The Meaning of Daily Activity in Family Caregiving for the Elderly

Betty Risteen Hasselkus

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Sixty ethnographic interviews with 15 family caregivers for frail older people living in the community were analyzed to understand the meaning of activity in caregiving. Schön's (1983) reflection-in-action framework was used to organize the data. Three goals of caregiving activity were derived: (a) getting things done, (b) achieving a sense of health and well-being for the care receiver, and (c) achieving a sense of health and well-being for the caregiver. The family caregiver was conceptualized as a lay practitioner involved in the clinical reasoning and ethical dilemmas integral to the provision of health care for the care receiver. The caregivers' judgments regarding the prioritization and attainment of goals determined the forms of caregiving activities. Implications for occupational therapy practice and the relationship between the caregiver and the professional are discussed.

Family caregivers are the primary source of support for long-term care for frail older people living in the community (Shanas, 1979). Research to understand the subjective experience of family caregiving has focused on such variables as a feeling of burden (Montgomery, Gonyea, & Hooyman, 1985; Zarit, Todd, & Zarit, 1986) and a sense of strain (Cantor, 1983; Robinson, 1983). Using a grounded theory approach to study the intergenerational caregiving experience, Bowers (1987) found that daily activities were organized by the invisible work of caregiving, such as anticipatory caregiving (making decisions on the basis of anticipated possibilities).

Recent research has focused on the relationship between informal family caregiving and formal caregiving systems (Clark & Rakowski, 1983; Litwak, 1985; Simmons, Ivy, & Seitz, 1985). Bowers (1988) and Chenoweth and Spencer (1986) found that family members believed that health professionals do not have adequate backgrounds or training to provide quality care. The family members perceived a need to teach health care professionals how to care for their relatives (Bowers, 1988). Similarly, in my ethnographic study of the meaning of caregiving (Hasselkus, 1988), family members described the need to critique the professionals' caregiving and to teach the professionals how to provide care.

These findings suggest the need for further research on the meaning of family caregiving for the elderly and on the relationship between formal and informal caregiving systems. Eighty percent of all family caregivers for the elderly provide unpaid help 7 days a week; of these caregivers, only 10% use formal services for assistance (Stone, Cafferata, & Sangi, 1986). Hofer (1985) called for better integration of the formal and informal care systems and for increased recognition by professionals of the family's authority: "The existing family caretaking system, however unstructured and cumbersome, is the focal point for assistance to the older person and should be relied upon in tailoring services to fit the family situation" (p. 12).

Occupational therapists have begun to develop programs and special services to support family caregivers who are learning the tasks and responsibilities of the caregiving role (Gessert, 1987; Hasselkus & Brown, 1983). This paper provides the results of an ethnographic study on the meaning of family caregiving for the elderly. The purpose of this analysis was to achieve a better understanding of the meaning of daily activity to family caregivers for the elderly. This knowledge will assist occupational therapists in helping caregivers enhance their skills, thereby better supporting the family as a caring unit.

Previous empirical studies on the meaning of ac-
A series of four 1-hour ethnographic interviews (Spradley, 1979) was conducted with each of 15 family caregivers in their homes. The caregivers' ages ranged from 54 to 82 years, and all were related by blood or marriage to their care receivers. The care receivers all required daily personal care, instrumental care, or both. All interviews were audiotaped and transcribed by the author. (For further information on the characteristics of caregivers and care receivers and the ethnographic interview process, see Hasselkus, 1988.)

On the basis of a sense of fit for the data, Schön's (1983) reflection-in-action framework was used to organize the data for analysis. Originally proposed as a model of practice for professionals, reflection in action emerged as an appropriate model of practice for lay caregivers as well. The transcribed data were coded into 25 problem situations (see Table 1). The Notebook II software database management program for text (ProTem Software, 1985) was then used to organize the verbatim transcripts into the fields of Schön's model—Naming (those things to which the caregivers attended), Framing (the context in which these things were attended to), Action, and Judgment (judgments about the consequences of the action). The data were then analyzed for themes of meaning and patterns of activity. (See Hasselkus, 1988, for a more detailed description of the methodology.)

Results

Goals of Activity

Three broad goals of caregiving activity were generated from the data: (a) achieving a sense of getting things done, (b) achieving a sense of health and well-being for the care receiver, and (c) achieving a sense of health and well-being for the caregiver.

