Caring for a Family Member With Chronic Mental Illness

Yun-Hee Jeon
Irena Madjar

The aim of the phenomenological study described in this article was to depict the lived world of caring for a family member with chronic mental illness. Through two individual in-depth interviews, 14 participants were asked to describe their experience of caring for a son, daughter, or parent affected by chronic mental illness. The main themes emerging from the study related to temporality, the need to "live each day as it comes" without being able to make long-term plans, and to relationality, the need to "look at the world through the other's window," always aware of how the world responds, not only to oneself but also to the person with mental illness.

During the past two decades in Australia, as in many other Western countries, the deinstitutionalization movement has gained momentum and has resulted in increasing numbers of people with chronic psychiatric illnesses living in the community (McCausland, 1987; National Health Strategy, 1993). Community-based care, however, is not a panacea either for patients or for those expected to provide day-to-day oversight and care for them. As in the case of the elderly and those affected by Alzheimer's disease, it is often one family member who assumes primary responsibility for the care of a frail or ill relative (Parsons, 1997). A major inquiry into human rights of people with chronic mental illness in Australia highlighted the need for readily accessible support, respite, and acute care services for these people, not only to lessen the personal impact of their illness but to enable family members caring for them to sustain commitment and continue to provide community-based care (Human Rights and Equal Opportunity Commission, 1993).

A crucial question to be asked in relation to community-based care is "Who takes on the caregiving role most of the time?" Without a doubt, most of the responsibility for caring, whether for the elderly or for physically or mentally disabled family members, falls on the female kin, most often mothers and daughters (Fine, 1992; Guberman, Maheu, & Maille, 1992; Home Care Service of New South Wales, 1988; Rutman, 1996). The social expectation that women will take on the major work of caregiving persists, often impinging on women's desires and abilities to pursue a career and/or to enjoy social activities outside the home. Competing demands and the work involved in caring for a chronically ill relative may lead to family conflicts and feelings of guilt. Unresolved pressures and conflicts may eventually lead to health problems in those expected to care for others. By failing to understand the experience of family caregivers and by reinforcing societal expectations that families will take care of their own, consciously or unconsciously,

health professionals can add to the stress of family caring and the emotional conflict that many caregivers experience (Anderson & Elfert, 1989; Leong, 1997).

The purpose of this phenomenological study was to explore the taken-for-granted everyday experiences of family caregiving in order to develop a deeper understanding of these experiences and describe the phenomenon of family caregiving in the context of chronic mental illness.

BACKGROUND

There is evidence in the literature that family caregivers construct diverse meanings about mental illness, its causes, and its consequences. As deinstitutionalization has taken hold, increasing numbers of researchers have shown an interest in the effects that living with and caring for a mentally ill person have on other family members (Maurin & Boyd, 1990; Montgomery, Gonyea, & Hooyman, 1985). Since initial research by Grad and Sainsbury (1963), others have focused on the impact of mentally ill persons living with their families or significant others and on the relationship between discharge from the hospital of the mentally ill persons and the stress experienced by those family members who take on their subsequent care (Anderson & Lynch, 1984; Cook, 1988; Solomon, Beck, & Gordon, 1988; Solomon & Marcenko, 1992). For example, in interviews with family members at 1 month postdischarge of a relative from a psychiatric hospital, Solomon and Marcenko (1992) found that more than half of the family caregivers expressed a great deal of concern about their relatives' readiness to live in the community. The level of concern had not changed 1 year later, whereas other significant concerns regarding their own daily living and the burden of getting along with the ill relative and meeting the person's daily needs increased.

Generalizations from individual studies need to be treated with caution, however, because studies focusing on nonprofessional caregivers are not consistent even in their definitions of caregivers and caregiving. Some include informal caregivers in general who may have no family ties to the care recipient (Nolan, Grant, & Ellis, 1990), whereas others choose to include only specific family caregivers, such as those who care for their elderly relatives (Bull, 1990; Cantor, 1983; Montgomery et al., 1985), and a smaller number focus on family members caring for mentally ill relatives (Coyne et al., 1987; Jacob, Frank, Kupfer, & Carpenter, 1987; Noh & Turner, 1987). Furthermore, findings from such studies indicate that correlations between objective activities and subjective perceptions of caring and the burden of caring are not well established, at least in part because there are obvious differences in the study samples and the diversity of contexts of care.

