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Family Involvement in Residential Long-Term Care: A Synthesis and Critical Review*

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Abstract

The objective of this review is to critically synthesize the existing literature on family involvement in residential long-term care. Studies that examined family involvement in various long-term care venues were identified through extensive searches of the literature. Future research and practice must consider the complexity of family structure, adopt longitudinal designs, provide direct empirical links between family involvement and resident outcomes, and offer rigorous evaluation of interventions in order to refine the literature.

Keywords

Family Involvement; Nursing Homes; Assisted Living Facilities; Family Care Homes; Family Caregiving; Informal Care

Over the past several decades, various research studies have demonstrated that family members remain involved in the lives of their loved ones following placement in residential long-term care facilities (e.g., Bowers, 1988; Maas et al., 2000; Rowles & High, 1996; Smith & Bengston, 1979; York & Calsyn, 1977; Zarit & Whitlatch, 1992, to name a few). These collective findings have helped debunk the myth that families abandon their relatives in nursing homes or similar settings to die in isolation (Rowles, Concotelli, & High, 1996). Although the roles of families in residential long-term care have continued to receive attention in the literature, the findings are diverse as studies are often conducted from different perspectives and are dispersed across various disciplines. The purpose of this empirical review is to critically integrate the disparate, albeit essential, literature on family involvement in residential long-term care. While prior efforts have attempted to review the existing literature (e.g., Davis & Buckwalter, 2001; Moulton, 1993; Naleppa, 1996), no critical review to date has comprehensively examined issues ranging from visits, to types and predictors of family involvement, to family involvement's influence on resident outcomes, to interventions designed to facilitate family involvement in residential contexts. Such a review is timely; an increasing number of studies have documented the prevalence and potential importance of family involvement in long-term care environments and the current effort will offer a conceptual framework for future studies in this area.

The review begins with a description of family involvement. Family involvement is a multidimensional construct that entails visiting, socioemotional care, advocacy, and the

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provision of personal care. Studies that examined various types of involvement were synthesized and critiqued. Second, those factors that potentially influence family involvement in residential long-term care are reviewed. Prior research has found that a number of domains, including facility-level, resident, and family characteristics can affect family involvement following placement. This review will synthesize existing research attempting to address such questions. Third, studies that examine the potential effects of family involvement on important resident outcomes such as psychosocial status, discharge, or mortality are discussed. A prevalent hypothesis in many studies is that family involvement is important for elderly residents in long-term care. This review will determine if current research supports such a postulation. A critical analysis of interventions that are designed to increase family involvement follows. Several programs have been developed to facilitate family involvement in nursing homes, and this review will examine the effectiveness and merit of these evaluations.

The critical review concludes with a discussion of the research and practice implications of family involvement in residential long-term care. Particular attention is given to existing gaps in the field and recommendations to guide future research on family involvement.

Methods

All available studies of family involvement in residential long-term care were reviewed. Articles that were primarily anecdotal were excluded. An extensive search was conducted on the MEDLINE, PSYCINFO, CINAHL, and AGELINE databases, using terms such as ‘family involvement in long-term care,’ ‘families in nursing homes,’ ‘family and nursing homes,’ ‘visits and nursing homes,’ ‘family caregiving and nursing homes,’ ‘family care and nursing homes,’ and ‘informal care/help in nursing homes.’ The term ‘nursing home’ was substituted with other types of residential facilities, such as ‘assisted living’ or ‘adult foster care’ to obtain studies conducted in a wide variety of settings. A snowball approach was used; the references of studies located in our initial database searches were examined to identify additional analyses of interest.

Since the current review focuses primarily on U.S. models of residential long-term care (i.e., nursing homes, assisted living facilities, and family care homes; see above), studies from the U.S. were primarily considered. Heterogeneity in the size, case mix, and regulation of residential environments within the U.S. does exist. However, focusing the review on long-term care settings in the U.S. allowed for a more effective match between findings on family involvement and residential environments of interest (ranging from the more medicalized, hospital-based model of the U.S. nursing home to the social, hospitality-based models of U.S. assisted living to the homelike settings of family care homes).

