

## **À la recherche d'un soutien : stratégies d'interaction utilisées par les aidantes naturelles auprès des professionnels de la santé**

**Myrna Heinrich, Anne Neufeld et Margaret J. Harrison**

Un soutien de la part des professionnels de la santé peut aider les aidantes naturelles à accomplir leurs tâches et produire un effet positif sur leur santé. Cette étude a pour but d'explorer les perceptions que détiennent les femmes concernant le soutien qu'elles peuvent obtenir des ressources communautaires en situation où elles prennent soin d'un membre de la famille atteint de démence. Les questions énoncées dans le cadre de cette recherche sont les suivantes : quels sont les facteurs influençant les interactions des aidantes naturelles avec les professionnels de la santé lorsque celles-ci demandent de l'aide? Quelles stratégies les femmes emploient-elles dans leurs interactions avec le personnel de la santé pour s'assurer un soutien? L'interaction symbolique a servi de fondation théorique dans le cadre de cette étude, qui incluait une analyse secondaire de 62 entrevues réalisées auprès de 20 femmes portant sur leur vécu en tant que dispensatrices de soins. De plus, de nouvelles données ont été recueillies auprès de deux groupes de discussion avec l'aide de huit volontaires recrutées au sein des 20 participantes originelles. Selon les données, les attentes des femmes concernant leur rôle de pourvoyeuses de soins et leur évaluation de l'état de la personne recevant les soins ont influencé leurs interactions avec le personnel soignant lorsqu'elles ont demandé de l'aide. Elles avaient recours à quatre stratégies élargies : la collaboration, l'entente raisonnable, la réticence et la bataille / la lutte. Le recours à ces stratégies variait selon le degré de partage décisionnel dont elles bénéficiaient avec le personnel soignant et était accompagné d'expériences positives et négatives. Ces résultats confirment l'importance de la réciprocité dans les relations avec le personnel soignant et appuie l'utilisation de modèles de pratiques professionnelles axés sur le partenariat et l'autonomisation.

Mots clés : démence, femmes

# Seeking Support: Caregiver Strategies for Interacting with Health Personnel

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Support from health professionals can assist family caregivers and have a positive impact on their health. The purpose of this study was to explore women's perceptions of support from community resources while caring for a family member with dementia. The research questions were: What factors influence female caregivers' interactions with health personnel when seeking support? What strategies do women employ in interactions with health personnel to secure support? Symbolic interaction was the theoretical foundation for the study, which included secondary analysis of 62 interviews with 20 women concerning their caregiving experience. In addition, new data were collected from 2 focus groups with 8 volunteers recruited from among the original 20 participants. The data indicated that the women's expectations of their caregiving role and their appraisal of the care recipient influenced their interactions with health personnel when seeking support. They employed 4 broad strategies: collaborating, getting along, twiggling, and fighting/struggling. A woman's use of strategies varied according to the degree of mutuality in decision-making with staff and was accompanied by both positive and negative experiences. These findings confirm the importance of mutuality in relationships with health personnel and support the use of partnership and empowerment models of professional practice.

Keywords: family caregiving, social support, qualitative, dementia, women

Family members, particularly women, continue to be the primary source of assistance to older people with Alzheimer disease and other forms of dementia (Chappell, 1992; Martin-Matthews, 1999). As the demands of caring for a relative with dementia accelerate, women experience a negative impact on their personal health (Lee & Porteous, 2002) and require community and institutional assistance to sustain their caregiving role (Liken, 2001; Stevenson, 1990). The use of community resources concurrent with support from family and friends may assist family members caring for elders (Chappell).

The purpose of this research was to explore women's perceptions of support from community resources while caring for a family member with dementia. The specific research questions were: (a) *What factors influence female caregivers' interactions with health personnel when seeking support?*

and (b) *What strategies do women employ in interactions with health personnel to secure support?* The women's sources of support included the staff and resources of continuing-care institutions and community health-care services such as respite services, home care, or adult daycare.

