives were apparent and appeared to mitigate the aversive aspects of their responsibilities.

Tuck, du Mont, Evans, and Shupe (1997) continued this delineation of the context of caregiving processes by exploring the lived experiences of 9 parental caregivers of adult children with schizophrenia. Participants were obtained through referrals from mental health professionals and a National Alliance for the Mentally Ill (NAMI) chapter. The study revealed that a diagnosis of schizophrenia was viewed as a destructive force that interrupted and radically transformed the normative family life trajectory. The caregiving experience was described as a grief-filled one in which the imagined, idealized child was lost and the physically present child was transformed into a needy stranger.
Similarly, Mays and Lund (1999) explored the lived experiences of 10 male caregivers of severely mentally ill relatives, recruited from community mental health centers and a NAMI chapter, by using an informal interview guide that addressed psychosocial, physical, financial, and crisis-management categories. These researchers found themes of burden, commitment, and role affirmation. Relative to these themes, the caregivers experienced decreased levels of stress over time, a long-term commitment to the role based on duty and emotional attachment, and a sense of pride in accomplishment of their roles.

A few researchers have more explicitly explored the actual phenomenon of caregiving processes in SPMI families. An early study by Chesla (1989) explored the lived experience of schizophrenia as understood by the parents who care for these individuals. These parents were recruited from NAMI chapters. Chesla found evidence of four distinct illness models that characterized the parents’ personal understanding of the causes, nature, course, and appropriate treatment of schizophrenia. The models included the strong biologic, the rational control, the normalizing, and the survival-through-symptoms model. Not surprisingly, the caregiving processes that these parents engaged in were substantially shaped by the illness model that they held.

Rose (1998b) conducted an important qualitative study of family caregivers of persons with serious mental illnesses, recruited from two large urban hospitals, in an attempt to increase understanding of the meaning that they assigned to the caregiving experience. Rose’s findings indicated that “caregiving meant accepting a responsibility to influence the impact of the illness on the relatives’ lives” (p. 371). Furthermore, the meaning of caregiving revolved around three concerns. First, caregivers were concerned with finding the essence of the person obscured by the illness and thus worked toward not losing sight of the person beneath the illness. Second, the theme of finding a place for self in influencing the illness emerged and was related to caregivers’ attempts to develop routine responses to illness-related behaviors that would make the illness better. A final theme, helping the relative to move forward, involved focusing on the future by setting goals, sustaining hope, and stepping back.

Schene, van Wijngaarden, and Koeter (1998) also explored family caregiving processes for persons with schizophrenia. Their random sample of 480 caregivers was obtained from the Dutch family organization for persons with schizophrenia. Data were obtained via mailed
questionnaires, and principal component factor analysis was performed. Four caregiving domains were identified including tension, supervision, worrying, and urging. Tension referred to the strained interpersonal relationships between caregivers and their relatives, whereas worrying dealt with painful interpersonal cognitions about the clients’ safety, care, and health. Supervision, on the other hand, included the caregiver’s tasks of ensuring and guarding relative to issues of medication, dangerous behaviors, and rest. Finally, urging referred to activation and motivation of clients to engage in activities of daily living and other activities.

In the broader caregiving literature, an emphasis on family burden is also apparent (Cain & Newsome Wicks, 2000; Sisk, 2000). Several exceptions were noted where the emphasis was clearly placed on understanding family caregiving processes. For example, Bowers (1987) explored the caregiving of adult children for their aging parents and distinguished family caregiving activities by purpose rather than task. Five conceptually distinct categories of family caregiving, including anticipatory, preventative, supervisory, instrumental, and protective care, were identified.

Schumacher, Stewart, and Archbold (1998) spoke of the fact that the concept of “doing caregiving well” was just beginning to be explored in the nursing literature, and thus, there is a lack of clarity as to the meaning of this concept. In an effort to develop this concept, family caregiving for cancer patients was examined by interviewing the patients as well as their primary caregivers (Schumacher, 1996; Schumacher, Stewart, Archbold, Dodd, & Dibble, 2000). Using qualitative analysis, the concept was defined as the “ability to engage effectively and smoothly in nine core caregiving processes” (Schumacher et al., 2000, p. 199). These nine core caregiving processes included monitoring, interpreting, making decisions, taking action, making adjustments, providing hands-on care, accessing resources, working together with the ill person, and negotiating the health care system (Schumacher et al., 2000).

