
The relation between the perceived role of family and the behavior of the person with dementia

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Abstract

The purpose of this study was to investigate the relation between the perceived role of family and the behavior of the person with dementia in a sample of older adults. Two instruments were used in data collection: The Family Perceptions of Caregiving Role (FPCR) and the Cohen-Mansfield Agitation Inventory (CMAI). A total of 40 persons with dementia were included in the study. Each had a family respondent and a nurse respondent.

The data analyses produced three major findings. First, it was revealed that there was no significant difference between agitation levels of persons with dementia who received more frequent family visits and those who did not. Secondly, the study revealed that family caregivers did not perceive a partnering relationship with staff. Finally, correlational analysis provided little evidence of a link between the family's perceived role in partnering and the behavior of the person with dementia, specifically in relation to agitation levels.

Although no significant relation was established between the family's perceived role in partnering and the behavior of the person with dementia, there was high family and caregiver satisfaction. The clearest element of the family's perspective was the desire that staff members care about the individual with dementia as a person.

Key words: agitation, dementia, family, partnering

Introduction

Although intuitively it might be expected that families play significant roles in the adjustment of persons with dementia to life in a care facility, relatively little research has addressed this issue. Tickle and Hull¹ conducted a qualitative study, using a participation-observation

methodology, to determine the role and function of family members visiting in long-term care settings. They found that some family members want and need to be involved in caring for their relative in long-term care. When they do participate in caring, the assumption may be that residents are more satisfied.¹ It has been suggested that feeling unsafe and insecure is a common feature of the dementing process² and that the presence of family may help persons with dementia feel more satisfaction and less frustration. The main objective of the present study was to examine the relation between the perceived role of the family and the behavior of the person with dementia.

Research has shown that family support of the resident may ultimately have a beneficial effect on the behavior of some agitated residents. Cohen-Mansfield et al.³ conducted a three-month observational study of 24 agitated and severely cognitively impaired nursing home residents to document the typical ways residents spend their time and how time use relates to the manifestation of agitated behaviors. It was revealed that these residents were involved in no activity during 63 percent of the observations. Yet data analysis revealed that residents manifested a greater number of agitated behaviors when they were unoccupied and fewer agitated behaviors when involved in structured or social activities. This study demonstrated that residents who had visitors exhibited a significantly lower level of total agitation than residents who did not have visitors.³ Results of another study showed that 93 percent of a group of 408 nursing home residents manifested one or more agitated behaviors at least once a week.⁴ Besides being a management problem, agitation seems to indicate discontent by the nursing home residents themselves.

Less clear and less well documented, however, are the specific roles that families assume in the care of their elderly members in nursing facilities and the specific degree of family involvement. Family roles in nursing facilities have been ambiguous due to an apparent difference

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in attitudes and perceptions between the nursing home staff and family and friends of the residents.⁵ Researchers conducted a study that examined role expectancies in essential nursing services between nursing home professionals and relatives of residents.

Overall, the level of agreement was remarkable between staff and relatives as to the assignment of responsibility. The results of their study showed that serious and sympathetic efforts on the part of staff to encourage increased family participation will, in many cases, help foster a partnership between staff and families and generate broader support for the residents. Duncan and Morgan⁶ examined family caregivers' views of their relationships with nursing home staff. Their results pointed to the families' desire for emotionally sensitive care and not just for technically competent performance of tasks. Bowers⁷ found that nursing-home based family caregivers emphasized the social and emotional aspects of care and not merely a task-oriented division of labor. The clearest element of the family's perspective was the desire that staff members care about the resident as a person.

The purpose of this study was to:

- determine whether the behavior of persons with dementia differs for those who receive family visits more frequently, compared to those who receive family visits less frequently
- examine the partnering relationship between family and staff caregivers
- examine the relation between the perceived partnering role of family and the behavior of the person with dementia

Method

Participants

Participants for this study included staff, families, and patients in the Lower Mainland of Vancouver, British Columbia. A total of 40 persons with dementia were included in the study. Each had a family respondent and a nurse respondent. Thus, there were 40 family members and six nurses (the nurses who best knew the patients). Two locations were used to obtain the study sample: a 75-bed extended long-term care facility in Vancouver and a 75-bed intermediate care facility in Richmond. These facilities were used for data collection purposes to ensure an adequate number of clients. The data were collected over a two-month period.

