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**CAREGIVER ASSESSMENT
OF PROBLEM BEHAVIORS IN RELATIVES
WITH DEMENTIA**

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Caregiver Assessment of Problem Behaviors in Relatives With Dementia

Caregivers were asked to rank the presence and difficulty of 15 specific behaviors in their relative with dementia. Results showed that in most cases, female caregivers ranked the prevalence and the difficulty of the behaviors higher than the male caregivers. In this study, caregivers experienced positive outcomes from the caregiving experience.

Adult day care centers provide structured daytime activities, mental stimulation, and social contact for the frail elderly. They also provide respite for their community-dwelling caregivers, who are typically family members. The vast majority of the elderly clients in the day care setting have some degree of dementia and display behaviors that are challenging to both the day care staff, as well as to their family caregivers. Over time, the person with Alzheimer's dementia displays progressive functional losses, while at the same time exhibits increasingly difficult behaviors. The family caregivers need to adapt to the ever changing behaviors that are exhibited by their relatives with dementia. Many caregivers have concrete ideas on the specific behaviors that are most problematic for them, and these problem behaviors create the most stress for caregivers¹. These difficult behaviors are unique to each caregiving dyad, but in general are problem behaviors that are common to persons with dementia. By assessing the caregiver's thoughts on these specific behaviors, the health care professional can intervene in a meaningful way by offering specific suggestions and strategies for handling the problems as they arise, and can also support the caregiver in this challenging role.

Literature Review

Family caregivers often cite dementia-related behavior disturbances as a primary reason for nursing home placement, although Steele, Rovner, Chase, and Folstein found no differences between institutionalized and non-institutionalized patients on standard cognitive tests². Caregivers who do not understand the dementing process and how it affects cognitive functioning and behavior, often attempt to deal with the behaviors in ineffective and nonproductive ways. As a result, the difficult behaviors can escalate and the stress experienced by both the caregiver and the person with dementia can intensify³. Behavior factors in the person with dementia that contribute to the difficulty of the caregiver's role include the elderly person's pre-morbid personality, the presence and number of difficult behaviors, the degree and the amount of direct care required to maintain this person, and the general state of health^{4,5}. Some studies have found the specific behaviors that increase the risk of institutional placement for the person with dementia to be incontinence, aggressive behavior, hallucinations, and delusions^{4,5}.

According to Stewart, at some point during the dementing illness, most patients display agitation, aggression, sleep disturbances, wandering behaviors, depression, hallucinations, and delusions. It is usually these behavioral problems rather than cognitive impairments that can result in institutional placement for the person with dementia⁶. There is some agreement that it is the onset of disturbing behaviors in the person receiving care that increases the risk of placement in a long-term care facility. Paranoia, aggression, wandering, and incontinence are specific behaviors that are found to be troubling, and the physical task of dealing with incontinence has been found to be the most troubling

behavior of all⁴, whereas other studies find aggressive behavior to be most difficult for caregivers⁷.

Hamel, Pushkar-Gold, Reis, Dastoor, Grauer, and Bergman studied aggressive behaviors in the elderly person with dementia. They specifically looked at ways to predict aggressive behavior in a caregiving situation and looked at the consequences of that behavior. The authors found that a difficult relationship prior to the elderly person's illness can predict conflict in the caregiving situation. This conflict can then result in aggressive behavior from the person with dementia. This elderly person who displays aggression is likely to be judged as being more impaired by their caregivers⁸. These findings lead the authors to conclude that aggression is one symptom of dementia that makes caregiving very difficult^{7,8}.

Haley, Brown, and Levine appraised 31 specific behavioral problems in the dementia patient living in the home setting. The authors found that the most stressful behavioral problems were agitation, hallucinations with dangerous behavior, embarrassing behavior, and hiding things. They found disorientation and forgetting familiar people to be low on the stress generating scale, as was incontinence⁹. This is in direct contrast to other studies which found incontinence to be the most difficult behavior of all for caregivers⁴. Haley et al., proposed that the low rating for incontinence on their study may result from caregivers learning how to better handle the incontinence problems through toileting schedules and the use of adult diapers⁹. Other studies found that the majority of the diagnoses that resulted in institutionalization involved difficulty with mobility, and problems related to dementia such as confusion, poor memory, eating with hands, and also incontinence¹⁰.

