Nurses' and Family Members' PERCEPTIONS OF NURSING HOME RESIDENTS' NEEDS

ABSTRACT
The purpose of this study was to determine the degree of agreement between nursing home staff and families in assessing the needs of cognitively impaired nursing home residents. A convenience sample of 36 family members of nursing home residents with cognitive impairment and the nurses assigned to those patients was recruited from three nursing homes. The Nurse and Resident Perceptions Questionnaire, adapted from Lindgren and Linton (1991), was used to assess functioning in activities of daily living, physiologic, and psychosocial areas. Significant differences were found for eight items of physiologic and psychosocial functioning: difficulties with chewing, swelling of feet, orthopnea, weakness, easy bruising, recognition of people, lack of privacy, and boredom. Nurses rated all these areas less problematic than did the family members. Collaborative efforts of family members and nurses are needed to develop effective plans of care for these problems of nursing home residents with cognitive impairment.

CAROLYN L. LINDGREN, PhD, RN, AND ANNE MARIE MURPHY, RN, GNP
The following conversation was overheard one morning at shift change report:

I called Mrs. X’s daughter to let her know her mother had fallen out of the wheelchair. The daughter goes, ‘Why was my mother up in a chair at 6 a.m. if breakfast isn’t until 8 AM?’ These families don’t understand everybody doesn’t magically get up at 8. Each one takes time. You have to start ahead.

The nurses and aides receiving report generally agreed with the nurse’s evaluation. “These families don’t understand” is an underlying theme in many encounters between nursing home staff, who are responsible for many patients at one time and family members with questions about their relatives’ care. Nursing home staff experience daily pressures and stress including caring for residents with multiple deficits, continual cutbacks in staff and supplies, and high personnel turnover.

Families too, are distressed because they have had to place their relative in a nursing home, especially those emotionally closest to the resident, namely, spouses and adult children. For spouses, institutionalization reduces the intimacy and companionship of the marriage, and adult children experience role reversal as they make decisions for their parents. Family members’ emotional suffering includes feelings of sorrow, failure, resentment, helplessness, shame, guilt, ambivalence, and loneliness (Kellett, 1998; Lindgren & Aldrich, 2000; Maas et al., 1994; Ross, Rosenthal, & Dawson, 1993).

Nursing home residents with cognitive impairment comprise two thirds of patients and are among the most difficult to care for (Bravo, DeWals, Dubois, & Charpentier, 1999; Cohen, Hyland, & Devlin, 1999). They must rely on the nurses and their families to interpret their needs. Families usually remain involved with institutionalized relatives and are a main source of information about the resident’s unique personality and accomplishments because they have more insight and information about the residents when they were cognitively intact (Kelley, Swanson, Maas, & Tripp-Reimer, 1999). Family members who were once at-home primary caregivers with much control over care, shift in the nursing home setting becoming an outsider with little control, yet, with a vested interest in their relative’s care. They are in an ambiguous role as a family member and are a neglected resource for providing quality care in the nursing home (Maas et al., 1994; Maas, Swanson, Buckwalter, Weiler, & Specht, 1998; Schwartz & Vogel, 1990).

Successful nursing homes attempt to provide ways for families and nurses to deal positively with the realities of providing efficient care for elderly residents who are frail. It is important for both families and nurses to understand that while their perspectives might vary, each knows the resident in a different way and has a significant contribution to make toward the resident’s well-being. To provide direction for improved collaboration between family and nursing home staff, examining the nature of perceptions between family and nursing staff is warranted. The purpose of this study was to compare family members’ and nursing home nurses’ perceptions of the needs of residents who are cognitively impaired.

BACKGROUND AND SIGNIFICANCE

Need for Family Involvement

Care of residents who are cognitively impaired requires rallying all potential resources including their families. The level of cognitive status of nursing home residents has been found to be the strongest link, and a negative one, to quality of care in a recent study of 301 residents randomly selected from 88 facilities (Bravo et al., 1999). This was especially true in larger facilities with heterogenous needs among residents. The residents who were cognitively impaired were less likely to receive necessary attention. Only in those facilities with larger numbers of external collaborators and those with better trained staff was the quality of care for residents with cognitive impairment somewhat improved (Bravo et al., 1999).