At each nursing home, the researcher discussed with the nurse clinician the nature and purpose of the study,

the approach to be taken, and the expectations of the participants. The nurse clinician was asked to identify, for invitation to participate in the study, individuals with dementia who were known to have families who visited. The sample consisted of persons with dementia and their family members. The study used a convenience sample, examining persons with dementia.

Identification of the person with dementia was not made on the basis of age or gender. The criteria for selection did not include agitated behavior. In fact, at the time of this selection process, the researcher had no knowledge of whether or not the person with dementia was agitated. Forty persons with dementia were identified. For each of these individuals, one staff informant and one family informant participated in the study.

Letters of explanation were then mailed to the family member outlining the project. The family member then contacted the researcher to indicate if they wished to participate. The willing participants were asked to sign a consent form to participate in the study. Persons with dementia were not asked to sign a consent form. For persons who had a "committee of person" in place, the legal guardian was contacted concerning participation in the study. If the guardian expressed interest in having the patient take part, the researcher then obtained consent.

The rationale for involving family members was that the family may be affected in some way by the outcome of the person with dementia, and they also may influence the outcome by their perception of their caregiving role with the staff. Of these family members, 35 percent of the visitors were daughters, 12.5 percent were sons, 22.5 percent were husbands, 10 percent were wives, 10 percent were nieces, and 10 percent were friends.

The nurse clinician also identified the nurses who best knew each person with dementia for invitation to participate in the study. A letter was sent to each nurse outlining the project and the purpose of the study. Each nurse contacted the researcher if they were willing to participate. All staff members who were contacted agreed to take part in the study. Willing participants were then asked to sign a consent form to participate in the study. Each staff informant was then given a Cohen-Mansfield Agitation Inventory (CMAI) questionnaire to complete concerning the behavior of the person with dementia he/she was identified as knowing best.

Approval to conduct this research was applied for and received from the University of Victoria Human Research Ethics Committee.

Instruments

The measurement battery consisted of two instruments: the Family Perceptions of Caregiving Role Tool

(FPCR) and the CMAI. The FPCR is intended to examine outcomes and measurement issues related to caregivers for persons with Alzheimer's disease. This instrument was selected because it measures the family's perception of the caregiving role. Separate dimensions of the instrument measure stress from the caregiver role and the quality of interactions with staff, the burden of the caregiver role, and loss resulting from the caregiver role.⁸ From research on 112 family members, Buckwalter et al. reported Cronbach's alphas 0.90 for the total scale. Cronbach's alpha is a test of internal consistency and compares each item in the scale simultaneously with each other. A coefficient of 0.90 means that the FPCR demonstrated reliability; the closer to 1 the coefficient is, the more reliable the tool. Re-analysis of the FPCR suggested three subscales corresponding to: Family Role; Captivity/Burden, with the emphasis on Captivity; and Loss (David Reed, personal communication, August 20, 1999). Subscale composition is being re-evaluated, although alphas currently are greater than 0.80 for all three subscales. Test-retest reliability with 12 family members for a three-week interval was 0.79 ($p < 0.001$). This means that, when the FPCR was administered to the same subjects under similar conditions on two or more occasions, there was a correlation coefficient of 0.79. The magnitude of this correlation supports the idea that the FPCR had the attribute of stability.

In the present study, the first 20 questions and questions 41, 42, and 43 were selected from this tool. The rationale for selecting these questions from the original scale of 81 items is that these 23 items all deal with interactions between family and staff. These items measure the quality of interaction between family and staff described by Buckwalter et al.⁸ Each of the statements in the family interview described something about the family role in the care of the family member. Upon interview, families responded to each statement in terms of the extent to which they agreed or disagreed. For this reason, Questions 4, 7, 12-14, 17-19, 41, 42, and 43 were items that needed to be reversed before the scores were calculated. The last question on the FPCR was open-ended and allowed the family to comment on any personal insights into their caregiving role. But these comments were not analyzed for this study.