These findings point out some examples of the inconsistent findings in the literature regarding these difficult behaviors.

The results of a study by Steele et al., suggests that potentially treatable, noncognitive, behavioral and psychiatric symptoms are risk factors for institutional placement, and treating these symptoms might delay or prevent nursing home admission. The authors suggest that this could have important public health consequences, because it has the potential to reduce the many billions of dollars that are spent annually for nursing home care for the demented elderly². Seltzer and Buswell find that although there is disagreement on the prevalence of these difficult behaviors, it is the management of the symptoms of these behaviors that presents the major challenge¹¹. There are other compelling reasons to postpone institutional placement of the elderly person with dementia. Many studies report a very rapid downward spiral in physical and mental functioning after institutional placement¹².

Many of the existing instruments measure caregiver burden in relation to difficult behaviors that are exhibited by the relative with dementia. The authors presume that burden exists, and the instruments are worded in such a way that there is not a possibility that it does not exist. According to Stull, Kosloski, and Kercher, in a caregiving situation, if caregivers are told that caregiving is a burden, then they presume that they are burdened, and their consequent behaviors are shaped by this label¹³. In reality, caregivers can master techniques for shaping the behaviors of an impaired elder, can learn to change their response to it, and can improve their problem-solving skills. Over time, caregivers can grow from the caregiving experience, and can also derive a sense of mastery over their lives according to Skaff, and Pearlin¹⁴. Mastery, in this context, is the control that an

individual has over the forces that shape their lives. Growth, or self-gain, refers to the sense of personal enrichment or character building that comes from having coped with a difficult situation and mastered it¹. Therefore, this study does not ask what has been lost, and does not presume that burden exists in the caregiving relationship. The purpose of this study was to determine whether specific behaviors are exhibited by the elderly person with dementia, how difficult these behaviors are for the caregiver, and then does this affect caregiver mastery and self-gain?

Conceptual Framework

The elderly person with dementia experiences much internal stress. The difficult behaviors and the cognitive declines that they exhibit, plus the loss of former unique personality traits combine to gradually take away the person that once existed. This creates stress for the caregiver who is continually forced to adjust to this changing person and their changing behaviors. This causes the stability of the caregiving dyad to always be challenged. The goals of nursing interventions, according to Neuman, are to help maintain client system stability. Neuman's model focuses on the reactions of client systems to stress. Stress is assessed by identifying the internal and external forces that surround individuals at any given time, and by then considering the reaction of the individual to the stressor. Neuman states that health exists on a continuum that runs between total wellness and total illness, where wellness equals stability. Client systems maintain varying degrees of stability through the process of interaction and adjustment to stressors, and at times need assistance from health care professionals to move to their desired level of wellness¹⁵.

The person with dementia and the caregiver are susceptible to stress both individually and within the caregiving situation. The caregiver responds to stress based on perceptions

of the situation and on established coping strategies. The person with dementia responds to stress with behaviors that are not always understood, but that are partly based on the pre-morbid personality and partly based on old established coping patterns. The goal of these behaviors is to release the stress that is being experienced from an environment, both internal and external, that is no longer making sense¹⁵.

Method

A structured questionnaire was developed based upon behaviors that are most frequently cited in the literature as being difficult for caregivers, upon observation of the population in an adult day care setting, and upon conversations with caregivers. The questionnaire was first reviewed by nurses who are experts in the field of Gerontology. Based on their input, revisions were made, and the questionnaire was then redistributed to a new group of nursing and social service experts. A final review was made by lay people in the community to ascertain ease of use. The input of the experts lends content validity to the questionnaire.