## **Background**

Care of a family member with dementia generates physical and emotional demands that may result in exhaustion, social isolation, and negative health effects such as depression (Grasel, 2002; Stevenson, 1990; Tennstedt, Cafferata, & Sullivan, 1992) or reduced immune response (Kiecolt-Glaser, Dura, Speicher, Trask, & Glaser, 1991). Social support can have a positive impact on the health of caregivers (Redinbaugh, MacCallum, & Kiecolt-Glaser, 1995; Robinson-Whelan, Tada, MacCallum, McGuire, & Kiecolt-Glaser, 2001), either by meeting social needs for information, esteem, aid, and reliable alliance directly or by influencing the effect of stressful experiences (Stewart, 1993). Sources of social support include family members and friends (informal support) as well as professional or community services (formal support). Formal sources of support are frequently sought to supplement the care of family and friends when caregivers are unable to provide the amount of assistance needed (Edelman & Hughes, 1990) or lack the necessary technical expertise (Chappell & Blandford, 1991; Litwak, Messeri, & Silverstein, 1990).

Social support from both formal and informal sources is best understood in the context of the relationships through which support is experienced (Badr, Acitelli, Duck, & Carl, 2001). Caregivers, like other individuals, hold expectations and beliefs about preferred means of support in specific relationships.

Previous research has addressed interactions with staff and expectations of family caregivers about participation in decisions concerning the care of persons living in the community or in various types of supportive-care facilities. In a study with caregivers of family members living in the community, Adams (2000) used discourse analysis to examine conversations during home visits between a family caregiver of a person with Alzheimer disease and psychiatric nurses. The caregiver used creativity by employing language and a caregiver identity of "worrier" to influence decisions about care. Duncan and Morgan (1994) explored the expectations of caregivers concerning their relationships with staff caring for a relative with Alzheimer disease in community agencies and residential institutions. Their qualitative study comprised 29 focus groups with 179 caregivers and 10 individual interviews. Caregivers sought to

influence care by building ongoing relationships with staff and facilitating positive and emotionally connected interactions between staff and their relative. They expected staff to recognize their expertise in caring for their family member.

Several researchers have examined family caregivers' involvement in decisions about care in institutional settings. Walker and Jane Dewar (2001) used participant observation of multidisciplinary team meetings (in which family caregivers were included) and interviews to study caregivers' involvement in decision-making concerning relatives in respite care or in assessment units of a psychiatric hospital in the United Kingdom. The findings confirm those of previous research indicating that caregivers want to be involved in decision-making but feel they are inadequately informed about how decisions are made and lack influence when they do participate. Bowers (1987, 1988) found that family caregivers of persons institutionalized with a chronic health condition expected staff to provide care in ways that nurtured their relative's individuality and personhood, thus helping caregivers to preserve his or her identity. Health-care personnel, however, often did not recognize or meet these expectations. Hertzberg and Ekman (2000) examined interaction between relatives of persons with dementia and staff in nursing homes in Sweden. Their study involved three weekly focus group discussions with staff and relatives over a period of 9 weeks. Caregivers emphasized the importance of influencing the care of their relative. They took the initiative by establishing ongoing relationships with staff and actively seeking information about their relative. When the caregivers' contributions and suggestions were not taken into account, they felt neglected, distrustful, and frustrated. Hurley, Volicer, Rempusheski, and Fry (1995) conducted a grounded theory study of the nursing role in advance planning for end-of-life decisions. The study included nurses and family caregivers of persons with late-stage Alzheimer disease in an institutional setting. They generated a model of consensus decision-making that included participation of family caregivers and contextual influences such as staff development, unit philosophy, patient status, and family coping.

In summary, the literature indicates that as caregivers seek support they want to participate in decisions about the care of their relative, whether he or she resides in a community or institutional setting. Several studies have found that caregivers rely on strong, ongoing relationships with staff to achieve this influence. In one study, a caregiver used creative communication to influence care. There is a need for further research to identify how caregivers perceive formal support from health professionals and the strategies they employ in their relationships with health personnel in community and continuing-care settings.

