Sociocultural Aspects of Transitions From Assisted Living for Residents With Dementia

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Purpose: Negotiating transitions and residential relocation are especially difficult for residents with dementia and their families. This article examined the decision-making process regarding retention or transfer of persons with dementia in assisted living facilities. Design and Methods: Using an ethnographic approach, this study observed residents and facility life, and interviewed residents, staff, and family members in three assisted living facilities. Results: Facility managers and administrators are pivotal figures in determining the timing of transitions and transitional care. Operating within the context of care requirements of dementia, they, the facility culture, and the family members' involvement in resident care mediate interpretations of and responses to change and decline, and ultimately influence decision making regarding retention or transfer. Implications: Transfer or retention may occur differently depending on whether managers are on- or off-site, the assisted living culture is dementia-friendly, and families are involved in care. Sensitizing assisted living managers and educating potential residents and family members to the importance of these factors may affect the eventual likelihood and timing of discharge.

Key Words: Transitional care, Culture, Leadership, Family

As “nonmedical” residential environments, assisted living facilities are not necessarily the final care setting for many residents as their needs change. Residents may transition from a “general” facility to a dementia-specific facility or unit, a nursing home, or a special care unit within a nursing home. They also may transition from the facility to an acute care hospital and to a rehabilitation facility and back to the facility. Obviously, the possible trajectories are multiple, varied, and individual.

Several earlier studies (Hawes, Rose, & Phillips, 1999; Kane & Wilson, 1993; Stocker & Silverstein, 1996) have investigated reasons for discharge of residents from assisted living facilities, based on administrator responses to cross-sectional inquiries (mailed surveys, interviews, and telephone surveys, respectively). Their findings indicate that needing more care than the facility could provide, specifically related to behavioral, medical, and functional problems, was the most frequently cited reason for discharge. In the most recent of these studies (Hawes et al.), more than 50% of assisted living facility administrators reported they would not retain residents with moderate to severe cognitive impairment, and 76% of the facilities cited behavioral problems as the most common reason for discharge.

In a study specific to discharge of residents with dementia from assisted living facilities to skilled nursing care, Aud (2000, 2002) used single ethnographic interviews to examine resident behaviors that contributed to the decision to discharge. Aud found that the interaction of behavior with environment, rather than any isolated behavior, most strongly influenced staff decision making. Also, enforcement of a state regulation related to fire safety, which required mandatory discharge of residents who failed to demonstrate successfully their ability to independently navigate a predefined “path to safety” within a prescribed period of time, resulted in the transfer of numerous residents with dementia from assisted living.

To date, the term “transition” has been used in the gerontological and health services literature to denote relocation from one health care setting to another, or from home to a residential care setting (Hersch, Spencer, & Kapoor, 2003; Peete, 1999; Wilson, 1997). Relocation transitions involve moving from one place of residence to another, or from one
area within a current place of residence to another (e.g., from the independent living to the assisted living section of a continuing care retirement community). Personal health crises can represent an intrapersonal transition that necessitates changing one’s habituated functional state of being. In some instances, intrapersonal transitions may result in a misfit between the individual and his or her current environment, and ultimately in the need for a relocation transition either into or from assisted living.

Unfortunately, relocation transitions and health crises are among the top 10 life stressors for people of all ages, but are especially stressful for older adults due to their association with loss and ultimately the end of life (Danemark & Ekstrom, 1990; Lander, Brazill, & Ladrigan, 1997; Rowles, 2000; Ryff & Essex, 1992; Thomasma, Yeaworth, & McCabe, 1990). Other more subtle types of intrapersonal transitions, such as the gradual loss of cognitive, communicative, and functional abilities associated with advancing dementing illness, and their relationship to relocation transfer of assisted living residents, have not been thoroughly discussed in the literature. This lack of attention is of concern because negotiating transitions, and transitional care, can be especially difficult for persons with dementia and their families (Bredin & Kitwood, 1995; Dehlin, 1990; McAuslane & Sperlinger, 1994; Robertson, Warrington, & Eagles, 1993). Consequently, recognizing and understanding the complex transactions between residents with dementia, their families, and facility caregivers in relation to retention and transfer from assisted living is highly important.

