Family Satisfaction With Nursing Home Care for Relatives With Dementia

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Families of residents with dementia from five nursing homes were interviewed to assess if they believed improvements were needed in the care provided to their relatives. Quality of care was assessed in a variety of service and staff areas that factored into two domains of care: (a) environmental and administrative services and (b) direct care. Families who perceived significant improvements were needed in environmental and administrative services had more negative interactions with staff, perceived nurse assistants as being insensitive, and helped relatives with more activities of daily living (ADL). With respect to direct care, families perceived significant improvements were needed when they had more negative interactions with staff and helped their relatives with more ADL. These findings highlight the importance of promoting positive family-staff interactions, providing direct care in a sensitive manner, and exploring the reasons why families get involved in ADL to improve family satisfaction with care.

The last two decades have seen a tremendous growth in the consumer satisfaction movement in health care (Crawford, 2000). The growing popularity of satisfaction surveys is seen as a welcome development because it reflects a long overdue recognition that the consumer—in this case, the resident or alternatively a family member—is a credible source of information on both quality of care and quality of life in long-term care (Zimmerman & Bowers, 2000).

AUTHORS' NOTE: This study was made possible by a grant from The Cleveland Foundation (Grant No. 93-0662). The authors would like to thank the families, staffs, and residents of the participating nursing facilities: Aurora Manor Special Care Center, Bradley Bay Health Center, Kethley House of Benjamin Rose, Mount Alverna Home, and The Health Center at The Renaissance.

The Journal of Applied Gerontology, Vol. 21 No. 3, Septemer 2002 368-384 © 2002 The Southern Gerontological Society

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A survey of randomly selected nursing homes in Ohio found 80% (64 of 81 facilities) of facilities participating in consumer satisfaction surveys (Noelker, Ejaz, & Schur, 2000). Although Ohio may be unique with regard to such high prevalence rates, the survey found typical problems associated with the conduct of satisfaction surveys, including the quality of the information provided and the reliability of the data (Noelker et al., 2000). Although satisfaction surveys are burgeoning across the industry, they lack conceptual models, are narrowly defined, and are often beset with methodological and psychometric problems. Zimmerman and Bowers (2000) believe that the critical challenge facing such surveys in long-term care is that if they do not take on a more expanded role, their utility will be reduced and their relevance compromised.

This study took an innovative approach by assessing family satisfaction with nursing home care provided to relatives suffering from dementia in five nursing facilities in Ohio. By drawing on a larger sample, psychometric evaluation of the measures was possible. Furthermore, satisfaction was assessed using a conceptual framework that drew from issues in the family caregiving literature on the transfer of family responsibilities to nursing home care.

The literature on family caregiving suggests that the transfer of responsibility to a nursing home takes place when families can no longer meet the challenges of caring for elderly relatives, especially those with dementia. Despite this transfer, many families continue to remain involved in the care of their relatives (Bowers, 1988; Zarit & Whitlatch, 1992). Research suggests that family caregivers of institutionalized elderly sometimes undergo a stressful transition from primary caregiver to visitor and from an insider role in the caregiving process to an outsider role. These changes create stress and conflict with staff, which, in turn, might affect family perceptions of the quality of care provided to relatives (Maas et al., 1994). Perhaps, levels of stress dissipate over time, and the longer a relative resides in a facility, the more adjusted or satisfied caregivers become with the care provided to their relatives.

Another issue that families often struggle with is the perception that care provided in nursing facilities is impersonal. Formal organizations such as skilled nursing facilities are structured to manage care-related tasks, including round-the-clock service to all residents, by standardizing the services that each resident receives (Litwak, Messeri, & Silverstein, 1990). However, families expect staff to provide care that is technically competent as well as sensitive and individualized. When nursing staff are seen as treating a resident as part of their workload, as an object rather than as a person, families are often upset (Duncan & Morgan, 1994).

Expectations for individualized care are particularly applicable to staff who provide the hands-on or direct care to residents. It is estimated that 80% to 100% of the direct care that residents receive in nursing facilities is given by nursing assistants (NAs) (Institute of Medicine [IOM], 1986). Some reports have described NAs as uncaring and incapable of delivering compassionate or high-quality care (National Citizens' Coalition for Nursing Home Reform [NCCNHR], 1985). However, depending on their shift, NAs may care for 8 to 20 residents at one time (Foner, 1993). Even in high-quality institutions, NAs are encouraged to finish tasks on schedule and may be reprimanded for spending too much time on "emotional work" with residents (Foner, 1993). However, families who believe that NAs provide care that is personalized and sensitive are likely to be more satisfied with a facility.