Broadly defined, a family care home (also called ‘adult foster home’) is in a residentially zoned area, is a private residence, and is licensed to provide long-term care to 1–5 individuals with functional and/or cognitive impairments. A ‘resident manager’ who lives in the family care home provides housekeeping, personal care, and family-style meals to clients. The resident manager may also perform specific nursing services, although the conditions under which such services are delivered vary from state to state (Kane et al., 1989). An assisted living facility is a residential setting not licensed as a nursing home where personal care and routine nursing services are delivered or arranged on a scheduled and unscheduled basis (Kane, 1995; Kane & Wilson, 1993). At their most ‘homelike,’ assisted living facilities are comprised of privately occupied apartments with independence enhancing features such as full bathrooms, kitchenettes, and locking doors. Residents control their space, furnishings, time, activities, and care plans within those apartments. Assisted living facilities are heterogeneous and vary according to size, services offered, and case mix (Hawes et al., 1999).

Results

Describing Family Involvement

Early studies of families and nursing homes (NHs) tended to emphasize the potential isolation residents experienced. For example, researchers characterized the institutionalization of an elderly parent as the 'nadir' of life, or a time of intensified isolation and depression experienced by both caregivers and their relatives (Cath, 1972; Jones, 1972). Additional work on family involvement in long-term care viewed the family member as interfering, disruptive, and critical of professional policies, staff, and the overall facility environment (Bates, 1968; Blum, 1960). A special task force organized by Ralph Nader in 1970 designed to highlight the deficiencies of NH care found that 60% of residents in 10 NHs in West Virginia received visitors once a week, and the other 40% were visited once a month or less (Townsend, 1971). The findings indicated that many residents did not receive regular visitors, but the non-scientific nature of this inquiry makes it difficult to determine the reliability of the findings. This section synthesizes and critiques the findings of subsequent research describing family involvement.

Visiting—A number of empirical studies have sought to determine how often family members visit loved ones in residential long-term care settings (particularly NHs). Research throughout the 1970s sought to dispute the notion that families 'dumped' their relatives in NHs to relinquish responsibility, leaving residents in isolation. For example, data collected from the 1973–1974 National Nursing Homes Surveys indicated that many NH residents received visitors; 61% of residents were visited at least once a week, while 25% were visited less than weekly. Only 11% of residents received no visitors. The majority of residents (50.3%) received visits from children (National Center for Health Statistics, 1977, 1979). A study of 1,114 older adults recruited from Detroit, Michigan-area (U.S.) NHs found that many residents received visits: 75% had a visitor in the month prior to the survey (Gottesman, 1974). A study of 95 NH residents recruited from two counties in Canada found that 1 month and 1 year following admission, 96% and 94% had been visited by relatives, respectively (Spasoff et al., 1978). Relatives tended to visit a few times a week in most cases. These studies provided initial information on family visits; however, detailed data on the frequency or duration of visits were often not described.

Subsequent work explored family visits more directly. Early research by York and Calsyn (1977) examined the quantity and quality of patient-family interactions prior to and following institutionalization in three NHs. The family members of 76 residents visited their loved ones 12 times per month, on average. Similarly, early qualitative work by Smith and Bengtson (1979) emphasized that social interactions and relationships between 100 family members and their institutionalized relatives continued after NH placement. Work by Moss and Kurland (1979) explored family visits in NHs among a sample of 43 women and their relatives. Telephone interviews with relatives found that most (79%) visited at least once a week and generally visited for half an hour or more (79%). Subsequent research efforts throughout the past two decades have continued to emphasize the frequency of family visits following institutionalization. A study by Hook, Sobal, and Oak (1982) examined family visiting patterns among a sample of 349 NH residents and 629 visitors from 3 facilities. Over half of all residents (54.4%) received at least one visitor during the study. Almost 80% of these visitors were family members. In-person interviews with 332 cognitively intact NH residents in Wisconsin (U.S.) found that 52% of residents reported weekly visits (Bitzan & Kruzich, 1990). A smaller study of a dementia special care NH unit found that among 29 family members of residents, 37.9% reported visiting their institutionalized relatives several times per week or more (Monahan, 1995). A recent study of 276 Alzheimer's caregivers who institutionalized their loved ones from 1 month to 21 years earlier found that a considerable number (76%) visited their loved ones once a week or more (Tornatore & Grant, 2002). Clearly, results from small analyses to larger-scale efforts demonstrate the significant amount of visiting that family members engage in following a loved one's institutionalization in a NH.