This study uses a qualitative ethnographic approach including participant observation combined with informal and formal face-to-face interviews to explore the decision-making process regarding retention or transfer of persons with dementia. Further, to the extent the data allow, it aims to examine the behavior and environment interaction theme proposed by Aud (2000, 2002) and to shed light on the seeming contradiction between the reasons for discharge found by Hawes and colleagues (1999) and the existence of large populations of residents in assisted living who have moderate to severe cognitive impairment, exhibit behavioral problems, and/or require increased care found by Zimmerman, Sloane, Eckert, Buie, and colleagues (2001). Unlike prior studies that relied on cross-sectional structured interviews of assisted living facility administrators, this study provides an in-depth longitudinal multivocal perspective derived from repeated interviews and observations of multiple parties (administrators, managers, staff, family members, and residents) collected over an extended period of time (approximately 6 months) in each facility. It is based on analyses of 101 field notes and 89 ethnographic interviews of 62 study participants in three assisted living facilities collected during a 21-month period. Quantitative methods do not allow for this type of in-depth understanding of complex issues.

Design and Methods

The Transitions from Assisted Living: Social and Cultural Aspects study (the Transitions Study) is part of a larger family of studies known as Collaborative Studies of Long-Term Care (CS-LTC). The central aim of the Transitions Study was to examine social and cultural aspects of transitions into and out of assisted living facilities in Maryland. The design called for sequential ethnographies lasting 5 to 6 months to be completed in each facility. Data for these analyses were collected between April 2002 and December 2003 in three facilities reflecting two of the CS-LTC facility strata: those with less than 16 beds (two facilities) and one “traditional” facility. A traditional facility has 16 beds or more but is not indicative of a “new-model” facility that caters to a more impaired population; in lay terms, it is similar to board-and-care-style long-term care. Details of the CS-LTC facility strata can be found elsewhere (Zimmerman, Sloane, & Eckert, 2001).

Data Collection

Two PhD-level ethnographers and two gerontology doctoral students conducted participant observation and ethnographic interviews with residents, residents’ family members, facility owners, administrators, and managers, staff, and third-party health care providers. During active fieldwork in each facility, data collectors were on-site for a minimum of 8 hr per week in the smaller facilities and 16 hr per week in the traditional facility. Periodic follow-up consisted of bimonthly telephone conversations with the facility manager and on-site visits as needed to track new transitions as they occurred.

Participant Observation

The field team observed activities and interacted with residents, family members, and staff in the public areas of the facility. Each ethnographer compiled her own field notes. Members of the field team often were on site simultaneously, allowing corroboration of the individual observations and insight into the same event as seen from two perspectives. This procedure was particularly important with regard to observations of those residents with dementia who communicated nonverbally and could not participate directly in formal ethnographic interviews.

Ethnographic Interviewing

Ethnographic interviewing allows the researcher to capture the personal experience of participants and was used for all interviews. This method empowers informants to discuss experiences in their own terms. It permits understanding or exploration of the social actors’ perspective, definitions, and experiences and...
uses the informant’s naturalistic utterances as new starting points for additional inquiry (over those supplied by the interviewer) and discovery.

Ethnographers used sets of qualitative entry questions to elicit initial common responses from all informants, followed by reflexive probes and follow-up items tailored to prior responses. All interviews were tape-recorded and ranged in length from approximately 20 min to 5 hr. In some instances, individuals were interviewed multiple times over a period of months. Resident interviews were conducted in designated areas of the assisted living facilities where privacy could be assured. The draft transcript and tape recordings were reviewed by the ethnographic interviewer and edited as needed prior to submission of the document for review by the investigative team.

**Data Analysis**

A collaborative coding methodology was used for this project. Hardcopies of all documents were distributed to coding teams, consisting of two project team members (investigators and research assistants). Each individual coded each document independently using a code list that emerged inductively from investigator review and discussion of documents produced by the field team. The two coders then met to jointly create a master copy reflecting their reconciliation of coding differences. Unresolved coding issues were brought to biweekly project team meetings and the code list was reviewed, critiqued, and revised as necessary. Each ethnographer served as a member of the coding teams, but did not code any documents that she created. All documents and codes were entered into Atlas.ti, version 4.2 (Scientific Software Development, 1998) for analysis.

To capture issues related to residents with dementia, Atlas.ti queries were run for each of the following codes: dementia or cognitive impairment, problematic or inappropriate behavior, and transitions. In this way, dementia was loosely defined in accordance with how the term and such residents were categorized by respondents. Textual analysis for themes associated with transitional care of residents with dementia by resident, facility, and across facilities was performed on all documents and portions of documents resulting from the Atlas.ti queries.