A significant influence on the caregiving experience is the extent to which caregivers' own needs are recognized and met. A number of research studies have identified caregivers' needs for social support as well as for information and appropriate community and hospital services (Crotty & Kulys, 1986; Gantt, Goldstein, & Pinsky, 1989; Hanson & Rapp, 1992; Leong, 1997; MacCarthy et al., 1989; Norbeck, Chafetz, Skodol-Wilson, & Weiss, 1991; Thompson & Weisberg, 1990), whereas others have explored the relationship between social support and perceived burden of care (Potasznik & Nelson, 1984). Among these studies, few have used qualitative research approaches and methods (Hanson & Rapp, 1992; Norbeck et al., 1991; Rutman, 1996).

The Norbeck et al. (1991) study is of particular relevance, not only because the authors used careful sampling and clear definitions of key variables, but because the study used qualitative methods. There were three categories among the 60 caregivers in the study related to the age of their care recipients—namely, children, adults, or elderly individuals—which also related to their diagnoses of pervasive developmental disabilities, schizophrenic or bipolar disorders, and Alzheimer's-type dementias, respectively. Using content analysis of interview data, Norbeck and her colleagues differentiated the needs across the groups in relation to four need categories: emotional, feedback, informational or cognitive, and instrumental support. Informational support was reported as the area of most need by all three groups. Furthermore, the results indicated that the caregivers of children with developmental disabilities and adults with severe mental illness showed extreme concern regarding the future of their care recipients, whereas the caregivers of elderly individuals with Alzheimer's disease did not indicate similar concerns. Thus, perceptions and expectations of the future, and not only present concerns, may play an important part in the experience of family caregiving.

In a phenomenological hermeneutic study of caregiving practices of parents of young adults with schizophrenia, Chesla (1991) identified different styles of interaction and caregiving, which were labeled *"engaged care, conflicted care, managed care, and distanced care"* (p. 454). In *engaged care*, parents continued to care for their offspring and to show an understanding and acceptance of their sometimes difficult and inappropriate behaviors. In *conflicted care*, parents showed little understanding or acceptance of their offspring's illness and behavior and tried to minimize any impact on their own lives. Even though these parents continued to provide care, their approach often resulted in conflict and extreme dissatisfaction with their life situation. In *managed care*, parents were characterized by being eagerly active and objective in managing and learning to cope, yet they found the experience very draining, and they expressed a strong need for breaks from the work of caring. Finally, *distanced care* was evident mostly in fathers who entrusted the direct caregiving work to another member of the family, most often their wives, yet reported feeling emotionally hurt and excluded from their son's or daughter's lives. What Chesla (1991) does not report is whether the key themes identified were in any way sequential or associated with the duration of the caregiving experience. Nevertheless, these interpretive findings offer new insights and increased understanding of caregiving practices in the family context and provide a different perspective from previous studies on the caregiving experience, which have focused largely on the stress and burden of caregiving. Continuing on from previous research, the aim of the present study was to uncover and describe the meaning of family caregiving in the context of chronic mental illness and family life.

METHOD

The phenomenological approach was selected as the most effective means by which to achieve the aim of the study and provide answers to the key research question; namely, "What is it like being a caregiver for a relative with chronic mental illness?" Methodologically, the research was guided by the work of Benner (1994) and van Manen (1990) and involved the phases of (a) selecting a phenomenon of current

interest to the researcher and nurses working in community mental health, (b) investigating the experience of family caregivers as lived by them rather than as observed by others, (c) reflecting on the main themes that characterize the experience and structure the phenomenon of family caregiving, and (d) describing the phenomenon through the use of researchers' and participants' voices.