Longitudinal research that emerged from several prospective studies has also examined the influence of the NH transition on family visits following placement. Ross, Rosenthal, and Dawson (1997) combined qualitative and quantitative data for a 9-month study of visiting among 46 wives of NH patients. Wives reported extensive visiting; 80% visited several times a week or more, and 20% visited daily. The duration of a typical visit was between 2 and 4 hours, on average. An analysis of visits over time found that the frequency of visits did not change significantly ($p = .57$). The findings of the study by Ross and colleagues suggest that some family members continue to visit frequently long-after NH placement. A large-scale study by Port and colleagues (2001) collected pre- and post-NH admission data to determine frequency and predictors of contact for 1,441 NH residents. Two weeks following placement, significant others contacted residents an average of 19.9 times. The Caregiver Stress and Coping Study (CSCS) examined the transitions experienced by 555 dementia caregivers over a 3-year period (Aneshensel et al., 1995). Institutionalization interviews conducted over 2 years found that initially following placement caregivers visited their relatives about 5 hours per week; at 36 months, relatives visited 4.2 hours per week. Penrod et al. (2000) examined 282 primary caregivers and their institutionalized care recipients who were followed over a 6 week period in 3 metropolitan areas. During the first two weeks after NH admission, 53% of caregivers visited the care recipient daily.

Since residential options such as assisted living facilities (ASLs) and family care homes (FCHs) have emerged recently, research on these environments is relatively nascent when compared to NHs. A longitudinal study of 397 FCH residents and 395 NH residents in Oregon found that 41% of FCH residents and 31% of NH residents reported frequency of visits in the past few months as ‘about weekly’ (Kane et al., 1989). A study of quality of life in ASLs conducted by Mitchell and Kemp (2000) included 201 residents of 55 ASLs in California. Residents reported, on average, that 2.7 family members lived within an hour's distance of the facility and 77% of residents indicated monthly family contact. A smaller-scale study of 30 assisted living residents in 5 ASLs in central and northeast Oklahoma also examined visiting patterns (Thompson, Weber, & Juozapavicius, 2001). On average, ASL residents were visited 14.3 times per month. A comparative study of 123 NH, ASL, and community-residing older adults found that in the day preceding the interview, ASL residents spent an average of 75 minutes interacting with family members, compared to the 72 minutes of NH residents (Pruchno & Rose, 2002). Another study focused on informal care provided in board and care homes across 8 states in the U.S. (Hopp, 1999). Among the sample of 617 older adult residents, many (36.9%) had family members who visited 2−3 times per month or more. These studies provide some of the first available information on family visits in residential venues other than NHs.

The existing literature emphasizes that family members remain involved in the lives of their relatives following relocation to a NH, ASL, or FCH. While the frequency and duration of visits vary somewhat, the data certainly seem to dispute the notion that family members leave their loved ones in NHs or similar types of institutions to die in isolation. However, several limitations specific to research on visiting are apparent. Issues arise with regard to the conceptualization of visiting in many studies. The analyses reviewed above tended to collect information from single informants (e.g., residents, family members or staff) on frequency of visits. Problems such as social desirability, recall error, and an overall lack of reliability in hour estimates may influence estimates of visit frequency. Utilization of multiple sources of data to determine informant agreement would offer more detailed data on the actual intensity of family involvement that occurs.

Types of family involvement—Unlike care in the community, where family members often provide intensive care assistance unilaterally (e.g., Whitlatch & Noelker, 1996), a distinct shift occurs when an elderly relative is placed in a long-term care setting. Initial models of family care in NHs were based on the concept of 'dual-specialization' (Dobrof & Litwak, 1977; Litwak, 1985): staff provide personal, hands-on care while family members offer psychosocial support. However, Moss and Kurland (1979; see above) found that most relatives (72%) did a number of 'special things for the resident that might not otherwise be done,' such as grooming, cheering the resident up, or having conversations with the loved one. In a 9-month follow-up questionnaire of 25 family members of NH residents, Linsk et al. (1988) found that family members engaged in an even wider range of activities, such as talking with the relative, holding hands or touching the resident, and helping the resident groom (26%). Early research also explored perceptions of family members' responsibility in providing various types of assistance to institutionalized elderly relatives (Bonder, Miller, & Linsk, 1991; Rubin & Shuttlesworth, 1983; Schwarz & Vogel, 1990; Shuttlesworth, Rubin, & Duffy, 1982). These interrelated studies suggested that caregivers felt responsible for a wide range of tasks, including personal (e.g., grooming, clipping fingernails), instrumental (e.g., laundry, arrange for hair grooming, shop for resident) and socioemotional (e.g., writing letters, maintaining resident's apartment, dealing with family guilt feelings) help. In addition, families felt responsible for new dimensions of assistance not originally engaged in the community, such as reporting abuse to authorities, promoting family understanding of NH policies, and initiating actions to ensure good staff/family relations. When caregivers and staff were asked who had primary responsibility for such tasks, a considerable amount of role ambiguity was apparent (i.e., staff felt that a particular task was the NH's responsibility, while family members felt that certain care tasks remained their responsibility), making it difficult to determine who actually provided assistance.