Preparation for families assuming the caregiving role is an underexplored area in the caregiving literature as well. It appears as though many families are thrust into the role without the prerequisite information and training. Although some psychoeducational programs for SPMI families have been developed, tested, and found to produce positive outcomes (Dixon & Lehman, 1995), Lefley (1996) identified a “notable lack of information and help from the treatment system” (p. 7) for families dealing with behaviors associated with
serious mental illness. In the broader caregiving literature, preparation is a concern as well (Brereton, 1997; Levine, 1998). Specifically, caregivers for persons with a variety of chronic, physical illnesses spoke of feeling unprepared, both technically and emotionally, for their caregiving responsibilities (Levine, 1998). Some empirical work has been directed toward increasing the level of preparation for caregivers of older adults (Archbold et al., 1995).

When reviewing the empirical research related to family caregiving, it is important to make a distinction between family-related research and family research (Feetham, 1991). Family-related research derives data from individuals and explores relationships among family members, whereas family research focuses on the family unit as the entity of investigation (Feetham, 1991). Conceptualizations and definitions of family must correspond with the type of research being conducted (Feetham, 1991). Although some of the family caregiving research is explicit about the perspective taken and the definitions used, other studies are less clear.

Thus, the caregiving research is limited in terms of studies that clearly delineate the type of family research that is being conducted, those that explore family caregiving in families with SPMI members, and those that approach this phenomenon from a process orientation. Therefore, using a family-related approach where the parental care providers’ perspectives are captured, this study investigated the processes of family caregiving in SPMI families, including issues of preparation, quality of care, and professional understanding. Such an explicit focus on the actual caregiving processes in SPMI families has only been addressed in a select number of studies to date.

METHOD

This qualitative research was part of a larger, quantitative investigation examining factors contributing to family health in caregiving families. Simultaneous methodological triangulation (Morse & Field, 1995) was used to obtain a richer perspective on the interface between family caregiving processes and family health in families with a young adult member with an SPMI. This article focuses on a “question analysis” of the written responses of 76 caregivers for young adults with SPMIs to open-ended inquiries about their caregiving experiences (Morse & Field, 1995). Inclusion criteria required that the respondent be a parent and a caregiver for a young adult member
with a diagnosis of schizophrenia, bipolar disorder, or schizoaffective disorder. Participants were recruited from NAMI chapters throughout the United States. E-mail contact was made with the president of the NAMI chapter, and the president solicited volunteers from among group members. Questionnaire packets were either mailed directly to the participant or in bulk to the chapter president who distributed them. Packets included an informed consent form and a stamped, addressed envelop for return of the materials to the researcher.

Respondents were asked to provide narrative responses to four questions related to their caregiving experiences. The questions were as follows:

1. What is involved in caring for your relative who struggles with a mental illness?
2. What type of information did you need as you learned to care for your relative? Where did you find this information?
3. How do you know when you are doing a good job caring for your relative?
4. What do you wish mental health care professionals understood about the experience of caring for a relative with a mental illness?

Following receipt of the narrative data, participants’ responses were transcribed from the actual questionnaires and sorted by question. The question sort provided four a priori categories into which the family caregiving data were organized: processes, preparation, competence, and professional understanding.

At this point, Morse and Field (1995) suggested that a question analysis is similar to a content analysis. Therefore, all responses to a question were read in their entirety, treating each separate idea as a distinct data element. Preliminary themes were identified by reading each element in the context of the complete narrative. The process of identifying preliminary themes was facilitated by use of the Ethnograph V5.0.

In an attempt to enhance the trustworthiness (Lincoln & Guba, 1985) of the study, two procedures were used. First, an attempt was made to ensure neutrality (Lincoln & Guba, 1985) by circulating the elements and preliminary themes to the other members of the research team for evaluation of the fit between the element and the corresponding theme. In addition, the thematic label was evaluated to ensure clarity. Second, the preliminary themes were shared with two parents who functioned as family caregivers to a young adult
with an SPMI to determine the credibility (Lincoln & Guba, 1985) of the results.

Pertinent sample characteristics are listed in Table 1. The family caregivers were primarily female, middle-aged (M = 55.80 years, SD = ±9.84), and highly educated (M = 15.63 years of education, SD = ±2.7). The clients were young adults (M = 29.76, SD = ±6.38) and had been ill an average of 9.21 years (SD = ±3.12).