Study Participants

Fourteen family caregivers, contacted through community health centers and community support groups, took part in the study. Their involvement in caring for a relative with chronic mental illness ranged from 6 months to 36 years, although the actual period was often longer because the range was calculated from the time of the confirmed diagnosis. At the time of the study, six of the care recipients lived in the family home with parent caregivers, whereas others lived elsewhere in the community but were visited regularly by family caregivers who took primary responsibility for their well-being. (It is, however, important to note that persons with chronic mental illness changed residence from time to time and often returned to their parents' home for periods of weeks or months.) The participants, who ranged in age from 37 to 79 years, were mostly parents caring for a son or daughter with schizophrenia, the latter ranging in age from 16 to 51 years. One caregiver was a daughter caring for her elderly mother who suffered from major depression, and 1 of the parent caregivers had two young adult sons with bipolar disorder. Of the 14 participants, 8 were married, 3 were widowed, 2 were separated, and 1 had never married. The socioeconomic status of the participants ranged from lower to upper middle class. The majority were in paid employment, and only 4 of the women and 1 man had no work outside the home.

Data Collection and Analysis

Study participants were interviewed individually on two separate occasions. Each interview was audiotaped and lasted from 45 to 90 minutes. A preliminary analysis of initial interviews was used to generate issues for clarification and further questions in follow-up interviews.

The treatment and analysis of data focused on thematically disclosing and interpreting the meanings of the lived experience from the participants' perspective by using a hermeneutic phenomenological method described by van Manen (1990). The following procedures were followed:

1. All interviews were transcribed, and each transcript was read several times to gain a sense of the whole experience of caring for a family member with chronic mental illness. The main aim at this stage was to gain a sense of what it means for a person to live the experience. Individual portraits of family caring were sketched for later comparison and more detailed analysis.
2. Selective reading was undertaken, and significant statements, directly related to the phenomenon of family caring, were identified and demarcated. These were read and reread to formulate conceptual meanings and explore essential qualities of described experiences. Emerging conceptual categories and themes were then discussed individually with some of the participants, with nurse colleagues, and with a nurse experienced in phenomenological research to seek a consensual validation of the conceptual meanings developed by the first author (Stern, 1991).

3. As the themes began to emerge, components of each participant's statements relevant for each meaning unit or theme were highlighted. Redundancies in the units were eliminated, and the relevant statements were clustered and finally consolidated into a comprehensive account. Two key themes, composed of 11 subthemes, formed the basis of the final text on the lived experience of caring for a family member with chronic mental illness (Jeon, 1995).

Ethical Considerations

The proposal for the study was reviewed by the research ethics committees of the university and the area health service of the region in which the study was undertaken. Participation was voluntary and on the basis of informed consent. All participants were assured of their rights to anonymity and confidentiality and the right to withdraw from the study at any time without explanation or repercussions in terms of the services normally available to them. These rights were respected throughout the study.

FINDINGS

The findings of the study center on two interrelated existential themes: that of *temporality*, or the experience of lived time, and that of *relationality*, or the experience of being with others. The description and analysis of these themes and their constituent subthemes reveal the complexity of the experience of family caring, as well as pointing to the interconnectedness rather than the mutually exclusive nature of the different aspects of the experience.

Temporality and Family Caring: Taking Each Day as It Comes

The strongest theme drawing on the experience of time, taking each day as it comes, relates to the participants' experience of time as different from how others not engaged in the care of a relative with chronic mental illness experience time. They saw their time as less predictable and less certain. Unable to make long-term plans, they lived from day to day; the passing of time for them was punctuated by events and situations related to the care of the ill relative.

In the early stages of looking after a relative who appeared to be unwell or disturbed, the caregivers experienced a great deal of confusion, particularly before the final diagnosis of mental illness was made. The insidious onset of mental illness and the protracted period of months or years before a firm diagnosis was made created a perception of slow, directionless time, "dragging" and going nowhere. Families were often left alone trying to figure out what was happening to the ill relative, looking for causes to relate to the problems, and attempting to solve the problems on their own. Without a clear understanding of what was happening or what, if anything, they could do, families were left floundering in the dark. As a parent of a daughter with schizophrenia explained,

> It was dreadful because you knew nothing about the illness, and you didn't understand the illness. You are floundering, you're always floundering in the dark because you didn't know how to . . . what the best thing to [do] was.