The first part of the questionnaire consisted of 5 demographic questions. Although not central to the study, this information was used to help explain the results by linking the demographic data to the study's findings. The second part consisted of 15 questions. Each question described a specific difficult behavior that is characteristically exhibited by the elderly person with dementia. The ordering and wording of the questions were carefully considered. Each question consisted of two parts: "Part A" asked the caregiver, "Does the person you are caring for exhibit this behavior?" The respondent ranked the behavior using a 4-category, Likert-type scale. "Part B" asked the caregiver, "Is this behavior difficult for you?" The respondent again ranked the difficulty of the behavior

using a 4-category, Likert-type scale. The last three questions, each with sub-questions, were adapted from a scale by Skaff and Pearlin that assessed caregiver mastery and self-gain, again using a 4-category, Likert-type scale. This sub-scale has an alpha coefficient of (.74)¹⁴.

In the 1992 study, Skaff and Pearlin examined the “loss of self” through the absorption of the caregiver in the caregiving role. The caregiving role can become all encompassing and can leave little room for self-definition separate from, or beyond the caregiving experience. The authors examined two role-specific aspects of the self: (1) caregiver competence; and (2) caregiver self-gain. The caregiver competence questions ask the respondent to evaluate the adequacy of their own performance in the job of caregiver. It includes items that assess the quality of the care given and is positively related to both mastery and self-esteem. The caregiver self-gain items ask the respondent to reflect on the personal growth that may be attributed to the job of caregiver, and it asks the respondent to evaluate the personal meaning of the caregiving experience as it applies to their sense of self. The self-gain questions are highly related to optimism, coping skills, and the ability to redefine a situation in positive terms¹⁴.

The questionnaires were mailed to 75 caregivers. The convenience sample was recruited from an adult day care center in the San Francisco Bay Area. The subjects consisted of live-in caregivers who provide direct care to their elderly spouse or relative with dementia. The sample consisted of both male (n = 15) and female (n = 31) caregivers, and included “spouse” caregivers (n = 23) and “other relative” caregivers (n = 23). Of the 75 questionnaires that were mailed, 46 were completed and returned.

Results

The length of time that the total caregiver population ($N = 46$) had been in the caregiving role ranged from 2 months to 252 months (21 years), ($M = 60.46$ months [5.04 years], $SD = 51.96$ months [4.33 years]). The female caregivers were 45.2% spouses and 54.8% other relatives to their elderly person with dementia. Of the female respondents, 61.3% were caring for males and 38.7% were caring for females. The female caregivers had been in the caregiver role ranging from 12 months to 252 months (21 years). The male caregivers had been in the caregiving role ranging from 2 months to 120 months (10 years). The male respondents were 60% spouses and 40% other relative to the elderly person with dementia, and of the male caregivers, 93.3% were caring for a female (Table 1).

The Likert-type scales contained four choices. Part A asked, "Does the person you are caring for exhibit this behavior?" The 4 possible responses were, "Very Much," "Somewhat," "Just a Little," and "Not at All." Part B asked, "Is this behavior difficult for you, the caregiver?" The 4 possible responses were "Very Difficult," "Difficult," "Minor Difficulty," and "No Difficulty." The cumulative percentages were derived by compressing the response choices into two categories by combining the two highest categories, "somewhat" with "very much," and "difficult" with "very difficult," and by combining the two lowest categories, "just a little" with "not at all," and "minor difficulty" with "no difficulty" for the total sample of caregivers. This manipulation resulted in a dichotomous, "yes" or "no" choice.

Using these compressed percentages in Part A, the prevalence of the difficult behaviors were ranked as follows by the respondents: "Neglects to perform own personal care,

including bathing, dressing, brushing teeth, or combing hair,” was ranked as being the most prevalent behavior with 76.1% of the elderly exhibiting this trait according to the caregivers. “Has trouble with communication,” was ranked second in prevalence, with a cumulative score of 69.6%. The third ranked behavior was, “Acts depressed, including crying easily and not showing interest in activities,” with a score of 67.8%. “Seems awkward and unsteady when walking,” had a score of 65.2 % and was fourth ranked in prevalence. “Shows clinging behaviors, such as following you, and wanting to be constantly with you,” was ranked fifth in prevalence with 56.5% (Table 2).