Subsequent empirical research in the family caregiving literature also adopted a task-based approach when analyzing family involvement following NH placement. Stephens et al. (1991) found that a greater percentage of 60 in-home caregivers provided help with personal and instrumental activities of daily living (ADLs) when compared to 60 institutional family caregivers, although statistical comparisons were not conducted. Studies on caregiving costs (n = 93 community-residing and n = 94 institutionalized dementia patients and caregivers; Max, Webber, & Fox, 1995; Rice et al., 1993) and time use (n = 77 NH caregivers; n = 88 community-based caregivers over a 5-month period; Moss, Lawton, Kleban, & Duhamel, 1993) compared the help provided by home-based and institutional family caregivers. These studies suggested that caregivers tended to relinquish intensive ADL care to NH staff, but remained socially involved with residents and offered other types of help, such as supervision and monitoring of quality of care. Although the Max et al. (1995) and Rice et al. (1993) studies did not conduct statistical comparisons, the Moss et al. (1995) analysis found a number of significant group and group by time differences between NH and community caregivers' on instrumental and personal help ($p < .01$). The results suggested that prior to and after institutionalization, NH caregivers were more likely to report sharper decreases in family care provision.

Other prospective caregiving research indicated that caregivers may provide more personal and instrumental ADL assistance than originally hypothesized. The post-acute informal care study by Penrod et al. (2000; see above) as well as the 36-month analysis of dementia caregivers in the CSCS (Aneshensel et al., 1995; see above) emphasized that caregivers provided considerable amounts of ADL and IADL assistance, often long after the relative had been institutionalized. In the study by Penrod and colleagues, 8.5% of caregivers provided 0 hours of help, 31.9% provided 1 to 34 hours, and 58.2% provided 35 to 224 hours. In the Aneshensel et al. (1995) analysis 40.6% of caregivers helped their loved ones to eat and 50% helped residents get around facility grounds after institutionalization. Unlike cross-sectional comparative studies of home-based and institutional family caregivers, these prospective analyses offered the opportunity to explore patterns of family involvement over time.

Several researchers have questioned empirical analyses of family care in NHs that explore division of tasks. Using qualitative methods, these studies demonstrate that family members and staff members of institutionalized older adults do not discuss caregiving in terms of task allocation, but instead describe care by its purpose (Bowers, 1988; Duncan & Morgan, 1994; Hertzberg, Ekman, & Axelsson, 2001; Karner, Montgomery, Dobbs, & Wittmaier, 1998; Keefe & Fancey, 2000; Kolb, 2000; Rowles & High, 1996; Tickle & Hull, 1995; Tilse, 1997). Through in-depth, open-ended interviews with small and diverse samples, these studies often found that family members' primary purpose in remaining involved in the NH was preserving the identity of the institutionalized older adult. Family members stressed that preserving the identity of the relative could be accomplished only through collaborative efforts with staff. Oftentimes family members perceived effective involvement as not providing direct care themselves, but instead serving as a teaching resource to staff members so that aides and nurses would deliver sensitive, nuturant, and individualized care to the institutionalized relative.

