

Changes in Family Involvement Following a Relative's Move to a Long-Term Care Facility*

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RÉSUMÉ

L'objectif de cette étude consistait à étudier les changements dans la participation de la famille après le déménagement d'un proche dans un établissement de soins de longue durée ainsi que les facteurs liés à ces changements. Des données quantitatives fondées sur des entrevues actives et approfondies ont été recueillies auprès de 35 membres des familles des patients à deux moments différents après le déménagement de leur proche dans un établissement. Les résultats révèlent certains changements, en matière de contacts, liés aux conditions personnelles, sociales, institutionnelles et médicales. Dans certains cas, de nouveaux types de soins ont été fournis; dans la plupart des cas les soins ont été redéfinis ou fournis de manières différentes. La plupart des participants ne se voyaient pas comme des prestataires de soins, une perception qui est restée stable au cours du temps. Conformément à la théorie de la continuité, dans la plupart des cas, les familles cherchaient à trouver des manières d'adopter une approche constante en ce qui a trait à leurs rôles de proches et de soignants, surtout au cours de la première année qui a suivi le placement. Le personnel des établissements devrait néanmoins être conscient des facteurs qui peuvent causer des changements au cours du temps, du point de vue du rôle joué par la famille en matière de soins, et offrir du soutien aux familles qui doivent gérer ces questions.

ABSTRACT

The purpose of this study was to examine changes in family involvement following a relative's move to a long-term care facility as well as factors associated with these changes. Qualitative data, using in-depth, active interviews were gathered from 35 family members at two points in time following a relative's move to a facility. Findings showed some changes in contact that were related to personal, social, institutional, and health conditions. Occasionally, new types of care were provided; more often care was rebalanced or expressed in alternative ways. The majority of participants did not view themselves as caregivers, a perception that remained stable over time. Consistent with continuity theory, families, in most cases, tended to seek ways to maintain consistency in their roles as family members and carers, particularly in the first year or so after placement. Nonetheless, facility staff should be aware of the factors that might influence changes over time in family caregiving roles and offer support to families dealing with these issues.

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Introduction

Studies have shown that families continue to visit and provide a range of support to their relatives following a move to a long-term care facility (Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995; Bitzan & Kruzich, 1990; Dempsey & Pruchno, 1993; Smith & Bengtson, 1979; Stephens, Kinney, & Ogrocki, 1991). The continued involvement of family members following relocation has been described by Aneshensel et al. (1995) as part of an ongoing "caregiving career", characterized by a trajectory of experiences that takes shape over time. Nonetheless, the majority of the research on caregiving generally, and family involvement in long-term care facilities more specifically, is cross-sectional in design. Consequently, our understanding of the nature of continued family involvement in the long-term care setting remains quite limited. The purpose of this study was to learn more about the perceptions that family members have of their involvement following a relative's move to a facility and to explore changes in involvement that take place over the first year or year and a half after placement, as well as factors associated with those changes.

Much of the research on family caregivers following relocation has focused on caregiver burden. Studies have found that many family members experience guilt or worry about their relative's welfare at the time of placement (Aneshensel et al., 1995; Riddick, Cohen-Mansfield, Fleshner, & Kraft, 1992). Family caregivers may experience a reduction in role overload and role captivity (Aneshensel et al., 1995), though the emotional strain of caregiving often continues following relocation (Aneshensel et al., 1995; Pratt, Schmall, Wright, & Cleland, 1985; Stephens et al., 1991; Zarit & Whitlatch, 1992). Post-relocation studies of family caregivers have found that caregiving generally has a greater negative impact on women than on men (Brody, Dempsey, & Pruchno, 1990), on spouses than on adult children (Riddick et al., 1992), and on those who are older, have spent a shorter period of time in a caregiver role prior to relocation, are currently more involved in providing hands-on care, or have expectations of nursing home care that are low (Tornatore & Grant, 2002).

A small body of literature has examined the visiting patterns of caregivers following a relative's move to a facility. Overall, family members continue to have frequent contact with their relatives (Aneshensel et al., 1995). Some research suggests that adult daughters make up the majority of family visitors (Brody et al., 1990) and that women visit more regularly than men (Hook, Sobal, & Oak, 1982). Cross-sectional research

suggests a decline in family visitation over time (Greene & Monahan, 1982), though longitudinal research has tended to find relatively stable patterns for a majority of family members (Linsk, Miller, Pflaum, & Vicik, 1988). In a recent study, for example, Yamamoto-Mitani, Aneshensel, and Levy-Storms (2002) found that the average number of days per week that family members visit their relatives declines only slightly over a 5-year period. Port et al. (2001) found a significant positive correlation between pre- and post-admission contact. Other factors associated with greater frequency of contact include living nearby, being white, and having a relative without a cognitive impairment (Port et al., 2001; Yamamoto-Mitani et al., 2002).

Research has shown that family members continue to provide both technical and non-technical care to their relatives following a move to a long-term care facility. This includes personal, instrumental, relational, recreational, and "preservative" care, as well as monitoring staff performance and advocating for relatives (Aneshensel et al., 1995; Bowers, 1988; Brody et al., 1990; Gladstone, 1995; Ross, Rosenthal, & Dawson, 1997; Zarit & Whitlatch, 1992). A few studies have compared the expectations that families and staff in long-term care facilities have of one another. Families and staff have been found to differ in terms of the types of care that each expects the other to provide (Schwartz & Vogel, 1990; Shuttlesworth, Rubin, & Duffy, 1982). Bowers (1988) and Duncan and Morgan (1994) have shown that families want staff to provide not only technical care but also social and emotional support for their relatives. These expectations may be associated with the various types of relationships that families develop with staff (Gladstone & Wexler, 2002).