**RESULTS**

The results will be presented in terms of the a priori categories that were used to obtain and analyze the data. Each category will be presented in terms of the themes derived from the content analysis.
Caregiving Processes

The content analysis revealed five major caregiving processes in operation in families with a relative with an SPMI. Caregivers were involved in monitoring, managing the illness, maintaining the home, supporting/encouraging, and socializing.

Family caregivers engaged in monitoring that can be understood as “making sure.” They monitored for medication compliance, presence of symptoms, and attendance at appointments, as shown in the following statement.

I have to make sure that he goes to all of his appointments and takes his medication as he is supposed to (time and dosage). I have to watch that the prescription doesn’t run out. I always observe his behavior to see if he is getting sicker.

Family caregivers took an active role in managing the illness as well. This aspect of caregiving encompassed the process of attending to those needs that were specifically related to the mental illness. The following statement illustrates how one family operationalized managing the illness.

I take him for lab work and attend appointments with him. . . . I call his case manager, doctors, and nurses to see that he’s getting good care. . . . I set up his medications. . . . There is a lot of paperwork that needs to be kept up with and I need to do that. . . . He has taken overdoses of aspirin so we have to keep everything locked up.

At times it was necessary to assist with personal care.

I have done everything from bathing her to deciding what she should wear. She can now do her hygiene most of the time.

The family caregivers also took an active role in maintaining the homes of their relatives struggling with mental illness. This was a multifaceted process that involved helping with routine household chores as well as providing critical support in the area of child care for dependent children of the ill young adult. This aspect of caregiving appeared to be operational whether the ill relative lived in the family home or outside.
She is often not capable of making a meal, cleaning the house, picking up after herself, buying groceries, or doing her laundry. . . . I help with managing finances—budgeting, paying bills and balancing the checkbook. . . . I often need to transport her because she doesn’t have a car.

We are regularly involved in caring for her children (our grandchildren). Sometimes we have responsibility for them for extended periods of time. We try to provide stability and consistency for them.

The families saw supporting/encouraging as an essential caregiving process. This component of the caregiving role was operationalized via telephone, e-mail, or face-to-face contact. All methods of contact were used to enhance and fortify the client.

I function as an overall support system. . . . so I make sure to talk to him daily by phone. . . . I try to support and encourage him in his efforts to be self-sufficient. . . . I try to give positive feedback for the things he is able to do. . . . I’m there for him when he’s struggling. . . . I am available to him when he needs to talk.

The final caregiving theme was that of socializing. Socializing focused on the provision of social activities for the purpose of structuring time in a positive manner. This is seen in the following statements.

We try to spend as much time with him as possible—going to the movie theater, restaurants, etc.

We have family dinners and play ping-pong. . . . He goes out for coffee with his father.

We go for walks. . . . We try to keep him occupied so that he doesn’t smoke four packs a day or drink Coke so much.

Preparation for Caregiving

Families identified a need for an array of information to equip themselves for their role as caregivers. Much of the desired information pertained to the illness itself. For example, the need for specifics related to the diagnosis and prognosis was prevalent, as illustrated in the following statement.
We need information about the illness itself and what to expect next. What we have been told is just some general information and that it affects everyone differently so it’s just a guess as to what will happen next.

Predictably, the family caregivers also wished for information related to psychotropic medications.

We need an explanation of the medications. How long does it take for medication to start working? Does a relapse occur when the person is on medication? What are the side effects of medication? What do you do about non-compliance?

Information pertaining to the development of interventions for dealing with symptoms was also a need expressed by the families.

How do you deal with anger—like when he just went off on me? I don’t know what to do when he is silent, withdrawn, or has erratic behavior. How am I supposed to react when he has hallucinations, delusions, and paranoid ideas?

In addition to illness-related information, the family caregivers desired greater knowledge of the resources available to them and their ill relatives and how to access them.

We needed to know where to go and how to go about getting services such as support groups, therapy, public aid, SSI [supplemental security income], rehabilitation, and vocational training.

Finally, some family caregivers gave indication of the breadth of information that they needed, as shown in the following statement.

We needed to know EVERYTHING! We previously had no clue about schizophrenia.

