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## Families and Assisted Living\*

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### Abstract

**Purpose**—Despite growing research on assisted living (AL) as a residential care option for older adults, the social ramifications of residents' transitions to assisted living is relatively unexplored. This article examines family involvement in AL, including family structures of residents, types of involvement from family members living outside the AL, and outcomes for these family members.

**Design and Methods**—We reviewed current literature utilizing the MEDLINE, PSYCINFO, and CINAHL databases to identify AL studies that examined issues pertaining to families or informal care. Following the screening of abstracts, 180 reports were retrieved for further review, and 62 studies were selected for inclusion.

**Results**—Families visit residents frequently and provide a wide range of instrumental assistance but provide only minimal personal care. Studies of family outcomes indicated relatively high satisfaction, but potential care burden as well.

**Implications**—How family care and involvement occurs in AL in relation to formal care provision and whether various types of formal-informal care integration influence family outcomes remains unclear. We suggest a research agenda that attempts to tease out causal relationships for family involvement, differentiate family roles, and implement longitudinal analyses for a range of family outcomes.

Long-term care in the U.S. is supplied by two key sources: “formal,” or paid, care providers, and “informal,” or unpaid care resources (e.g., family members). Many studies have treated the move of a disabled older person to a 24-hour residential care setting as the termination of family care, assuming that all informal care responsibilities are substituted in favor of the services provided by the long-term care facility. As a number of researchers have noted, such substitution does not occur across all care domains or all families; some families continue to provide a range of assistance to relatives living in nursing homes (e.g., Gaugler, 2005). Family involvement may be even more apparent in emerging residential milieus that are neither designed nor organized to provide intensive care assistance; in such environments families may provide more diverse forms of assistance when compared to skilled nursing facilities.

This article examines how informal help is integrated in an emerging model of residential long-term care: assisted living. We begin with a conceptual exploration of how informal care varies in assisted living (AL) settings when compared to more scrutinized residential contexts where

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formal and informal care may interact—the licensed and/or certified nursing home (NH). The second section of this paper surveys the literature in order to ascertain whether current research findings support our conceptual model of informal care in AL. We conclude with a series of recommendations designed to guide future research on the interface of informal and formal long-term care in AL.

## Conceptualization of Informal Care in Assisted Living

### Domains of Family Involvement

Since the early 1970s, researchers have attempted to describe the care provision and general involvement of family members following a relative's move to a nursing home (see Gaugler, 2005, for a review of this literature). These studies identify several different types of family involvement. One way to quantify family involvement is in terms of *visits*. Family visits can be considered a gross measurement of overall family involvement, but what family members actually do during a typical visit may entail one or several other dimensions of family involvement.

Family involvement in residential settings can both supplement and supplant the formal care offered. *Personal care* includes activities of daily living (ADL) assistance, such as grooming, caring for a relative's skin, assisting the relative walk, helping with eating/feeding, and providing aid in going to the bathroom or dressing (Maas et al., 2004). Family members may provide these services when they perceive that a facility is not doing so.

Families can also provide instrumental activities of daily living (IADL), or *instrumental care*. Instrumental care provided by facility staff may supplant care that was once provided by families, such as assistance with laundry, cleaning or organizing the relative's room/apartment, preparing and storing food and beverages, and offering transportation (Maas et al., 2004). Other instrumental tasks are “supplemental” (or, both informal and formal care providers offer assistance) such as arrangement of, participation in, and follow-up of doctor's appointments and related services, financial affairs and bills, and health care decision-making. Although residential facilities may vary in their provision of instrumental care, family members appear to continue providing at least some supplementary services (Gaugler, Leach, & Anderson, 2003).

Other dimensions of informal care are of potential interest following entry into a residential setting. For example, one type of care that has received little attention in residential-based studies of family involvement is *socioemotional support*. Socioemotional support encompasses a number of activities, including talking with the resident, holding hands with the resident, reminiscing, and engaging in social activities (Maas et al., 2004). The need for socioemotional support is likely high given the challenges of moving from a familiar place into an entirely new setting, coping with change, re-establishing routines and relationships, and (as much as permitted by the setting) reorganizing personal belongings.

Additional dimensions of family involvement may highlight the ambiguous delineation of care roles between informal and formal care providers following residential care placement. For example, with the introduction of formal facility staff in the care system many family members may feel the need to *monitor* care provision or *advocate* for their relatives. As Bowers (1988) noted with reference to NHs, family monitoring of facility care can encompass supervising or “keeping a watch over” nurse aides or other day-to-day care staff. Other aspects of monitoring may include coordinating with care staff in order to maximize the quality of care provided, such as sharing personal information about the relative to staff (Maas et al., 2004). Similarly, while personal and some forms of instrumental care may be relinquished to formal care providers, families may feel it necessary to either direct formal care provision or “give a

voice” to the concerns of the relative or other residents. Advocacy can range from the actual direction of care provided by staff, to working with an ombudsman or other facility officials in an attempt to improve the formal care delivered in a given facility.

### Expected Family Involvement across the Long-Term Care Landscape

In hypothesizing variations of family involvement across AL and NH settings, we rely on prior work that has specified formal-informal care patterns in community settings (Lyons & Zarit, 1999; Noelker & Bass, 1989). Litwak (1985) suggested that the type of task determines how older adults utilize formal and informal sources of care. For instance, formal providers usually carry out caregiving tasks that require specialized skill and are performed at predictable times, whereas informal caregivers perform tasks that require less skill and occur unpredictably. A model developed by Edelman (1986) stipulates that formal support is merely used to alleviate the burden and time demands of tasks already carried out by informal caregivers (i.e., *supplementation*); in residential care, supplementation may emerge when both informal and formal care providers provide assistance for some care need. Greene (1983) hypothesized that assistance once provided by informal caregivers is eventually replaced by formal care (i.e., *substitution*). Other models suggest that informal care providers continue to provide the bulk of assistance for certain tasks, even with the introduction of formal care (*kin dependence*; see Lyons & Zarit, 1999).

This framework of formal-informal care patterns may help to distinguish family involvement among various dimensions of support in AL. As illustrated in Table 1, the nature of formal care in AL and NH care may affect the informal personal care delivered to residents. Informal personal care is more likely to operate according to the substitution model in NHs; for the most part, family members relinquish ADL tasks to facility staff. Due to regulatory concerns of NHs, families may be discouraged from engaging in certain care responsibilities, such as bathing or ambulation, due to potential risk. While there may be instances where family members still perform certain personal care activities on an intermittent basis in order to maintain intimacy in the care relationship (e.g., helping a relative eat during facility meal time), the overall pattern of formal-informal personal care in NHs could be considered substitution. In contrast, some AL residents are less likely to need such care. For those who do, informal care may supplement the formal care provided by AL staff (residents may rely on both family members and AL staff equally to perform certain ADL tasks such as grooming). In other instances, formal care by AL staff or other formal providers may substitute informal care (e.g., ambulation, bathing, dressing). Due to the heterogeneity of care needs and AL service delivery models (which may fluctuate according to various pricing levels), the range of informal and formal personal care in AL may vary considerably.