After the initial stage of shock and confusion, family caregivers managed to cope but only by taking each day as it comes, trying to accept the present and not think too far into the future. There was a need for ongoing adjustments in family life, requiring constant changes and recognition that for some members, particularly the primary caregiver, the future options in life were forever curtailed. With time, the caregivers were able to develop a relatively optimistic view overall while being realistic in their expectations. They learned to differentiate between things they could change and those they could not and to make short-term rather than long-term plans. Such acceptance of their situation came only after the caregivers had experienced a great deal of disappointment, anger, and grief related to life dreams and wishes that they gradually learned to give up. As the parent of a son with a 5-year history of schizophrenia stated,

> You just can't sort of go bang into a new situation and expect him to be able to handle it because he can't. . . . As I said, we just take it as it comes. If he decides one day he wants to stretch his wings and move down town, when he is ready. He is not ready yet . . . fair enough, you know, but until then we just manage. . . . I just take each day as it comes. You can't plan ahead say 6 months or 12 months or something like that. You just take each day . . . when you survive that, you take the next day (laugh).

Taking each day as it comes involved more than passive acceptance of one's situation. It also required that family caregivers learn how to deal with hitherto unfamiliar, frightening, and unpredictable behaviors and events. Much of that learning occurred by trial and error, what the participants referred to as "learning by experience." The amount and quality of information received from health professionals was often insufficient, whereas community support groups such as the Association of Relatives and Friends of the Mentally Ill (ARAFMI) and Schizophrenia Fellowship were seen as more helpful, at least by those family caregivers who attended their meetings and were prepared to seek help. Learning from their own and others' experience was a slow and often frustrating process, adding to the feeling of floundering in the dark.

At the same time, the caregivers suffered from *ongoing grieving* for the loss of the past, present, and future in the sense that both the ill relative and they themselves had lost possibilities for a different kind of life. The grieving was not limited to one's own losses; rather, it focused on the person with mental illness and what he or she had lost. As the mother of a son recently diagnosed with schizophrenia said,

> There is that ongoing grieving for the person that he was. . . . It's terribly hard. When we, you know, whenever we sort of think this is awful, you know, for all of us . . . but it's 10 times worse for him, isn't it, than it is for us. You know, he's got to live with it 24 hours a day. We get breaks away from it.

There was an almost palpable, embodied sense of sorrow for the parents watching the struggle of the chronically ill son or daughter trying to cope and lead some kind of normal life. Although they grieved for the loss of what might have been and the loss of hope, the fear of the future grew as well, in particular for the elderly caregivers who were acutely aware of their own mortality. Even for younger parents, the loss of the hoped-for future was painful and filled with fear, particularly when they were sole caregivers or when they knew that no one else in the family wanted or was able to be responsible for the ill relative.

With time and experience, caregivers came to know that they needed to have physical and emotional respite in order to be able to maintain their caring responsibilities. This self-recognition was in part achieved despite others', including the ill person's, obliviousness to the demands the caregivers were experiencing on their time and energy. *Self-preservation through time out* for the majority of the caregivers began with the realization that if they were to be able to meet the needs of the ill person, then at least for a time they needed to attend to their own needs also. As one mother said,

> There's a tendency to sort of put all your energies into the sick person . . . and um . . . you've got to look after yourself because if you go down then there's no one else to pick up the pieces. It doesn't matter that you back off, you've got to attend to self-preservation. And learn to, you know, take the illness and . . . you've just got to learn to live with it. It's not going to go away, it's going to be there a long, long time.

Thus, temporality is a key dimension of the phenomenon of family caring. It points to the intangible yet extremely real sense of loss related to the past that cannot be recaptured, the present that is different and uneasy, and the future that holds more fears than dreams. In such a situation, taking each day as it comes is a way of living through a challenging and often stressful experience. It involves a degree of passive letting go of those things that are not possible and an active struggle to achieve the possible and to make the best of it.

Relationality and Family Caring: Looking at the World Through the Other's Window

Caring is an interpersonal process that connects those who care and those cared for. Thus, the phenomenon of family caring is essentially one of relationality, of living in relation to the other. The relation of the carer to the family member with chronic mental illness is only one part of the experience. The relation to the world is just as important and perhaps just as affected by the presence of chronic mental illness and all that it brings.