Besides the perception of the type of care provided by NAs, studies suggest that family interactions with staff in general are related to how satisfied families are with the care being provided to their relatives (Brannon, Cohn, & Smyer, 1990; Duncan & Morgan, 1994). Some family members wish to establish ongoing relationships with staff, to have an active influence, and be a part of the team caring for their relatives (Duncan & Morgan, 1994). Yet, there is ambiguity over the nature and extent of family involvement in institutional settings—the extent to which they want to use services for their families—and how much help they actually want to provide in caring for their relatives (Litwak, 1981).

In summary, the literature on family caregivers of nursing home residents and family perceptions of care can be grouped under four broad themes: (a) some family members experience placement-related stress, (b) families' perceptions of care may be related to their involvement in the provision of care to their relatives and to their own use of services for residents' families, (c) families expect NAs to provide care that is individualized and sensitive, and (d) family and staff should have positive interactions. Investigators used these themes to test a preliminary conceptual model to explain family satisfaction with nursing home care. The model was refined while developing the psychometric properties of the measures used in the study (see Figure 1).

The central research question addressed by this study was:

How are family members' perceptions of the quality of care provided to their institutionalized relatives affected by placement-related stress, by their involvement in resident care and nursing home services, by the type of care they think NAs provide, and by family-staff interactions?

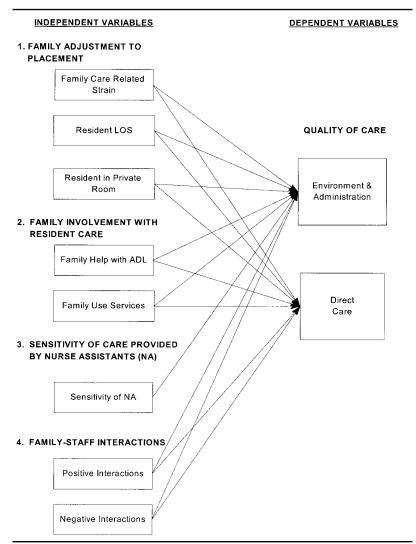


Figure 1. Conceptual Model. NOTE: ADL = activities of daily living.

Method

Study Design and Sample

The study used a cross-sectional survey design to conduct in-person structured interviews with the family members of nursing home residents diagnosed with dementia. Five suburban nursing facilities in the greater Cleveland area participated in the study. The basis for site selection was that the facilities primarily served residents with Alzheimer's disease or other types of memory impairment and were diverse in size, levels of care, payer mix, and auspice. Two of the facilities were proprietary whereas three were non-profit, four of the five had special care units, and they ranged in size from 82 to 203 beds (Looman, Noelker, Schur, Whitlatch, & Ejaz, 1997; Schur, Noelker, Looman, Whitlatch, & Ejaz, 1998).

The process of selecting eligible family members to participate in the study involved convenience sampling techniques. In the first step, each nursing home supplied research staff with a list of residents meeting the following criteria: had a diagnosis of Alzheimer's disease or other form of dementia, had been residing on the nursing unit or floor for at least 2 months, and had a family member listed as the primary responsible party. Each site also provided the contact information for the primary family caregiver for a total of 331 family names. In the second step, these family members were sent a letter (signed by the administrator of a facility and on nursing home letterhead) briefly describing the study and indicating that they would be contacted for research purposes. In the third step, research staff telephoned family members to screen them using the study's eligibility criteria, which were that they visited their relative at least twice a month and had "any" contact with the NAs who cared for their relative. Of the original list of 331 family names, 30.5% (101) were found to be ineligible (24.8% of the family members did not visit the resident at least twice a month or had no contact with NAs, and an additional 5.7% families had relatives who were deceased), leaving a potential sample of 230 eligible families. Of these 230 eligible families, 25 families could not be contacted and 72 families refused to participate. In the fourth step, contact information for family members who met these criteria were then forwarded to trained interviewers to schedule and conduct the interviews. The final sample was composed of 133 family members (57.8% of the 230 families who were potentially eligible).