The CMAI is a nurses' rating questionnaire consisting of 29 agitated behaviors.⁴ The CMAI measures how frequently episodes of agitation occur. Each item is rated on a seven-point scale of frequency (1 indicates the person never engages in the specific agitated behavior, and 7 indicates the person manifests the behavior on the average of several times an hour). In the nursing home, inter-rater agreement rates were calculated for each behavior on the CMAI (using 0-1 point discrepancy as agreement)

for three sets of raters (in three units of a nursing home). These averaged .92 ($n = 16$), .92 ($n = 23$), and .88 ($n = 31$). Because the CMAI is an instrument that depends on direct observation of a behavior, it is important that it be tested for inter-rater reliability. The consistency or reliability of the observations between observers is extremely important.⁴ The above scores indicate a high degree of inter-rater reliability.

Although this questionnaire consists of 29 agitated behaviors, the present study used the short-form version of the CMAI, which consists of 14 agitated behaviors, each rated on a five-point frequency scale instead of a seven-point frequency scale. For the purpose of this study, the researcher adjusted the scale to read from 0 to 4 (0 indicates the person never exhibits the agitated behavior, and 4 indicates the person engages in the behavior a few times an hour or continuously for half an hour or more). This scale relies on subjective information given by the rater. For the short version of the CMAI, inter-rater reliability was as follows: exact agreement = .82; 0-1 point discrepancy = .93.⁴ These coefficients demonstrate an acceptable level of reliability and assure the researcher that the CMAI is a reliable tool.

Procedure

The researcher interviewed 40 families. Each family member was asked to answer the 23 items from the FPCR relating to interactions between family and staff around the care of the person with dementia. In addition, the family members were asked how frequently they visited and also to comment on any other factors that might impact their caregiving role. These comments were included as personal insights at the end of the interview.

The CMAI questionnaire was then completed by the nurse who best knew the patient. The nurse was asked to rate the frequency of occurrence of 14 behaviors of the person with dementia and also to comment on any other factors that might contribute to the behavior of the person with dementia. These comments were included as personal insights at the end of the questionnaire. The questions concerning these behaviors were then organized into two categories: verbal behavior and physical behavior. For analysis purposes, it is not useful to calculate a total score by adding all the categories.⁴ The rationale for using this combination of items relates to the behavior itself and how the person with dementia is displaying the behavior (note that item #4 denotes both verbal and physical behavior).

Next, the frequency of visitation was established according to how the family pattern of visitation occurred. The distribution of the frequency of family visit was bimodal. Given this distribution, two groups

were formed, with 19 residents receiving visits three or more times per week (Group 1) and 21 residents receiving visits twice per week or less (Group 2). The rationale for selecting this breakdown for the groups was based on the fact that the group sizes needed to be fairly even, and a bimodal distribution was representative of the family visitation pattern. The significance of these results will be discussed elsewhere in the paper.

Results

The data analyses consisted of three parts. First, a t-test was performed comparing Group 1 (three or more visits per week) and Group 2 (visits twice per week or less) on the CMAI scores to determine if there was any significant difference between the agitation levels of persons with dementia who receive more frequent family visits and the agitation levels of those persons who have less family visiting. Next, a distribution of scores on the FPCR was created to determine to what extent families feel they are partnering with staff. Finally, a correlation was undertaken between the FPCR and CMAI scores to determine if there was a relation between the family's perceived role in partnering and the behavior of the person with dementia. The Microsoft Excel 97 Data Analysis program and the XY (Scatter Plot) Graphing Tools were used to analyze the data. The results are presented for each hypothesis investigated.

A significance level of .05 was used for all statistical tests. This choice of standard for an acceptable probability is the risk one assumes of rejecting a null hypothesis when it is true. The higher the significance level used for testing a hypothesis, the higher the probability of rejecting a null hypothesis when it is true.