**Results**

Information about the three facilities and respondents in this study is provided in Tables 1 and 2. The two smaller facilities are in a suburban setting; the traditional one is in a rural setting. All are privately owned, for profit, and serve an elderly clientele. The most notable difference, reflective of the sampling design, is the larger number of beds in the traditional facility (Facility 3) compared to the smaller facilities (34 vs 6–8).

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Facility 1</th>
<th>Facility 2</th>
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<tr>
<td>Type</td>
<td>&lt; 16 beds</td>
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<td>8 beds</td>
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<td>Nonadministrative staff</td>
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<td>31</td>
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<td>Resident age</td>
<td>79–96</td>
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Type refers to categories established by the Collaborative Studies of Long-Term Care (CS-LTC; Zimmerman, Sloane, & Eckert, 2001). These categories are “small” (facilities with < 16 beds), “traditional” (facilities with ≥ 16 beds that do not meet the criteria for “new-model”), and “new-model” (facilities with ≥ 16 beds built after January 1, 1987, and that meet at least one of the following additional criteria: offer 2 or more private pay monthly rates, > 20% of residents require transfer assistance, > 25% of residents are incontinent daily, have RN or LPN on duty at all times).

Overall, data sources consisted of 101 field notes and 89 ethnographic interviews with 62 different individuals. Data were collected specific to 29 residents with dementia, and also about the issues under study, more generally. The majority of respondents were female (79%) and White (85%). Only 5 of the interviewees were Hispanic. Approximately one third of respondents were residents, one third were family, and one third were facility staff or other professionals. Reflective again of the larger pool in Facility 3, two thirds of all data were derived from that facility.

All of the facilities admitted residents with dementia and reported retaining at least some of these residents over a period of several years, during which time their dementia worsened noticeably. Some residents with dementia were admitted but not retained in these facilities and some potential residents with dementia were never admitted to the facilities. During initial interviews, facility administrators articulated retention or transfer criteria regarding residents’ degree of cognitive impairment, specific types of dementia-related behavioral problems, and level of care needed. Based on these interviews, it appeared that strict, unyielding decision-making criteria existed; however, observations and interviews with other parties showed that implementation of these decision-making standards was individually applied, thus appearing inconsistent and sometimes contradictory.

Findings indicate that problematic behaviors, such as wandering, agitation, incontinence, and dependence in activities of daily living, were common among the residents with dementia in these facilities. Also, many of these behaviors and residents’ ability to communicate successfully were reported to change during the 6 months of data collection, although subtly. Furthermore, although they were a source of
stress for assisted living facility managers, staff, and family members, no one type of dementia-related behavioral or communicative transition was uniformly associated with either intra- or inter-facility relocation transitions. That is, development of mild dementia and/or advancement to moderate or severe stages of dementia while in residence did not emerge as explanatory themes for relocation transitions. In fact, most of the interfacility relocation transitions were associated with non-dementia-related health crises, as was true for the nondemented residents of these facilities as well. Further, no state or local regulations per se appeared to influence transitions and transitional care of residents with dementia in the study facilities.

Instead, stories of “who,” “how,” and “why” residents with dementia transitioned within and from these assisted living facilities revealed four predominant themes related to how transitions were perceived and decisions were made—the facility manager, the resident’s care needs, family member’s involvement and willingness to work with the facility to provide care, and the degree to which the facility environment is dementia-friendly (i.e., able and willing to accommodate the changing needs of individual residents with dementia, mediate resident transitions, and influence the manner in which residents with dementia’s increasing needs for care are or are not accommodated by the facility).

**Theme 1: Facility Manager’s Pivotal Role in Determining the Timing of Transitions**

The manager of each of the study facilities had substantial experience running an assisted living facility and had been the sole manager of the facility throughout its operation. He or she was the pivotal figure on whom relocation transition decisions depended. The theme of the manager’s influence appeared in the form of stories told about the processes by which individual residents with dementia were admitted to the facility, assisted during the settling in period, accommodated as the dementia worsened, and were either retained or transferred from the facility. These stories about the manager’s pivotal role were told by the managers themselves, assisted living staff, family members, residents, and other health care professionals. One manager, for example, expressly noted that aging-in-place is not guaranteed, when discussing her decision to transfer a new resident.