Only a few researchers have examined the way that family members define their roles in long-term care settings. The majority of wives in Ross et al.'s (1997) study indicated that visiting their husbands and providing companionship and emotional support were the most important caregiving activities that they felt they performed. Bowers (1988) found that family members did not think of their roles as much in terms of task performance as they did in terms of overall purpose, the essential purpose of their roles being maintaining their relative's dignity and sense of identity. In Duncan and Morgan's (1994) study, family members placed much value on their experiences as caregivers prior to relocation and wanted to share their insights around their relative's care with staff in the facility.

In a more recent study, Dupuis and Norris (1997; 2001) highlighted that adult daughters caring for persons

with dementia who are at different stages of their institution-based caregiving careers may think differently about their caregiving roles, experience their roles in very different ways, and thus choose alternative ways to play out those roles. Women earlier in an institution-based caregiving career tended to take on an “active monitor role”. Once they became more comfortable with the facility and with the care provided, adult daughters usually took on a “regular visitor” role. Women in the later phases of the institution-based caregiving role tended to take on a relinquisher role, where they relinquished most, if not all, care to the facility staff and began to focus on reclaiming their own lives and well-being.

Research suggests that continued, valued family involvement can be beneficial to both residents and the family. Residents who continue to attach importance to continuity of social relationships tend to have higher morale (Harel, 1981). Further, those who are visited more frequently appear to receive more attention from the staff (Gottesman, 1974), have a higher overall quality of care because of the personal knowledge about their relatives and the expertise that families have (Bowers, 1988; Dempsey & Pruchno, 1993), and demonstrate significantly lower levels of psychosocial impairment (Greene & Monahan, 1982) as well as improvements in emotional well-being (Quayhagen & Quayhagen, 1989).

Despite the known benefits of family involvement in long-term care settings, little is known about how families perceive of themselves as caregivers or about how their involvement may change over time. The objective of this study was to extend our understanding of family involvement in long-term care settings in three particular ways: (a) by examining the perceptions that families have of themselves as caregivers; (b) by using a longitudinal design to explore the ways that these perceptions, patterns of contact with relatives, and provision of care may change over time; and (c) by identifying factors associated with these changes.

Methods

Research Design

Guided by the interpretivist paradigm, the design of this study focused on the collection of qualitative data—from family members who had a relative with dementia living in a long-term care facility—at multiple points in time, using a naturalistic methodological approach (Lincoln & Guba, 1985). Such an approach allows for the emergence of multiple perceptions or multiple meanings created by the

participants themselves (Lincoln & Guba, 1985; Schwandt, 1994) as well as the examination of how family-member roles within a long-term care setting shift and are redefined over time.

Sample

Following the tenets of maximum variation sampling (Patton, 1990), selective sampling procedures (Schatzman & Strauss, 1973) were used to determine which family members within two long-term care facilities would participate in the study. Maximum variation sampling aims at capturing and describing shared patterns and themes that cut across the varied characteristics of participants experiencing a similar phenomenon. It also provides the opportunity to identify and describe the unique variations among the different participants (Lincoln & Guba, 1985; Patton, 1990). Selective sampling refers to a decision made prior to beginning a study to sample participants according to an initial set of criteria. The participants in this study were family members caring for persons with cognitive impairments who were living in a long-term care facility. Family members were also in relatively early phases of their institution-based caregiving careers; that is, they had been caring for a relative in the long-term care facility for no more than 9 months. Using maximum variation and selective sampling strategies allowed us to focus on a particular stage in the family’s caregiving career, while capturing both common and divergent themes related to their experiences.

All participants had relatives living in one of two nursing homes in southwestern Ontario—a 206-bed facility and a 217-bed facility. Both nursing homes were proprietary facilities with family-oriented policies (Montgomery, 1983); for example, post-admission care conferences were held with families, visiting hours were open, and family efforts to assist their relatives were supported.

There were 59 potential participants who met the sampling criteria. The data presented in this paper were gathered from 35 family members who agreed to participate in both sets of interviews. An additional 12 family members withdrew from the study after taking part in the initial interview. Of these 12 family members, 7 stated that they were not interested in a follow-up interview, 2 declined because their relative had passed away, 2 could not be located, and 1 person declined due to lack of time. The 35 family members who participated in both interviews included 2 spouses, 19 adult daughters, 8 adult sons, 3 grandchildren, 2 siblings, and 1 friend who had power of attorney. At the time of the first interview, most family members (67%) were in their 40s or 50s.

The majority (68%) were female, were employed full-time (51%) or part-time (12%), and were either married or in common-law relationships (78%). At the time of the interviews, family members held a wide range of jobs, such as secretary or clerk, nurse, teacher, police officer, engineering and computer technician, bus driver, or courier. Relatives had lived in the facility for an average of 6 months, ranging from 1 to 9 months.

Female and male caregivers in our sample were similar in terms of age, marital status, and work status, in that the majority of both genders were in their 40s or 50s, were married, and worked full-time. Male caregivers ($M=7.09$ months) had been caring in the facility for slightly longer than had their female counterparts ($M=5.88$ months).

Procedure

Two senior managers, one in each facility, provided the names of key family contacts listed on the charts of each resident who had been admitted to the facility in the previous 9 months. This cut-off time was selected to allow for a diversity of family experiences, while remaining as close as possible to the peak "adjustment period" for families, which appears to be around 6 months post-relocation (Aneshensel et al., 1995). Family members were then contacted by telephone and the study was described to them. If they were interested in participating, an interview time was arranged. Prior to each interview, family members were informed about confidentiality and anonymity. Although the names of potential participants had been provided by the facility, the names of those who agreed to participate and who were interviewed by the researchers were not revealed to the managers or administrators at the facilities. At the end of the first interview, family members were asked for permission to re-contact them in approximately 12 months time.