Hypothesis #1 states that persons with dementia who received more frequent family visits would experience less frequent episodes of agitation behaviors than those persons who received family visits less frequently. To investigate this issue, a t-test (One-Tailed Test for Difference Between Means) was performed. A one-tailed test was selected because the researcher expected that the family visitation would impact the agitation levels of the person with dementia. This particular test was selected because it showed the difference between means and gave direction of the effect.

The frequency of responses observed for families with more or less visitation were broken down by item on the verbal and physical subscales of the CMAI. It is interesting to note that the percentage of zero scores was modestly higher for Group 2 than for Group 1. In other words, a slightly larger percentage of people with dementia who had less frequent family visiting showed agitated behavior. The t-test comparing the groups on the

scores for verbal behavior category of the CMAI did not detect a significant difference between the groups: $t(1,2) = .78, p = .15$. Similarly, no significant differences between the groups were detected by the t-test used to examine the scores on the physical category of behavior on the CMAI: $t(1,2) = -1.02, p = .22$.

For the verbal category of behavior, the upper limit of acceptance was $1.7 \times 7.4 = 12.6$. This indicates that the difference between the two sample means (1.6) lies within the acceptance region. To reject the null hypothesis, the observed difference of sample means would need to fall sufficiently high in the right tail of the distribution. Thus, the null hypothesis was accepted.

For the physical category of behavior, the upper limit of acceptance was $1.7 \times 6.8 = 11.5$. This indicates that the difference between the two sample means (-1.1) lies within the acceptance region. To reject the null hypothesis, the observed difference of sample means would need to fall sufficiently high in the right tail of the distribution. Thus, the null hypothesis was accepted.

It appeared from the results that one must accept the null hypothesis. There was no significant difference between the agitation levels of persons with dementia who received more frequent family visits and agitation levels of those persons who received less frequent family visits.

Hypothesis #2 stated that family caregivers viewed themselves as sharing the caring role. That is, family caregivers perceived a partnering relationship with staff. To investigate this issue, a distribution of scores on the FPCR was created.

The group scores were derived from how the respondent answered the item on the FPCR. It is important to note that if the individual responded to 1 to 23 items, then 23 would be the lowest possible score (also denoting strongly disagree on the scale). If the individual responded to 7 to 23 items, then 161 would be the highest possible score (denoting strongly agree). The largest number of responses (21) came from the group score of 47-69, which actually denoted an average response on the FPCR of 2 or 3. This was leaning toward the strongly disagree end of the scale. The mean for this distribution of scores was 69. The median was 65.5, which denoted the midpoint of the data set. The mode was 47, which represented the most frequently recurring total score and was represented by the highest point in the distribution curve. This positively skewed distribution showed the researcher that the most responses came from family members who responded at the strongly disagree end of the scale. In this case, the median (65.5) was the best measure of location and showed the researcher that the family's responses were leaning toward the strongly disagree end of the scale. In other words, family caregivers did not perceive a partnering relationship with staff.

Hypothesis #3 stated that those family caregivers who felt they were in a partnering relationship with staff were families of patients with less agitated behavior. This would mean that high scores on the FPCR (reflecting partnering) would be related to low scores on the CMAI (reflecting less agitation). That is, a significant negative correlation between the two measures was anticipated. Both the size of the correlation and the size of the sample affected the determination of significance: as either increased, the probability of significance also increased. To investigate this issue, correlations between the FPCR score and each of the CMAI scores were calculated. Because the CMAI contained a diversified group of behaviors, the verbal and physical behaviors were first categorized.

Pearson product-moment correlation coefficients were calculated between the variables (FPCR score and each of the CMAI scores). The dependent variable (CMAI score) is on the vertical axis (Y-axis) and the independent variable (FPCR score) is on the horizontal axis (X-axis). These scatter diagrams portray the relation between these two variables of interest. Note that if the correlation was weak, there was considerable scatter about a straight line drawn through the center of the data. The correlation coefficient value for the CMAI verbal score was $r = 0.087128$ and for the CMAI physical score was $r = 0.128065$. These coefficients of correlation showed there were weak positive correlations between the FPCR and each of the CMAI scores (i.e., verbal and physical). In other words, although the family perceived there was some partnering relationship, the person with dementia remained agitated.