Looking at the world through the other's window speaks of the intentionality of the caregivers' being-in-the-world as they established and tried to maintain their relations with others while placing the interests of their ill relative at the fore. As a consequence, the caregivers often experienced being torn between their ill relative and the rest of the family members who also needed attention and care. Despite the caregivers' efforts to keep family relations intact and as harmonious as possible, other family members were affected by the presence of the mentally ill relative and the energy expended in his or her care. The impact on other siblings could be considerable, in particular, if they had to share caring responsibilities with their parents. Parent caregivers sometimes regretted that their children had been deprived of normal life experiences and often suffered from feelings of guilt as a result. The following comment is provided by a mother who had many times faced the painful choice between the needs of her ill son and the needs of the rest of the family:

> Because of his illness it caused a lot of heartache for all the family. As a result, his brother and his sister are over 30 now and still haven't married. And so it's affected their lives in a very large degree because we are a very close family. . . . I was very,

very torn between my husband and T. [the mentally ill son] and T. and his brother and sister, too. Because you . . . you know, you have to try to do the best for all of them. And there are times when the other members of the family get very sadly neglected because you're spending so much time trying to help him, trying to accommodate his needs. The other members of the family can miss out [on] what their lives can become.

No matter how much couples shared the responsibilities of caring for their offspring, marital relationships were commonly affected. Conflicts were often due to disagreements related to the provision of the best possible care for the ill relative. Conflicts also arose due to the limited time and energy that couples could spend on activities that built up their own relationship. If one spouse, in most cases the husband, withdrew from the caregiving work, the other who became a sole caregiver often experienced feelings of isolation and anger. Most participants reported increasing pressure within their home and a growing sense that their home environment was no longer regarded as a place of comfort.

Despite their awareness of the impact that caring for the ill relative could have on the family relationships, in situations of conflict, most caregivers felt that it was important and natural to consider the ill relative's needs before anyone else's. This was exemplified in the notion of looking at a situation through the eyes of the other, the one who suffered emotionally and physically and whose life was forever affected by mental illness. They perceived their own concern and commitment as different from the care provided by health professionals or others outside the family because caring in this sense went beyond helping and looking after someone in need. In most cases it involved unconditional love that continued even when it went unrewarded by others. In this light, it was not surprising to find that even when the caregivers experienced physical and emotional health problems, most of them persisted in their commitment to provide care.

Sensitive to how their ill relative experienced the world that had little understanding for someone so different, family caregivers felt a need to make the world more accepting, more tolerant. Looking at the world as seen by the person with mental illness, they wanted to make it a less threatening place. An example of this is seen in the caregivers' general reluctance to call for police help, even though in some situations of extreme aggression or violent behavior this was necessary. If the situation was unavoidable and the police were called, family caregivers experienced strong feelings of guilt.

Despite the problems that caring for a family member brought into the caregivers' lives, by looking at the world through the eyes of the other, they were constantly reminded that life was more difficult for the person with mental illness. This aspect of the caring relationship helped them to see the pain and suffering of their ill relative and, in some cases, to sustain a generosity of spirit that was quite remarkable, as seen in the following comments from a daughter who was the sole caregiver for an elderly mother affected by a serious and long-standing depressive illness:

So it's very hard for an 80-year-old woman to outlive maybe two children, to have two children dead. Since mum has been ill, on and off for last 5 years, it's been a test of compassion for me, too, tolerance, because I'm not perfect, and I've tried to teach her about the illness, and she has grown in the last 5 years. So it's been like a teacher, teacher-student situation, and I hope I've grown through in that point. I'm not perfect, I lapse back if I get annoyed and frustrated. But she has grown in the

> last 5 years. . . . Very difficult for both of us to work out the daughter-mother relationship, to try and get away from dependency, emotional dependency that my mother has . . . because I do love her, you know, she's had a hard life.

The theme of relationality not only included the relation between the caregiver and the cared for, it also involved their individual and common relation with the world, which was often experienced as unwelcoming to both the ill relative and the family caregiver, making them feel isolated and undesirable, that they were being "swept under the carpet." The stigma attached to mental illness in the society around them contributed to a sense that their experiences did not matter, that they should keep quiet, that others did not want to know the person who was ill. One caregiver who felt unsupported even by her close relatives described her experience.

> But the problem also with a lot of mental illness is, um . . . people might just sweep it under the carpet. They don't . . . you don't want to know about it, you don't want to be talked about or . . . seen, you know, because people don't feel comfortable with mental illness. Even the medical profession tends to sweep it under the carpet a bit. . . . Mental problems are not an easy problem to solve, and I think people not only want to sweep it under the carpet, I think they're not really prepared probably even to learn about it and find out about it.