“That’s why I always tell them. I don’t guarantee them anything, even if you sign the papers that I have to keep them for one year. I tell them, if I cannot take care of them, if they become destructive, they hurt themselves or somebody else, or are being combative, they have to go.”

The managers also reflected on the influence of market conditions and staff retention issues on their decision making regarding potential transitions of residents with dementia.

**Theme 2: Care Requirements Related to Transitions**

Beliefs about what constitutes dementia, its causes, probable outcome, viable treatments, and expectations regarding the capabilities of persons...
with dementia varied widely among study participants. Among those interviewed, the assisted living managers, third-party case managers, and a registered nurse had more formal training and greatest understanding of dementia and dementia care than did residents and family members; however, only one of the three managers had familiarity with differential diagnosis of dementing illnesses and associated treatment protocols. Most staff members defined dementia as memory loss only, associated it with normal aging, and generally did not believe that it required transition from the facility; however, staff members were aware of the care needs of residents with dementia.

“She is becoming total care, which eventually she will have to be put in a nursing home. She needs a lot of attention. Basically we have got to keep up because when she goes to the bathroom, she don’t wipe herself, so we have to do it for her. We have to basically give her—we have to dump the meds into her mouth, otherwise she won’t. She is just becoming total care . . . Some of it is from dementia. The rest of it is laziness. Most of the residents that I have up here have dementia—starting into Alzheimer’s, it’s not complete Alzheimer’s—it’s more dementia.”

In contrast, problematic or inappropriate behaviors, such as undressing in public areas, verbal and physical agitation, and wandering, despite being associated with worsening dementia, were not ascribed to normal aging. All three assisted living managers screened potential incoming residents for these behaviors and denied admission if they were apparent. Care responses to and decision making regarding transitions of already admitted residents who displayed these behaviors varied greatly, often reflecting either the assisted living manager and/or staff’s emotional attachment to particular residents, the family members’ influence, or occasional deference to the wishes of other residents.

**Theme 3: Family Involvement Influencing Care and Transitions**

The manner in which family members participated in the care of and decision making for residents with dementia varied. The family members who participated in this study were those persons who had been the primary caregiver prior to admission and remained in active contact. These family members had commonly observed the onset of dementia, sought diagnosis, treatment, and care prior to assisted living placement, ultimately decided when it was time for placement, selected the assisted living facility, and engineered the actual admission procedure. The residents had varying degrees of involvement in decision making regarding these processes and their timing. Family members included sons, daughters, siblings, nephews, nieces, grandchildren, fictive kin, and their spouses.

After assisted living placement, family roles consisted primarily of regular visitation, oversight of care provided by staff and third-party health care providers, arrangement of and transportation to and from medical appointments, receipt and delivery of residents’ medications (in some facilities), advocating for the resident, and working with the facility manager and staff to lessen the number of instances and severity of the resident’s problematic behaviors. These family interventions often were cited as key to averting transitions from assisted living.

In addition, family members frequently engaged in second-guessing previous placement choices and attempted to predict likely outcomes of potential transitions into and out of the study facility. For example, two key family concerns voiced in this study were (a) the fit between the resident’s current ability to participate in activities and the level and type of activities provided by the facility, and (b) making the right choice regarding return to the assisted living facility versus entering a nursing home following discharge from a hospital or rehabilitation facility. Family members indicated acceptance of the facility manager as the ultimate decision maker with regard to the resident’s potential discharge, noting that they trusted the manager to make a sound decision when the time came. Although they indicated that they would prefer to have the resident with dementia age in place in assisted living, the family members we interviewed did not expect this to happen. However, family members did recognize and exert their influence regarding the timing of transitions from assisted living and intrafacility transitions, such as room reassignments and relocation from general assisted living to a dementia-specific unit within the same facility. Family members even used tactics such as offering to incur additional expense in order to forestall a relocation transition.

“I’ll buy an aide because I don’t want to move her. I love her with Amy [the assisted living manager], and I want her to stay there with Amy. But I don’t want her to be locked up, even at Amy’s . . . That’s why I told Amy, that if she needed another aide to, like, sit outside with her and take her for walks, do that kind of stuff, I would do that because it would be worth it to keep her where she is to me to do that. So, no, I’m not second guessing myself about the place, but I’m worried that I might have to make another move because her disease [Alzheimer’s] is going to go. It just depends I guess on how rapidly her disease goes.”