It appeared from the results that one must accept the null hypothesis: There was no significant relation between the family's perceived role in partnering and the behavior of the person with dementia, specifically the agitation levels.

Discussion

A limitation of this study centers on the instruments themselves. The FPCR was selected primarily because it measures the family's perception of the caregiving role. The original FPCR scale contains 81 items. In the present study, the researcher selected 23 items, all dealing with interactions between family and staff. Due to this modification of the original version, it is difficult to measure the validity and reliability of the shortened version. However, in testing with data from current research ($N = 112$ family members), Cronbach's alphas were .90 for the total scale. Subscale composition is being re-evaluated, although alphas currently are greater than .80 for all three subscales. Test-retest reliability with 12 family

members for a three-week period was 0.79 ($p < 0.001$).⁸ A good methodological approach for future studies might be to administer the FPCR to the same subjects under similar conditions on two or more occasions to support this attribute of stability.

Similarly the modification of the CMAI may present limitations to the conclusions drawn in this study. This questionnaire consists of 29 agitated behaviors; however, the present study used 14 agitated behaviors. Because the CMAI is an instrument that depends on direct observation of behavior, it is important that it be tested for inter-rater reliability. In testing the psychometric properties of the short version of the CMAI, inter-rater reliability was as follows: exact agreement = .82; 0 to 1 point discrepancy = .93.⁴ Inter-rater reliability was not assured in the present study. Future studies might involve interviewing the family caregiver as well. The goal is to achieve the most accurate reflection of the frequency with which these agitated behaviors occur.

Results from the analyses provide evidence relevant to the questions of interest in this study. This study examined agitated behaviors for persons with dementia who received family visits more frequently compared with those who received visits less frequently. It also examined relations between the perceived partnering role of the family and the agitated behavior of the person with dementia. Although it was hypothesized that more frequent visitation and a higher perceived level of partnering would be related to lower agitation levels, these relations were not observed in this study. These findings will be discussed within the context of each hypothesis investigated in this study.

Relation between family visitation and behavior

The results do not support the relation between the frequency of family visitation and the agitation behaviors of those persons with dementia. Although previous research suggests a positive correlation between visiting and its relationship with level of agitation, this phenomenon was not evident in the present study. In Cohen-Mansfield's study,⁹ 24 study participants were selected on the basis of their high agitation and cognitive impairment. These were not criteria for the present study, only that the person had dementia. Also, in Cohen-Mansfield's study, a research assistant observed each resident over the course of three months. During each observation, a research assistant recorded the number of times each resident manifested each of the agitated behaviors. In the present study, the nurse observed and recorded the behavior of the person with dementia one time only.

Many other factors may have influenced the individual's behavior. For example, verbally disruptive behaviors

may be associated with discomfort such as pain. Others, such as requests for attention and aggressive behaviors, may be adaptive and may signal an attempt to communicate needs.¹⁰ In a subsequent study, Cohen-Mansfield et al.¹¹ examined the link between agitated behaviors and cognitive functioning in a study of 408 nursing home residents. Results showed that cognitively impaired residents manifested aggressive behaviors and physically nonaggressive behaviors.¹¹ Several possible factors that may have impacted the behavior in the present study include: environmental influence on agitation, time use related to manifestation of agitated behaviors, past experience of the individual as a predictor of agitation, and the relation between sleep and agitation.

The family's partnering relationship with staff

Previous research has indicated that there may be role ambiguity between staff and family members caring for persons with dementia.⁵ Staff have been encouraged to view the resident's family as clients,¹² as needed resources for resident care,¹³ and as partners in care.¹⁴ However, Bowers⁷ and Duncan and Morgan⁶ agree that family members do not completely set aside their roles and responsibilities when their relative moves to a nursing home. In fact, families appear willing to share or assume responsibility for over half the tasks. In Bower's study, it was suggested that biographical knowledge about the person with dementia is necessary to understand what makes that person unique, including knowledge about personal preferences that might influence the person's activities of daily living.