Instrumental assistance is expected to demonstrate variable formal-informal care patterns across ALs and NHs. Several IADL tasks that fall under the instrumental dimension, such as medication administration and laundry, are more likely to be assumed by NH staff. The regulatory nature of NHs and the emphasis on resident safety (based, in part, on OBRA 1987 legislation and other policy developments) has meant that NHs are less likely to facilitate family involvement that involves potential harm to the resident such as medication administration. In contrast, the stated emphasis on control, privacy, and autonomy in ALs coupled with the less disabled nature of clientele and reluctance of AL facilities to provide intensive 24-hour supervision may lead many family members to continue to supplement formal instrumental care. For example, while ALs may offer some transportation services and some assistance with medication administration (e.g., reminders), families may be either encouraged or motivated to provide any additional instrumental help to their relatives in AL. For yet other types of instrumental care, families in both NH and AL facilities may provide the bulk of such assistance with little aid from formal care providers (e.g., shopping, finances).

Socioemotional support, and by extension, visits, are likely to assume supplemental patterns of formal and informal care across both ALs and NHs. While there may be some variation in the amount of each provided by formal care staff (e.g., if certain AL facilities employ less staff at various shifts, this type of engagement may be offered less frequently), it is assumed that regardless of regulatory environment, case mix, or care delivery schedules there are staff in both types of facilities that provide such support. Formal socioemotional support and visits may occur because they are encouraged by the facility environment (e.g., smaller, family-style types of AL settings) or because of particular staff in each type of setting who are caring and committed to engaging in meaningful relationships with their residents.

In contrast to the other domains of family involvement, it is expected that monitoring and advocacy are more likely to assume a kin dependent structure. These types of assistance are based strongly in the concept of “preservative” care (Bowers, 1988), where family members play an integral role in attempting to maintain the identity of the relative via these activities. Whereas staff may monitor their care provision for reasons related to job responsibilities, families are likely motivated to engage in monitoring or advocacy due to their kin relationship with the relative and their more intimate knowledge of the person the relative is and was prior to entry in a residential setting.

## Survey of the Literature: Families and Assisted Living

### Methods

We attempted to identify research on AL related to family involvement or with some type of research focus on family-related variables. Since definitions of “assisted living” in the research literature have ranged from residential environments that are not NHs to more specific apartment-style settings, a particularly wide-ranging topical search of research databases was conducted. In December 2005 and January 2006, the MEDLINE, PSYCINFO, and CINAHL databases were searched simultaneously using the following keywords: “assisted living” (1705 abstracts), “adult family living” (123 abstracts), “congregate housing” (116 abstracts), “adult family home” (398 abstracts), “continuing care retirement community” (191 abstracts), “personal care home” (104 abstracts), “adult foster care” (176 abstracts), and “residential care and family” (603 abstracts). Each abstract was screened by the principal author, and any abstract that included some mention of family, family involvement, or family-related variables was included. Larger-scale national studies of AL were also considered to aid in the description of family structure. Following this review process, 180 reports were obtained for further analysis and potential inclusion. The principal author reviewed each report and selected articles for final review that provided information on the following extraction categories: 1) family structure in ALs ( $n = 10$ ); 2) types and predictors of family involvement in ALs ( $n = 49$ ); and 3) family-related outcomes ( $n = 12$ ). This resulted in the selection of 62 reports for the literature survey (several reports provided information across two or more of the extraction categories). One-hundred and sixteen reports were excluded because their study content did not fall into one of the three review categories ( $n = 116$ ) or the original report could not be located despite follow-up emails with study authors or inter-library loan searches ( $n = 2$ ). As the original inclusion criteria of the literature review were broad, a considerable number of articles were excluded. The principal author reviewed and re-reviewed the content of each excluded article. Fifteen were excluded because the samples identified were either not based in AL or were pooled across residential settings; 9 were excluded because the article included family members as proxy respondents for resident outcomes; a further 18 articles were excluded because the focus of the analysis was on resident outcomes and not the family data included in this review; 15 more articles were review papers and did not present pertinent family data in AL; 35 reports were excluded because family data were not reported; 15 additional articles were excluded because the data presented were a subsample of a larger parent study already included; 1 article

was excluded because it was not in English; and a final 8 articles were excluded because although they provided some data on family support in AL, they were largely based on perceptions of residents and staff and thus not relevant for inclusion in the current review.

## Results

**Family structure in assisted living**—To examine family structure we limited our analysis to studies that included detailed sampling frames of AL facilities and residents at the national, multi-regional, state, or regional levels. We excluded studies utilizing convenience samples of AL residents. Those studies that reported data on at least 2 key family structure variables (e.g., marital status, living children, traveling distance of nearest family member) were included and summarized in Table 2.

The data presented in Table 2 suggest two important trends related to the informal care potentially available to individuals in AL. First, approximately 70% or more of AL residents are widowed, and few AL residents (7% or less) are living with a spouse in AL facilities. For those who have no spouse or family support available within the AL setting, personal and instrumental care needs may be met either through the formal support available in AL or via informal care resources that are external to the AL facility. Second, most residents appear to have proximate family members that may serve as sources of informal support. It is important to note that a small proportion of residents (approximately 10%) have no proximal family member.

Table 3 provides additional information on three important need characteristics: resident age, cognitive impairment, and functional status. On average, residents in AL are 80 years of age and over, with some samples indicating that more than half of residents are 85 years of age or over (i.e., the “oldest-old,” see Hawes et al., 2000,2003;Zimmerman, Sloane, & Eckert, 2001). Approximately 20% of residents suffer from severe cognitive impairment, with roughly an additional 25% suffering from moderate cognitive impairment. Similarly, roughly 20% of AL residents are dependent on 3 or more activity of daily living dependencies. These results suggest that while AL residents are not as functionally or cognitively impaired as nursing home residents (e.g., see Magaziner et al., 2000), for a segment of the AL resident population there are considerable care needs present.