**Theme 4: Dementia Friendliness of Facility Culture in Relationship to Transitions**

Each assisted living facility had its own distinct culture. Following Geertz (1973), in this study the
Term “culture” refers to “webs of significance” or, more specifically, the tacit and overt assumptions that frame experience and the meanings ascribed to them (p. 5). Facility cultures are dynamic and change over time. Each facility’s culture was dementia friendly to some extent; however, the facilities were markedly more dementia friendly toward their existing residents and families than they were toward potential new residents. For example, when a long-time resident became incontinent, refused to cooperate with staff attempts to manage her incontinence, and did not wish to relocate downstairs, the manager took a more person-centered approach.

“I have a different—not philosophy—I have a different take on it. Have we had to go in there and had her carpet cleaned? Yes. Could I have put her downstairs where we have the tiles so if she does that, we just wipe up the tiles? Put a bedpan on the chair and get her, like, a duster to wear, which is more like what she wears? You know, I could have done that. I could probably do that at any time, or tell the family if they refuse, although I don’t think they would. But if they refuse, the one that is going to refuse is her, and out she goes. But again, I try to be more liberal ... Another place like us is not going to tolerate it. They are going to put her in a diaper and if she doesn’t they are going to give 30 days notice to get out. I mean, I am much more liberal than a lot of places, in trying to let these people enjoy what time they have left and not put too many rules and constraints on them.”

Dementia friendliness often was framed as references to whether or not an individual resident “belongs here” or “is one of us.” Facility culture dictated who sat with whom in the dining room or other public areas and the “punishments” meted out to transgressors of facility norms.

At a more subtle level, facility culture dictated when tacit agreement had been reached that the facility was going to, or in fact already had, transformed from an assisted living facility providing housing and care to a predominantly cognitively intact population to a largely de facto dementia assisted living facility. Each facility, but especially the smaller facilities, also had to grapple with changes in its culture resulting from its residents becoming increasingly demented. Culturally defined behavioral norms and assisted living staff and manager’s roles and daily activities changed in the face of advancing dementia. These changes in turn influenced decision making regarding possible transitions from the facility.

Ultimately, each facility culture was also impacted by death, the final transition from assisted living. During our study, no resident with dementia, non-demented resident, nor assisted living staff member died on-site; however, several died off-site. In one case, the resident with dementia had been one of the facility’s original residents, lived in the facility for almost 7 years (including several years during which she was severely demented), and was retained by the facility until two days prior to her death at which time she was transferred to the acute care hospital in which she died. Each facility dealt with issues surrounding communication with residents with dementia regarding deaths of other residents and assisted living staff in its own way. For example, the managers of the two small facilities opted not to share information about deaths with residents with dementia, indicating that they did not believe these residents would remember their former co-Residents or even notice they were no longer residing there; they were concerned the residents would be unnecessarily upset by the news of the death. The traditional facility’s culture was more open about sharing information with both its demented and nondemented residents.

Discussion

By conducting extensive ethnographic fieldwork over many months and listening to the voices of multiple parties affiliated with each assisted living facility, this study has explored the meanings and decision-making process associated with retention and transfer of residents with dementia. All three facilities under study routinely retained residents with moderately severe cognitive impairment. Although none of these facilities were willing to admit residents with severe dementia, two facilities retained individual residents even after they developed severe dementia. Decisions regarding retention or transfer of residents with dementia who were dying were made on a case-by-case basis. Keyword and thematic analysis of more than 200 block quotations coded dementia or cognitive impairment, problematic or inappropriate behavior, and transitions revealed four important themes associated with resident relocation and intrapersonal transitions. These themes are the facility manager, resident care needs, family member’s involvement and willingness to work with the facility to care for the resident, and the extent to which the facility culture is dementia-friendly—that is, able and willing to accommodate the changing needs of residents with dementia. By reading the narratives associated with these four themes it is possible to gain a better understanding of the manner in which the needs of residents with cognitive impairment, dementia-related behavioral problems, and increased needs for care are accommodated by these facilities.