For the caregivers, therefore, being in the world with others was often challenging and sometimes painful. To cope with the demands placed on them, they looked for someone with whom they could talk freely, without fear of stigma or discrimination, for someone who understood their feelings and the effort they were making. For many, involvement with community support groups became important in reducing feelings of isolation and grief and in learning how to deal with other difficulties.

Most caregivers expressed some feelings of anger and isolation in relation to health professionals and were particularly hurt and disappointed when nurses and others failed to be understanding and supportive. By such actions, health professionals did little to bolster caregivers' self-esteem and added to the feeling that they and their concerns were being swept under the carpet, made invisible, and ignored.

The caregivers had to "battle to get help," often with little support from others. Sometimes the battle was with the ill person. In the eyes of family caregivers, their relatives were not always capable of making responsible decisions or acting in their own best interests; for example, by denying their illness, refusing to take medication, or resisting admission to hospital. Despite such behaviors, the wishes of the ill person generally prevailed over the family caregiver's judgment of the situation.

As well as having to battle the system and the ill person in order to get help, the caregivers also had to battle health professionals (in particular, doctors) who did not seem prepared to believe the caregivers' judgment and needed to be convinced that the ill person needed hospitalization or medical intervention at a particular time. Delays in obtaining help meant that sometimes the worst of the crisis was over, and the patient's behavior (when he or she was finally seen by a nurse or a psychiatrist) reinforced the health professionals' perceptions that families exaggerated the situation. If the ill relative was discharged too early, a similar situation could arise. The caregivers' intimate knowledge of how the ill person reacted in different situations over time often suggested possibilities that health professionals seemed to ignore.

Thus, the caregivers not only had to deal with the demands and stresses related to the care for the ill relative, they also had to battle the health care system and the professionals who worked within it. Rather than being allies or partners, the health professionals were often seen as a barrier to what family caregivers considered to be necessary care and the best interventions for the ill person. The resulting feelings of frustration, guilt, and powerlessness invariably communicated themselves to the person with mental illness, who did not always appreciate the caregivers' efforts on their behalf and who sometimes blamed the family caregivers for the failures that were outside of their control. The cumulative impact on the caregivers could be devastating in terms of pent-up anger and frustration. Admitting to such anger and despair was not easy. It often brought on feelings of overwhelming guilt, which, unlike anger (which was usually transient), stayed with them for a long time. In a way, battling their own feelings was part of the struggle to maintain themselves in the work of caring and to obtain the help they and their ill relative needed.

Despite such negative experiences, most caregivers did, at times, experience support from a few people who understood or tried to understand. To feel understood was to feel supported and to "feel the difference," which kept them going and helped them continue to care. What was clear from the study was that interpersonal communication, often taken for granted before, could be a source of meaningful support that made all the difference to people struggling to cope with difficult situations. Support from community groups was particularly meaningful, reducing the caregivers' feelings of isolation and increasing their feelings of confidence. Feeling the difference came through recognition that there were others, including some health professionals, who could understand and be sympathetic. For example, a mother who was forced to call the police to help her deal with her severely disturbed son found it hard coping with his subsequent rejection. She found a great source of support from a nurse who seemed to understand both her and her son's feelings:

> There was a very good nursing sister there at that time who was excellent with him and with me. She just said, "Well, just keep coming, just letting him know that you're there." Then she said, "I know, it's hard for now, turning his back on you, walking away when you go to hospital." . . . "But," she said to me, "just keep coming because he needs to know that you, you're still there, even though he doesn't want to see you, he's very hurt and angry."

CONCLUSION

The study participants' own perceptions of what it is like to provide care to a family member with chronic mental illness indicate the existence of a unique life world centered on the person who develops mental illness and is seen as needing ongoing protection and care. This world of caring is defined subjectively by a strong sense of responsibility, and therefore this responsibility constructs the caregivers' life in particular ways, in terms of both temporality and relationality.