A challenge to any comprehensive review of a particular area of research is the critique of not only empirical analyses, but also qualitative studies that utilize decidedly different techniques (e.g., Morse, Swanson, & Kuzel, 2001). ‘Desirable features’ investigators can utilize when critiquing qualitative work include the values, characteristics, and techniques of qualitative inquiry that potentially lead to theoretical refinement. Utilizing these criteria as guidelines, qualitative studies of family involvement in NHs exhibit several strengths and weaknesses. Many of the studies highlighted above, by emphasizing open-ended interview techniques and eliciting themes important to family members, suggest a strong sense of empathy and collaboration that many quantitative analyses, which rely heavily on task-based approaches, do not. The studies by Bowers (1988), Duncan and Morgan (1994) and Rowles and High (1996) in particular examine the context of NH care and how family involvement is often a function of ‘permeability,’ or community integration, of a given facility as well as how family involvement and decision-making is embedded within constellations of other individuals, such as the resident, nursing staff, and administrators. The techniques of inquiry vary across these qualitative investigations; with the exception of the Rowles and High (1996) study which collected and triangulated data from a number of individuals, including family members, residents, staff, administrators, and even physicians, most qualitative analyses focus on interviews solely with single family members. The rich open-ended data across qualitative investigations, however, do suggest a more complex role for family members following placement than those offered in analyses that rely on task-based assessments.

Some work explores the role of family members in other types of residential long-term care venues, such as ASLs. Research by Gaugler and Kane (2001) compared informal (i.e., unpaid) ADL and IADL assistance provided to NH and ASL residents in Oregon (U.S.) over a one-year period. At baseline and 6 months, ASL residents reported more informal help with arranging appointments and transportation ($p < .05$). The small-scale study by Thompson et al. (2001) found that ASL residents in Oklahoma, U.S. engaged in a number of personal activities with family members both inside and outside their facilities; residents named sitting and visiting/playing games as the most frequent activity with family members. The multi-state board and care home study conducted by Hopp (1999; see above) reported that few residents received informal assistance with ADLs, but of those residents who needed help with one or more IADLs approximately 40% received informal help with at least 1 IADL. The findings of these various studies suggest that family members are a vital source of care for older adults who live in less ‘institutional’ care settings, and may be integral to achieving economies of scale in these environments.

A number of efforts have described how families remain involved in the lives of their relatives following placement in a long-term care facility. However, specific shortcomings in the designs of these studies emphasize the need for further inquiry. As qualitative researchers rightly noted, much of the empirical research on family involvement is task-based; little is known about the various roles family members play following placement, or how these roles interact following the transition from in-home care to institutionalization. The contributions of findings from many studies are limited by describing family involvement in terms of ADL or IADL help. As with research on family care in the community (see Gaugler, Kane, & Kane, 2002), there is a need to consider dimensions of family involvement above and beyond instrumental or personal care, such as socioemotional forms of help to the resident and family members' interactions with staff (e.g., monitoring or directing care). For these reasons, a broader operationalization of family involvement is needed to fully illustrate the process of family integration in residential care contexts.

Factors that Influence Family Involvement

Several studies have identified predictors of family involvement following institutionalization. The early work by York and Calsyn (1977) reported that preplacement phone contact was moderately and positively correlated with number of family visits ($r = .28$, $p < .01$). Research by Hook, Sobal, and Oak (1982) found that the geographic proximity of family members ($r = .42$; $p < .001$), family members who visited alone ($r = .32$, $p < .001$), and residents with shorter lengths of stay ($r = .31$; $p < .001$) were positively correlated with NH visits. A handful of studies also examined the role of facility-level variables or institutional policies as potential factors that could influence family involvement. The early Detroit, U.S. study by Gottesman (1974) indicated that residents in non-profit NHs with a low proportion of public pay residents had more visitors in the month prior to the survey, although significance levels were not reported. A study of 104 randomly sampled residents from 3 NHs in the upper-Midwestern U.S. found that the facility most oriented to treating families as ‘clients’ (family members have needs and desires that should be met) was most likely to facilitate family integration and positive family relations (Montgomery, 1982). Subsequent work by Friedemann and associates (1997, 1999) built on Montgomery's research by developing a 20-item questionnaire to assess family-orientation in 24 facilities in the Detroit, Michigan (U.S.) area. While some facility policies such as encouragement of visiting were associated with similar family involvement patterns, other types of involvement not promoted by the facility, such as hands-on care by family members, did not dissuade some families from continuing to provide this assistance.