Again using the compressed percentages from the “difficult” and the “very difficult” categories in Part B for the total population, the respondents ranked the difficulty of the behaviors as follows: “Has trouble with communication,” and “Neglects to perform own personal care, including bathing, dressing, brushing teeth, or combing hair,” were tied with 47.9%, and were both found to be the most difficult behaviors for the caregivers in this sample. “Has incontinence,” was ranked second in difficulty for caregivers with a score of 42.2%, and “Acts depressed, including crying easily and not showing interest in activities,” was ranked third with 36.9%. “Has trouble sleeping,” with 36.4% was ranked fourth. “Shows clinging behaviors, such as following you, and wanting to be constantly with you,” was fifth ranked in difficulty by caregivers with a score of 33.3% (Table 2).

The ratings were lower on all of the Part B, “Difficulty for the caregiver” portions of the questions, than the ratings of the Part A, “Prevalence of the behavior” portion of the questions. This seems to indicate that the caregivers in this sample are coping well with the caregiver role, and this is consistent with the findings from the portion of the questionnaire that assesses mastery and self-gain, questions 21, 22, and 23. In this study,

the majority of the respondents think that they are doing a good job in the caregiver role. Male caregivers responded to the question, "Do you feel that, all in all, you are a good caregiver?" with 53.3% saying that they are "somewhat" and 46.7% saying that they are "very much" a good caregiver. Females ranked themselves lower on this question with 3.2% responding in the "not at all" category, 3.2% responding in the "just a little" category, 25.8% responding in the "somewhat" category, and 67.7% responding that they are "very much" a good caregiver. The compressed percentages, the combination of the "somewhat" and the "very much" categories, for the total population ($N = 46$) were used to evaluate the responses for each of the questions concerning mastery and self-gain. The scores ranged from 70.5% for "Have you become more self-confident?" to 95.7% for "How competent do you feel?" and 95.7% for "Are you a good caregiver?"

Discussion

In this study, the female caregivers rated the behaviors exhibited by their relative with dementia as being more prevalent and more difficult than the male caregivers on most questions. A possible reason for this finding is that greater than half of the female caregivers (61.3%) are caring for a male relative. It is possible that the larger physical size of the male in comparison to the female, can make the physical chores of a female caring for the opposite gender very hard work. The female caregivers have been in the caregiving role longer than the male caregivers, ($M = 70.81$ months [5.9 years], $SD = 56.15$ months [4.69 years]), for the females and ($M = 39.07$ months [3.26 years] $SD = 34.57$ months [2.88 years]) for the male caregivers. Therefore, the increased number of years in the caregiving role, may give the female caregivers a more negative perspective.

Although the male caregivers found the behaviors exhibited by their relative with dementia less prevalent and less difficult than the female caregivers, there was one very notable exception. This was the question that pertained to depression. The compressed score on Part A, the prevalence of depression in the elderly relative was ranked at 26.7% by the male caregiving population, but on Part B, the level of difficulty in caring for the elderly relative with depression was ranked at 73.3% by the male caregivers. The total population ranked the prevalence of depression on Part A at 67.8%, much higher than the male caregivers, while the total population ranked the level of difficulty in caring for a depressed relative, on Part B at 36.9%, much lower than the score by the male caregivers. This same finding occurred, but to a lesser degree, with the question pertaining to communication. Male caregivers rated less prevalence of the behavior, "Trouble with communication" in their relative with dementia (66.7%), compared to the total population (69.6), but found the behavior to be more difficult to handle (53.4%) than the total caregiving population (47.9%).