**Types of family involvement in assisted living**—A number of quantitative and qualitative studies examine family involvement in AL. Table 4 summarizes existing quantitative research on types of family involvement provided in AL settings. Few studies take a comprehensive approach to family involvement in AL; most quantitative research focuses on either visits or contact frequency (i.e., telephone calls) as opposed to more intensive types of care provision. Nonetheless, the research appears to emphasize the considerable degree of family contact AL residents experience via frequent telephone calls (often weekly or more) or in-person visits. Most residents across these quantitative studies indicated an average of once-weekly visits or more while living in various AL environments. Families are engaged most frequently with socioemotional help (e.g., Kane et al., 1991;Keating, Fast, & Eales, 2001;Lough & Schank, 1996;Port et al., 2005;Stacey-Konnert & Pynoos, 1992;Thompson, Weber, & Juozopavicius, 2001). Instrumental assistance is provided consistently but on a more moderate basis; available reports indicate that families generally perform instrumental care 1-3 times per month. In contrast, personal care provision is rarely performed by families; several studies suggest that family members spend 1 hour or less per month providing ADL care (Abbey, Schneider, & Mozley, 1999;Gaugler & Kane, 2001; Newcomer, Breuer, & Zhang, 1994; Stacey-Konnert & Pynoos, 1992). Very few studies have examined monitoring or advocacy performed by family members; Port et al. (2005) found families engaged in relatively frequent medical and financial monitoring of relatives in AL (approximately 5 times in the past

month), whereas another study in Canada suggested much less frequent monitoring or advocacy (.27-1.63 hours in past month; Keating et al., 2001).

While these studies provide some description of family involvement in ALs, the data make it difficult to determine how informal care is integrated with formal care delivery. Given the frequency of visits, socioemotional support, and instrumental care, it is likely that families are at least providing supplemental assistance with these dimensions in conjunction with the facility, if not outright kin dependent care (for example, see Newcomer et al., 1994). The low frequency of personal care implies that families may relinquish these care responsibilities to the facility, and could be considered a substitution formal-informal care pattern. The lack of studies or consistent findings on monitoring and advocacy makes it difficult to ascertain how families and formal care staff interact to offer these types of care assistance.

Several quantitative studies have also attempted to identify correlates or predictors of family involvement in AL (Gaugler & Kane, 2001; Gaugler et al., 2003; Hopp, 1999; Port et al., 2005; Pruchno & Rose, 2002; Zimmerman et al., 2003). Of particular interest in these studies have been comparisons between various types of AL settings and NH environments. For example, some studies have suggested that family members of AL residents are more likely to engage in instrumental/IADL assistance (Gaugler & Kane, 2001; Leon et al., 2000), family interaction (Pruchno & Rose, 2002), and monitoring of cognitively impaired residents' medical, emotional, and financial well-being (Port et al., 2005) when compared to informal care providers of NH residents (although a statewide study of adult foster care found no such differences; see Kane et al., 1991). Other efforts have examined correlates or predictors of family involvement in AL; variables that are consistently associated with greater family visits and more personal/IADL family care include geographic proximity of a family member to the facility (Gaugler & Kane, 2001; Gaugler et al., 2003) and residents who are women (Gaugler & Kane, 2001; Hopp, 1999; Zimmerman et al., 2003). Other variables with significant but diverse effects on family involvement across studies include race/ethnicity, resident length of stay, functional and cognitive status, and age (Gaugler & Kane, 2001; Gaugler et al., 2003; Hopp, 1999; Pruchno & Rose, 2002; Zimmerman et al., 2003). Beyond facility type, no studies examining correlates of family involvement assess facility-level characteristics in reliable fashion when ascertaining the influence of facility environment on informal care provision (e.g., Gaugler & Kane, 2001; Gaugler et al., 2003).

While the majority of quantitative studies have focused on different types of family involvement once a relative has moved into an AL, single studies have examined other potential dimensions of family involvement. These include analyses of family members' influence over relatives' decisions to move to apartment-style AL settings and their preferences (Reinardy & Kane, 2003; see also Hawes et al., 2000; Krout et al., 2002; Sales et al., 2005; Silverstein & Zablotsky, 1996; Tornatore et al., 2003). Specifically, family dimensions appear to play an important role as to whether an older moves to an AL-style setting, as these various analyses indicate that older adults who are unmarried (Sales et al., 2005), proximal location to family and friends (Krout et al., 2002; Silverstein & Zablotsky, 1996), family preferences for AL (Reinardy & Kane, 2003) and even family abuse (Weatherall, 2001) are all variables that positively influence relocation to AL. As with predictors of nursing home admission (e.g., see meta-analysis by Gaugler, Duval, Anderson, and Kane, 2007), informal support appears to influence older adults' entry into residential long-term care.

In addition to several case studies (Baldwin & Shaul, 2001; Kane & West, 2005; Pitts, Krieger, & Nussbaum, 2005), various qualitative efforts have explored the process of family involvement in AL. These studies include anywhere from 6-78 family members in various types of residential care settings. Seven of these studies took place in the U.S. (Ball et al., 2004; Carder & Hernandez, 2004; Mead, Eckert, Zimmerman, & Schumacher, 2005;

Perkinson, 1995; Sanderson & Meyers, 2004; Schmidt, 1987; Wellin & Jaffe, 2004) and four took place in the U.K. (Roe, Whattam, Young, & Dimond; Seddon, Jones, & Boyle, 2002; Train et al., 2005; Wright, 2000). Five of these studies relied on semi-structured interviews with either family members or residents to inform the process of family involvement in AL, whereas the other 6 studies relied on multiple informants or participant observation/ethnographic approaches (Ball et al., 2004; Carder & Hernandez, 2004; Mead et al., 2005; Perkinson, 1995; Train et al., 2005; Wellin & Jaffe, 2004). The themes derived from these various qualitative studies overlap with the quantitative studies presented above; family members remain engaged in socioemotional forms of assistance such as visits and regular contact and were active in monitoring and attempting to “preserve” the well-being of AL residents. However, more personal forms of care assistance tend to be relinquished to AL or other formal care providers, implying a substitution model of formal-informal care integration. However, other themes emerge in these qualitative analyses that are relatively unexplored in quantitative research efforts, such as the importance of prior family-resident relationships in dictating the quality and type of family involvement (Sanderson & Meyers, 2004; Seddon et al., 2002), the role of “family-oriented” facility characteristics, environment, and policies in affecting family inputs in care planning and decision-making (Carder & Hernandez, 2004; Wright, 2000), and “deviant” family caregivers, or those who prefer to operate outside of group norms of family involvement and care (Perkinson, 1995).

