

CLINICAL INVESTIGATION

FAMILY CAREGIVING IN LONG-TERM CARE FACILITIES: VISITING AND TASK PERFORMANCE

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Background: Family caregiving within institutional settings is a neglected area of health-care research. In an era of cost containment, more and more is being asked of families of institutionalized persons. We investigated visiting and task performance by family caregivers following the admission of an elderly relative to a long-term care facility.

Methods: 122 family members responded to a mailed questionnaire about their experience of visiting and task performance in long-term care facilities in the Ottawa-Carleton Region.

Results: The majority of family members (70%) visited at least weekly. In large measure, they felt that they had surrendered care to the facility and did not know how to best optimize their visiting. Families continued to feel responsible for ensuring that the necessary care was provided. 40% acted as advocates, keeping a close watch over their relative. They also engaged in direct and indirect care. Families provided personal care (26%), personalized the environment (33%), monitored their relative's health status (19%), acted as advocates, arranged appointments and provided transportation (40%) for their relative.

Conclusion: Findings belie the notion of family abandonment following admission of seniors to long-term care facilities. They also point to the need to enhance the visiting experience and facilitate task performance by family members who are willing and able to continue their caregiving relationship with elderly relatives who have been admitted to long-term care facilities.

Key words: Elderly, long-term care facilities, family caregiving

INTRODUCTION

Family caregiving in institutional settings is a phenomenon that is well known to clinicians but less well known to researchers. Despite a voluminous literature on family caregiving in the community, with few exceptions¹⁻⁷ little is known about the continuation of caregiving relationships following admission of an elderly relative to a long-term care

facility. Caregiving now takes place within the context of visiting, integration into a new social environment and the establishment of new and meaningful relationships with the resident and others. Families have been portrayed as burdened, demanding and lacking understanding about the challenges to care in an institution.^{8,9} They have also been characterized as strangers, intruders and interlopers to nursing homes, even when they are there on a daily basis and for extended periods of time.¹⁰ Nevertheless, in this era of cost containment, more and more is being asked of families of elderly persons who live in long-term care facilities. Thus, it is important to more fully understand the situation of families who continue to provide care following the institutionalization of elderly relatives. The purpose of this study was to explore visiting and task performance by family members in long-term care facilities. We also wished to develop recommendations aimed at facilitating and supporting visiting and task performance by families following the admission of an elderly relative to a long-term care facility.

METHODS

Design

The study employed a descriptive exploratory design and a secondary analysis of a larger study designed to explore family caregiving in institutional settings. The University of Ottawa Human Research Ethical Review Committee provided ethical clearance for the study. A purposive, 2-stage procedure was used for data collection. A list of the 19 long-term care facilities providing care to seniors in the Ottawa-Carleton Region was generated, and 9 facilities were invited to participate in the

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study. Facilities were selected to represent provincial patterns of size, rural/urban location, language, and type of ownership. Facility staff identified family members who visited their relative at least monthly, and a random sample of 194 was invited to participate in the study. The number of participants invited from each long-term care facility was proportional to the number of seniors residing in the institution. Potential respondents received a letter from the facility explaining the purpose and objectives of the study, the study questionnaire and a request for their participation. They were asked to respond directly to the researchers to ensure confidentiality.

Instrumentation

Questionnaires employed both open-ended and fixed-choice questions to gather data about the characteristics of family members and their elderly relative, patterns of visiting and assistance provided during visiting.

Visiting was measured by a fixed choice question asking about the frequency of visiting. This item was similar to that used to measure visiting in other studies.^{7,11} Responses were coded as every day, several times a week, once a week, several times a month, once a month, several times a year and less than once a year. Respondents were asked to estimate the average length of their visits in minutes and to provide the reasons that they visited as they did. Their reasons for visiting were coded according to emergent themes. Respondents were also asked how enjoyable they found their visits. Responses were coded *not enjoyable at all*, *fairly enjoyable*, *enjoyable*, and *very enjoyable*.