## **Method**

Symbolic interaction (Blumer, 1969; Prus, 1996) was the theoretical foundation for this study. Individuals engage in social interaction on the basis of the meaning they bring to the situation and modify their understanding of a situation by reflecting on the experience. Consequently, information about family caregivers' perceptions of support from health professionals is an important basis for understanding their interactions with health professionals.

Caregivers' perceptions of support from health personnel were explored through secondary analysis of interview data obtained in a previous study and two focus group interviews with participants recruited from the original study. The original study addressed the perceptions of social support and relationships of caregivers of cognitively impaired older adults. The findings on informal support from family and friends are reported elsewhere (Neufeld & Harrison, 1995). In the original study, 20 women participated over 18 months in three or four in-depth interviews about their caregiving experience, for a total of 62 interviews. The interviews lasted approximately 90 minutes and were audiotaped and transcribed verbatim. The interviewers were nurses experienced in working with families in similar situations and trained by the investigators in qualitative interviewing methods. The participating women were recruited through health-care agencies and advertisements in community newspapers. Women were included in the study if they defined themselves as the primary caregiver of a relative 60 years of age or older with dementia (the time of life when dementia is most common) and if they spoke English. Most interviews were conducted in the home of the caregiver.

The present study included secondary analysis of data from these interviews in relation to formal support. In addition, new data were collected from two focus group discussions with eight volunteers recruited from among the 20 original participants (all of whom had been invited to participate). The first author led the focus group discussions, which were held at a university location. The purpose of these discussions was to confirm and elaborate on the themes identified during secondary analysis of the interview data. In the focus group discussions, preliminary findings on women's strategies to secure formal support were shared. The women were asked to indicate whether these were similar to or different from their own strategies, to describe variations in their own experience, and to indicate whether they used other strategies. The discussions were audiotaped and transcribed verbatim.

The transcripts were reviewed in detail and categories generated (using the participants' own words where possible) to group data por-

traying similar dimensions and properties. Similarities and differences in caregivers' experiences were noted and possible relationships among categories were explored to identify linkages. Data from all interviews with each woman were compared, as well as data from different women. Coding and memoing, including diagrams, were used throughout the analysis to record the researchers' thoughts and questions (Morse & Field, 1995). The Ethnograph computer program was used to assist with the coding and analysis of data.

The original study and the present study were cleared separately by the university ethics review committee. All participants gave their written consent.

## **Findings**

### ***Sample***

Of the 20 caregivers interviewed, nine were daughters of the care recipient, eight were wives, two were daughters-in-law, and one was a granddaughter. The women were between the ages of 37 and 71 and had been caregiving from 1 to 20 years. Their education levels were: post-secondary (13), high-school completion (2), and less than Grade 12 (5). Annual household incomes (in Canadian \$) were: under \$20,000 (3), \$20,000 to \$40,000 (7), and over \$40,000 (10). The characteristics of the subgroup of women who chose to participate in the focus group were similar to those of the group as a whole.

Of the 20 care recipients, 12 were male and 8 were female. Nine were reported as having Alzheimer disease, five had vascular dementia, three were described as having senile dementia, and three had cognitive impairment of unknown cause. When the interviewing commenced, 12 care recipients were in nursing homes, seven were residing with the caregiver, and one lived alone in her own home. At the completion of the interviews, 18 months later, 12 were in nursing homes, including three who had moved from their home during the study, five remained at home with the caregiver, and three were deceased.

### ***Influences on Caregivers' Interactions with Health Personnel***

The women's descriptions of caregiving support included both assistance with their caregiving role and assistance given to their relative that indirectly relieved their perceived demands as a caregiver. In seeking support, the women interacted with health personnel in the context of their role of preservative caregiving.<sup>1</sup> In this role they acted as ombudswomen for

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<sup>1</sup>As our description of caregiving is similar to that of Bowers (1987, 1988), we use Bowers's term, preservative caregiving, to represent caregivers' overall goal of preserving their relative's identity and personhood.

their relatives, managing care and preserving their personhood, making decisions on their behalf if they were no longer competent to make decisions independently, and seeking to sustain their unique personhood. These decisions required the women to maintain a constant vigil, checking the care recipient and seeking information from all available sources.