Consistent with interpretivism and the naturalistic methodological design of the study, an in-depth, active interview approach (Holstein & Gubrium, 1995) was used as the primary data collection strategy. Active interviews emphasize a collaborative and interactional process that involves both researchers and participants and recognize that all knowledge is co-constructed. An interview guide was developed for both interviews. The first interviews elicited information regarding how family members thought about and described their roles within the long-term care facility, what types of activities they performed as part of their caregiving roles, whether or not role perceptions and activities changed at all over the early phases of their caregiving careers, and if so, how they changed.

Follow-up interviews were designed more specifically to elicit information about changes over the previous year in the caregiving role and about factors that may have contributed to those changes. In five cases, the relative in care passed away between interviews. In these cases, family members still participated in the follow-up interviews and were asked similar questions; for example, "Before your relative died, did your role caring for your relative here at the facility change in any way from when we interviewed you last year at this time?"

Interviews were conducted by the authors and by four research assistants who were experienced in interviewing and were trained in active interview procedures. Interviews, which were, on average, approximately one-and-a-half hours in length, were tape-recorded and transcribed verbatim. The majority of the interviews took place in the family member's home, although some were held in a private location in the facility.

Analysis

Thematic categories relating to perception of the care role and to factors associated with changes in family involvement were inductively derived from the data, using the constant comparative method (Glaser & Strauss, 1967; Strauss & Corbin, 1998). This comparison of categories, and of properties within them, serves to identify variations in patterns found in data. Transcripts were first read in their entirety, with notations being made in the margins corresponding to emerging themes (Luborsky, 1994). A line-by-line analysis of the transcripts was then conducted in order to examine the data in a detailed and systematic fashion. Open coding was used in order to examine the data for similarities and differences and to develop categories that distinguished concepts from one another (Strauss & Corbin, 1998). Categories were distinguished by identifying key words, phrases, or common ideas expressed by participants. Properties that characterized thematic categories were developed through the process of axial coding. The emerging thematic categories were then compared as between the first and second interviews and were also compared across the two facilities and by relationship to the resident (i.e., husband/wife, adult daughter/son, etc.). As a final step in the analysis, the emerging thematic categories were compared with themes or sensitizing concepts presented in the existing literature (Glaser & Strauss, 1967), particularly those rooted in the work of Bowers (1988), Duncan and Morgan (1994), Ross et al. (1997), and Dupuis and Norris (2001).

Trustworthiness (Lincoln & Guba, 1985) was established in a number of ways. Concerted efforts were made to develop a trusting relationship with participants. For example, questions were asked as part of a conversational, mutual exchange that allowed participants to take the role of “storyteller” and to present their experiences in the form of narratives (Gubrium & Holstein, 1997). The technique of triangulation through multiple analysts (Patton, 1990) was employed by using two members of the research team to code the data independently and discuss the categories until consensus was reached. Negative case analysis was also conducted to ensure all family members’ experiences were reflected. Finally, returning the first interview transcripts to family members and having the opportunity, after the follow-up interviews, to clarify by telephone issues raised in the interviews enhanced the credibility of the data and the development of emerging patterns and thematic categories (Kincheloe & McLaren, 1994).

Results

Contact

At the time of the first interview, family members visited their relatives an average of 2.34 times per week (visits ranged from daily to once per month); at the time of the second interview, an average of 2.53 times per week (visits ranged from daily to once every 3 weeks). Of the 35 family members, 37 per cent had less contact, 40 per cent had the same amount of contact, and 23 per cent had more contact at the time of the second interview than they had at the time of the first. Changes in contact were associated with four conditions: personal, social, institutional, and health.

Personal Conditions

Three properties were associated with this category: *emotional difficulty visiting*, *feelings of guilt*, and *competing demands*. These properties reflected the internal experiences of family members that were associated with a reduction in visits to their relatives. A number of the family members indicated that contact with their relatives was reduced because they found it emotionally difficult to visit. This discomfort was experienced in more than one way. For some, visiting triggered a sadness at watching their relative deteriorate. One daughter, for example, whose visits declined from twice a week at admission to once every 2 weeks at the time of the first interview confided that “I could find more time to visit but I can’t do it (daughter in tears). My mother died 10 years ago. This little old lady is not my mother.

She’s just a shell of a woman that I’m taking care of and that’s how it’s so hard.”

For others, visits were an unsettling time because they had to brace for the unpredictable behaviour of their relative. As another daughter stated, “I have to kind of get prepared mentally to go and see her. It’s not a really relaxed kind of situation because I have to be careful what I say to her and how she’s going to respond. If I throw too much at her that conflicts with her sense of reality, then it’s going to cause some difficult situations.”

Family members who found it emotionally difficult to visit often said that it was easier to do so when they came with someone else. One son, for example, liked to visit his mother with his wife because “I find that with her I talk about it so there’s an element of support there.” Even when visits were emotionally difficult, however, family members might visit alone, and in the rare case, preferred to do so. A daughter, for example, purposely visited her mother alone even though visiting was emotionally stressful. Her feeling was that “if I’m there with someone else, we chat and my mom just sits there. So I’ve been there physically but I haven’t really talked to her. She didn’t get any attention.” A few family members who were uncomfortable going to the facility paid for “friendly visitors” to compensate for the reduction in their own visits.