Getting things done. The ability to get things done depended partly on the caregiver's carefully made decisions about the assumption of new tasks:

He had always done all the upkeep and improvements on the house. So after he couldn't do it anymore, then I became the apprentice. He was a really good instructor and would tell me what to do. I'd got so I could wire, and we put in another toilet in the basement and I did some soldering. (Caregiver 14)

Female caregivers sometimes described discomfort with assuming tasks they perceived to be masculine:

Now I do all the driving, which before I was glad that he could do. I mean, I thought, well, that's a man's job to drive. (Caregiver 5)

The decision to give up certain customary activities was also a part of getting things done. Often, these decisions revolved around the caregiver's perceived lack of time and energy:

I try to go to mass in the mornings, but I've been so tired. By the time you're up and down three or four times in the night . . . I don't go out to lunch, I don't go to plays. I used to go to travelogues. (Caregiver 11)

Caregiver 6 poignantly described her decision to quit her job:

Before that I went to work a couple times a week and I enjoyed that and looked forward to that. When this came, I knew I could never go back again, I had to stay here. And I'll tell you, I had a heavy heart.

Some caregivers described their efforts to persist with valued activities, despite caregiving demands. Said Caregiver 7, “We got the elderly bus to pick us up and take us to the football game and meet us and bring us back home. It takes a bit of doing but we really enjoy that.” Caregiver 8 expressed his concerns about being able to continue to work:

I'm trying to hang in there until I'm 65. I'll have to stop work if I can't get things done. If I did retire, jobs that I try to get done in the evening or on the weekend I could get done during the week if I wasn't working.

Leaving the care receiver alone briefly (often while the care receiver was in bed) was viewed by some caregivers as acceptable management in order to get things done. “I will go to the store or bank while she's in bed. My neighbor has a key to the house, so if I wouldn't get home, she could get in” (Caregiver 11). Caregiver 13 remarked, “I've learned...
Table 1
Problem Situations in Caregiving

<table>
<thead>
<tr>
<th>Problem Situation</th>
<th>Code</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Activity change</td>
<td>AC/CH</td>
<td>Giving up an activity; taking on an activity or responsibility</td>
</tr>
<tr>
<td>Cleaning</td>
<td>CLEAN</td>
<td>Keeping the environment clean (e.g., laundry, bed linens); getting rid of germs; preventing infection</td>
</tr>
<tr>
<td>Communication</td>
<td>COMM</td>
<td>Speaking unintelligibly; having difficulty hearing</td>
</tr>
<tr>
<td>Dressing</td>
<td>DRESS</td>
<td>Helping care receiver with dressing; helping with brace; lifting</td>
</tr>
<tr>
<td>Eating</td>
<td>EAT</td>
<td>Requiring special diets; liking and disliking certain foods; care receiver's appetite</td>
</tr>
<tr>
<td>Feelings</td>
<td>FEEL</td>
<td>Caregiver's worrying about own feelings (e.g., impatience, giving up)</td>
</tr>
<tr>
<td>Finances</td>
<td>FIN</td>
<td>Meeting health care costs and payments; paying bills, taxes; banking</td>
</tr>
<tr>
<td>Future</td>
<td>FUT</td>
<td>Asking such questions as, What if caregiver gets sick or dies? What if care receiver gets worse?</td>
</tr>
<tr>
<td>Going out</td>
<td>GO</td>
<td>Getting around in the community with care receiver; finding transportation; receiving help from others</td>
</tr>
<tr>
<td>Getting ready</td>
<td>GR</td>
<td>Getting care receiver ready to go out; getting care receiver ready before someone comes in</td>
</tr>
<tr>
<td>Getting things done</td>
<td>GTO</td>
<td>Feeling that caregiving takes so much time; having no time to get things done</td>
</tr>
<tr>
<td>Health care</td>
<td>HC</td>
<td>Dealing with emergencies; working with professionals; perceptions about care receiver's illness; making decisions; medication; hospitalizations</td>
</tr>
<tr>
<td>Hygiene</td>
<td>HYG</td>
<td>Bathing, cleaning care receiver; caring for skin; preventing infection</td>
</tr>
<tr>
<td>Living situation</td>
<td>LIV</td>
<td>Needing a change (nursing home?); consequences of a change</td>
</tr>
<tr>
<td>Moving around</td>
<td>MA</td>
<td>Lifting, transferring; helping with exercises, walking; using equipment (e.g., walker, cane); falling</td>
</tr>
<tr>
<td>Mental state</td>
<td>MENT</td>
<td>Forgetfulness; anger; unpredictability; overly emotional; physical threat; bad thoughts; demanding</td>
</tr>
<tr>
<td>Relationships</td>
<td>NET</td>
<td>Receiving support or nonsupport of family, friends, changing roles; disagreeing with family about caregiving</td>
</tr>
<tr>
<td>Night problems</td>
<td>NOC</td>
<td>Suffering from broken sleep; care receiver wandering, falling out of bed; keeping the bed dry; going out at night</td>
</tr>
<tr>
<td>Daily activity</td>
<td>OCCUP</td>
<td>Thinking of things for care receiver to do; persuading and enabling care receiver to do things; caregiver's finding own time to do things</td>
</tr>
<tr>
<td>Own going in</td>
<td>OGI</td>
<td>Spending time with care receiver (when living apart); spending time with care receiver when in hospital</td>
</tr>
<tr>
<td>Own going out</td>
<td>OGO</td>
<td>Getting out of the house; getting away; getting time out; making arrangements if caregiver needs surgery, respite</td>
</tr>
<tr>
<td>Own health care</td>
<td>OHC</td>
<td>Needing relief; needing medical care for self; needing assistance</td>
</tr>
<tr>
<td>Personality change</td>
<td>PERS</td>
<td>Observing that care receiver used to be so talkative, outgoing; is like a different person; used to be mean</td>
</tr>
<tr>
<td>Risk</td>
<td>RISK</td>
<td>Falling, leaving cigarettes to burn; not leaving care receiver alone, not being far from doctor</td>
</tr>
<tr>
<td>Toileting</td>
<td>TOIL</td>
<td>Controlling bowels and bladder; getting to the toilet, bowel regularity</td>
</tr>
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to go to the grocery store on the fly." Arrangements for the care receiver to spend time at a community adult day center also provided the caregiver with time to get things done.