The study did not address what areas of care the family should address to improve the quality of care. Residents who are cognitively impaired are more likely to be vulnerable to “acting out” and disruptive behaviors without involvement and support of the family, who can provide familiar and meaningful environmental cues (Maas et al., 1998).

Family and Nursing Home Staff Perceptions and Misperceptions

Family and staff each have their perceptions of their motives and roles. Often, those perceptions differ, putting them in adversarial positions (Pillemer, Hageman, Albright, & Henderson, 1998). The nature of family involvement was qualitatively documented as assistance in decisions about crisis, competence, transfer, treatment, physical environment, and daily living using residents, family members, administrators, nursing staff, non-health-care staff, and physicians as subjects (Rowles & High, 1996). Family members can help staff assess residents’ needs in relation to customary routines, life-time patterns, and idiosyncrasies (Kellett, 1998; LaBrake, 1996).

Family members’ perceptions of their motives and roles are documented as being faithful to the nursing home resident, assuring quality of care and well-being for the nursing home resident, and maintaining family ties and relationships (Kelley et al., 1999). Eighty percent of the family members studied by Bowers (1988) believed if they failed to assure preservatory care, which refers to maintaining the “older person’s older self” (p. 362), their relative would become depressed. Elements of preservatory care were listed as main-
taining family connectedness, the relative’s dignity, and hope of recovery. The author reported that overwhelmingly “family members were distressed over the staff’s failure to provide preservative care” (p. 367).

Such caring beliefs were also found by Kellett (1998) in a qualitative study of 14 family members. These beliefs were identified as the meaning the family members gave for their existence and motivation for continuing their care. However, they believed the nursing home staff considered their involvement in the resident’s care as intrusion, leaving family members in limbo with little voice or control. The family members also believed that deterioration in their institutionalized relative was from poor quality of care versus the natural progression of the disease process. Relatives believed they would be able to provide better care that would not allow for such deterioration. Such beliefs established a gulf between the families and the nursing staff (Kellett, 1998).

Misperceptions between family members and nursing home staff were identified by Ryan and Scullion (2000). Families’ perceptions of their involvement were overestimated when compared to the nursing staff’s perception of such involvement. Families perceived the staff as providers of technical care while they, the family members, provided the emotional care. Families had greater trust in the staff to provide appropriate care than the staff had in the families’ abilities in providing care. The conclusion was the families were willing to help and were somewhat undervalued as a resource for care of the resident.

Similar findings were obtained by Duncan and Morgan (1994). Families perceived themselves as part of the care team and expected to have ongoing connections with the other members of the care team, namely the nursing home staff. Conflict with the staff arose over their lack of recognition of the family members’ expertise and contribution to the care the nursing home resident. Families were found to actively establish relationships with staff to influence staff behavior that would lead to better quality of care for the resident (Duncan & Morgan, 1994).

Miscommunication between family members and nursing home staff identified in a Swedish study (Hertzberg & Ekman, 2000) occurred when the staff’s perceptions of their professional responsibility kept them from delegating care tasks to the families. Family members felt rejected and like outsiders. Distrust built between the family members and nursing home staff because family members wanted more information than given about their relative’s care. Uncertainty escalated with high staff turnover because some staff knew very little about the residents (Hertzberg & Ekman, 2000).

Special care units (SCUs) for residents with dementia have been established and family involvement is considered an important part of those care designs (Karner, Montgomery, Dobbs, & Wittmaier, 1998; Kelley et al., 1999; Specht et al., 2000). Families reported motive and roles congruent with those previously discussed, namely family faithfulness to the resident and being the “eyes and ears” to monitor and promote better care (Kelley et al., 1999). In reports by staff (e.g., certified nurse’s assistants [CNAs]) on satisfaction of SCUs studied by Karner, Montgomery, and Wittmaier (1998), family assistance with care was generally welcomed, providing some workload relief for the staff along with the personal information about the resident. Family members with high distress levels, especially with the disease process, increased the burden on the staff. The CNAs believed some families, especially those who visited less often, did not appreciate the continual, regular care the CNAs provided. The CNAs considered themselves to be substitute families.