Key Measures

Summary information on all key variables is shown in Table 1. Relationships between the dependent and independent variables are presented in the study's conceptual model (Figure 1).

Dependent Variable: Quality of Care

The construct for the study's dependent variable was families' perceptions of the quality of care received by their institutionalized relatives. Quality of care was assessed as a multidimensional construct composed of 13 service/ care areas and two staff areas using a Likert-type scale. Items assessed whether improvement was needed in each area, and answer categories included 0 = a great deal of improvement, 1 = some improvement, and 2 = noimprovement. Another response category related to whether the family was unfamiliar with the particular service area. Responses coded as being unfamiliar were treated as missing data in the analysis. These types of response categories ("improvement needed") were preferred over the typical "how satisfied are you" for two reasons. The literature has suggested that satisfaction scores are consistently skewed in the positive direction and probably reflect respondents' giving socially desirable answers. In fact, the lack of score variability renders many measures of satisfaction virtually useless (Ventura, Fox, Corley, & Mercurio, 1982). Investigators of this study had used both types of response categories in earlier consumer satisfaction studies and found that "improvement needed" yielded better response variability. Although the term satisfaction is used interchangeably with "improvement needed," the focus of the present study is on the extent to which improvement is needed in different service areas in nursing homes providing care to residents with Alzheimer's disease or other types of memory impairment.

The 13 service/care areas were those commonly found in nursing homes: food, laundry, cleanliness of the facility, variety of activities, odors in the facility, noise level, convenience of parking, privacy available during family visits, management of medications, amount of care provided by staff, personalized attention by staff, quality of care in relation to the cost of care, and the management of family concerns/complaints. The two staff areas included NAs and registered nurses and licensed practical nurses (RNs/LPNs). Originally, a total of 19 types of staff were assessed, including social workers, physical therapists, medical director, housekeeping, and dietary staff. How-

ever, due to the extent of missing data because families were unfamiliar with the other categories of staff, only the two questions pertaining to nursing staff (NAs and RNs/LPNs) were used in the analyses.

A principal-axis factor analysis using varimax rotation was performed on the 15 questions (13 service and 2 staff areas). Factor analysis was used to identify the constructs or groups of questions underlying quality of care. Principal-axis factoring was used to obtain estimates of the common factors that had a good fit (Norusis, 1994). However, these factors have to be rotated to allow for better interpretation. Therefore, varimax rotation, which is the most commonly used method in factor analyses, was used to minimize the number of variables that have high loadings on a factor, thereby enhancing interpretability of the factors (Norusis, 1994). Toward that end, a factorloading criterion of .35 was used for inclusion in a factor, whereas a factor loading of .40 on more than one factor was used as an exclusionary criterion. The final rotation identified two usable factors. The first factor had an eigenvalue of 3.60 and explained 36% of the variance in quality of care. It was comprised of seven items (cleanliness, odors, noise, food, laundry, activities, and care provided by RNs/LPNs). It was termed environmental and administrative services. It is interesting that the care provided by RNs/LPNs factored with this. Past research has shown that professional nurses spend too much time doing paperwork and administrative tasks and rarely use their clinical skills (only 12 minutes a day) to care for nursing home residents (Duncan & Morgan, 1994; IOM, 1986).

The second factor had an eigenvalue of .91 and explained 9% of the variance in quality of care. It was comprised of three questions, amount of personalized attention, the amount of care received by one's relative, and the quality of the care provided by NAs; it was termed direct care. Although this factor had an eigenvalue of less than 1, both factors were retained because of their conceptual importance. Together, they explained 45% of the variance in quality of care and were treated as separate dependent variables in the analyses. See Table 1 for information on means, standard deviations, and alphas for variables in the conceptual model.

Independent Variables

Family adjustment to relative's placement in the nursing home. Three measures assessed family adjustment to a relative's placement in a nursing home.