In some cases, a decline in visiting was associated with family members’ feeling less guilty about their relative’s move. Visits between one son and his father went from four times a week at admission to twice a week at the time of the first interview. This son explained, “I’d visit him quite a bit originally because I felt partly guilty. I wanted him to also feel that he wasn’t abandoned...I still feel guilty, but not as guilty as at first.” Feeling less guilty may have been related to family members becoming more comfortable with the care that their relative was receiving. As one son explained, “[A]s far as the staff at the facility—I sleep well at night knowing he’s well taken care of. I don’t feel there’s any safety issue and he’s well fed.” Becoming more comfortable with the care may, in turn, lead to a realization that, in the words of one daughter, “I’ve done the best I can for my mom.” As this daughter went on to say, “I couldn’t look after her the way the staff here, who are skilled to look after folks with dementia. You always feel I could probably do it better, but no, I can’t do it better.”

Some family members referred to competing demands as a reason for cutting back contact with their relative. In each of these cases, families spoke about other pressures that competed with the time and energy they devoted to their relative.

These demands included work, leisure activities, and the responsibilities of caring for a spouse, for children, or for another person in the family. A daughter, for example, cited “wear on the caregiver,” while a sister, who reported a reduction in visiting her sibling at both the first and second interviews commented, “I tell myself I have to keep the rest of my life going.”

Social Conditions

Three properties were associated with social conditions: *unawareness of / unresponsiveness to visit, difficulty carrying on a conversation, and additional family involvement*. These properties reflect interactive processes involving relatives and members of the family network and, like personal conditions, were associated with a reduction in visiting. Several family members attributed the decline in their visiting to their relative’s unawareness of how often they visited or whether they came at all or to the relative’s unresponsiveness to them during visits. In these situations, family members appeared to take cues from their relatives as to the significance of their visits. When their relatives’ responses, albeit driven by dementia, did not indicate that the current amount of contact was necessary, family members were prone to cut back—though not cut out—the frequency of their visits. One wife, for example, reduced her visiting from three times a week at admission to twice a week at the time of the first interview, saying that her husband “doesn’t seem to notice if I don’t come as often”. Similarly, a daughter went from seeing her mother two to three times a week at the time of the first interview to once a week at the second interview, stating that “it doesn’t bother me as much anymore because it doesn’t seem to bother her. She seems to ignore the fact I’m there.”

A number of family members referred to difficulties that they had carrying on a conversation with their relative as a reason for reduced contact. Family members felt that they had to do all the initiating of conversation, that their relatives would repeat themselves often (as one son stated, “[W]e’re just in a loop with the conversation”), that there was little to talk about with the relative, or that the content of conversations was “irrational”. Family members used various strategies to cope with the difficulty of conversing with their relatives. One daughter, for example, tried to generate conversation by bringing in “props”. She explained, “We try to take snapshots or something so that we have something to talk about. I can’t even say to her, ‘Did you have a nice lunch today, mom?’ because she can’t remember whether she had lunch. I find that very difficult. Therefore we

take the props.” Other family members developed unobtrusive ways to end their visits. As one son stated, “I don’t like sitting there sort of dumb-founded. So usually what happens is I visit her just before lunchtime or dinnertime and that provides a natural break.”

A couple of family members indicated that they visited less frequently because other family members were now seeing their relatives more often. One daughter, for example, had been visiting her mother daily, but, at the time of the first interview, had reduced her contacts to four times a week. She explained, “If I know somebody else is going, I don’t go. Originally it was everyday. But I’ve asked the family members to be there. To be perfectly honest, I’ve been putting the guilt trip on some of them saying your grandma was always there for you, now she needs you.”

Institutional Conditions

Two properties were associated with conditions related to the facility: *satisfaction with care and adaptation to the relative’s new environment*. These properties were also associated with a reduction in visiting. Many of the family members reported that their visiting decreased because they were more comfortable with the care that their relative was receiving. This degree of comfort usually took time to develop and was based on watching how staff cared for their relative, how informative staff were regarding their relative’s condition, and how responsive staff were to family members’ questions and suggestions. As one daughter stated, “[I]n the first 3 months we were here almost every night to help mother settle in. I didn’t want mother sedated, where she’d just sit. I wanted to be in their face.” At the second interview, this daughter said that she now visited once a week because she “ha[d] more confidence in the care. For example, they do have staff who call me if she’s had a spill.” Noted in this as well as in other studies (Gladstone & Wexler, 2002; Ross et al., 1997) was the fact that families’ comfort with care did not preclude their continuing to monitor staff to ensure that an acceptable level of care was maintained. When the standard of care was questioned, family members often increased their frequency of visits in order to keep a closer eye on what staff were doing, to be more visible so that staff would know that they were being observed, and/or to provide more hands-on support to their relative because they did not feel staff were doing enough. In some extreme cases, families were so dissatisfied with the care that they arranged for their relative to be moved to another facility.

A few family members said that they visited less often because their relative had adapted to life in the facility. One sibling's visits, for example, went from three times a week to twice a week at the time of the second interview, partly because her sister was perceived "to be more content at the facility" and to have developed "a bit of a social life there".

Health Conditions

The key property attached to the category of health conditions was a *sudden deterioration in a relative's health or functioning*. Not surprisingly, family members tended to increase their contacts when this occurred. Families were often alerted by staff, who sometimes requested that the family assist with their relative's care. One daughter increased her contact from once to four times a week after her mother's stroke, saying, "She was becoming dehydrated. They couldn't get her to drink. They couldn't get her to eat. The doctor wanted me there because he was afraid that because of the stroke that she may choke. He wanted me to make sure that that didn't happen and because they're short-staffed there as well." Families were especially likely to become mobilized when a relative's health took a critical turn and her/his life was seen to be approaching the end. A son, for example, stated, "[V]isits were more intensive at the end because we were convinced she would be passing away. I visited every other day. Some family member was there daily."