Health and well-being for the care receiver: Many of the activities aimed at health and well-being for the care receiver consisted of daily routines of caregiving:

I keep track of the blood sugar and the weight. I weigh him every week. I do the blood test every morning. I usually look at his feet every morning and cream them, and I soak his feet every so often and then take care of his toenails. I'm somewhat methodical; I want to be sure things are right. (Caregiver 14)

Extensive measures designed by the caregivers to prevent any worsening of the care receiver's condition were often incorporated into these daily routines. The caregivers were particularly concerned with preventing falls. "When he gets up, I get up. I'm behind him or beside him all the time 'cause I don't want him to fall" (Caregiver 13). Other routines were aimed at the prevention of infection, constipation, and skin breakdown. The diligence with which such precautions were maintained affirmed the caregiver's sense of providing excellent care and coincidentally, reinforced the caregiver's decision against nursing home placement:

The nurses are all so surprised when they come that her bottom's as clean as it is. I use an antiseptic cream on her all the time after I wash her. So far, she doesn't have any bedsores, I keep track of the blood sugar and the weight. I weigh him every week. I do the blood test every morning. I usually look at his feet every morning and cream them, and I soak his feet every so often and then take care of his toenails. I'm somewhat methodical; I want to be sure things are right. (Caregiver 14)

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Monitoring for health changes was another component of health and well-being for the care receiver. Monitoring involved deciding whether a change had occurred and whether to call the doctor.

This week, he complained some about his stomach, so I don't know what's developing now. I'll have to find out, if this continues (Caregiver 14)

Besides attending to health care tasks, the caregivers felt responsible for helping the care receivers...
to experience a variety and balance of activities in their daily lives:

All he does is just sit. He doesn't want to do anything. The occupational therapist, now she comes, but he'll say, "I can't do it." Last Christmas we got him making cookies. I said to the neighbor, "I have to keep him busy." (Caregiver 5)

He doesn't get as much exercise as he should. The therapy after we got home was wonderful for him—That gave him something to look forward to, and that's probably what he's missing now. I try to have magazines and books around, but this is where I fall down—thinking of things for him to do. (Caregiver 7)

Caregiver 9 placed a high priority on increasing her mother's social activity:

My mother is not a social person. She doesn't participate in a whole lot of activities unless I call her or something. Now I've asked the apartment office to send me a calendar of events and I call her to remind her, and I circle them on the calendar in her apartment.