Other studies have found differences between males and females giving care to their spouses. The findings seem to coincide with the outcome from this current study. Female caregivers reported more burden than male caregivers. Female spouse caregivers were upset by their husband's dependency, while husbands as caregivers were distressed that their wife was no longer able to interact with them. Husbands have also been found to have a greater tolerance for memory and behavior problems, and report less burden. Husbands adopt a task-oriented approach to daily problems, while wives have difficulty maintaining the emotional distance necessary to consider alternative strategies for handling

problems¹². The similarity of these findings to other studies lends criterion-related validity to this study.

Conclusion

To be able to intervene in an effective way with caregivers, we must first know what areas to target, because not all caregivers find the same behaviors to be difficult¹². This tool can give direction to interventions. The 15 behaviors, both parts "A" and "B" can be used to initiate discussion in caregiver support groups by providing a concrete way for the caregivers to organize their thoughts and to begin to express their feelings. The top behaviors causing caregiver difficulty could be targeted for nursing interventions and also for further research. The tool can also be used in a longitudinal study format, by repeating the survey at 6 month or 1 year intervals to note the progression of behavior changes exhibited by the person with dementia, and also to note the progression of caregiver coping patterns. The positive tone of the last three questions, encourages caregivers to contemplate their accomplishments, and to reframe some of the caregiving challenges in a more positive way.

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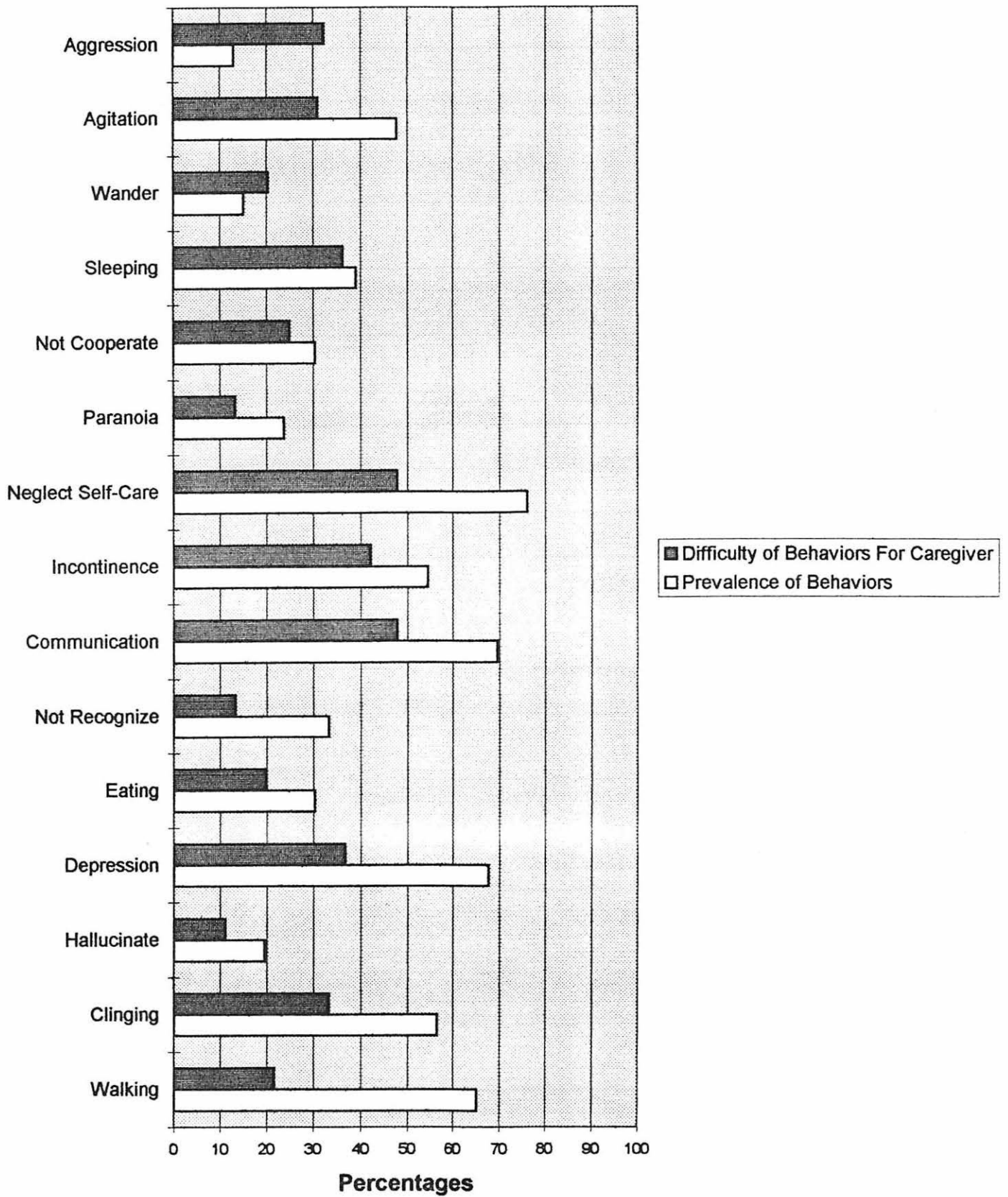
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Table 1
Demographics