The women's expectations of themselves as family caregivers and their appraisal of the cognitive status of their relative influenced their work as preservative caregivers and their strategies in interacting with health personnel. For example, they described a keen sense of personal responsibility and a belief that they were the best person to take care of their relative:

*I'm the only one around who is really close to my mom, that knows her... What if I was in that same position and I didn't have anyone around that really...cared about me...knew the way I used to be?*

The daughters, daughters-in-law, and granddaughter considered caregiving an opportunity to reciprocate for all the elder's past contributions. The wives spoke of a strong marriage commitment, believing their husband would do the same for them. When the marital relationship was conflicted, they described their caregiving role as an obligation. Family expectations also supported the women's belief in filial responsibility:

*My mom kept saying, "We never put our people in a nursing home"... That was a very powerful message to me.*

One woman feared she would be disowned by her family if she did not continue to care for her husband on her own:

*I think I'll go over and say to them, "Are you going to disown me if I put him in long-term care?"*

Because of personal and family beliefs that women are responsible for caregiving and are the "best" caregivers, the participants were vulnerable to a sense of failure when they sought assistance and continued to view themselves as responsible for care of their relative. The perceived expectations of health personnel and health-care policies also influenced their interactions with personnel and their requests for help. For example, one woman described a need to establish a good track record; she felt she had to demonstrate that she had done everything she could before the professionals would consider her request for help. Others thought that nursing-home staff expected them to do more for their relative, and the wives believed that physicians expected them to "be there" for their husbands. Nearly all of the women believed that health-care resources are scarce and accepted the societal expectation that public resources be available only to those who need them most. This made them hesitant to

seek help. In some cases, the women waited until a crisis occurred before requesting aid.

Appraisal of the person's cognitive status influenced the caregivers' ability to secure assistance. However, the unpredictability of the course of dementia made it difficult for the caregivers to anticipate when they would need help. The women did not want to place their relative in a nursing home before it was necessary, but found it difficult to know when to make the decision, particularly since facilities had waiting lists with uncertain wait times. As a result of the variation in and unpredictability of the care recipient's cognitive status, it was difficult for the women to get timely and appropriate assistance.

When the care recipient was in the early stages of dementia, the women could access help from formal sources only when it was acceptable to their relative. One woman described talking the care recipient into accepting certain kinds of help, but the mother of another woman refused to sign the necessary forms because she did not want to have people in her home:

*In order to really get my mother [into] the system, she would have to sign the forms, which of course she would refuse to do because she doesn't need any help in her mind — "Thank you very much but get out of here."*

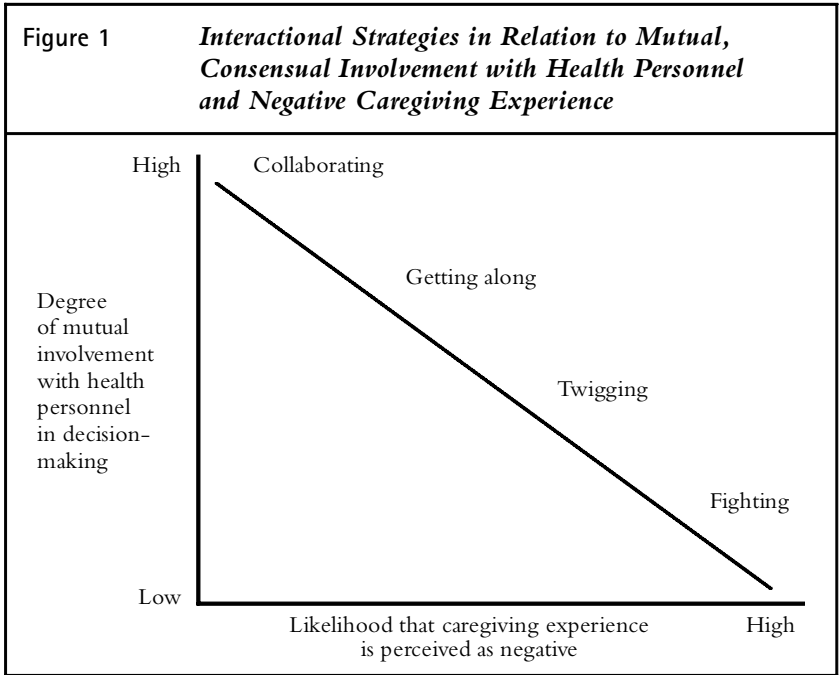
This caregiver did not want to go against her mother's wishes and seek guardianship through the courts. In the later stages of caregiving it became easier to access help; when the care recipients were unaware of what was happening, the women felt they were able to make decisions on their behalf.