Family members view themselves as monitors of quality of care, promoters of residents’ psychosocial and physical well-being, and supporters of family connections. Family members perceive that staff view them as superfluous to the resident’s care, leaving the family members with no defined role or value as important collaborators in the care process. No studies were found that measured the specific differences between family members and nursing home staff perceptions of the resident.
Interventions for Families

Intervention protocols have been developed to improve family involvement and collaboration in nursing home care. Social workers Hansen, Patterson, and Wilson (1988) conducted an 18-month project to increase family involvement on a 30-bed long-term care unit for older adults who were mild to moderately impaired. Family members increased their time of care involvement from an average of 3 hours per month to 6 hours per month through the end of the 18-month period. They found that the families wanted to be involved, but needed support and clarification from the facility.

Family interaction and visits were increased in a controlled intervention study of family members and nurses of 12 residents with dementia in a Veterans Affairs facility. Anderson, Hobson, Steiner, and Rodel (1992) sought to improve family visits and make the nursing care plan more responsive to individual needs. During the study, nurses diagnosed plans, and interventions addressing psychosocial needs increased. Nurse's notes contained more of an active focus on interaction. Family interaction and visits increased and families were more involved in the unit, medical center, and support groups. Needed medication use for the residents decreased.

The issue of resolving communication and perception conflicts between family members and nursing home staff was addressed in a project entitled "Partners in Caregiving" (Pillemer et al., 1998). Evaluation results were positive for satisfaction with the program and reports of behavior, change by the participants, including better understanding of each other's roles and reduced interpersonal conflict.

Family Involvement in Care (FIC) is a 5-year intervention program for family members and nursing home staff to improve their partnership in addressing the care needs of residents with dementia (Kelley et al., 1999; Specht et al., 2000). Specht et al. (2000) compared the effectiveness of this program between Black and White family members. At baseline, Black families were more dissatisfied with care and became more proactive in monitoring care. White families were less satisfied with nursing home management of care and activities provided. Nursing homes in the Black community were more open to family involvement; whereas, in the White facilities, families perceived that staff considered them "disruptive" and a bother. The complexities of improving family involvement must include sociocultural issues if these programs are to be successful.

Intervention programs have shown some fruitful results in the areas of interaction, conflict resolution, and direct involvement of care. Effective collaboration between diverse families and complicated administrative care hierarchies is a complex process requiring attention to multiple factors, many of which are not fully understood.

Correlation of Nurse and Nursing Home Resident Assessment

In the previous work to learn about family involvement, tap misperceptions, and attempt to incorporate family care into the institutional setting, none have documented the family member's specific assessment of the nursing home resident and its alignment with the staff's perceptions of the resident. Other researchers have addressed correlations between staff and competent resident's assessments of their needs. Such work reveals parts of the nursing home resident's assessment that is being missed by staff when the perspective of the resident, or in the case of the resident with dementia, a family member who knows the resident intimately, is not included.

Lindgren and Linton (1991) studied 31 relatively competent nursing home residents and 24 licensed vocational nurses and compared their perceptions of residents' activities of daily living (ADL) and psychosocial needs. Residents rated themselves as needing less help with bathing compared to the nurses' ratings and deemed the loss of bladder control more significant than the nurses. Residents assessed themselves as having difficulty breathing at rest, decreased sense of smell, and loss of usefulness—problems not recognized in the nurses' assessment. Lindgren and Linton concluded that nurses need more training in sensitivity to resident concerns in areas highlighted by incongruent responses, especially the significance of loss of bladder control and loss of usefulness.
Quality of care was examined by Bliesmer and Earle (1993) who compared nursing home resident and staff perceptions. The researchers used 17 quality-of-care indicators and compared the rankings of 15 residents and 15 staff members each at two nursing homes. Minimal to moderate congruence was found between resident and staff ratings of importance and occurrence. Residents ranked as important good staff attitude, bathroom cleanliness, prompt attention, opportunity to practice religion, and privacy. Staff agreed and included home-like atmosphere. Residents ranked occurrence highest for physician availability, bathroom cleanliness, room cleanliness, privacy with physician, and opportunity to practice religion. Only two of those items appeared in staff rankings.