Caring for a family member with chronic mental illness is a lived experience that is embodied both personally and in the fabric of family relationships. It is different and goes beyond the idea of professional caring for a person who is essentially a stranger or who has neither a chronic nor mental illness. Although

some may argue for the benefits of balancing engagement with detachment in relationships involving both professional and informal caregiving (Carmack, 1997), this is not easy to achieve in the day-to-day experience of family caring. Whatever the professional perspective on the value of balanced involvement, it is often passionate concern, guilt, or anger that leads to the self-denial involved in seeing the world through the other's window and makes possible caregiving that extends over many years and sometimes a lifetime. Nevertheless, family caregivers do need skills to manage strong emotions and difficult and often challenging situations. This and other studies suggest that they do not always receive help to develop such skills. Family caregiving in the context of an ongoing mental illness entails a personal inner knowing developed in and through one's way of being in the world, of which the ill person is an integral part. It is easy to argue that individuals with chronic mental illness are best cared for within a family home, where they may be expected to experience a better quality of life; however, the substantial personal, social, and financial costs that family caregivers often have to endure can be taken for granted and neither recognized nor eased by others.

In the light of current trends toward greater emphasis on community-based care, it is essential that nurses and other health care professionals recognize and understand the human experiences that are the outcomes of such far-reaching policies. It is important that health professionals appreciate the temporal and relational qualities of family caring, which are different from the essential qualities of professional caring. What this study has documented are the very real and ongoing needs of family caregivers of relatives with chronic mental illness. Society and the health care system depend on families taking on the responsibility for the long-term care of their ill and frail members. Yet, often, they fall short of providing family caregivers with the recognition and support they need and often fail to acknowledge and make best use of the expertise family caregivers develop through their ongoing experience. The findings from this study, together with those from previous studies, provide directions for nursing practice that is committed to not only the management of illness but to the promotion of health within families and communities. Such practice needs to involve family caregivers as partners and collaborators when their own health, as well as the health of their family members, is concerned.

REFERENCES

Anderson, E. A., & Lynch, M. M. (1984). A family impact analysis: The deinstitutionalisation of the mentally ill. *Family Relations, 33*(1), 41-46.

Anderson, J. M., & Elfert, H. (1989). Managing chronic illness in the family: Women as caretakers. *Journal of Advanced Nursing, 14*, 735-743.

Benner, P. (1994). The tradition and skill of interpretive phenomenology in studying health, illness, and caring practices. In P. Benner (Ed.), *Interpretive phenomenology: Embodiment, caring, and ethics in health and illness* (pp. 99-127). Thousand Oaks, CA: Sage.

Bull, M. J. (1990). Factors influencing family caregiver burden and health. *Western Journal of Nursing Research, 12*(6), 758-771.

Cantor, M. (1983). Strain among caregivers: A study of experience in the United States. *The Gerontologist, 23*, 597-604.

Carmack, B. J. (1997). Balancing engagement and detachment in caregiving. *IMAGE: Journal of Nursing Scholarship, 29*(2), 139-143.

Chesla, C. A. (1991). Parents' caring practices with schizophrenic offspring. *Qualitative Health Research, 1*(4), 446-468.

Cook, J. A. (1988). Who "mothers" the chronically mentally ill? *Family Relations, 37*(1), 42-49.

Coyne, J. C., Kessler, R. C., Tal, M., Turnbull, J., Wortman, C. B., & Greden, J. F. (1987). Living with a depressed person. *Journal of Consulting and Clinical Psychology, 55*(3), 347-352.

Crotty, P., & Kulys, R. (1986). Are schizophrenics a burden to their families? Significant others' views. *Health and Social Work, 11*(3), 173-188.

Fine, M. (1992). *Community support services and their users: The first eighteen months* (No. 100). SPRC Reports and Proceedings, Social Policy Research Center, Kensington, University of New South Wales, Australia.

Gantt, A. B., Goldstein, G., & Pinsky, S. (1989). Family understanding of psychiatric illness. *Community Mental Health Journal, 25*(2), 101-108.

Grad, J., & Sainsbury, P. (1963). Mental illness and the family. *Lancet, 1*, 544-547.

Guberman, N., Maheu, P., & Maille, C. (1992). Women as family caregivers: Why do they care? *The Gerontologist, 32*(5), 607-617.