### ***Interaction Strategies***

In their role as preservative caregiver the women employed several strategies in their interactions with health personnel as they sought support. A woman's strategies varied according to the degree of mutuality with staff in decision-making. Although the strategies are described individually, they are not mutually exclusive; each caregiver may have used several in her interactions with personnel. The women's perception of the caregiving experience varied according to the strategies used. For example, when they were able to collaborate, something that entailed a high degree of mutuality, they perceived the caregiving experience as positive. When they fought with staff, however, mutuality was absent and they perceived the experience as negative. These strategies and the caregivers' experiences are illustrated in Figure 1.

***Collaborating.*** A state of collaboration resulted when the caregivers' relationships with staff were characterized by the sharing of information and goals. In these complementary relationships, the caregivers con-





tributed their knowledge to the decision-making process and the staff valued their contribution:

*We get our heads together with [the] charge nurse... Any time we have a problem, we all get our heads together and deal with it.*

One woman described the staff's sharing of information at a conference soon after her family member had been placed in a nursing home:

*I think one of the things that I really found helpful was...a caregivers' conference... I learned more from that and felt more at home, more able to relate to those people, better understood what they did and why they did it.*

The opportunity for collaboration was facilitated by certain characteristics of the relationship with health personnel. For example, some professionals affirmed the women's caregiving work, expressed emotional support, and demonstrated an understanding of family caregiving that was based in experience as well as professional knowledge. Sometimes a physician would affirm the woman's preservative caregiving role:

*He said, "You look after your mother but you don't let her sit around and vegetate." ...He knew how I always kept her going...there were always some little chores for her to do.*

Staff members expressed their emotional support by taking an interest in both the caregiver and the care recipient, being friendly, having a positive attitude, and showing compassion:

*When I see them [the home-care nurse and the physician] they always ask... People don't realize how much that helps...just asking, "Is there anything I can [do]?" or "How are things going?" ... Then you know they care...they wouldn't ask otherwise.*

Collaboration was facilitated when staff members had experiential as well as professional knowledge of caregiving. The women valued interactions in which a staff member who had personal caregiving experience shared this experience with them. They believed that only those personnel who understood the caregiver and the cognitively impaired person could provide the affirmation and emotional support necessary to facilitate collaboration. Such understanding required both formal education and practical experience caring for an elderly person with cognitive impairment.

Collaboration was inhibited, however, when caregivers were excluded from decision-making. They often attributed their exclusion to inadequate knowledge and lack of understanding on the part of staff. Some said that the care needs of their relative were not being met because staff had inadequate knowledge. One woman was frustrated and angry when she learned incidentally that her mother had long been receiving an anti-anxiety agent without her knowledge:

*She was like a zombie... It was bothering me terribly... I called the doctor... The nurse...said, "Oh...I think your mother should be cut back on the tranquilizers," and I said, "the what?" And I found out at this time that they had her on...Ativan three times a day... This is what her problem [was]... Then I was really angry.*

Stereotyping by health personnel was another barrier to collaboration:

*They're inclined maybe to stereotype people...especially a younger person [staff member]. I mean, a hundred [years old] — you're supposed to be out for the count... [but] we knew different.*

The women felt that stereotyping encouraged a standardized rather than an individualized approach to care. Some women also thought that illness in elderly people was treated less seriously than in young people:

*It was really scary how weak she was, and...listless... They were saying they were feeding her... Nobody saw it... She was just weaker and weaker, and they were accommodating her weakness by keeping her in bed and feeding her and doing nothing about it.*

This woman felt that staff overlooked her mother's symptoms because they attributed the changes to the aging process rather than to a specific health issue.