Health and well-being for the caregiver. The caregivers' sense of responsibility for their own health care and their perceived need to have a balance and variety of activity in their own daily lives contributed to a sense of health and well-being for the caregiver. The caregivers' health concerns were both ongoing ("When she rests, I rest") and temporary ("I think I have to go in for a little surgery, and to make all those arrangements [for the care of the care receiver] is really something").

Caregiver 6, who had a heart condition, described the need to persuade her care receiver to hire one to shovel snow from the driveway: "He didn't care about me hiring anybody, and I said, 'Dad, it's going to be cheaper for us to pay to have the drives cleaned out than for me to have a heart attack or a stroke.' " Other caregivers felt the need to keep their concerns to themselves. Said one caregiver, "I pray every night that the Lord will let me take care of her." The caregivers expressed almost apologetically their need to plan variety and change in their own lives. "This makes it kind of hard to do things that you normally used to do—It gets kind of boring. I always hated to be in the house. . . . Sometimes I just put on my hat and coat and go for a walk" (Caregiver 8). Caregiver 5 stated softly, "It just seems like it's the same, day after day—You're here all the time." Caregiver 12 remarked, "I know how to escape sometimes, but I try not to escape too often because it concerns me if [I'm away] too long."

Because of the cost of paying someone to stay with the care receiver, even for a few hours, many caregivers felt uncomfortable about going out, except on rare occasions. "How can you go any place and enjoy yourself when you know it's going to cost $40?" (Caregiver 5). For others, the cost was emotional: "If I go out and I'm gone too long, when I come back he's so angry it just spoils my day. So I've been trying to stay home so he doesn't get so angry" (Caregiver 13).

A sense of escape was sometimes achieved by the caregiver's simply retreating to another part of the house. Dining out often provided caregivers with social contact and a sense of relaxation. Attendance at a local stroke club provided a change of routine for Caregiver 13: "The stroke club met every Wednesday, and that was nice, and I think that gave me a lot of support. That was my outing."

Some caregivers, however, expressed the need for a more dramatic change. "Right now I'm in need of a vacation—I need a break from all of this. I'm just tired and I need to get away" (Caregiver 4).

Dilemmas of Caregiving

In every problem situation of caregiving, the caregiver was confronted with the need to make a judgment about the consequences of an action on his or her own well-being, on the well-being of the care receiver, and on getting things done. Dilemmas arose when actions were perceived to serve one goal but not another (e.g., "The therapist said to put sandbags on [his leg] every hour, but I wondered how I was ever going to get my work done" [Caregiver 1]) or when the caregiver's view of how to achieve a goal differed from another person's view (e.g., "The doctor said to give her Mellariil, but I don't believe in too much of that" [Caregiver 11]). Such dilemmas required the caregiver to judge which goal should take priority, whose view should prevail, or whether an action based on a compromise of views or goals would be satisfactory.

The activity of caregiving was driven by this tension between goals and between conflicting views regarding how to reach the goals. The least stressful situations seemed to be those in which the caregiver perceived the views of others (e.g., care receiver, professional, family) to be compatible with his or her own. Compromised activities often resulted from the caregiver's trying to achieve compatibility between goals or views. For example, instead of the hourly sandbags, Caregiver 1 substituted having the care receiver perform "exercises in bed in the morning so I'd know he could get [the leg] straightened out, and it seemed to work pretty well." In many instances, the caregiver's view clearly prevailed: "They told me to let him do some of that [washing up] himself, but it takes him so long—He'd be forever at it and he'd never get his breakfast. So I do it and I do a better job, use soap and that" (Caregiver 1).

In setting priorities between conflicting goals, the caregivers often subordinated their own needs for the health and well-being of their care receivers:
“When he first came home, I decided it was the best thing for him to have me stay here. I felt that was one of my duties” (Caregiver 5). Caregiver 2 stated, “I don’t have time to take care of myself. It’s always him first and me second.”