Several qualitative studies have moved beyond family roles in AL to explore family involvement at various transition points during a relative's stay in AL. A recurring theme in several qualitative studies is the importance of family roles and history prior to admission, such as the role of health problems, emotional stress, and psychological upheaval related to at-home care provision as triggering the need for AL and potentially continuing after entry (Liken, 2001a, 2001b, 2001c; Russell, 1996; Sanderson & Meyers, 2004; Seddon et al., 2002; Wright, 2000). Other qualitative inquiries examine family involvement and transitions from AL; analyses suggested that family intervention and involvement in monitoring care, administering medications, collaboration with staff, and purchasing of external formal care services (i.e., home health aides) were key to allowing residents to age-in-place in ALs. However, family members also suggested a degree of comfort in allowing AL directors to make final decisions and judgments in determining whether a relative could remain in the AL setting; families also indicated a lack of formal discussion regarding such matters (Ball et al., 2004; Cartwright & Kayser-Jones, 2003; Mead et al., 2005). Additional qualitative research has examined interaction of families with inter-disciplinary geriatric care teams at the onset of Alzheimer's disease in AL (Liken, 1999) and physicians in general (Schumacher et al., 2005); both studies suggested the need for continuity of physician care in the context of chronic illness in AL, as well as the need to enhance communication in the long-term care environment between staff, physicians, and family members to improve the delivery of chronic care.

Two additional qualitative studies have explored marital status in AL-type settings as dictating the type and degree of social contacts with other residents (Perkinson & Rockemann, 1996) and attempts of married AL residents to continue to maintain their spousal roles when entering a residential care setting (Schmidt, 1987). An ethnographic study of 47 older adults in a continuing care retirement community examined the onset of care provision in such settings. Semi-structured interviews and field notes found that older residents were active participants in initially eliciting informal care from family members, and then engaging in negotiation and evaluation with family caregivers throughout the informal care process. The findings suggest a more dynamic role for the resident than conceptualizations of the passive care recipient that dominates much of the family caregiving literature (Russell, 1996).

## Family Involvement and Family Outcomes

Table 5 summarizes available quantitative research on family outcomes in AL. A handful of studies have attempted to examine family members' satisfaction with various aspects of the AL environment. Of the four studies that compared resident and family ratings of satisfaction, all but one found that residents reported lower overall satisfaction with the AL environment as well as with specific aspects of the AL environment, AL staff, and AL care provision (Buelow & Fee, 2000; Gesell, 2001; Sloane et al., 2003). One exception is the work of Levin and Kane (2006) which incorporated ratings of "importance" for various aspects of ALs (e.g., control, care, programs, etc.) as well as satisfaction for these dimensions, and found that family members alternatively rated importance as higher on resident control, care provided, and programs offered and satisfaction as lower when compared to residents. Overall, the trend of findings suggest that families and residents view satisfaction and quality of care differently on a number of important dimensions in AL, with residents' satisfaction often lower when compared to family members.

A few other analyses examine family members' emotional responses to informal care provision in AL. Studies of various dimensions of caregiver "burden," or the financial, social, emotional, and physical load of informal care suggest that while community caregivers may experience greater work-related strain than AL family members (Leon et al., 2000), family members in AL indicate more burden than families of NH residents, due perhaps to the frequency of informal care provision in AL (Port et al., 2005). In the one longitudinal analysis of stress in AL, Seddon et al. (2002) found that feelings of guilt (i.e., "I feel I have failed my relative in some way") remained for family members over a 10-month period, while perceived stressfulness on items related to visits and interactions with staff decreased. The scarcity of empirical analyses of emotional distress makes it difficult to discern overall trends of stress and adaptation for family members in AL.

Available qualitative research on family outcomes in AL suggests a process based in pre-admission experiences, and also indicates important psychosocial outcomes for future consideration. Both positive and negative emotional outcomes for family members may follow a relative's move to an AL. For example, in an interview of 20 family members of AL residents, Liken (2001a) indicated that the move resulted in relief for 15 family members due to greater supervision and emotional/personal care provided by the AL facility. Similarly, in their analysis of open-ended responses, Seddon et al. (2002) reported that stress decreased due to religious coping, attempts by family members to make each visit as stimulating as possible, and a sense of "freedom" on the part of family members. Across each of these studies, sustained guilt following a relative's move to AL consistently emerged (Liken, 2001a, 2001c; Sanderson & Meyers, 2004; Seddon et al., 2002). Other negative responses were based in feelings of loneliness and increased strain in the relationship with the relative (Sanderson & Meyers, 2004; Seddon et al., 2002).

A pair of studies examined family members' reactions to end-of-life care in AL. As shown in Table 5, one quantitative study suggested that many family members appeared unaware of a resident's approaching death when compared to families of NH residents (Sloane et al., 2003). Qualitative focus-group work indicated a number of concerns family members held regarding palliative care in AL, such as doubts that AL staff could handle the complex personal care and disease management requirements and a perceived lack of communication. However, family members were also vocal in expressing satisfaction with the individuals who provided care for their relatives at the end-of-life (Dixon, Fortner, & Travis, 2002). These quantitative and qualitative findings suggest important barriers to end-of-life care in AL, as well as the need for greater research in this area.



## Research Recommendations

While this paper is the first to synthesize quantitative and qualitative research results on family involvement in assisted living, there are several important limitations to note. Due to available resources, only the principal author was able to conduct the literature review, screen for inclusion, and extract data. As existing guidelines note, assessing the inter-rater agreement of multiple reviewers enhances the rigor of the data extracted and reported for the purposes of a systematic literature review (Pettiti, 2000; Stroup et al., 2000). Also, due to the relatively nascent literature on families and AL, the sampling strategy adopted in the literature search was necessarily broad; in addition to AL settings, other environments such as board and care homes, residential care settings, and adult foster care homes were included in the review. Family involvement may operate differently across these settings due to facility-level diversity or other important environmental factors.

Although prior work on informal and formal care in the community emphasizes the complex relationships between these two sources of assistance (Lyons & Zarit, 1999), quantitative and qualitative research has just begun to explore family integration in AL. As the survey of the literature suggests, families of relatives in AL appear to contribute considerable amounts of instrumental, socioemotional, and monitoring support (along with frequent visits) when compared to other residential settings such as NHs. However, the relationship of facility-level characteristics to family involvement and activities, the longitudinal ramifications of family involvement, the causal processes of family involvement, and effective assessment tools to capture various forms of family involvement are less apparent in the literature. Similarly, few studies have begun to examine the impact of the AL experience on family outcomes beyond ratings of satisfaction. This concluding section offers recommendations designed to guide future research and conceptual work on the process of family involvement in AL.