The present study revealed that families do not perceive a partnering relationship with staff. However, in examining the distribution of scores for each item on the FPCR, families do perceive a partnering relationship around some issues, but not others. The data reveal that families perceive partnering around: visitation, being asked to remain when care is provided, being included in priority setting for their relative, feeling comfortable making suggestions to the staff about their relative's care, having a sense that they still are the primary caregiver for their relative, and feeling included in the care of their relative. On the other hand, family members feel they should be partnering and are not being included in: decision making, providing personal care, feeling a sense of control over the care their relative receives, offering input about what care will be provided for their relative and how, feeling concern that their relative is not being cared for as an individual, or feeling they can interact purposefully with staff about the care of their relative.

Family involvement is recommended as a goal in the

holistic care of patients with dementia who reside in long-term care institutions.¹⁵ To recognize the personal histories, values, and preferences of these residents, the staff needs to enhance the roles of the family in facilitating the individualization of care.¹⁶ Cutillo-Schmitter¹⁷ agrees that incorporating family members in the care of patients with dementia provided pertinent psychosocial data, led to mutual decision-making regarding care, and produced changes in the responses of the residents with dementia, as well as in the family and nursing staff. The authors discuss the importance of fostering affectionate connections and competency among family members as they readjust to changing circumstances. For many families, fostering this connection may involve partnering with the nursing staff in the setting of the nursing home.

The discrepant finding for Hypothesis #2 may result from several factors. First, transition to the nursing home was an extremely difficult time for family members. These family caregivers demonstrated uncertainty about how to perform their changing roles. Second, to implement a partnership between family and staff caregivers, there needed to be a more consistent staffing pattern. Family members voiced concerns to me that almost each time they visited, there seemed to be a different nurse working. Finally, it was apparent during the course of this study that the family members were engaging with the nursing assistants when they had information to share regarding the condition of their loved one. It was unclear if this information was being communicated to the registered nurse. Family members felt that although the nursing assistants were indeed listening to them, they did not see this information being integrated into the care plan of their loved one.

Perceived role of family and behavior

The results show that there is no significant relation between the family's perceived role in partnering and the behavior of the person with dementia, specifically the agitation levels. However, the literature suggests otherwise. Buckwalter and Hall¹³ maintain that families are a neglected resource for providing quality care to their relatives with Alzheimer's disease. They suggest that families and staff should form a partnership, with clearly delineated cooperative role behaviors designed to maximize the cognitive and functional abilities of the patients, while enhancing satisfaction and reducing stress of families. This relationship was not evident in the present study. It was expected that high scores on the FPCR (reflecting partnering) would be related to low scores on the CMAI (reflecting agitation). In fact there was a weak positive correlation between the family's perception of partnering and the agitation levels of the person with dementia. This

means that although the family is partnering with staff, the person with dementia remains agitated.

In addition to the influences on behavior previously discussed by Cohen-Mansfield et al.,⁹ interventions by family and staff can also have a profound effect on behavior.¹⁸ Grant's study¹⁹ supports the need to acknowledge the importance of families in recognizing individual functional, cognitive and emotional changes in the individual, and the importance of family and staff sharing this information. Droes et al.²⁰ concur that integrated family support, in which patients and caregivers are both supported by the professional staff, is more effective in influencing behavior problems and mood of the dementia patient than nonintegrated support.

In the present study, when family members were asked to comment on any personal insights, they stated they did not always feel acknowledged by the nursing staff, nor did they feel that staff would share important information with them. This is supported by the empirical data. When family members were asked the items on the FPCR—such as being included in the decisions about the care of their relative, having a secondary role since their family member was admitted to the nursing home, feeling control over the care their relative receives, and agreement on care priorities for their relative—the results reflected a nonpartnering role.

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