Discussion

In this study, the family caregiver was conceptualized as a practitioner, and Schön’s (1983) model of reflection in action was used to organize and interpret the practice of the caregivers. Reflection in action provided a framework for analysis in which activity and context were not separated. The three primary goals of activity in caregiving—getting things done, health and well-being for the care receiver, and health and well-being for the caregiver—were derived from the meaning and context of the situation, that is, from the values, standards, and cultural beliefs represented in the Naming and Framing fields of the problem situations. How these goals were reached and prioritized differed among the caregivers, but the activity of caregiving was directed broadly toward the achievement of these overarching objectives.

The Therapeutic Relationship

The conceptualization of the family caregiver as a practitioner provides insight into the process of family caregiving and into the relationship between the professional and the caregiver. The therapist who wanted the patient to do the washing up by himself had not taken the time to learn the caregiver’s standards for getting things done (“He’d be forever at it and he’d never get his breakfast”). Another caregiver modified the prescribed hourly use of sandbags to better fit the goals of getting things done and achieving a sense of health and well-being for the care receiver. Differences between the caregiver’s and the professional’s views of reaching caregiving goals sometimes led caregivers to drastic action:

The occupational therapist wanted to come early and watch me, what I did and everything. When they come early like that it makes me so nervous. I’d get real irritated, so I asked the occupational therapist not to come anymore. (Caregiver 1)

Schön (1983) suggested the need for a reflective contract between the professional and the layperson. In a reflective contract, the client and the practitioner examine the problem situation together. Each person recognizes that his or her expertise is embedded in a context of meanings, and each person makes those meanings accessible to the other. Any action taken is the result of this reflective conversation.

Data from the present study suggest that, too often, reflective conversation never takes place. Meanings are not exchanged between the professional and the family caregiver, and the professional’s initial advice is soon modified or simply ignored, unless it fits the caregiver’s meaning.

Ethical Dilemmas

In the clinical reasoning of health care practice today, “there is not one right answer but, rather, multiple options, all of which may be resolutions or compromises and not solutions that are correct for all time” (Neuhaus, 1988, p. 289). Kyler-Hutchison (1988), in her paper on ethical reasoning in health care, concurred: “Actions and judgments are the final result of applying a certain code of ethics to a given situation” (p. 283).

Caregiving dilemmas are ethical, derived from conflicts in values and goals. Repeatedly, the family caregiver faces the three generic questions of clinical judgment (Pellegrino, 1979): What is wrong? What can be done? and What should be done? For example, Caregiver 14 said, “This week he’s complained some about his stomach, so I don’t know what’s developing now. I’ll have to find out if this continues.” The ethical decision making mandated by the question, What should be done? encompasses utilitarian and moral foundations. The caregiver is constantly making judgments about the value of the consequences of all actions (“that seemed to work pretty well”) and the fulfillment of the sense of obligation (“I felt that was one of my duties”). For the family caregiver, then, as well as for the professional, there is seldom one right answer, and reasoning is adjusted as new information and experience are accumulated. Actions and judgments result from the caregiver’s applying his or her own code of ethics to caregiving practices.

Therapists who work with family caregivers need to recognize the ethical decision making that pervades the caregiving role. To paraphrase Rogers (1983), the goal of the clinical encounter must be to devise a therapeutic plan that preserves the caregiver’s values and represents a mutual understanding between the therapist and the caregiver. Services must be tailored to fit the family caretaking system, “however unstructured and cumbersome” (Hofer, 1985, p. 12). Both the therapist and the family caregiver (a) bring knowledge and experience to the situation (What is wrong?); (b) produce clinical data to identify options appropriate to the care receiver’s needs (What can be done?); and (c) bring their own codes of ethics to the selection of a course of action (What should be done?). If the therapist and the caregiver can collaborate on this clinical reasoning process, then tension can be minimized and a sense of shared responsibility and shared ethical decision making can result.
Balance of Activity

The pervasive cultural beliefs regarding the need for variety and balance in daily activity affirm a basic tenet of occupational therapy theory and practice (Clark, 1979; Kielhofner, 1980). Apparently, it is unnecessary for the therapist to persuade people that they need a balance of daily activities. However, it is necessary for the therapist to take the time to determine each caregiver’s understanding of the meanings of balance and variety. Statements made by caregivers such as “I always hated to be in the house” and “It just seems like it’s the same, day after day” reveal a sense of imbalance in daily activity.