Care and Support

The type of care and support provided to relatives by their families was wide-ranging and included preservative care; for example, maintaining a relative's connectedness to family and preserving a relative's dignity. Families also provided social, emotional, instrumental, and personal care. Few family members referred to changes in the type of care given to relatives once they had moved to the facility. Those changes that were discussed fell into three categories: a new type of care was provided, one type of ongoing care was emphasized over another, or ongoing care was expressed in new ways.

New Type of Care

A couple of family members indicated that they provided a new type of care to their relatives following the latter's move to the facility. In both cases, daughters engaged in personal care for the first time by helping to feed their parents who were unable to eat on their own. This new type of care, which was added to the assistance they were already giving in other areas, was offered in response to a particular need. One daughter continued to assist her father until his passing a short time later. The other daughter

stopped when her mother's health improved and she was able to eat by herself.

Rebalancing/Refocusing of Care

The majority of families who expressed a change in the type of care provided seemed to describe a rebalancing or refocusing of care. A number of families who provided several types of care to their relative, for example, increased the care given in one of these areas. As one daughter put it, "I think the balance has changed. Once upon a time the balance was physical needs for my mother and now the balance has become the emotional need." These families were shifting their emphasis from one type of care to another, but without discontinuing the first type of care. Like those who offered new care, these family members were responding to a heightened dependency on the part of a relative. One daughter, for example, had been performing services for her mother as well as providing her with emotional support. While continuing to take her mother to appointments, to buy her clothes, and to do her banking, this daughter reported in her first interview that she felt the need to become even more emotionally supportive of her mother. She stated, "[A]s she deteriorates, I'm taking on more, simply because it makes her more comfortable and relaxed. For example, if they give her the B12 shot while I'm here, she'll go along with it."

Alternative Expressions of Care

Other families continued to provide the same type of care to their relative but found new ways of expressing this type of care. One daughter, for example, used to take her mother out for drives but stopped doing this when her mother became confused and disoriented. This daughter, however, still provided social support, albeit in other ways, by taking her mother for walks down the hallway or going to the lounge for coffee and a treat. These changes occurred as family members adapted to a decline in their relative's physical or cognitive functioning. Families did not let go of the support they were providing but looked for new ways of expressing this support in an effort to reach their relatives. One daughter spoke about her efforts to find new ways of bringing her mother pleasure: "It became sort of these little tiny things that you could do to kind of tell that she'd appreciate. She'd be having some blueberries and she'd say 'umm good.' So doing something to give her a little bit of enjoyment."

Perception of the Care Role

Aside from their perceptions of the tasks they performed and their purpose or role in their relatives' care, family members' overall perceptions of the care role fell into two main categories, those who did not

think of themselves as a caregiver and those who perceived themselves to have a caregiving role. In fact, the majority of family members did not consider themselves to be “caregivers”. Rather, they saw themselves as “family”, acting the way that they perceived family members should act towards one another. The fact that their relative was in physical or cognitive decline or that their relative was living in a long-term care facility appeared to be irrelevant to most family members in terms of their sense of commitment and the support they provided to their relative. One daughter described her role in the following way: “I’m just a daughter visiting, spending time with her. I don’t see myself in another role...if she needs doctors’ appointments or she needs her eyes checked or she needs dental care, whatever, like I still do all that. It’s just part of what I do for her.”

For some, the role of caregiver appeared to have been relinquished when their relative entered the facility because they no longer had to provide physical or hands-on care. Other family members did not identify themselves as caregivers, defining this concept as “a business term”. One daughter stated, “I think a caregiver is somebody who gets paid to do that stuff. You hire caregivers for your children; your children go to daycare. The people who work here are caregivers. I am a loving family member. That’s my mother. So I don’t think of myself in those terms.”

A minority of family members did regard themselves as caregivers. Differences between these family members and those who did not call themselves caregivers lay along three dimensions, which related to *perceived responsibility*, *monitoring*, and *expectations around provision of care*. Family members who thought of themselves as caregivers appeared to take on a greater sense of responsibility for ensuring that their relative’s daily needs were met. One husband, for example, viewed himself as “the sergeant major” who had looked after his men in the army and who planned to continue looking after his wife of 53 years as well. Family members who did not consider themselves to be caregivers may have felt an overall responsibility for their relative’s well-being but were more likely to hand day-to-day responsibility over to the facility, saying, “[I]t’s their job” or “[T]hey set the pace”.

Both *caregivers* and *non-caregivers* monitored the actions of staff. Caregivers, however, did so in a more proactive manner, looking for specific indications that staff were doing what families thought they should be doing. As one daughter commented, “I’m the number one caregiver. When I come and visit my mother, it’s never really a visit.

It’s fix this for her, do this for her, you know continually...If they gave my mother the care that she’s entitled to, that I feel I could trust them, I could come here more for a visit and not to check on to see if everything is all right.” Family members who did not regard themselves as caregivers entered the facility more benignly, being observant, but not looking for irregularities.

Finally, family members who identified themselves as caregivers were more likely to perform tasks in the facility that they had not expected to be doing. This is illustrated by the daughter above who felt that she had to “fix” things, as well as by another daughter who said that her mother would never go to the nurses with “a problem”. Her mother would only come to her, and she would then have to alert the staff. In these cases, it was not necessarily the particular tasks that defined caregiving but the feeling on the part of the family member that s/he had to act in ways that s/he had not intended or the relative would be disadvantaged.

Most family members did not report any change in the way they perceived their role vis-à-vis the facility or their relatives. The few shifts that did occur were disclosed at the second interview and were likely to reflect an easing up in the functions that family members felt they had to carry out. In some cases, family members still viewed themselves as an important source of emotional support, but felt that they could relax (though not eliminate) their monitoring of staff, largely because they had grown more confident that good care was being provided. One daughter, who did not call herself a caregiver, described her role in the following way:

I guess I’ve kind of let go of some things, like it’s ok for my mother to be in a long-term care facility. You come to terms with that. This is where my mother should be and I now really feel that my mother has an extended family here with the staff and the nurses. I’m really the bystander now. My role has changed because I’m not really the primary caregiver anymore.