While the finding that resident care needs relate to transitions has been reported by others (Hawes et al., 1999), and the importance of the role of the family in assisted living is becoming evident (Port et al., 2005, this issue), little has been written about the role of the manager and the assisted living facility culture—both overall and in relation to influencing transitions for residents with dementia. Assisted living managers in both this study and the Hawes study (Hawes,
Phillips, Rose, Holan, & Sherman, 2003) added an “it depends” qualifier to their responses concerning the criteria for retaining or transferring residents with dementia. They treated “it depends” as “no” because they felt that residents and family members who were concerned about these criteria could not rely on admission or retention in these facilities. However, Hawes and colleagues also noted that these facilities’ criteria are likely products of the resident case-mix they desire and the market niche they wish to pursue. Aud (2000, 2002) suggested that the interaction between resident behaviors and the assisted living facility environment (defined as the physical nature of the facility, location, site features, state regulations, facility services, program, and staffing) is the key decision-making criterion for retention or discharge of residents with dementia. Aud described the retention or transfer decision-making process as a linear direct cause and effect sequence in some instances and as a balancing of needs versus factors in others. While this study’s findings support both Hawes and Aud’s, they go a step further. Most notably, these findings highlight the human component integral to assisted living decision making and the realization that decisions are in fact individualized and dependent on multiple factors. The decision whether to retain or transfer seems to be based on the assisted living manager’s perception of the existing facility culture, the specific care requirements related to dementia (and the facility’s ability to address them), and the role of the family; these factors seem to lie at the heart of the “it depends” qualifier.

To date, the terms assisted living manager and administrator have been used interchangeably in both the practice and research literature. Oftentimes in practice, one person fulfills both roles, as was true in two of the study facilities. In the third, the manager and the administrator were sisters, worked closely with each other and with the residents and families, and exhibited virtually identical responses to resident care and transition dilemmas. However, in other facilities this may not be the case, especially in the case of new-model facilities that are parts of corporate chains. The separate influence of assisted living managers and administrators on decision making regarding resident transitions has not yet been explored and may well merit attention if the key authority is a prescribed policy that does not recognize the “it depends” of each individual resident.

Indeed, Allen (1999) notes that administrators “give life” to the assisted living philosophy by organizing the resources and finances to meet resident needs. In our three facilities, the on-site administrator or managers retained the ability to set, interpret, and implement admission or discharge and intrafacility relocation policies for persons with dementia. This structure accorded them much latitude in decision making and accommodating the perspectives of a large number of players (i.e., the resident with dementia, other residents, family members, staff, other health care professionals, and outside regulators). Together, they were able to develop individualized solutions for handling problematic resident behaviors and retaining residents with dementia as they progressed through the disease process. In larger corporate-owned facilities, however, administrative responsibilities may be split between board members, administrators, care coordinators, and others, some of whom may work off-site. Further, policies for these facilities may be set off-site by upper echelon administrators in consultation with the corporate board of directors, and then uniformly applied to assisted living facilities operating in widespread geographic areas. This “top-down” management could certainly influence decision making regarding retention and transfer of persons with dementia. In such instances, it seems more likely for decisions to be influenced by market forces (the need to keep beds filled, which may or may not be favorable to retaining residents with dementia) than by a truly person-centered focus.

Similarly, the administrator or manager’s awareness of external labor and market conditions may lead him or her to focus attention on the effects of staff burden from caring for assisted living residents (i.e., staff turnover), or on one segment of the resident population over another. In doing so, a tone is set for the facility, which manifests itself in the facility culture and decision-making processes. In our study, all three managers modeled great compassion and concern for residents and their family members and exhibited manager-centered leadership; however, they varied in their awareness of and response to outside labor and market conditions. The Facility 1 manager’s decision making regarding retention or transfer of persons with dementia was least affected by these conditions, whereas the Facility 2 manager was concerned about market conditions and the type of residents she would be able to attract if she retained particular residents. The Facility 3 manager was more influenced by labor conditions, favoring protecting and meeting the needs of his staff over those of individual residents.

In this way, the dementia friendliness of a facility’s culture also was influenced by the manager’s awareness of external labor and market conditions. Both admission and transfer decisions were influenced by the presence of other assisted living facilities in the geographic area. For example, the Facility 2 manager had not intended to provide housing and care for persons with dementia when she opened her facility 14 years ago; however, she noted that as more assisted living facilities opened in her area, increasingly those seeking admission were persons with mild to moderate dementia. In order to keep her facility operating at maximum or near-maximum capacity, she found it necessary to admit and retain persons with increasingly severe dementia. The resultant facility culture became dementia friendly to the extent that persons with dementia who could safely ambulate
up and down stairs and did not wander off premises were allowed to remain in residence. The Facility 1 manager’s admission and retention or transfer decision making reflected her sensitivity to another aspect of market conditions: the difficulties that family members in her geographic area faced in finding high quality care for persons with dementia at an affordable price. Her response was to retain residents with severe dementia, transforming the facility’s daily mode of operation to meet the changing needs of these residents. The resultant facility culture was focused on provision of highly individualized care that enabled residents to age in place in the facility. Facility 3’s manager and staff proudly noted that the facility cared for persons whom no one else would take. The result was a facility culture in which persons with dementia comiled with nondemented residents and with residents with mental illness. Behavioral eccentricities were tolerated and/or actively managed by both pharmaceutical and nonpharmaceutical means, to retain this case-mix.