The occupational therapist’s validation of the caregiver’s needs for balance and variety in daily activity might dispel some of the caregiver’s guilt associated with escaping or with spending money to hire someone for respite care. “This is where I fall down—thinking of things for him to do” clearly communicated a caregiver’s burden from her sense of responsibility for her care recipient’s daily activities. An occupational therapist can play a major role in assisting that caregiver to be more comfortable and more effective with this responsibility.

Relationship to Other Research

These ethnographic data on family caregiving for the elderly provide a rich context for the study of meaningful activity in daily activity. Commonalities between these findings and those of other research studies suggest a beginning typology of consistent themes of meaning in activity. For example, Johnson and Deitz (1985) described the spatial patterning of activities. The thick descriptive data in the present study, however, provides a spatial concept that surpasses the physical location of an activity. The caregivers went in and out of the caregiving and the sense of being in, going out, getting away, or escaping from the caregiving reflected both psychological and physical spatial meanings of caregiving, as illustrated by such quotes as “Right now I’m in need of a vacation... I’m just tired and I need to get away” (Caregiver 4).

Kielhofner (1977) described temporal adaptation as the integration of an entire spectrum of activities, the organization of which supports health on a daily basis. The caregiving day was organized around the goal of getting things done, a culturally constituted temporal framework derived from the caregiver’s values and goals and from the perceived need to assume roles and tasks prescribed by society. The careful balancing of the tasks to be accomplished, discarded, or modified to get things done was the crux of the caregiver’s day, week, month, and year. “I still plan to take her to the day care sometimes if I retire, because there’s times I still want to get something done” (Caregiver 8).

The goals of health and well-being in caregiving are similar to research findings that have demonstrated positive relationships between participation in valued activities and such variables as morale (Marino-Schorn, 1985–1986), life satisfaction (Gregory, 1983; Maguire, 1983; Ray & Heppe, 1986; Smith et al., 1986; Thornton & Collins, 1986), positive body image (Donohue, 1982), and perceived health and well-being (Maguire, 1983; Thornton & Collins, 1986). Thornton and Collins concluded from their study of activity among older adults, “There is no doubt that older adults pursue activity with purpose; ‘being active’ and ‘promoting one’s well-being’ are essential reasons for both leisure and physical activity” (p. 23).

Schwartzberg (1982) found that gratification from activities was related to such themes as social integration and a sense of participation in valued activities. From this finding, one can extrapolate that, to the extent that the caregivers perceived these variables to be present in their situations (e.g., social integration), the caregiving activity would be gratifying and thus contribute to a sense of well-being. Note the stress that occurred when such a variable was not present, as with Caregiver 6, who finally “laid down the law” by telling her husband, “I have to see other people.”

Several studies (Adelstein & Nelson, 1985; Froehlich & Nelson, 1986; Kremer et al., 1984; Nelson et al., 1982; Rocker & Nelson, 1987) have relied heavily on the use of a standardized measure of affective meaning (Osgood, 1952) to study the meaning of activity. Of Osgood’s three factors of affective meaning—power, evaluation, and action—evaluation seems closest to the themes of meaning in the present study. The ethical dilemmas of caregiving seem to stem from the caregiver’s continual weighing of the positive and negative consequences of an action. Data from this study suggest that new understandings of the meaning of daily activity might be best gained from naturalistic research carried out within the natural context of the activity.

To understand the meaning of activity and to promote health through that meaning is the essence of occupational therapy. “For us, in occupational therapy, the most fundamental area for research is, and probably always will be, the nature and meaning of activity” (Reilly, 1960, p. 208). Findings from the present study have yielded new insights into the meaning of activity in family caregiving for the elderly. Recognition of the family caregiver as a lay practitioner engaged in clinical reasoning and the resolution of ethical dilemmas suggest a need to reconceptualize the professional–caregiver relationship. This relationship can be viewed as a partnership in-
Volving the exchange of expertise, values, and interests. Sensitivity to the spatial, temporal, and evaluative components of meaning in caregiving will enable professionals to work more comfortably with family caregivers and thereby be more supportive of the family unit’s role as a health provider for frail elderly people in the community.

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