When caregivers were able to collaborate with staff they expressed satisfaction with their relationships with health-care providers. Collaboration served to affirm their contribution to the care of their relative and increase their understanding of the role and contribution of health-care providers. Collaboration caused the women to perceive the caregiving experience as positive.

**Getting along.** Sometimes the women used a strategy of getting along to establish and maintain a good working relationship with personnel in institutional and home-care settings. In adopting this strategy, the women were not engaged in a reciprocal relationship with staff, but had assumed personal responsibility for maintaining a positive connection despite indifference or intimidation on the part of staff. They viewed staff members as busy and tired and were reluctant to be a "pest." One woman said it was not easy to talk to staff members "standing there in a uniform... in a hurry and [with] things on their minds." They reported that personnel responded abruptly to their requests for information, were threatened by their questions, or viewed the caregiver as snooping or checking up on them. The women felt that staff members were less available to them as a source of support if they were very young or, because of frequent staff turnover, were strangers.

Getting along had two components: initiating action diplomatically and negotiating among multiple providers. One woman described how she initiated action diplomatically when she found something amiss with the care recipient:

*I get things going... I don't go [to the nursing home]...half-cocked, either, because I'm annoyed... [I say,] "Let's just see what the problem is."*

A woman caring for her husband at home had to negotiate among multiple health professionals and secure their ongoing commitment. This was demanding and stressful work:

*A lot of your time is spent just acting as a little go-between...and hoping everybody will get along...to buoy everybody up...to keep going for [the care recipient] and be cheerful and keep Home Care going, and always negotiating, always having to...play the end against the middle and hope somebody won't get angry or quit or [that] this won't fall apart.*

The primary conditions influencing the use of the strategy of getting along were perceived discomfort, intimidation, or indifference in relationships with agency staff. Getting along enabled the women to maintain a satisfactory relationship with professionals but inhibited the free

exchange of information. For example, one woman expressed overall satisfaction with her interactions with formal providers but said that caregivers sometimes withheld information from staff because they were afraid of the response:

*We don't always tell [health personnel] everything we'd like to tell them. They're just not another shoulder to cry on... they're paid to do their job... Lots of times we're afraid to tell them some of the things we'd like to.*

The women also found getting along to be fatiguing: "You're just giving like that all the time, and that's very tiring."

The women who employed this strategy often found their caregiving role to be a negative one. Getting along made them feel alone and as if they were doing all of the relationship work. Their relationship with health personnel could be characterized as draining.

**Twigging.** Some women described "twigging" the staff to unmet needs or showing them how to meet the needs of the care recipient. The caregivers also shared information about changes in health status. Although some felt this was part of their role because it was they who best knew the care recipient, other caregivers were disappointed by the staff's inattention. One woman tried daily to have nursing-home personnel insert her mother's dentures and hearing aid, which, she said, were important for her mother's quality of life even though she could not ask for them herself. The daughter was frustrated that these "basics" were being neglected even though she had posted signs to remind staff. Another woman was concerned about her mother's declining appetite. She was disappointed that she had to ask nursing-home staff to give her a dietary supplement. Another daughter observed symptoms of a urinary infection that the staff had not recognized:

*It just dawned on me that somebody should be checking something... I phoned the nursing supervisor at the nursing home the next day...and said, "I think we should do the basic [urine] test anyway" ... Within a day they had given her the preliminary test and reported to the doctor and they had her on [medication]... It was just amazing to see how she perked up... Mother would have been close to...death...if this [had not] been done.*

One woman had to speak up to ensure that her husband was included in social activities at the nursing home.

Twigging included teaching others, including health personnel, how to be helpful. One woman spent a great deal of time teaching the care attendants who came to her home how to meet the complex care needs of her husband. Women initiated twigging or sharing of information when their vigilance revealed inadequacies in care or a change in their

relative's health status that put them at risk. Use of this strategy implied that the women expected staff to act on their feedback. The women found that twigging could be stressful:

*It kind of concerned me that any time I made a big fuss about something or other they would retaliate on my mom... When her glasses disappeared at one time, I [wondered] did they take them away from her...because I had complained about something?*

As this quotation illustrates, some women feared retaliation against the care recipient if they consistently urged health personnel to change their relative's care.