### Non-simplistic causal models of family involvement in assisted living

The review of the literature, particularly quantitative research, revealed rather simplistic causal models of family involvement in AL. For example, several studies have attempted to determine correlates or predictors of family involvement in AL, such as resident functional status, family members' geographic proximity, and similar characteristics. However, motivation for involvement on the part of family members may be influenced by a more dynamic process. For example, family members could be motivated to provide increased involvement (such as monitoring) because the facility is not offering adequate care or is providing much technical care at the expense of residents' emotional well-being. In other instances, the provision of certain types of assistance (such as socioemotional support) at the expense of more hands-on types of care (i.e., personal, instrumental) may suggest that families are content or comfortable enough to engage in psychosocial forms of support as responsibilities related to "technical" hands-on care are relinquished to the care facility. Overall, it is difficult to identify the causal direction of family involvement and potential predictors, given the lack of longitudinal research and conceptual models. For example, some studies have indicated that AL resident length of stay and family visits are negatively correlated (Pruchno & Rose, 2002), implying that as AL residents remain in their respective settings for longer periods of time families are less likely to remain involved. However, it may also be the case that family members who are more involved with residents in AL may be more likely to facilitate an earlier move-out from AL back to the community or some other setting (as has been found in NH studies; see Gaugler, 2005).

Stronger conceptual models are needed to guide the process of family involvement in AL. Some of this work has begun in qualitative research, which has suggested the importance of factors that can influence family involvement and are subject to family involvement (see above). However, quantitative studies have not addressed why various types of family

involvement occur or not. Incorporation of conceptual models may begin to better address the issue of how families are integrated within the formal care service systems of AL settings (e.g., Gaugler, 2005; p. 114).

We would also argue that the consideration of formal-informal care patterns when examining family involvement in AL is useful, as this conceptual approach may acknowledge the place of AL in the long-term care landscape. As presented in the literature review above, how formal and informal care is arranged in AL is dynamic. But are these formal-informal care patterns similar to care arrangements in NHs? It may be that formal care provision in AL is more analogous to home care settings, where family members arrange for some formal assistance on certain care tasks (e.g., bathing) and continue to provide considerable informal support for others. The difference in AL is that the resident and/or family has purchased systematic assistance for housekeeping and meal preparation and may negotiate at move-in and during the resident's stay for additional types of formal care services (either provided by the facility or some external, contracted organization). Subsequent research that examines the expectations of AL facilities for family care, whether family-level assessments are conducted, the involvement of family members in formal service planning, and programmatic efforts on the part of AL to support families would help to ascertain how formal and informal care in AL operates in relation to home/community-based settings or more traditional residential contexts.

### **Differentiating family involvement in AL**

Quantitative research on family involvement relies largely on task-based approaches to assessing frequency and type of informal care in AL. However, such approaches may obscure the overlap of certain types of family assistance in AL. For example, the provision of instrumental types of support may be integrated with socioemotional forms of help such as reminiscing with a relative while the family member takes her/him to an appointment. The segmentation of family involvement into various types may increase the risk of double-counting informal assistance.

In comparing various methods of assessing informal care inputs, reviews of the family caregiving literature suggest that calendar- or diary-based approaches may most effectively capture the amount and dimensions of informal help provided to disabled older adults (Gaugler, Kane, & Kane, 2002; for an example in AL see Pruchno & Rose, 2002). For example, a calendar-type of instrument can collect information on a daily basis regarding family visits and what occurred during each visit; moreover, administering these measures over time can capture periods of intensified family involvement due to particular crises the AL resident may experience (e.g., the resident fell). Although data monitoring is critical to ensure complete data, the incorporation of these assessment tools (as opposed to forcing respondents to choose categories of family involvement *a priori*) may capture the empirical richness of family involvement implied in qualitative research.

It is also apparent that few studies examine family involvement in AL from a dyadic or systems-level perspective. There may be family-level assessment techniques that are important to consider when examining the integration of formal and informal care in AL (e.g., such as those used in family systems theory development and family social science). These approaches may better incorporate the perspectives and importance of the *resident* in family involvement in AL; as is evident in our review of the literature, the voice of the resident is conspicuously absent from most analyses of family involvement (see Russell, 1996).

### **Incorporation of facility-level characteristics associated with family involvement**

As suggested in the survey of the literature, there are differences in the amount of family support provided to AL or NH residents. While much of this variation may be due to variations in

resident function and cognition, few studies adequately control or adjust for heterogeneity in samples. Moreover, the examination of facility type, given the extensive diversity in size, staffing, environmental amenities and other characteristics within and across ALs and NHs may make such comparisons simplistic. There may be a range of facility-level characteristics that could potentially influence or facilitate family involvement in residential settings such as “family orientation” of facilities, or the degree to which facilities encourage family involvement via specific policies and programs (e.g., flexible visiting hours, family participation in service planning; see Friedemann, Montgomery, Maiberger, & Smith, 1997).

Ethnographic studies have explored whether skilled nursing settings such as NHs are able to overcome the notion of “institution” and instead create a community-oriented context that is integrated within and outside facility walls (Rowles, Concotelli, & High, 1996). Building on this work, research in alternative residential environments has examined factors related to perceptions of AL as “home;” among these factors is attachment to AL of which perceptions of family involvement in AL is an important factor (Cutchin, Owen, & Chang, 2003). The promotion of these “blurred boundaries” appears to result in greater resident adaptation to lives in the facility as well as continued connection to roles and lives outside the residential care setting. Beyond facility size and other basic characteristics, no study to date has similarly examined the environmental context of AL and its potential effects on family involvement. It could be hypothesized that AL facilities, which actively market amenities such as choice, individuality, and control over one's environment may facilitate greater family involvement when compared to NHs, even when adjusting for the myriad differences between such settings. However, we would argue that such comparisons are not illuminating; more rigorous descriptions of AL facility environment (e.g., via a tool such as the Multiphasic Environmental Assessment Procedure; see Moos & Lemke, 1996) would allow researchers to pinpoint those characteristics and policies that may best influence family integration and resident well-being across the long-term care landscape.

### **Family structure and its potential effects on family involvement**

An additional conceptual limitation in family involvement research is its general focus on available family members. Most research tends to examine family involvement from the perspective of a “primary” family member, or that person who is most involved or feels most responsible for the relative in AL. However, as Table 2 suggests, there are various other configurations worthy of analysis in future research. For example, up to 10% of residents in AL are living with spouses in the facility. How family involvement operates in instances where spouses are living in the AL unit, and presumably providing considerable informal care to each other, may be an important variation of family involvement to explore. Moreover, the general underlying assumption of much of the research is that residents have available family members to rely upon. Some residents have no available family members to provide informal support and it is not clear whether existing studies of family involvement in AL exclude or consider these individuals in analyses. How formal-informal care patterns operate in situations where residents have no family members at all would contribute to our understanding and conceptualizations of family involvement across various family structure types.