The first, care-related strain, was developed based on the stress and burden experienced by family caregivers of frail elders living at home (Bass, Noelker, & Rechlin, 1996). It comprised seven items (eigenvalue = 3.97; explained

Table 1. Key Variables in Study

-	Numbe					_
	of Items	Score Range	Direction	Mean	SD	Alpha
Dependent variables						
Environment and administration	7	0 to 14	High scores mean less improvement needed	10.8	2.75	.78
Direct care	3	0 to 6	High scores mean less improvement needed	4.07	1.54	.81
Independent variables Family's adjustment to placement						
1. Care-related strain	7	7 to 28	High scores mean increased strain	13.83	4.36	.90
Resident length of stay in 6-month intervals	1	0 to 10	High scores mean increased length of stay (in 6-month intervals)	4.66	3.03	_
 Resident in private room 	e 1	0,1	1 = Private room	_	_	_
Family involvement						
Family help with activities of daily living (ADL)	6	0 to 6	High scores mean more ADL provided	3.30	1.58	.53
Use of services by families Sensitivity of care by nursing assistant (N.)		0 to 7	High scores mean more use of services	2.63	1.48	.76
Sensitivity of NA	6	0 to 18	High scores mean greater sensitivity	13.87	2.76	.83
Family-staff interactio	ns		-			
Number of positive interactions with other staff	e 4	0 to 4	High scores mean more positive interactions	2.60	1.17	.56
Number of negative interactions with other staff	/e 3	0 to 3	High scores mean more negative interactions	0.69	1.02	.73

variance = 56.8%) and was assessed on a 4-point scale ranging from 1 = $strongly\ disagree$ to 4 = $strongly\ agree$. Items were prefaced by the phrase: "Because my relative is in a nursing home" (a) I don't have enough time for myself, (b) I have more things to do than I can handle, (c) I feel that my social life is limited, (d) I feel pulled between trying to give attention to my relative and attending to other family responsibilities, (e) I have trouble managing the demands on my time, (f) It's hard to plan things because of my relative's situation, and (g) It interferes with my going on vacation or weekend trips.

The second, relative's length of stay in the nursing home, was assessed in 6-month intervals ranging from 1 = 0 to 6 months to 9 = 55 to 60 months. Values above 5 years were coded as 10.

The third, relative in private room, was dichotomous (0 = shared room and1 = private room).

Family involvement with resident care and nursing home services. Two measures were developed to assess family involvement with care.

The first, family help with activities of daily living, comprised six items and assessed whether or not (yes = 1, no = 0) families helped their relatives with (a) personal care, grooming, or dressing; (b) feeding; (c) tidying or straightening up the room; (d) doing laundry; (e) taking inventory of their relative's clothing; and (f) taking the relative for outings.

The second, use of services by families, was created by summing seven dichotomous items (yes = 1, no = 0) regarding whether family members read, used, or participated in the following commonly available services: (a) newsletters or other informational materials; (b) dining events such as meals. socials, picnics; (c) special parties to celebrate family members' birthdays or other significant events; (d) family forums or discussion groups; (e) individual counseling for families; (f) family support groups; and (g) education for families to understand the progression of dementia or other conditions or about different staff. Higher scores reflected greater family involvement.

Type of care provided by nurse assistants. The measure used a 4-point Likert-type scale ranging from 3 = strongly agree to 0 = strongly disagree to examine items specifically assessing the quality of care provided by NAs. A principal components factor analysis identified six items falling into one factor (eigenvalue of 3.44, explained variance = 31%). These items were (a) seeing NAs as warm and caring people; (b) believing that NAs rarely abuse the residents; (c) feeling NAs are insensitive to the residents' feelings (reverse scored); (d) recognizing that NAs and residents become attached; (e) feeling that NAs, in general, do a good job of taking care of the residents; and (f) trusting the NAs. A measure entitled sensitivity of NA was developed by summing these six items.

Family-staff interactions. Measures of positive as well as negative family interactions with NAs and other staff members were developed. However, the measure of family interactions with NAs was highly correlated with the measure on the sensitivity of care provided by NAs and was dropped from subsequent analyses. The two measures of interactions with other staff were retained.

The first, positive interactions with other staff, was composed of four items (only items that had 20% or greater variability were included in all investigator-developed measures), which were coded dichotomously (yes =

Table 2. Percentage of Respondents Indicating Extent of Improvement Needed in the Following Services

	No Improvement Needed	Some Improvement Needed	A Great Deal of Improvement Needed
Please check the box that indicates whether improvement is needed with			
Environment and administration			
Food at the nursing home	52	40	8
Cleanliness of the home	74	25	2
Way your relative's clothing is launde	red 46	32	22
Variety of activities for residents	57	35	8
Way the home smells	65	27	8
Noise level	76	21	3
Registered nurses/licensed practical			
nurses	63	35	2
Direct care			
Amount of care your relative receives	46	49	5
Personalized attention your relative		.0	· ·
receives	52	43	5
Nurse assistants	31	58	11
INUISE assistants	31	50	1.1

1; no = 0). The items assessed whether or not (a) families confided in other staff, (b) staff reassured families when they were upset, (c) staff laughed or joked with them, and (d) staff were affectionate toward family members. Despite its low alpha (Table 1), it was included in the study because of its conceptual relevance. A historical study had found that residents believed that caring staff workers were critical to nursing home quality (NCCNHR, 1985).