Families employed multiple methods of obtaining the information that they deemed necessary. The most frequent source of information was family support groups or family educational programs conducted by NAMI. Families also did their own research using books, magazines, and newsletters as well as Internet sites. Mental health professionals were the final and least cited source of information.
Competence in Caregiving

When asked about competence in caregiving, families cited a variety of client indicators as outcome data. Many of these indicators related to a theme of client stability. Caregivers felt as though they were successful and effective in their caregiving role when the client demonstrated stability along several dimensions including medication compliance, independence, productivity, symptom control, communication with social network, and happiness. These aspects of stability are seen in the following statements.

Twenty-four hours passes and we don’t go to the hospital or the police don’t come here.

When he takes his meds.

When she lives on her own without any crises and her reliance on us decreases.

When he is in remission and can sometimes work or take classes.

He laughs, jokes, he’s happy! . . . When we can all sit and talk openly.

Some family caregivers spoke of their own internal cues that led them to believe that they were effective in their role as a caregiver.

We go by how we feel we’re doing. . . . We are caring people and only doing good for him.

It was interesting to note that another prevalent theme relative to competence in caregiving was uncertainty. In spite of the significant commitment that caregivers made to their role and its accompanying responsibilities, they remained unclear about the effectiveness of their efforts.

I don’t know when I’m doing a good job. I take each day separately and hope that tomorrow won’t be the day that I’m dreading.

I’ve only felt I’m doing a good job for moments . . . especially early on.

Most of the time I don’t know if I’m doing a good job or not. . . . I don’t really know that I make any impact at all. . . . I just do the best I can.
Professional Understanding of the Caregiving Experience

Four major themes emerged relative to what family caregivers wished mental health professionals understood about their experiences. First, the families felt the need for greater understanding of the impact of the mental illness on the entire family unit. Some families spoke globally of the difficulties, as seen in the following segment.

It (mental illness) has a devastating effect on the whole family. . . . It can destroy the family.

Others were more specific about the areas of impact.

Everything is disrupted in an ordinary life. This includes daily schedules especially sleeping, work, family relationships, health of family, friendships, even neighborhoods.

The second theme pertained to the desire for professionals to understand the caregivers’ need to be included in the treatment planning process. Some family caregivers expressed this in terms of their right to inclusion.

Families are frequently the primary care provider and therefore have a place at the table in all decision making. . . . We are as much a part of the process as the client. This is a family disease like other chronic illness.

Others spoke of the benefits that could be derived from greater inclusion.

We can supply essential information, often not available otherwise, on our relative’s condition.

The third theme that emerged relative to the family caregivers’ wish for understanding related to the amount of time that they devote to their caregiving responsibilities.

The family works 24 hours a day, 7 days a week, 52 weeks a year. We don’t work an 8-hour shift and then go home—away from the client. We are always “on call.”

Finally, the families sought understanding of the primary emotion associated with the caregiving role.
The overarching thing associated with these responsibilities and activities is frustration. We experience frustration at all levels...frustration with the illness, the symptoms, our daughter, the system.

DISCUSSION

Similarities to previous work were documented in this study of families with a member with an SPMI. First, and perhaps most important, caregivers for persons with SPMI described purposeful processes of caregiving rather than a set of specific tasks. Several of these processes could be linked to previous empirical findings. Monitoring, as it was described in this study, appears to be analogous to the supervision of persons with mental illnesses by their caregivers described in Schene et al.’s (1998) work as well as the monitoring described by Schumacher et al. (2000) by caregivers for their loved ones with cancer. The overall process of managing the illness may be regarded as the mental health equivalent of providing hands-on care (Schumacher et al., 2000) or instrumental caregiving (Bowers, 1987). In addition, the component of managing the illness in which caregivers ensure adequate care is similar to Schumacher et al.’s (2000) negotiating the system. Furthermore, supporting/encouraging may parallel Bowers’s (1987) protective care where the focus was on safeguarding the self-esteem of the care recipient.

The most unique caregiving process identified in this study, as compared to the existing family caregiving literature, was that of socializing. The focus on structuring time in a constructive manner via social activities is, no doubt, specifically related to the nature of mental illness. The negative symptoms of schizophrenia (Stuart & Laraia, 2001) involved difficulties engaging in goal-directed behavior as well as difficulties maintaining social contacts.