These two studies show the areas of assessment and care missed by nursing staff observation and judgment of competent nursing home residents. Cognitive impairment of nursing home residents is a risk factor for reduced quality of care as previously discussed. What areas of assessment and care are being missed by not including family members’ perceptions of nursing home residents with cognitive impairment? As families and nursing home staff look for ways to work together for the best patient outcomes in this population, an understanding between these two groups related to how they view significant problems would be a starting point for planning.

While studies abound documenting the concerns of families, little work has been done comparing family members’ and nursing home nurses’ assessments of residents who are cognitively impaired, and these individuals make up the majority of the nursing home population. Clarification of how family members and nursing home staff view the residents should indicate areas where education, investigation, or collaboration is needed.

RESEARCH QUESTION
The research question addressed in this study was: What are the similarities and differences between the families’ and nurses’ perceptions of competency in ADLs, physiologic functioning, and psychosocial functioning in nursing home residents who are cognitively impaired?

Sample
The sample was obtained from three non-profit nursing homes in a large Midwest city. At each facility, the researcher requested the names of all confused residents who had regular visitors. Facility A, located within the city, has 121 beds. The 1989 census lists the median household income for that zip code as $30,665. Facility B is in an adjacent county has 187 beds and is part of a retirement community. The median income in that location is $39,134. Facility C, with 265 beds, is in a county suburb where the median income is $33,847. The sample contained family members of 36 confused nursing home residents and the nurses who cared for each of these residents. Family members were the contacts indicated by nursing home records. Nurses, RNs, and LPNs were the nursing home employees who worked on the unit where the resident resided and provided their care.

Twenty-five (70%) of the family member respondents were daughters (Figure). The average age of the family member was 61.7 (SD = 9.6). Twenty-five family members had been caregivers prior to their relative’s nursing home admission; 16 residents had lived with their relative prior to their institutionalization. Family members visited an average of 44 (SD = 41.5) minutes. Outlier responses were from one respondent who visited less than once a week, and a husband who visited his wife two or three times a day. Combining the information on frequency and length of visits indicates that the average resident was visited for 6.13 hours per week by the responding relative.

The nursing home residents had an average age of 84.9 (SD = 7.7), 33 were women and 3 (8.4%) were men. Residents had been in the nursing home an average of 31.7 (SD = 26.9) months. To confirm that the residents selected were appropriate for the study’s criterion of confusion, family members and nurses were asked three questions about the resident’s memory (e.g., remembers recent events, remembers year and season, recognizes people known).
Subjects without cognitive deficits were not included.

A total of 23 nurses participated (13 completed two questionnaires). The average age of the nurses was 37.8 years; six declined to give their age. All nurse respondents were women. Two were RNs, and 21 were LPNs. They had an average of 8.9 years of geriatric experience and had known the resident about whom they responded for an average of 17.6 months. Combining the information on the patient’s length of stay with the amount of time the nurses knew the residents indicated that nurses had been acquainted with the resident for 55% of the length of stay. For the most part, each nurse was working with 30 residents during a shift. Some nurses rotated to different sections of a nursing unit biweekly. Because of this work rotation, they took care of the resident for 2 weeks in a month.

**Instruments**

A demographic questionnaire was used to gather information about the family, resident, and nurse participants. Perceptions of the family member and the nurse were measured with an adaptation of the Nurse and Resident Perceptions Questionnaire developed by Lindgren and Linton (1991). Permission to modify the original instrument to use with families instead of nursing home residents was obtained from the authors. Content validity for the original tool was reported by the authors who had it reviewed by 10 RNs with expertise in geriatrics or research. The adapted Nurse and Resident Perception Questionnaire is composed of two forms of 45 items (one for family members, one for nurses). Using a Likert-type scale of 1 (does not need help) to 4 (cannot do even with help), nine questions are asked about the degree to which ADLs are problematic for the resident. A second section of 36 items covers health concerns and psychosocial factors, scored from 1 (no problem) to 4 (major problem) or not applicable.

Each item is an individual measure of agreement and there is no accumulative score of the items, negating calculation of an internal consistency coefficient. To prevent a Type I error using the multi comparisons, Alpha was raised to .01.

**Procedure**

The researcher obtained permission to conduct the study from the director of nursing (DON) or administrator at the three nursing homes. The social worker at each facility was contacted to identify possible participants. At Facility A, 26 family members were contacted by phone; 13 completed and returned the questionnaires that were mailed to them. Letters were sent to 53 family members at Facility B; 16 agreed to be contacted and returned questionnaires. At Facility C, 41 families were contacted by phone, and 20 agreed and returned questionnaires.