Task performance was assessed through a series of questions related to caregiving activities that were similar to those of other caregiving studies.^{6,11} Direct care activities involved “hands-on” care, such as personal care (bathing, grooming, toileting, feeding), providing specialized medical care (medications, wound care), accompanying relatives on outings and doing laundry. Indirect care involved the organization, supervision, and monitoring of care. Such activities included consulting with staff, arranging for appointments, providing entertainment, transportation and shopping for the resident. Respondents were asked whether they were currently performing each task. Items were scored as dichotomous variables (yes = 1; no = 2). Respondents were also asked to identify the most and least pleas-

ant activity in which they engaged during visiting. Responses were coded according to emergent themes.

RESULTS

Sample Characteristics

A total of 122 family members returned their questionnaires, for a response-rate of 63%. The vast majority of respondents were female (69%). Most were daughters (40%) or sons (15%), 20% were spouses, 14% were friends, and 9% were nieces or nephews. They were on average 61 years of age, ranging from 45 to 84. The majority were married with families of their own (73%), and a minority were employed outside the home (28%). Typically, their relative was female, on average 84 years of age, and physically frail with some degree of cognitive impairment. They had lived in the long-term care facility an average of 3.5 years, and their health had deteriorated since admission.

Visiting

Family members visited frequently (Table 1). The majority (70%) visited at least weekly. There were no statistically significant differences among categories of respondents with respect to frequency of visiting.

Visits ranged from a few minutes to several hours, and averaged 110 minutes. While the majority of respondents believed that they were well prepared or fairly well prepared for visiting, a substantial proportion (35%) felt that they were not at all prepared for visiting. In large measure, respondents felt that they had surrendered care to the long-term care facility and were uncertain about how best to occupy their time while visiting. Their reasons for visiting related to the provision of instrumental and expressive support, and demonstrated the enduring nature of the emotional bond between family mem-

Table 1. Visiting (N=120)

Frequency	Spouses (N=20)	Daughters (N=46)	Sons (N=29)	Others (N=25)
Daily	5(25%)	3(6%)		1(4%)
Several times a week	12(60%)	22(47.7%)	15(51.7%)	8(32%)
Weekly	1(5%)	14(30.4%)	9(31%)	6(24%)
Several times a month	2(10%)	4(8.7%)	4(13.7%)	2(12%)
Monthly		3(6.5%)	1(3.5%)	7(28%)

bers and seniors and the strength of their feelings for each other. Visiting allowed for the continuation of family relationships, facilitated a sense of connectedness among the senior, family and outside community, and provided the opportunity for contributing to a high quality of care. Visiting also allowed families to observe the physical and/or mental deterioration of their relative and contributed to their recognition of impending loss. Less than half of respondents (43%) rated their visits as enjoyable, and there were many verbatim comments suggesting that the term 'enjoyment' did not really capture the nature of their visiting experience.

Task Performance

Families continued to feel responsible for the provision of care following admission of their relative to a long-term care facility. Indeed, a substantial minority (40%) viewed their primary responsibility as ensuring that their relative received the care that they needed. They observed the care that staff provided and made suggestions about ways to more easily and effectively achieve the desired care outcomes. They also acted as advocates, raising issues and intervening in situations when their relative was unable to do so.

Families carried out many tasks for their relatives while visiting. One-third arranged appointments and provided transportation for visits home and to stores and restaurants. They also made efforts to personalize the environment with plants, books, pictures, and other mementos. One-quarter (26%) engaged in personal care activities such as helping with bathing and grooming and laundry.