The caregiving families in this study outlined extensive needs for information with which to prepare themselves for their caregiving role with a loved one with an SPMI. This desire for information has been cited previously in the SPMI literature (Ip & Mackenzie, 1998; Rose, 1997, 1998a), and three of the four topics (illness information, interventions for dealing with symptoms, and identification of resources) identified by the respondents in this study have been previously set forth as essential for caregivers of persons struggling with mental illness (Rose, 1998b; Winefield & Harvey, 1994). Interestingly, the families in the current study tended to obtain necessary informa-
tion from caregiving peers and independent research more frequently than from mental health care professionals. This coincides with Lefley’s (1996) observation that the treatment system has had limited involvement in the provision of information and assistance to SPMI families. It will be important for mental health care professionals to take an active role in delineating and providing the specific type of information that will be most useful to families caring for a mentally ill member.

This desire for information is operational in the broader caregiving arena as well. Schumacher et al. (2000) identified accessing resources as one of the caregiving processes that families used when caring for a loved one with cancer. Accessing resources included “obtaining what was needed to provide care, including information . . . help from community agencies . . . ” (p. 198).

When asked about competence in caregiving, the families identified an array of client indicators or outcomes that they used to evaluate their efforts. This paralleled the work of Schumacher et al. (2000), who labeled caregiving as effective “when it led to the best possible outcomes of care” (p. 199). The theme of uncertainty about effectiveness of caregiving efforts coincides with the work of Mishel (1990), who spoke of the continual uncertainty associated with chronic illness. Such uncertainty may suggest a role for mental health professionals. Mishel suggested that nurses assist chronically ill clients in developing a probabilistic worldview where uncertainty is seen as natural and can be used as a positive force in one’s life. Other empirical studies have shown that the uncertainty associated with chronic illness can be effectively reduced by means of nursing interventions (Ritz et al., 2000; Santacroce, 2000).

The caregiving families wished for mental health professionals to enhance their recognition of several issues. They spoke eloquently and consistently of the tremendous impact on the family, the associated frustration, and the time commitment that a mental illness exacts from the family unit. Although this has been previously outlined in the literature (Cook et al., 1994; Jones et al., 1995; Ricard et al., 1999; Tuck et al., 1997), positive aspects of caregiving, not noted in this study, have also been documented (Chafetz & Barnes, 1989; Mays & Lund, 1999). It is possible that the specific questions asked or the manner in which they were posed may have contributed to the limited variability evident in the responses. Caregivers were not explicitly asked about the rewarding aspects of their caregiving experiences and may have been less likely to write about a related but unsolicited
topic than to weave it into discussion in a focus group or interview. The families in this study also desired involvement in the treatment planning of their ill relatives, which is analogous to the previously documented call for affirmation, respect, and recognition of the significance of their role (Levine, 1998; Rose, 1997, 1998a).

The limitations of this study can be found in several areas. First of all, the respondents were members of NAMI family support groups, and, as such, they may differ in significant ways from the larger population of family caregivers for SPMI clients. They have explicitly sought out the resources offered by NAMI, which might indicate that they are either greatly affected by the illness or highly invested in advocating for the mentally ill. Furthermore, the caregivers were predominately mothers of the clients. There has been a call for broadening the understanding of caregiving experiences with SPMI clients by giving more attention to the experiences of male caregivers (Mays & Lund, 1999). Another limitation lies in the actual method of data collection. Soliciting handwritten responses to structured questions may result in somewhat truncated data and does not allow for interaction between the researcher and informant for the purpose of clarification and accurate interpretation.

CONCLUSION

A look at the caregiving processes of SPMI families allows us to expand our understanding of the uniqueness of this group of informal caregivers. In addition, such research enables us to identify commonalities in caregiving processes between client populations and, in so doing, allows us to move logically toward consolidation of the existing empirical findings. Such consolidation can strengthen the foundation for future intervention studies with family caregivers.

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Doornbos / Family Caregiving for Young Adults


Mary Molewyk Doornbos, Ph.D., R.N., is a professor of nursing in the Department of Nursing at Calvin College in Grand Rapids, Michigan. Her research continues to focus on family caregiving in the families of persons with serious and persistent mental illnesses as well as on interventions that would support these caregivers. Dr. Doornbos’s recent publications include “The Problems and Coping Methods of Caregivers of Young Adults With Mental Illness” (1997) in Journal of Psychosocial Nursing and “The Strengths of Families Coping With Serious Mental Illness” (1996) in Archives of Psychiatric Nursing.