Hanson, J. G., & Rapp, C. A. (1992). Families' perceptions of community mental health programs for their relatives with a severe mental illness. *Community Mental Health Journal, 28*(3), 181-197.

Home Care Service of New South Wales. (1988). *Community based care in the 1980s* (Background Papers No. 8). New South Wales, Australia: Author.

Human Rights and Equal Opportunity Commission. (1993). *Human rights and mental illness: Report of the national inquiry into the human rights of people with mental illness* (Vol. I). Canberra: Australian Government Publishing Service.

Jacob, M., Frank, E., Kupfer, D. J., & Carpenter, L. L. (1987). Recurrent depression: An assessment of family burden and family attitudes. *Journal of Clinical Psychiatry, 48*(10), 395-400.

Jeon, Y. H. (1995). *The lived experience of caring for a family member with chronic mental illness: A phenomenological study.* Unpublished master's thesis, University of Newcastle, New South Wales, Australia.

Leong, Y.N.J. (1997). *Needs of family carers of elderly people with dementia living in the community.* Unpublished master's thesis, University of Newcastle, New South Wales, Australia.

MacCarthy, B., Lesage, A., Brewin, C. R., Brugha, T. S., Mangen, S., & Wing, J. K. (1989). Needs for care among the relatives of long-term users of day care. *Psychological Medicine, 19*(3), 725-736.

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.

McCausland, M. P. (1987). Deinstitutionalisation of the mentally ill: Oversimplification of complex issues. *Advances in Nursing Science, 9*(3), 24-33.

Montgomery, R.J.V., Gonyea, J. G., & Hooyman, N. R. (1985). Caregiving and the experience of subjective and objective burden. *Family Relations, 34*(1), 19-26.

National Health Strategy. (1993). *Help where help is needed: Continuity of care for people with chronic mental illness* (Issue Paper No. 5). Melbourne, Australia: Author.

Noh, S., & Turner, R. J. (1987). Living with psychiatric patients: Implications for the mental health of family members. *Social Science and Medicine, 25*(3), 263-271.

Nolan, M. R., Grant, G., & Ellis, N. C. (1990). Stress in the eye of the beholder: Reconceptualising the measurement of carer burden. *Journal of Advanced Nursing, 15*, 544-555.

Norbeck, J. S., Chafetz, L., Skodol-Wilson, H., & Weiss, S. J. (1991). Social support needs of family caregivers of psychiatric patients from three age groups. *Nursing Research, 40*(4), 208-213.

Parsons, K. (1997). The male experience of caregiving for a family member with Alzheimer's disease. *Qualitative Health Research, 7*(3), 391-407.

Potasznik, H., & Nelson, G. (1984). Stress and social support: The burden experienced by the family of a mentally ill person. *American Journal of Community Psychology, 12*(5), 589-607.

Rutman, D. (1996). Caregiving as women's work: Women's experiences of powerfulness and powerlessness as caregivers. *Qualitative Health Research, 6*(1), 90-111.

Solomon, P., Beck, S., & Gordon, B. (1988). Family members' perspectives on psychiatric hospitalization and discharge. *Community Mental Health Journal, 24*(2), 108-117.

Solomon, P., & Marcenko, M. O. (1992). Family members' concerns regarding community placement of their mentally disabled relative: Comparisons one month after release and a year later. *Family Relations, 41*(7), 341-347.

Stern, P. N. (1991). Are counting and coding a cappella appropriate in qualitative research? In J. M. Morse (Ed.), *Qualitative nursing: A contemporary dialogue* (pp. 147-162). Newbury Park, CA: Sage.

Thompson, R., & Weisberg, S. (1990). Families as educational consumers: What do they want? What do they receive? *Health and Social Work, 15*(3), 221-227.
van Manen, M. (1990). *Researching lived experience: Human science for an action sensitive pedagogy*. New York: State University of New York Press.

Yun-Hee Jeon, R.N., is a doctoral student in the Faculty of Nursing, University of Newcastle, New South Wales, Australia, and was previously a lecturer at Kwang Ju Health College, Kwangsan-ku, Kwang Ju, Korea.

Irena Madjar, R.N., Ph.D., is a professor of nursing, Faculty of Nursing, University of Newcastle, Callaghan, New South Wales, Australia.