The nursing office at each facility then identified the nurses who worked on the patients’ units. Questionnaires were distributed to those nurses by the DON or an assistant. An attempt was made to give questionnaires to nursing staff who worked the shift in which family members visited their relative. Only nurses from the day or afternoon shift participated in the study. No nurse was asked to complete more than two questionnaires.

Because of staffing limitations at each facility (e.g., use of contingent staff, attrition, disinterest by staff) only 10 questionnaires were completed by staff at Facility A, 9 at Facility B, and 17 at Facility C. In at least four instances, supervisory nurses who knew the residents well completed questionnaires. All respondents, family members, and nurses signed a consent form as part of their participation. Each questionnaire was given a code number and the resident’s name was only on a cover letter, which the respondent detached before returning to the investigator.

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**TABLE 1**

<table>
<thead>
<tr>
<th>Factor</th>
<th>Nurse rates lower than family member</th>
<th>Nurse rates higher than family member</th>
<th>Same</th>
<th>z score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Difficulty chewing food</td>
<td>16</td>
<td>5</td>
<td>11</td>
<td>-2.74*</td>
</tr>
<tr>
<td>Swelling of feet or legs</td>
<td>16</td>
<td>4</td>
<td>12</td>
<td>-3.04*</td>
</tr>
<tr>
<td>Bruising easily</td>
<td>17</td>
<td>3</td>
<td>13</td>
<td>-3.33*</td>
</tr>
<tr>
<td>Difficulty breathing at rest</td>
<td>9</td>
<td>1</td>
<td>23</td>
<td>-2.52*</td>
</tr>
<tr>
<td>Weakness</td>
<td>15</td>
<td>3</td>
<td>12</td>
<td>-2.55*</td>
</tr>
</tbody>
</table>

* p < .01
* p < .001
TABLE 2
NURSE RATING OF RESIDENTS' MEMORY COMPARED TO FAMILY RATING \( (N = 36) \)

<table>
<thead>
<tr>
<th>Question</th>
<th>Nurse rates less impaired</th>
<th>Nurse rates more impaired</th>
<th>Same</th>
<th>z score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Recent events</td>
<td>12</td>
<td>5</td>
<td>18</td>
<td>-2.07</td>
</tr>
<tr>
<td>Year and season</td>
<td>8</td>
<td>7</td>
<td>20</td>
<td>-0.42</td>
</tr>
<tr>
<td>People known</td>
<td>15</td>
<td>4</td>
<td>16</td>
<td>-2.56*</td>
</tr>
</tbody>
</table>

\( ^* p < .01 \)

Data Analysis
Descriptive statistics were used for all variables. The Wilcoxon matched-pairs signed rank test was used to determine if the family member and the nurse were in agreement. In the statistical tabulation, skipped answers and not applicable responses were removed. Significance for analysis was set at .01.

RESULTS
To answer the research question, analysis of the differences and similarities of nurses’ and family members’ perception of residents’ needs was performed on each of the 45 questions. For 84.4% of the items there was no significant difference between family members and nursing staff rating of residents’ ADLs and psychosocial functioning. The initial nine items of the questionnaire related to resident ADL functioning. At all three facilities, there were no significant differences between nurse and family member ratings of the residents’ ADL functional status. Regarding questions of physical functioning, though, nurses tended to rate items as less of a problem than did families. There were significant differences in five areas between nurses’ and family members’ assessments of residents’ physical functioning (Table 1):
- Difficulty chewing.
- Swelling of feet or legs.
- Bruises easily.
- Difficulty breathing at rest.
- Weakness.

In the three questions about memory, nurses concurred with the family member’s assessment or found the resident less impaired than the family member did. There were not significant differences between family members’ and nurses’ responses concerning memory within each nursing home. At Facility C, nurses’ ratings indicated less impairment than family members’ ratings on “recognizes people he/she knows” \( (p < .03) \). For the total scores from all three facilities, this item was significant at \( p < .01 \) (Table 2).