In a couple of cases, families had moved their relatives to new facilities because they were dissatisfied with the care their relatives had been receiving. Feeling more comfortable with the services in the new facilities, they no longer felt that they had an adversarial relationship with staff. As another daughter put it, “In the other facility I felt that I was the caregiver. I was there to monitor and take care of her, unpaid (daughter laughs)! And here I feel like I’m a welcome visitor. I’m part of the team, but it’s not that I have to take a lot of the load on myself.”

Discussion

Findings showed that most family members had frequent contact with their relatives, visiting over twice a week on average, for at least 18 months following admission to the facility. This is consistent with longitudinal data presented by Yamamoto-Mitani et al. (2002); the largest group of family members in their study visited their relatives weekly over a 5-year period. Family members also provided numerous types of care to their relatives, often assisting in more than one way. These included preservative, personal, instrumental, emotional, and social care; monitoring staff; and acting as advocates for their relatives. These findings are consistent with those of other studies focused on family roles in long-term care settings (Aneshensel et al., 1995; Bowers, 1988; Brody et al., 1990; Dupuis & Norris, 2001; Gladstone, 1995; Ross et al., 1997; Zarit & Whitlach, 1992) and demonstrate that families continue to support their relatives following a move to a long-term care facility. Providing social and instrumental care was particularly evident among family members. As indicated by Ross et al. (1997) and Dupuis and Norris (2001), most families place a high value on visiting and derive satisfaction when they feel useful. Being able to socialize with relatives and perform services may have a beneficial impact on families (as well as on their relatives), leaving them with the feeling that their visits have made a difference.

The majority of family members did not perceive themselves to be caregivers, since they were not providing physical care and were not paid for what they did. Thus, for most of the family members in this study, the term *caregiver* was not relevant; it was more of an artefact created by professionals than a term with which they could identify. Instead, family members emphasized their roles as daughters, sons, spouses, and so forth, whose goals were to ensure that staff performed their functions effectively and to be a ready source of emotional and social support to their relatives. Nonetheless, a minority of family members did consider themselves to be caregivers or felt that their roles as family and caregiver were interwoven together. All but one of these family members were females, a fact that might reflect the greater "kin-keeping role" of women in the family (Rosenthal, 1985). These families appeared to feel relatively more responsible for the daily care of their relatives, either because of the perceived inefficiencies of staff or because of the dependency needs of their relatives. These findings are consistent with those of earlier studies and provide further support for the claim that families do not regard their role so much in terms of particular tasks as they do in terms of having

an overall purpose—maintaining the well being of their relative (Bowers, 1988; Duncan & Morgan, 1994; Dupuis & Norris, 2001; Nolan & Grant, 1995). The stories shared by the caregivers also suggest that engagement in a diverse range of activities is an important process through which family members find meaning in their changing roles (Kellett, 1998).

Data suggest that the family-oriented policies of the facilities had an impact on family members' experiences in a number of ways. The facilities encouraged family visiting, which gave families ample opportunity to observe staff and assess the type of care that relatives were receiving, as well as relatives' adjustment to the facility. These two "institutional conditions" allowed some family members to reduce their visits without feeling that their relatives would be neglected. Second, policies promoting family involvement in resident care resulted in staff's contacting families, especially when a resident's health or functioning deteriorated suddenly. Families appeared to respond favourably to these contacts, as such contacts allowed them to feel part of the care team (Gladstone & Wexler, 2002).

Our remaining research questions concerned changes in contact, support, and perception of the care role, as well as factors associated with these changes. An analysis of the findings showed some changes in frequency of contact—less so in cases of provision of support and perception of care role. Sixty per cent of the family members had experienced some change in contact since relocation, with over one third reporting a decrease in visiting between the first and second interviews. Several personal conditions were associated with a decrease in visiting, including emotional difficulty in visits with the relative, a reduction in feelings of guilt, and competing demands in other aspects of the family member's life. Dupuis & Norris (2001) also found that one group of adult daughters—the unaccepting relinquishers—had great difficulty visiting. As the parent's condition deteriorated, these adult daughters visited more and more infrequently and, when they did visit, seldom visited alone. Further, Aneshensel et al. (1995) found that a relative's move to a long-term care facility does not have a significant effect on the role strain experienced by caregivers in the areas of family and work. It would not be surprising, then, that prolonged role strain can lead to a reduction in visiting with relatives, as family members try to reallocate their limited time and energy.

A number of studies (e.g., Aneshensel et al., 1995; Riddick et al., 1992) have reported that feelings of guilt often increase in intensity following a relative's

placement because family members believe that they should have done more for their relatives. Several conditions may contribute to a reduction in guilt over time. Gaining confidence in staff's ability to care for a relative and sensing that relatives have become more comfortable with the facility may be associated with diminishing guilt. Some support for this can be found in the work of Whitlach, Schur, Noelker, Ejaz, and Looman (2001), who reported a positive relationship between a relative's adjustment to living in a nursing home and lowered caregiver depression. Carrying on conversations with relatives can be difficult and was offered as another reason for decreased visiting. The difficulties with visits described by family members in the present study are consistent with much literature that highlights the frustrating, painful, and difficult nature of visits for some family members with relatives in long-term care facilities (Edelson & Lyons, 1985). Some research suggests that activity-based interventions (Crispi & Heitner, 2002) and therapeutic family leisure programs (Dupuis & Pedlar, 1995) may provide opportunities for family members to find alternative ways of communicating and to enhance the quality of visits with their loved ones. In addition, Gladstone and Wexler (2002) have pointed out the advantages of developing friendly relationships with staff whom families can talk to during their visits. Being able to socialize with staff, even to a limited degree, may compensate for the diminished conversation with relatives and can add to the quality of the visit for families, thereby maintaining frequency.