The second, negative interactions with other staff (excluding NAs), was composed of three items, which were also coded dichotomously (yes = 1; no = 0). The items assessed whether or not staff (a) made families feel frustrated, (b) made them feel angry or provoked, and (c) got on their nerves.

Analyses

Measures of central tendency were used to analyze background information on subjects. Percentages of responses to individual items composing the two factors depicting improvement needed in quality of care are shown in Table 2. To address the study's major research question, two separate ordinary least squares multiple regression analyses were used to

examine improvements needed in (a) environment and administration and (b) direct care.

Results

Background Characteristics

Family members were predominantly adult children (67%), females (70%), married (80%), and Caucasians (84%), with a mean age of 61 years (range = 34 to 90 years). Nearly half the caregivers were employed either full-(30%) or part-time (15%). Their institutionalized relatives were mostly female (77%), with a mean age of 84 years (range 58 to 102), and 29% resided in special care units. Caregivers visited their relatives about two to five times a week (45%), whereas others visited three to four times a month (29%). During each visit, almost half spent 30 to 60 minutes (48%), whereas others stayed for a few hours (35%). During the visit, nearly all caregivers (more than 90%) talked with their relative, talked to RNs or LPNs, and talked to NAs.

Improvement Needed in Environmental and Administrative Services and in Direct Care

As evidenced by Tables 1 and 2, families generally believed that nursing homes were taking good care of their relatives. In certain areas, families believed that some or a great deal of improvement was needed (see Table 2). With regard to administrative and environmental services, more than 40% of family members believed that improvement was needed with the food, laundry, activities, the manner in which complaints or concerns were handled, and the quality of care in relation to cost. With regard to direct care, families believed that improvement was needed in all three items (amount of care, personalized attention, and NAs).

Predictors Associated With Improvement Needed in Quality of Care (Research Question/Model)

The first multiple regression analysis addressing the study's research question revealed that the equation accounted for 30% (adjusted R^2) of the variance in improvements needed in environment and administrative services

Table 3. Results of the Regression Equations

	Dependent Variable			
	Regression on Environment and Administration (n = 111)		Regression on Direct Care (n = 130)	
Independent Variable	b	β	b	β
Family's adjustment to placement				
Care-related strain	08	13	04	10
2. Resident length of stay	.06	.07	08	15
Resident in private room	.86	.16	11	03
Family involvement				
1. Family help with activities of daily living	35	20*	26	26**
2. Use of services by families	.14	.08	.14	.14
Sensitivity of care by nursing assistant (NA)				
Sensitivity of NA	.28	.28***	_	_
Family-staff interactions				
Positive interactions with other staff	09	04	.13	.10
Negative interactions with other staff	83	_	46	30***
	Adjusted		Adjusted	$R^2 = 24$, 6.85^{***}

NOTE: b = unstandardized beta coefficient; β = standardized beta coefficient *p < .05. **p < .01. ***p < .001.

(see Table 3). The findings revealed that families perceived significant improvements were needed in environment and administration when they had negative interactions with other staff (excluding NAs), when the care being provided by NAs was not perceived to be sensitive, and when family members gave more help to their relatives with ADL.

Prior to running the second multiple regression analysis (using direct care as the dependent variable), the sensitivity of care provided by NAs was dropped from the model because of its high correlation (r = .61) with direct care. The remaining seven variables were entered as independent variables. The final model explained 24% (adjusted R^2) of the variance in improvements needed in direct care (see Table 3). Findings indicated that family members who perceived that significant improvements were needed in direct care had more negative interactions with other staff and gave more help with ADL to their relative.

Discussion

The study findings reveal that quality of care in nursing homes can be divided into two domains: (a) environmental and administrative services and (b) direct care. The results also suggest that despite the overall high level of family satisfaction with care, families believe that nursing homes can somewhat improve administrative services such as food, laundry, and activities as well as aspects of direct care.