### **The longitudinal and transitional nature of family involvement in assisted living**

The large majority of research on family involvement in AL is cross-sectional. Whether family involvement changes over time, and how such changes are related to facility-level factors or resident function, is relatively unknown. A longitudinal perspective is important; as noted in research on family care in NHs, early cross-sectional studies suggested a negative correlation between family visits and resident length of stay. In contrast, prospective longitudinal designs suggested more variable and dynamic patterns of change in family visits and involvement than earlier cross-sectional research implied (e.g., Yamamoto, Aneshensel, & Levy-Storms,

2002). Similarly, as the qualitative research highlighted above emphasizes, the degree and type of family care provided appears strongly associated with family-resident relationships prior to admission. However, no quantitative study to date appears to have considered family caregiving patterns prior to a relative's move to AL, or how quality of family-resident relationships during and prior to admission influence family members' involvement or other outcomes. Adopting a transitional perspective in future quantitative research would provide greater insight on the process of family involvement in AL and other long-term care settings, in contrast to simply describing types and frequency of informal care. Along with longitudinal description, strategies should be incorporated to address the complications of attrition (see Gaugler, 2005).

### Family outcomes and intervention in assisted living

Of the three areas surveyed, family outcomes in AL was the most underdeveloped. It remains unknown how family caregiving roles prior to and after a relative's admission to AL change. The greater family care burden in AL compared to NHs suggests that increased or continued family involvement in various care domains (such as IADLs) may exacerbate caregivers' perceived stress following the care recipient's move to AL. Family stress and other negative outcomes often do not abate with placement in NHs (Schulz et al., 2004). In addition, the care expectations of families or AL facilities themselves (e.g., supplementation care patterns for instrumental or personal care domains) may stress caregivers. It is also possible that family outcomes in AL may require measurement approaches that move beyond traditional domains of stress. For example, assessment of family members' perceptions of role continuity as "caregiver" or more AL-specific types of family outcome measures (understanding of and satisfaction with disclosure and communication regarding extent of resident care in AL) may better describe family members' acclimation to AL. Subsequent research examining change in caregiver outcomes across the AL transition could shed greater light on families' adaptation, and may also point towards interventions designed to assist families during the AL experience.

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**Table 1**  
**Formal and Informal Care Provision in Residential Long-Term Care: Assisted Living and Nursing Homes**

Type of Care	Assisted Living	Nursing Home
Visits	Supplementation	Supplementation
Personal care	Independence	Substitution
Going to the bathroom, eating	Supplementation	Substitution*
Grooming	Independence	Substitution
Ambulation, bathing, dressing	Independence→Supplementation→Substitution	Substitution
Instrumental care		
Transportation	Supplementation	Supplementation
Shopping, finances	Kin dependence	Kin dependence
Medication administration	Supplementation	Substitution*
Laundry	Substitution	Substitution
Socioemotional support	Supplementation	Supplementation
Monitoring	Kin dependence	Kin dependence
Advocacy	Kin dependence	Kin dependence

\* NOTE: family involvement potentially discouraged

**Table 2**  
**Family Structure Characteristics: Selected Assisted Living Studies**

Study	Assisted Living Data Collection	Sampling Frame	Marital Status	Living Children	Distance of Nearest Family Member
National Survey of Assisted Living for the Frail Elderly (Hawes et al., 2000, 2003)	1998-1999 telephone survey of AL facilities selected via multi-stage probability sampling; residents randomly selected within each "high service-high privacy" AL (41% of eligible settings) and interviewed in-person. ( $N = 184,558$ )	National via 60 geographic areas/sampling units	12.1% married; 70.8% widowed, 7.2% divorced, 9.9% never married	75.8% had living children	85.9% had a relative within an hour's drive
Collaborative Studies of Long-Term Care/CS-LTC (e.g., Zimmerman et al., 2001)	1997-1998 telephone and in-person survey of AL/residential care facilities selected via multistage cluster sample of counties within 4 states (233 facilities). All eligible residents were recruited ( $N = 2,078$ )	Counties in four states: Florida, Maryland, New Jersey, and North Carolina	11.3% married, 69.6% widowed	-	9.9% indicated a "proximate" spouse; 85.5% reported a "proximate" family member or friend
Kane study (Levin & Kane, 2006)	1999-2000 telephone survey and in-person interviews with 60 randomly selected apartment-style AL facilities in multi-county, urban geographic "hubs." Ten residents randomly selected within each AL ( $N = 600$ )	Multi-county, urban geographic hubs in 6 states	7.3% married, 79.0% widowed, 5.8% divorced, 8.0% single	76.5% had living children	65.5% had a child within an hour's drive; 5.6% lived with a spouse
California residential care survey (Newcomer et al., 1994)	1993 mail and in-person survey of a multi-stage, stratified random sample of 386 residential care facilities and 1,051 randomly selected residents	Statewide sample of facilities in California	63.8% married; 11.7% widowed	-	75.6% of residents had a relative within an hour's drive
Kane Oregon study (e.g., Fryak et al., 2001; Gaugler & Kane, 2001)	38 of 39 AL facilities in Oregon in 1995 were recruited; 1/3 of residents from each AL randomly selected and interviewed in-person ( $N = 605$ )	AL facility population of Oregon	10.6% married, 80.3% widowed, 5.0% divorced, 4.1% single	84.5% had living children	7.1% lived with spouse
Maryland Assisted Living Study (Burdick et al., 2005; Rosenblatt et al., 2004)	Stratified sample of small and large facilities in central Maryland; residents were randomly sampled within each AL ( $N = 198$ ) and interviewed in-person and over the telephone	Urban and rural regional area of central Maryland	6.6% married, 70.7% widowed, 9.1% divorced, 13.6% never married	$M = 1.5$ ( $SD = 1.53$ )	3% lived with spouse
Los Angeles-Orange County study (Micheil & Kemp, 2000)	Stratified random sample of 55 residential care facilities; cognitively "alert" residents were randomly sampled within each facility and interviewed in-person	Los Angeles and Orange counties, California	69% of residents were widowed	-	Residents reported $M = 2.7$ ( $SD = 3.2$ ) family members were within an hour's drive

NOTE: AL = assisted living facilities;  $M$  = mean;  $SD$  = standard deviation; Three larger-scale studies were not included as they were not publicly available (American Seniors Housing Association annual report, AARP survey, and National Investment Conference survey) and the costs to obtain these reports were deemed prohibitive.