Increased frequency of visits was almost entirely related to the decline in a relative's health or to the approaching end of the relative's life. Some dynamics surrounding this increase have been suggested in the literature. Crisis situations, such as sudden illness of the resident, often force family members to redefine their role and find new resources and strategies in order to adapt to the demands of changing circumstances (Patterson, 1988). In these situations, families may, for example, want to provide additional care that is needed but unavailable because of short staffing. Two families in our study suggested this as a reason for increased visiting. Families may also want to ensure that their relative is not alone in a physical as well as a spiritual sense. Or, they may seek meaning in their relationships with a loved one as their relative's life draws to a close (Kayser-Jones, 2002). Two other family members in our study increased their visits in an effort to watch staff more closely when they were concerned about the care being provided. The monitoring role of families has been documented in the literature (Bowers, 1988; Gladstone & Wexler, 2002).

There were few changes in the way that families provided care to their relatives. The changes that did appear were related to shifts in emphasis or ways of expressing ongoing care rather than to introducing or terminating types of care. Changes may be more evident at the time of relocation. Families, for example, are known to provide physical care, such as bathing and transferring, when relatives are living outside of facilities (Cohen, 2000). Although some family members continue to provide hands-on types of care, many others turn to staff to perform these tasks at the time of a move to a facility because of the overwhelming nature of these activities or because they feel staff are more skilled to carry them out. While our data do not allow us to make clear statements about pre-relocation support, the type of care provided, in most cases, remained consistent once a move had taken place. The exceptions appeared to be when relatives were experiencing a health crisis. Two families stepped in to provide personal care that they had not offered in the past. In both these cases, families helped to feed their relatives because of staff shortages. Although small in number, these situations suggest that changes in the type of care provided by families can be as much a response to features of the facility as to the needs of relatives.

Few family members changed their perceptions of their care role once their relative moved into the facility. It is likely that a shift took place for many of the participants in this study—family members in earlier stages of their institution-based caregiving careers—at the time of the relative's move. Several family members, for example, stated that they did not see themselves as caregivers because they were no longer providing physical care. A change in perspective may also have followed a decrease in role overload and role captivity (Aneshensel et al., 1995), again occurring around the time of relocation. Rather than viewing themselves as caregivers, the majority of participants in our study simply thought of themselves as daughters, sons, wives, and so forth—in other words, as "family," whose primary purpose was to provide emotional and social support and keep track of the quality of care provided by the facility. Retaining or restoring an identity of self as "family", instead of "caregiver", following relocation may be a sign of what Aneshensel et al. (1995) describe as "successful emotional adaptation". Prior to their relative's move, family members may have been performing tasks and adopting an image of themselves that were not consistent with the long-standing way that they defined their relationships with their relatives.

In general, changes in family involvement did not appear to have a strong connection to gender or to

the relationship of the family member to the resident. The exceptions were that women were more likely than men to attribute decreases in contact with relatives to their becoming more satisfied with the care provided by staff, to the perception that their relative was becoming better adjusted to the facility, or to their experiencing competing demands in other areas of their lives. These findings reflect the social hierarchies associated with caregiving and the different meanings different social groups attach to caring for a family member (Bury, 1995). Women assume the greater responsibilities for hands-on care prior to relocation (Keating, Fast, Fredrick, Cranswick, & Perrier, 1999) and may attend more to institutional conditions in determining whether the facility is meeting its end of the contract and whether they feel comfortable cutting back on visits. Since relocation of a relative does not necessarily signal the end of a woman's caregiving role, it is not surprising that competing demands from others in her social network may also lead to diminished visiting over time. Other research suggests that male caregivers may not attach as much importance to monitoring care and are far less likely to be intensely involved in care in long-term care settings (Chang & White-Means, 1991; Stoller, 1990). In fact, male caregivers tend to adopt a "regular visitor" role upon placement and may remain in this role over time (Dupuis, 2002). Male caregivers, therefore, may have less reason to reduce their involvement in care because, in many cases, their contact was less to begin with. On the other hand, few spouses, including husbands, were in their early institution-based caregiving careers at the time of our data collection. Research suggests that spousal caregivers are the most intensely involved in care (Keating et al., 1999; Chang & White-Means, 1991), yet these caregivers are also older and may face a number of other issues, such as a decline in their own health and physical functioning, which influence changes in the caregiving role over time. Much more research is needed that compares changes over time in the institution-based caregiving role between females and males and among caregivers with different relationships to the care receiver (e.g., wives and husbands, spouses and adult children).

Taken together, findings from this study reflect a continuity of contact, support, and perception of care role following a relative's move to a long-term care facility and can best be conceptualized in terms of "continuity theory" (Atchley, 1999a; 1999b; 1989; Becker, 1993; Gladstone, 1995). According to this perspective, middle-aged and older persons strive to maintain a sense of continuity in their lives. They utilize skills and engage in interaction that is familiar