In response to an open-ended question about their most important task, close to one-fifth of family members (19%) reported monitoring the health status of their relative, observing their deteriorating health, and identifying problems such as urinary tract infections and problems with medication use. In addition, families performed the "little things" that staff was unable to do that enhanced the quality of life of their relative. These activities included making certain that birthdays and special occasions were celebrated, arranging for visits from friends and relatives, providing special foods, and running errands. In response to another open-ended question asking about their most and least pleasant care-related activity, respondents reported discussing family activities, making sure residents were com-

fortable, and participating in social activities such as watching TV and going for walks as the most pleasant activities that they engaged in while visiting. The least pleasant aspects of caregiving were being ignored by staff, hearing about pain, dealing with confusion and having to say good-bye at the end of a visit.

DISCUSSION

Although family caregiving in the institutional setting is a well known phenomenon to clinicians, little research attention has been paid to the experience of visiting and task performance by families. This project examined the involvement of families in the care of seniors following their admission to a long-term care facility. Findings concur with other studies^{4,7,12,13} showing that families do not abandon their elderly relatives; rather they remain involved and continue to participate in their care. Family members in this study visited frequently and continued to engage in task performance following the admission of their relative to a long-term care facility. They advocated for care, provided care, organized care, and managed care. Visiting and task performance allowed for the recognition of the impending loss of their relative and for the continuation of family relationships.

Although the majority of family members visited frequently, the majority did not enjoy visiting. They were unsure about how to best use their time while visiting and found relationships with health-care providers, who were all very busy, somewhat problematic. They found it difficult to observe the deterioration in their relative and other residents and felt responsible for ensuring that they received a high quality of care. This finding is congruent with other studies that have investigated visiting.^{7,14} It may be that the term "enjoy" is not an appropriate descriptor for visiting, failing to capture the nature of the experience. It may also be that the institutional setting is a foreign environment and that families require assistance to learn how to best occupy their time and energy while visiting.

With respect to task performance, family members continued to assume responsibility for ensuring that their relative received the care that was needed. They were very watchful of both the resident and the staff. The bulk of their care was indirect and non-technical in nature and involved advocating for, organizing, managing and supervising care. They also tried to ensure the emotional well-

being of their relative. To the extent that families also provided direct hands-on or technical care, these findings suggest that following institutionalization, while families transfer some responsibility for technical tasks to staff,^{15,16} they continue to provide assistance with both technical and non-technical tasks.^{6,4} In this way, families collaborate with staff in the provision of care. The nature of these relationships has been categorized as both supplementary (task sharing) and complementary (task segregation).⁵

Recommendations for Policy and Practice

Families need support in the care that they are able and willing to provide following the admission of an elderly relative to a long-term care facility. Family and person-centered policies and procedures that recognize the family as an important member of the health-care team, will go a long way toward supporting the continued involvement of families in caregiving following the admission of elderly relatives to long-term care facilities. It is important for administrators to:

Facilitate the visiting experience. Visiting can be a difficult and demoralizing experience. Family members need to become familiar with the routines and practices of the organization. They need to get to know the staff-members who will provide care for their relative. They need to understand their responsibilities in relation to those of the staff. Long-term care facilities can help by developing policies, procedures and programs that make the visiting experience as pleasant and meaningful as possible for families. Social activities in which both the resident and family members can engage, such as listening to music, watching old movies, tending plants, sharing a cup of tea, or any other number of activities, can help to provide a sense of home and make the visiting experience comfortable and enriching for both families and residents.

Strengthen support for task performance. Families need to be involved in care-related decision-making and to be viewed as members of the multi-disciplinary team. It is also important for staff to share information with family members about changes in residents' health status, including information about deteriorating health and care options. Excellence in the formal care that is provided by staff will increase the confidence of families that their relative is receiving the quality of care that

they need. Individual consultations and educational activities of a group nature that are targeted to the needs of family members will go a long way toward supporting the care that they can provide. As care needs escalate, it is also important to ensure that family members do not feel overwhelmed or uncertain about their role in the provision of care. They may require assistance to meet the changing care requirements that evolve over time as a result of deteriorating health. Families make a substantial contribution to the quality of life of residents and, therefore, play an important role in supplementing and complementing care in long-term care facilities. They need support.

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