All three facility cultures were dementia friendly if one interprets that phrase as referring to admission and retention of persons with dementia with differing and changing needs. Each facility’s philosophy of care was person-centered to the extent that it allowed individualization of care. However, if a dementia-friendly facility culture is defined as one that enables each person with dementia to achieve and maintain his or her highest possible level of physical, mental, emotional, and spiritual well-being throughout the course of the dementing illness, then all of these facilities were lacking in some respects. While the manager of Facility 3 appeared to understand many issues related to dementia, the staff had not been taught how to assess and treat various manifestations of the illness and how to tailor their interventions accordingly. The culture of Facility 2 was based on group activities chosen without regard for individual residents’ particular likes and talents, allowing only minimal accommodation for particular interests. Facility 1’s culture was compassionate and concerned for the needs of individual residents, family, and staff, but provision of dementia-friendly care and decision making were hindered by a uniform lack of knowledge regarding viable treatment options for persons with dementia, the unique manner in which persons with dementia often express physical pain and discomfort, and ways in which to assist persons with dementia in positive expression of their latent abilities.

This situation may be remedied, at least in part. Many assisted living managers and staff are licensed professionals who are required to participate in continuing education in order to retain their licenses. Training, such as that provided through the Alzheimer’s Association’s Campaign for Quality in Residential Care, offers dementia-care instruction for all levels of assisted living staff. However, challenges to training must first be addressed. Of note, small facilities often lack sufficient surplus funds to cover the cost of continuing education and may experience difficulty obtaining qualified temporary relief staff while they attend such programs. Policies that would allow small facilities to pool their resources to contract for outside services and qualify for group discounts for training could help them provide care and ultimately reduce relocation transitions for residents with dementia.

Admittedly, the three facilities under study are a small sample and are unique in that all of them have been overseen by the same manager for their entirety. It is feasible that the importance of both the role of the manager and the facility culture—which undoubtedly reflects the manager’s influence—may be markedly different in a facility that has experienced turnover in leadership. Considering that administrator turnover in long-term care averages 43% annually (Castle, 2001), it is advisable to explore this issue in a wider range of facilities. Indeed, all of the findings presented are limited due to small sample size (three facilities) and may not be generalizable to other facilities, particularly those with a different administrative structure. Future research is needed to expand the sample to include more small and traditional facilities as well as larger new-model ones in order to ascertain whether more bureaucratic management structures are associated with increased relocation transitions for persons with dementia. Some recent work by Zimmerman and colleagues (2005) suggests there may indeed be a tendency (albeit not statistically significant) for new-model assisted living to transfer more often, although these findings are not specific to residents with dementia. In addition, multisite studies of facilities in different geographic areas are needed to further understand the multifaceted issue of transitions for residents with dementia.

While residents with dementia and their families were aware that the assisted living facility may not be the older adult’s final place of residence, few individuals who participated in the study relished relocation. Thus, staff, residents, and families could benefit from greater understanding of the manager’s pivotal role and its intertwine ment with family involvement and facility culture as determinants of potential transitions. Given the often-seen propensity to fail to hear and/or to disregard the voices of residents with dementia (Barnett, 2000; Cotrell & Schultz, 1993; Goldsmith, 1996), heightened sensitivity of assisted living managers and family members to these three factors is even more critical. Considering and specifying criteria that potential assisted living residents and their family members might use to assess the fit between current and future needs of residents with dementia and the likelihood of a particular facility’s being able and willing to accommodate these changing needs could assist placement decisions. Most notably, clarifying the role of the family and their ongoing involvement...
may be especially helpful in the planning process. Work presented in this issue (Port et al., 2005) indicates that families are indeed involved in assisted living care, and so they may well appreciate understanding the true importance of their ongoing caregiving.

References


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