("external continuity"), while looking for meanings in their experiences that reaffirm their interpretation of self ("internal continuity"). Atchley (1999a) states that continuity can be conceptualized as "the persistence of general patterns rather than as sameness in the details contained within those patterns" (p. 2). Findings regarding provision of care showed that families were more likely to *rebalance/refocus care* or *express care* in alternative ways than to change the type of care given. In other words, families were apt to alter the "details" of the care rather than the care itself, again reflecting continuity in their actions. The ongoing perceptions that family members had of themselves as spouses, daughters, sons, or other family members reflected "internal continuity" and might represent efforts to counter the potential discontinuity brought about by the "role reversal" that many family members mentioned. One daughter, for example, referred to herself as "the adult" and her mother as "the child", adding, "[Y]ou feel like you're in the wrong role even though you have to accept the fact that you have to do this particular thing." In these cases, family members may have found themselves acting towards their relatives in unfamiliar ways ("external discontinuity") because of their relative's cognitive deterioration. Retaining an identity of self as a child (or spouse, etc.) may be an adaptive process that helps to link the past with a purposeful present (Atchley, 1989). Having a sense of purpose, direction, and order contributes to personal meaning (Reker, 1997), which shapes the role behaviour of caregivers following a relative's move to a facility (Dupuis & Norris, 1997). In fact, finding new possibilities for providing care and continuing to share familiar experiences and traditions with their relatives may be essential to caregivers' ability to cope with changing roles in the long-term care context (Kellett, 1998).

When concepts of self are challenged, people respond by redefining expectations, modifying activities, and looking for markers that signal continuity in relationships and a return to customary ways of thinking about self. Examples of these can be found in the data. One daughter, for instance, used to take her mother to quilt shows. She noted, "I do things on a smaller scale now. There's a quilt shop not far from there (the facility) and I've taken her there a couple times just to kind of look around and there's quilts on the walls. So it kind of serves the same purpose." Modifying the original activity may have served a dual purpose—to preserve the "internal continuity" of the mother and also of the daughter, whose performance of this role behaviour could provide her with a sense of comfort and predictability (Atchley, 1989). Family members also appeared to

pick up cues in their relative's behaviour indicating that role relationships and their sense of self within these relationships were not disrupted. These appeared in a number of different ways, including identifying familiar behaviour ("She could still do crossword puzzles"), observing the retention of skills ("I'm convinced because of certain conversations that I've had with her that she's living in this world a lot of the time"), and appreciating a relative's ability still to recognize the family member ("She'll occasionally refer to me as her brother. So the exact word and relationship may get a little muddled. But she knows I'm a close relative and she recognizes me"). These examples illustrate how personal meanings can be reassessed in light of changing situations and how a sense of continuity is constructed in the face of discontinuous events (Becker, 1993).

Continuity theory provides valuable insight into the role perceptions and behaviours of the caregivers of persons with dementia in long-term care facilities involved in this study. Yet it is not without its limitations. Continuity theory focuses on the individual and her/his personal history, roles, and relationships with others. However, it seems likely that a combination of personal, social, structural, and environmental conditions, as well as changing perspectives across generations influence changes in caregiving roles over time (Dupuis & Norris, 1997; Fry, 1992). From a historical perspective, for example, changes in attitudes towards and expectations about familial role responsibilities, as well as other demographic shifts over time, may influence how much choice caregivers have in opting to take on the caregiver role and how much freedom they have in how they play out that role. These conditions, in turn, may serve to enhance or constrain a caregiver's ability to maintain internal and external continuity. Other social and environmental factors, such as financial constraints or the quality of relationships with health care professionals and the characteristics of the long-term care facility itself may affect the degree to which individuals can maintain congruency and consistency over time.

The limitations of this study point to avenues for further research. The purpose of this study was not to make broad generalizations about family involvement in long-term care facilities but rather to come to an in-depth understanding of the perceptions and experiences of the care role and to identify factors that might contribute to changes in that role over time. Nonetheless, in order to expand our understanding further, it would be useful to broaden the sampling frame to include family members from a larger pool of facilities, both proprietary and non-proprietary. Family involvement is related, in part, to the quality of

professional care provided by staff. Greater variance among facilities would provide more detail as to the ways that families negotiate their roles with staff under varying conditions of care. There are presumably family members who have minimal or no involvement with their relatives. Gaining access to these family members would help us learn more about the ways that family roles are distributed after a relative's move to long-term facility. In addition, our data do not speak to the duration of visits that family members had with their relatives. Yamamoto-Mitani et al. (2002) have demonstrated the value of measuring duration as well as frequency when examining patterns of contact. It would be useful to determine whether conditions related to changes in frequency of visits also pertain to changes in duration. Finally, while this study used a longitudinal design, there were no pre-relocation data that would add to our understanding of continuity and change at various stages of the caregiving career. Following caregivers throughout their caregiving careers (i.e., from community care to an institution-based caregiving role to the death of the relative) would provide a more in-depth, comprehensive understanding of changes in the caregiving role over time.

Atchley (1999a) has made the conceptual distinction among "stability", "continuity", and "discontinuity". Family members may not want to have the same involvement that they have had in the past; yet they may want fluctuations in their involvement to remain within a personally acceptable range. Greater attention should be directed to the ways that facilities can promote "stability" or "continuity" rather than "discontinuity" if this is what families desire. Facilities can help by engaging families in a discussion about their preferred role in the facility. This discussion can take place at more than one time—for example, before a relative moves to a long-term care setting, at the time of relocation, and then later at the resident-care meetings with family members that are usually held at least annually. These meetings should be more than occasions to give families information about their relatives. Families can also be given the opportunity to talk about the amount of care that they would like to provide, the ways in which they would like to provide it, and the ways in which they are experiencing their new roles. Overlooked may be family members who want to have a voice but feel silenced by the perceived authority of staff. Family members who continue to view themselves as caregivers should also be acknowledged and be permitted to have a level of involvement that feels comfortable for them rather than one about which they feel they have no choice. Working towards a care model that recognizes and values

the expertise of all involved and emphasizes a collaborative approach to care can only improve the quality of life of residents, family members, and staff alike (Kellett, 1998).

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