**Table 3**  
**Need Characteristics of Residents: Age and Functional Status**

Study	Resident Age Data	Cognitive Impairment (CI)	Activity of Daily Living (ADL) Dependence
National Survey of Assisted Living for the Frail Elderly (Hawes et al., 2000, 2003)	10.9% under 75; 34.8% 75-84; 54.3% 85+; 96% 65+	11.9% = moderate CI; 13.0% = severe CI	12.7% of residents needed help with 1-2 ADLs; 8.1% needed help with 3+ ADLs; 19.3% required help with dressing
Collaborative Studies of Long-Term Care/CS-LTC (e.g., Zimmerman et al., 2001)	52% 85 and over	28.7% = mild/moderate CI; 24.7% = severe CI	25.9% of residents had 3+ ADLs; 58.1% required limited to total assistance with bathing; <i>M</i> = 1.96 ADLs (range = 1 - 6)
Kane study (Levin & Kane, 2006)	<i>M</i> = 86 years	-	-
California residential care survey (Newcomer et al., 1994)	<i>M</i> = 78.9 years	39.7% = mild/moderate CI; 18.3% = moderate to severe CI; <i>M</i> MMSE = 20.33 (range = 0 - 30)	30.7% = no ADLs; 23.8% = 1 ADL; 18.9% = 2 ADLs; 9.5% = 3 ADLs; 17.1% = 4+ ADLs; <i>M</i> = 1.74 ADLs (range = 1 - 6)
Kane Oregon study (e.g., Frytak et al., 2001; Gaugler & Kane, 2001)	<i>M</i> = 84.61 years ( <i>SD</i> = 7.06)	<i>M</i> MSQ = 5.99 ( <i>SD</i> = 3.38; range = 0 - 10)	<i>M</i> = 16.88 ADLs (on magnitude estimation scale of 0 - 100; see Frytak et al., 2001)
Maryland Assisted Living Study (Burdick et al., 2005; Rosenblatt et al., 2004)	<i>M</i> = 85.6 years ( <i>SD</i> = 8.2); range = 58 - 104	67.7% residents were diagnosed with dementia via consensus conference decision; <i>M</i> MMSE = 18.2 ( <i>SD</i> = 8.8)	<i>M</i> = 12.3 ADLs ( <i>SD</i> = 8.5; range = 0 - 39)
Los Angeles-Orange County study (Mitchell & Kemp, 2000)	<i>M</i> = 81 years ( <i>SD</i> = 9.6); range = 56-100	-	70% received assistance with 1+ ADL; 21% received assistance on 3+ ADLs; 21% <i>M</i> = 1.6 ADLs ( <i>SD</i> = 1.64; range = 1 - 7)

NOTE: AL = assisted living facilities; *M* = mean; *SD* = standard deviation; *MMSE* = Mini-Mental Status Examination; *MSQ* = Mental Status Questionnaire

**Table 4**  
**Types of Family Involvement in Assisted Living: Review of Quantitative Research**

Study	Design	Visits M(SD)	Personal Care M(SD)	Instrumental Care M(SD)	Socioemotional Support M(SD)	Monitoring M(SD)	Advocacy M(SD)
Hawes et al. (2000, 2003)	See Table 2	9.3% none; 26.7% once or twice; 27.6% once a week; 30.1% more than once a week; 6.3% daily in last 30 days	-	-	-	-	-
Port et al. (2005)	Telephone interviews with family members of 353 residents with dementia in 34 AL/residential care settings in 4 states (see CS-LTC, Table 2)	9.72(.68) times per month	2.10(.56) times per month (ADL care)	1.58(.39) times per month (laundry); 2.14(.25) times per month (IADL)	4.69(.86) times per month (call on phone/write letters)	5.81(.86) times per month (medical); 5.27(.44) times per month (finances); 6.25(.53) time per month (well-being)	-
Zimmerman et al. (2001; 2003)	CS-LTC (see Table 2)	69.4-83.3% of residents visited with family/friend in prior 2 weeks (M contacts = 3.2 - 4.3)	-	-	52.6-59.8% of residents telephone family/friends in prior 2 weeks (M contacts = 3.6-5.2)	-	-
Gaugler & Kane (2001)	440 residents from Kane Oregon AL study interviewed at baseline, 6 months, and 1 year (see Table 2)	-	.37 types of "personal care" assistance in past few months from family/friends at baseline	2.68 types of "instrumental" assistance in past few months from family/friends at baseline	-	-	-
Leon et al. (2000)	2 AL facilities from a sample of 13 sites in 9 states; telephone interviews with 161 family caregivers of residents with dementia in AL	-	11 hours of IADL help during an average month	-	-	-	-
Keating et al. (2001)	Telephone interviews with 19, 21, and 39 family members of 2 adult family living programs 1 AL facility, and 1 dementia care setting, respectively in Canada	-	.96 hours on personal care and .73 hours on skilled care in past month	6.22 hours on transportation, 2.00 hours on housework, 1.88 hours on shopping, 1.57 hours on financial management; .16 hours on arranging appointments in past month	23.25 hours on "enhancing well-being" in past month	1.63 hours on "keeping on eye on things" in past month	.27 hours in past month "speaking up for resident"
Gaugler et al. (2003)	In-person resident and telephone family interviews with 34 AL and 38 family care home dyads randomly selected from 5 ALs and 16 family care homes in Kentucky	11.76(9.78) and 3.09(3.41) family visits in AL and family care homes in past month; duration of typical visit: 61.81(51.18) in AL and 71.47	-	-	-	-	-