Time In Caregiver Role				Caring For Male	Caring For Female	Caring For Spouse	Caring For Relative
	Range	Mean	Standard Deviation				
Females n=31	1 Year To 21 Years	5.9 Years	4.69 Years	61.30%	38.70%	45.20%	54.80%
Males n=15	2 Months To 10 Years	3.26 Years	2.88 Years	7.70%	93.30%	60.00%	40.00%

Prevalence and Difficulty of Behaviors



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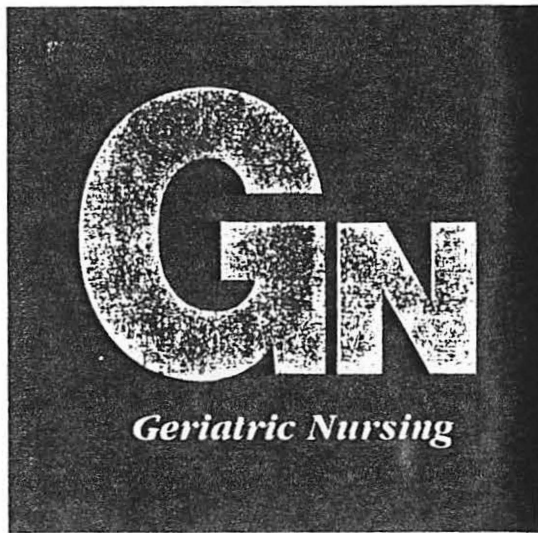
Dear Barbara;

I am writing in response to your request for permission to use our "Caregiving Competence" scale for your study of caregivers. As I told you when we spoke on the telephone, you are most welcome to use this scale. We have found it to be a useful measure of one of the ways in which caregiving has an impact on family members.

I would like to hear about the results of your study when you reach that point. Good luck with your project.

Sincerely,

Marilyn McKean Skaff
Marilyn McKean Skaff, Ph.D.

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- Short title
- Abstract
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Caregiver Survey

Caregivers frequently observe the following behaviors in their relatives with dementia. The purpose of this survey is to learn more about these behaviors, and to use the information to better meet the needs of caregivers. There are no right or wrong responses so please answer thoughtfully, and please answer all of the questions.

Directions:

For questions 1 through 5, please circle or fill-in the correct response.

Question 1

What is your relationship to the person you are caring for?
(Please circle)

Adult Child Spouse Relative Kin

Question 2

What is the gender of the person you are caring for?
(Please circle)

Male Female

Question 3

What is your gender?
(Please circle)

Male Female

Question 4

How long has the person you are caring for been ill?
(Please fill-in)

Question 5

How long have you been a caregiver to this person?
(Please fill-in)

Caregiver Survey

Directions:

For question 6 through 20, please mark the one 'best' answer. Each of these questions has two parts, part 'A' and part 'B'. Part 'A' asks about behaviors that you may see in the person you are caring for, and part 'B' asks how difficult this same behavior is for you, the caregiver. Please circle the answer that best describes your situation at the present time.