**Fighting/struggling.** Several women described their interactions with health personnel in institutional or home settings using words such as fighting or struggling. Unlike twigging, which was intended to elicit a positive response from staff, this strategy was employed when staff did not readily respond to caregivers' information about their relative and they believed the person was at risk. Their stories indicated that they were prepared to act until they secured the help needed.

One woman planned to persevere until she obtained information about the medications administered to her mother, who resided in a nursing home. In the past, this woman had received a monthly itemized list of her mother's medications and dosages. When her mother was reassessed at a higher level of care, she no longer received this information because the government paid for the medications:

*I'm not getting an itemized list from them... They will give the normal printout of the drugs the doctor orders...but not the specific amount in a month that is actually administered to her, which is what I want... I will not let it rest. There will be some way...maybe I'll have to go as far as being declared a legal guardian...which I will do.*

One caregiver was frustrated when she had to wait for necessary equipment for her home before her husband could be discharged from hospital:

*It went back and forth... I had to change the whole back entry...because he couldn't [climb] stairs... We put a lift in... They told me there's a grant for people like that. So I applied for the grant and I was pushed on time because [the hospital] had to discharge him... I was on the phone every day... I said, "I need this and I need this." So I was between the [hospital] who would like to send him home and Home Care who had the red tape from here to Rome.*

Another woman had to battle to secure adequate personal care for her family member:

*I have battled it out with Home Care... I have worked very hard on that... I do qualify for the time and I did get it...[but] with the Home Care situation you have to remember that it is re-evaluated very frequently and at any moment you may be cut back or you might have to go to bat for what you've got in the first place.*

She went on to describe the advice she would give to other caregivers:

*You have to be prepared for a long, long wait with the services... applications for pensions, you're looking at a year to a year and a half...it goes on forever; you just have to keep on going... If you want something, just don't back off. I mean, if you keep at it long enough...they're going to say yes to get rid of you.*

The women used the fighting/struggling strategy when their attempts to obtain support were met by a long wait, when their initial requests for help were rejected, or when they had to appeal a decision about the amount of support allocated. These experiences were highly stressful.

Women employing this strategy lacked affirmation in their caregiving role and were frustrated by their inability to secure the assistance needed by their relative. Although they found it stressful, they considered this strategy a necessary part of preservative caregiving if the health of their relative was threatened and it was the only way they could ensure a satisfactory level of care.

## Discussion

The finding that participation in the decision-making process is important for family caregivers when seeking support confirms the findings of other studies on the care of individuals with dementia. Walker and Jane Dewar (2001) found that caregivers were satisfied with their participation in decision-making when information was shared, caregivers were included in decision-making, there was a person available to contact, and the service agency was responsive to their needs. Hertzberg and Ekman (2000) also report that family caregivers of persons with dementia expect to participate actively in decisions about care and to have their expertise valued.

The importance of mutuality is also evident in research and theoretical models of the relationship between health personnel and family caregivers of persons who do not have a diagnosis of dementia (Eales, Keating, & Damsma, 2001; Gladstone & Wexler, 2002; Guberman & Maheu, 2002; Ward-Griffin & McKeever, 2000) and receive either home care (Guberman & Maheu; Ward-Griffin & McKeever) or long-term care (Gladstone & Wexler). The themes implicit in those models of the caregiver/professional relationship include a desire for mutuality with

staff concerning decisions about care and negative outcomes when mutuality is not achieved.