Family members and nurses rated lack of privacy and boredom significantly different, with family members rating the problems higher than the nurses. In the appended comments, several respondents, both family members and nurses, indicated they could not determine if an item was a problem because of the resident’s severe confusion. This resulted in total responses of less than 36 for most items, with an average of 29 responses per item.

DISCUSSION
Some areas of disparity between nurses and family members may have situational explanations or reflect differences in health knowledge. Responses that differed provide an area for improved communication among nursing home staff and families.

Problems with chewing was a major area of disparity. While not an item on the questionnaire, 16 family members indicated they visited at mealtime, and two stated they visited at that time to feed the patient. Difficulty in chewing might be more evident to these visitors than to nurses who rarely feed residents.

This is an area in which the family’s assessment can lead the nurse to consider interventions: instructions in swallowing skills with possible evaluation by speech therapy, investigation of dental status (four family members commented that dentures were lost), and nutritional supplementation if weight is lost. Further research of the perceptions of nurses’ aides who do most of the feeding of patients might improve staff communication and lead to better care for the resident.

Disagreements about the status of heart function with symptoms of swollen feet, weakness, or difficulty breathing at rest would seem to point a lack of common understanding of health status. Are family members noticing something the staff has not seen? Does the staff see these symptoms as less significant than the family? Has there been an attempt to educate the family about the patient’s condition and its manifestations?

Most of the nurses who responded to the questionnaires were working with 30 residents at the same time. Perhaps nurses compare residents and do not judge one resident’s problem as severe as another. Family members may compare their relative with a previous, healthier status.
A cardiorespiratory symptom, difficulty breathing at rest, also was identified by residents in Lindgren and Linton's (1991) study as significantly more problematic ($p < .02$) than nurses’ assessment. In that study, it was conjectured the patients did not want to bother the nurse when the symptoms abated. Nurses may become complacent about this symptom. Advising the family member that weight is being monitored to assess for edema, that compression stockings are applied if ordered, and reviewing the role of prescribed medications that may relate to these respiratory symptoms can reassure them that their concerns are significant and addressed.

Easy bruising is not uncommon in the nursing home population, and is actually a normal variation of aging skin. If family members were seeing bruises as evidence of poor patient care or dry skin ($p < .03$) as a function of failure to apply lubricants, this would be another area for education of the relative as to the fragility of aging skin. Additionally, as part of sharing the care with family, they could be encouraged to apply lubricants as part of their visits, use touch, and provide gently range of motion exercises.

Boredom and loss of usefulness ($p < .02$) were interpreted by several family members as a comment on the lack of planned activity, “she sits there with nothing to do.” Lindgren and Linton (1991) also found loss of usefulness a significant item ($p < .02$) of difference between residents and nurses. Similarly, concern by White family members over lack of activities was reported by Specht et al. (2000). Nurses who are passing medications, administering treatments, and monitoring the work of nursing assistants are rarely able to plan or implement activities for the residents.
process, nursing home staff needs to respect family members and allow communication to be open. Some family members will be more skilled at assessment than others, and nursing home staff can determine those levels as well as what other contributions to care the family member can provide. Such consideration adds the family member as a resource for improving the quality of care to the resident.

Limitations of the Study
In considering threats to validity of the study, selection bias must be addressed. The researcher was not given direct access to every chart. It is possible that staff felt some family members were inappropriate for the study, and their names were never made available. An objective dementia score, such as from the Mini-Mental State Examination (Folstein, Folstein, & McHugh, 1975), could have clarified the need for family rather than resident input. The nurses and family members assumed the resident was confused, and based their judgments and actions on that assumption. Additionally, the sample was small and the investigative tool had limited psychometrics.

In spite of the limitations, the study showed that family members are astute in their assessment of their relatives who are cognitively impaired. The nurse's role is to capitalize on the unique knowledge of the nursing home resident that family members possess.

REFERENCES

ABOUT THE AUTHORS
Dr. Lindgren is Professor and Associate Dean of Academic Affairs, University of Miami School of Nursing, Coral Gables, Florida. Ms. Murphy is a former GNP at the VAMC, Detroit, Michigan, and currently resides in Buffalo, New York.

Address correspondence to Carolyn L. Lindgren, RN, PhD, School of Nursing, University of Miami, 3801 Red Road, P.O. Box 248133, Coral Gables, FL 33124-3850.