	A.				B.			
	Does the person you are caring for exhibit this behavior ?				Is this behavior difficult for you, the caregiver ?			
	Very Much	Somewhat	Just A Little	Not At All	Very Difficult	Difficult	Minor Difficulty	No Difficulty
Question 6 Seem awkward and unsteady when walking.	4	3	2	1	4	3	2	1
Question 7 Show clinging behaviors, such as following you, and wanting to be constantly with you.	4	3	2	1	4	3	2	1
Question 8 Have hallucinations, such as seeing things that aren't there.	4	3	2	1	4	3	2	1

Caregiver Survey

	A.				B.			
	Does the person you are caring for exhibit this behavior ?				Is this behavior difficult for you, the caregiver ?			
	Very Much	Somewhat	Just A Little	Not At All	Very Difficult	Difficult	Minor Difficulty	No Difficulty
Question 9 Act depressed, including crying easily and not showing interest in activities.	4	3	2	1	4	3	2	1
Question 10 Have eating difficulties.	4	3	2	1	4	3	2	1
Question 11 Not recognize familiar people.	4	3	2	1	4	3	2	1
Question 12 Have trouble with communication.	4	3	2	1	4	3	2	1
Question 13 Have incontinence.	4	3	2	1	4	3	2	1
Question 14 Neglect to perform own personal care, including bathing, dressing, brushing teeth, or combing hair.	4	3	2	1	4	3	2	1

Caregiver Survey

	A.				B.			
	Does the person you are caring for exhibit this behavior ?				Is this behavior difficult for you, the caregiver ?			
	Very Much	Somewhat	Just A Little	Not At All	Very Difficult	Difficult	Minor Difficulty	No Difficulty
Question 15								
Act suspicious of others.	4	3	2	1	4	3	2	1
Question 16								
Not cooperate during caregiving chores.	4	3	2	1	4	3	2	1
Question 17								
Have trouble sleeping.	4	3	2	1	4	3	2	1
Question 18								
Wander, attempt to leave unaccompanied.	4	3	2	1	4	3	2	1
Question 19								
Appear agitated, restless, and anxious.	4	3	2	1	4	3	2	1
Question 20								
Exhibit aggression and anger, such as yelling, swearing, striking, and threatening behaviors.	4	3	2	1	4	3	2	1

Caregiver Survey

Directions:

Questions 21, 22, and 23 each start with one statement. The statement is followed by several questions that apply to that statement. Please circle the one 'best' answer that applies to your caregiving situation at the present time.

Statement for Question 21

Here are some thoughts and feelings that people sometimes have about themselves as caregivers. How much does each statement describe your thoughts about caregiving?

Questions 21	Very Much	Somewhat	Just a Little	Not At All
How much have you learned about how to deal with difficult situations?	4	3	2	1
How much do you feel that all in all, you are a good caregiver?	4	3	2	1

Statement for Question 22

Think of the ups and downs of being a caregiver, of all the jobs that you do and how you deal with the difficulties, by putting all of these things together:

Questions 22	Very Much	Somewhat	Just a Little	Not At All
How competent do you feel?	4	3	2	1
How self-confident do you feel?	4	3	2	1

Caregiver Survey

Statement for Question 23

Sometimes people can also learn about themselves from taking care of a close relative. What about you? How much have you:

Questions 23	Very Much	Somewhat	Just a Little	Not At All
Become more aware of your inner strengths?	4	3	2	1
Become more self-confident?	4	3	2	1
Grown as a person?	4	3	2	1
Learned to do things you did not do before?	4	3	2	1

If you have any questions regarding any of these items, please contact Ms. B. Glaze at (650)948-6591, for clarification.