Study	Design	Visits M(SD)	Personal Care M(SD)	Instrumental Care M(SD)	Socioemotional Support M(SD)	Monitoring M(SD)	Advocacy M(SD)
Newcomer et al. (1994)	See Table 2	(97.88) in family care home 57.6% of residents visited with relatives/friends 3 or more times in prior month	For those who needed help with dressing, eating, or bathing, family helped 1.1%, 2.2%, and 3.1% of residents in prior 7 days, respectively	For those who needed help with medications, managing money, or travel outside facility, family helped 0.9%, 39.6%, and 30.4% of residents in prior 7 days, respectively	49.9% of residents had telephone conversations with relatives/friends 3 or more times in prior month	-	-
Mitchell & Kemp (2000)	See Table 2	77% of residents indicated monthly family contact $M = 75$ minutes "interacting with family;" $M = 209$ minutes "with family"	-	-	-	-	-
Pruchno & Rose (2002)	51 AL residents in a Cleveland, OH facility; assessed on time use during the prior day	1.8 - 43.6 visits from others per month; $M = 14.3$	-	Frequency = 9 for shopping, 1 = laundry; 6 = family takes care of "business;" 6 = family bringing items that resident needs	Frequency of 1-28 for a number of activities inside and outside AL facility (e.g., playing games, reminiscing, dining out, etc.)	-	-
Thompson et al. (2001)	Interviews with 30 residents from 5 ALs in Oklahoma	89 visits per year (range = 1-365)	7% assisted residents with "personal/physical" care during typical visit	28% took the resident "out and about" and 10% helped with "chores" during typical visit	94% "socialized" with residents during typical visit	-	-
Abbey et al. (1999)	Mail survey of 228 visitors ( $n = 216$ family members) of residents in 17 residential care homes in the U.K.	51.9% of parents ( $n = 88$ ) visited with children several times a year 1995-1997; 27.8% visited with children less than several times a year 1995-1997	-	-	86.3% of parents had weekly telephone contact with children 1995-1997; 10.0% had less than weekly telephone contact 1995-1997	-	-
Erickson et al. (2000)	Interviews with 101 individuals in a CCRC in upstate New York; interviewed pre-move (1995) and post-move (1997)	-	-	-	-	-	-
Stacey-Konnert & Pynoos (1992)	50 randomly selected residents in a CCRC interviewed	-	.56 family members provided "assistance" for $n = 25$ residents	2.10 family members "loaned money" to $n = 14$ residents	.06 family members "socialized" with $n = 36$ residents; 1.43 family members served as "confidant" for $n = 44$ residents	-	-
Hopp (1999)	In-person interviews of 617 randomly selected residents of non-randomly sampled board and care homes from urban areas in 7 states	Visit frequency of family members: 22.7% weekly; 14.2% 2-3 per month; 8.2% monthly; 17.7% less than monthly; 25.9% no visits; 11.3% no available family member	For those with ADL limitations ( $n = 206$ ): 5.8% with received "informal" (family, friends, or other residents) help with 1 ADL	For those with IADL limitations ( $n = 519$ ): 26.4% received "informal" help with 1 IADL, 10.4% with 2 IADLs; 4.6% with 3-4 IADLs	-	-	-

Study	Design	Visits M(SD)	Personal Care M(SD)	Instrumental Care M(SD)	Socioemotional Support M(SD)	Monitoring M(SD)	Advocacy M(SD)
Kane et al. (1989; 1991)	1988 mail survey of all licensed adult foster homes in Oregon and in-person interviews with 400 randomly sampled residents	228 residents indicated regular visits with relatives or friends outside of care setting (57%); 36% indicated weekly or daily visits during last few months	-	-	32% of residents indicated weekly or daily telephone contact during last few months	-	-
Lough & Schank (1996)	In-person interviews with 47 older women in 6 congregate housing units in Midwestern U.S.	44 respondents visited relative/close friend in past month	-	-	92% reported feeling "close" to a relative; 93% received 5 or more calls from family/friends in past month	-	-
Adams, Sanders, & Auth (2004)	Mail survey with 234 residents in 2 independent living apartment units in northeastern U.S.	Residents reported an average of 3.13 ( <i>SD</i> = .94) visitors per week	-	-	-	-	-
Mullins & Dugan (1990)	Mail survey with 208 residents of 10 independent living facilities in Florida, U.S.	70% of those with children saw a child monthly; 51% of those with grandchildren saw a grandchild monthly; 27% of those with siblings or other relatives saw either monthly	-	-	-	-	-
Hellström et al. (2004)	Mail survey of 523 residents in "special accommodation" in southern Sweden	-	97 (18.5%) reported help from informal and formal sources	-	-	-	-

NOTE: AL = assisted living facility; *M* = mean; *SD* = standard deviation

Table 5

Family Outcomes in Assisted Living

Study	Design and Family Sample	Family Outcomes Assessed	Predictors/Correlates of Family Outcomes (effect size; p value)
Dobbs & Montgomery (2005)	Mail survey of 260 family members from 83 ALs in Kansas	Facility rating, overall satisfaction with AL, satisfaction with AL staff	Age of family member → facility rating (.14; .0051); Age of family member → satisfaction with staff (.05; .0051)
Buelow & Fee (2000)	Mail survey of 113 family members of 3 ALs in metropolitan area	Single item ratings of: overall care, "residents generally like staff," "residents are comfortable in AL," "staff are interested in residents," "complaints are acted upon," "aspects of care could be improved;" open-ended responses	Family members rated satisfaction higher than residents on the "staff are interested" (3.28 vs. 2.89; < .001) and "aspects of care could be improved" (3.06 vs. 2.61; < .001) items
Marsden (1999)	In-person interviews with 100 family members of residents in ALs of New York and Michigan, U.S., recruited from support groups	Rating of "homeyness" following view of pictures of various models of AL; open-ended responses	Across various facility categories, families tended to rank two-story environments as more "homelike" ( $p < .05$ ) when compared to residents
Gesell (2001)	Mail survey to all family members of 12 ALs in 8 states; $N = 350$	Multidimensional measure of satisfaction with: activities, personnel, aides, apartment, facility, and management	Overall, residents indicated lower ratings of satisfaction than family members ( $p < .05$ )
Levin & Kane (2006)	Kane study; see Table 1	Multidimensional measure of importance and satisfaction with: control, household services, care, programs, dining, and living situation	Family members' ratings of importance regarding control (16.76 vs. 14.97), care (18.02 vs. 16.85), and programs (15.78 vs. 14.29) were higher than residents' ( $p < .01$ ). Family members' satisfaction with control (16.74 vs. 17.59), household services (7.29 vs. 8.73), care (15.81 vs. 17.91), programs (13.45 vs. 14.87), and dining (7.57 vs. 8.33) were lower than residents' ( $p < .01$ )
Leon et al. (2000)	See Table 3 above	Multidimensional measure of caregiving burden: mastery, health change, relationship strain with care recipient, social activity restriction, work strain	Community caregivers reported greater work-related strain than AL family caregivers (2.1/2.0 vs. 1.7; .001)
Port et al. (2005)	CS-LTC; see Table 3 above	Single-item reports of preferred level of involvement and burden in caring for resident	Means adjusted for resident cognition, function, caregiver health, and sociodemographics found that family members of AL residents indicated greater burden than family members of NH residents (1.13 vs. .80; .015)
Seidon et al. (2002)	See above	Single item reports of perceived stressfulness of various care responsibilities recently after admission and 10 months thereafter	Feelings of guilt remained "very stressful" or "stressful," whereas visits and interactions with staff became less stressful
Sloane et al. (2003)	CS-LTC (see Table 2 above); 224 family members of 73 AL residents who died	Single-item reports of: knew death was approaching, believed death occurred in manner resident wanted, and believed resident died with dignity; satisfaction as assessed on a 20-item scale	Family members of AL residents were less aware of resident's approaching death (64.7% vs. 87.0%; .011); overall family satisfaction was higher for family members of AL residents than NH residents (32.1 vs. 41.2; .016) (note: lower score represents higher satisfaction on scale)

NOTE: AL = assisted living facility