In the present study, the caregivers' strategies for interacting with health professionals were influenced by their expectations of the professionals. Negative expectations hindered mutuality and the ability of family caregivers to seek assistance. Other research has found that the expectations or beliefs of staff and the psychological environment of the care unit can influence the ability of family caregivers and staff to reach consensus (Hurley et al., 1995). For example, in a respite and assessment unit of a psychiatric hospital in the United Kingdom (Walker & Jane Dewar, 2001), family caregivers were dissatisfied because meetings with staff were dominated by the professionals' agenda, there was no follow-up, they felt excluded, and they lacked information about how decisions were made. Health personnel were not proactive in approaching caregivers and caregivers were reluctant to disturb them. In a Swedish study, Hertzberg and Ekman (2000) report that staff thought family caregivers had unrealistic expectations and that family caregivers were frustrated by a lack of staff follow-up on their inquiries and were uncertain about and distrustful of staff members despite viewing them as "nice." Staff and family caregivers did not let each other know what they were thinking. The authors comment that it was as if each group avoided learning whether their view of the other was accurate.

In a study employing participant observation and interviewing in two long-term-care units, Gladstone and Wexler (2002) generated a model of five types of family-staff relationship: collegial, professional, friendship, distant, and tense. Their findings are consistent with those of the present study. The family caregivers viewed collegial, professional, and friendship relationships as positive. These involved interactions with staff that were focused around a specific purpose, shared experiences, and a sense of trust accompanied by positive feelings. Distant or tense relationships emerged when family caregivers were critical or distrustful of staff, angry, or frustrated. This type of relationship is consistent with the strategy of fighting/struggling described by the family caregivers in the present study. In a study of nurse and family caregiver dyads in a home-care setting, Ward-Griffin and McKeever (2000) found that tension can arise between family caregivers and nurses in the absence of mutual decision-making. They identified four relationship types: nurse-helper, worker-worker, manager-worker, and nurse-patient. In the nurse-helper relationship, tension arose when caregivers were uncomfortable assuming responsibility for the complex tasks delegated to them. In the manager-worker relationship, caregivers were upset when nurses withdrew emotionally and assumed the role of resource person. Tension also arose when nurses were caught between contradictory requirements — to meet the needs of the

care recipient as well as those of the caregiver — and when the nurse and the family caregiver had contradictory expectations of each other. None of these relationship types represented the partnership of mutual involvement in decision-making sought by the women in the present study. Usually the family caregiver assumed the greatest responsibility for care while the nurse was the primary decision-maker and the arbiter regarding available resources.

An implication of the present findings is the need for models that support the mutual involvement of health personnel and family caregivers in decision-making. Guberman and Maheu (2002) propose a partnership model for working with families of individuals with chronic conditions in home-care settings. This model, which is based on earlier research, reflects the value on mutuality as expressed by the women in the present study. In Guberman and Maheu's model, the caregiver and care recipient are co-clients and the family caregiver assumes primary responsibility for care while health professionals facilitate access to resources.

Given the importance of mutuality in the caregiver-professional relationship, partnerships between health professionals and caregivers of persons with dementia in home-care and long-term-care settings can be informed by perspectives on partnerships and empowerment from other settings and populations (Courtney, 1995; Courtney, Ballard, Fauver, Gariota, & Holland, 1996; Hulme, 1999). In Courtney's community partnership model, the professional negotiates a sharing of power with individual, family, or community partners. The emphasis is on mutual interaction and facilitation of client empowerment. This contrasts with the traditional model of professional practice in which professional expertise and decision-making dominate. Hulme's model of family empowerment was designed for interventions for families with a child with a chronic health condition. Empowerment is conceived as a four-phase interactive process that moves from domination by professionals to participatory interaction. The balance of power shifts from professionals to the family until, finally, collaboration is achieved and the family is a full partner in the care of their child. A prominent characteristic of partnership models is the mutual valuing of professional knowledge and the experiential knowledge of clients or family caregivers. The findings of the present study support the application of these models to the relationship between professionals and the family caregivers of individuals with dementia, in order to establish mutuality and share in decision-making power.

This study was limited to the perspective of family caregivers concerning their relationships with health personnel as they seek to engage in preservative caregiving of a person with dementia. It nevertheless contributes new information on the strategies that caregivers use in order to



influence care and confirms previous findings on family caregivers' experience of formal support. Future research might include the perspectives of health personnel as well as family caregivers and address the structural characteristics of health-care agencies and systems.

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