In the attempt to understand the predictors associated with families' perception of improvement needed in the quality of care provided to relatives, certain common elements emerged. The fact that negative interactions with staff (excluding NAs) was the strongest predictor of both outcomes suggests that family-staff interactions are closely tied to families' perceptions of quality care. Furthermore, whereas negative interaction with other staff was related to reports that improvements were needed in care, positive interaction was not. This suggests that negative interactions are likely to make a more lasting impression than positive interactions. From a practice perspective, it is critical to explore the sources of such negative interaction and their association with particular staff members, and this should be the focus of future research.

The relationship between negative family interaction with other staff, apart from NAs, on the two quality of care outcomes should not, however, obscure the importance of families' perceptions of the care given by NAs. In this research, families' perceptions of the care given by NAs could not be used to explain their assessments of direct care because the two measures were so highly correlated. The correlation highlighted the issue that family perceptions about the sensitivity of NAs was strongly related to positive and negative interactions with NAs.

Our study corroborates the findings of other studies (Bowers, 1988; Duncan & Morgan, 1994; Maas, Buckwalter, Kelley, & Stolley, 1991). In the 1980s, a study of 455 nursing home residents from 107 different facilities nationwide revealed that residents most frequently mentioned the need for staff with good attitudes and feelings when defining quality of life (Spalding & Frank, 1985). The desire on the part of families and residents for staff with good attitudes who provide personal care and promote positive family-staff interactions is likely to conflict with the demands on the nursing home industry for cost-reduction and efficiency. However, in a competitive market, facilities that consistently train and encourage staff to provide personalized care and promote family interactions are more likely to serve a satisfied clientele.

Another important factor in understanding families' perceptions of quality care was the extent to which they assisted their relatives with ADL. In this study, families with greater involvement were more dissatisfied with care. Reports from other research that families want to be considered part of a team in providing care to residents (Duncan & Morgan, 1994) should be interpreted cautiously, recognizing the considerable ambiguity about the amount and type of involvement actually sought by families (Litwak, 1985). Families may become more involved in direct care when they believe the care given by staff is inadequate. In fact, other reports from this study underscore the frustrations of family members with "short staffing," management practices that detract from the amount and quality of resident care, and their sensitivity to the constraints under which NAs work (Looman et al., 1997). Such issues are apparently industry-wide problems. In a recent forum before the Senate Special Committee on Aging, many NAs testified that they were overworked and understaffed, leaving them with insufficient time to care adequately for residents (Business Publishers, 1999). The issue of understaffing could also be related to the reasons why families get involved in direct care. Thus, administrators should be aware that high levels of family involvement in direct care may indicate dissatisfaction with both quality of care and management rather than a desire to be part of a caregiving team.

The implications of this research for facility management and practice include the need for greater attention to the nature of family and staff interactions, particularly negative interactions, and promotion of interventions that support positive interactions. Toward that end, some facilities promote the importance of family involvement in developing resident care plans. Unfortunately, most of the care planning is done during working hours when most family members are unavailable and cannot attend. Unless efforts are made to host care-planning conferences to accommodate the times when families can attend, their expectations of care and the type and level of involvement that they desire will remain unclear.

In summary, the highlights of this study include the fact that it examined the issue of family satisfaction with care in nursing facilities in the larger context of family caregiving issues related to nursing home placement. The conceptual framework proved useful in providing important guidelines for both researchers and practitioners in understanding family satisfaction with quality of care in nursing homes. Toward that end, it attempted to meet the challenge posed by Zimmerman and Bowers (2000): that unless satisfaction surveys are prepared to take on a more expanded role, their utility will be reduced and their relevance heavily compromised.

Despite these strides taken to enhance the role of consumer satisfaction surveys in a broader contextual framework, the findings from the current study should be explored further in empirical studies designed to overcome the limitations of this research. Some of these limitations include the fact that the study did not use a randomized sample of proprietary and nonprofit nursing facilities, was limited to one geographical area, and had a small sample size. For purposes of enhancing generalizability, these limitations will have to be addressed in future studies using larger and more diverse samples of family members of nursing home residents. Similarly, the preliminary conceptual model developed in this study and the psychometric properties of the new measures will have to be explored in future studies using larger, more representative samples.

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Article accepted December 6, 2000.

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