Prospective research has also identified a wide array of factors associated with family involvement in NHs. The large-scale study of 1,441 NH residents by Port et al. (2001) reported that pre-admission contact ($\beta = .30$; $p < .001$), contacts who were spouses or adult children ($\beta = .12$; $p < .001$), geographic proximity ($\beta = .14$; $p < .001$), less cognitive impairment ($\beta = -.15$; $p < .001$) and Caucasian racial identity ($\beta = -.10$; $p < .01$) were all significantly predictive of increased post-NH admission visits. An analysis of 185 caregivers of relatives with dementia prior to and following NH placement found that caregivers with less formal education ($B = -.83$; $p < .05$), caregivers who provided at-home care for shorter periods of time ($B = -.83$; $p < .05$), residents with a greater length of stay in the NH ($B = .46$; $p < .05$) and care recipients with a lower frequency of behavior problems prior to placement ($B = -4.18$; $p < .05$) were all variables that predicted more frequent family visits (Gaugler et al., 2000). The study by Max and associates (1995) ascertained predictors of ‘informal care’ costs, or the annual amount of informal care provided by family members and friends for a sample of 94 institutionalized older adults. Residents who were younger ($\beta = -.01$, $p < .05$), caregivers who were younger ($\beta = -.03$, $p < .001$), non-spousal caregivers ($\beta = -.54$, $p < .01$), caregivers who provided assistance for longer periods of time ($\beta = .01$, $p < .05$), caregivers who lived alone ($\beta = .37$, $p < .001$), residents who suffered from fewer cognitive ($\beta = -.04$, $p < .001$) and functional impairments ($\beta = -.20$, $p < .001$), and caregivers who were male ($\beta = .49$, $p < .001$) were all variables significantly associated with informal care provision in the institutional sample.

Additional studies have examined predictors of family care in settings other than NHs. The longitudinal analysis by Gaugler and Kane (2001) examined predictors of informal help over a one-year period among a sample of Oregon (U.S.) ASL and NH residents. Multiple models found a number of variables that influenced informal help over time; for example, families who lived closer to the facility were more likely to provide ADL or IADL help at baseline, 6 months, or one year ($p < .05$) in both settings. Residents who were older, more frail, and had completed less formal education also appeared more likely to receive increased informal care over the 1-year study period. Pruchno and Rose (2002), in a comparison of ASL and NH resident daily time use, found that individuals with a longer length of stay in ASL and NH care settings spent less time interacting with family members ($\beta = -.32$, $p < .05$). The multi-state board and care home study by Hopp (1999, see above) identified predictors of informal IADL help for older residents. Women ($B = .21$, $p < .01$) and Caucasian residents ($B = -.41$, $p < .01$) received more informal IADL help, and those who had more frequent contact with family members ($B = .16$, $p < .01$) were more likely to receive informal help with IADL tasks. Overall, research in ASLs and other settings suggest that residents who have traditionally stronger, more proximal connections to kin and social resources are likely to receive informal assistance.

Predictors of family involvement have also been explored in qualitative investigations. Work by Kelley and colleagues (1999) examined reasons for visiting among family members of institutionalized relatives in special care units. Thirty randomly selected family members from a larger study of family involvement in Iowa (U.S.) special care units (Maas et al., 2000) participated in a series of semi-structured interviews. Content analyses revealed various predictors of family visits, including family members' past interpersonal relationships with the resident, prior perceptions of NHs, and current social support from others. Reasons why family members visited included being faithful to the relative, being the ‘eyes and ears’ of the resident, and being family. Kellett (1998, 1999) examined family members' perceptions of caregiving in NHs. A series of semi-structured interviews with a small number of family members ($N = 14$) elicited several important themes in the process of family involvement. Motivation for and meaning of family involvement included sense of family life past, a sense of a break from caregiving, sense of change in engaged involvement (i.e., shift from personal, hands-on care to more socioemotional support), sense of worth (i.e., possessing special knowledge), sense of concern, and sense of continuity. A major strength of these qualitative investigations is the recognition that family involvement is embedded in prior family relationships; many quantitative studies have ignored family history when examining involvement following institutionalization. However, as with other qualitative investigations of family involvement in long-term care, a need to triangulate data sources is necessary when determining the processes of family involvement (i.e., moving beyond interviews with single family members and involving other important individuals).

Family Involvement and Resident Outcomes

It has been argued that increased family involvement is important to residents and is directly linked to improved quality of life. However, few studies have determined whether family involvement influences resident psychosocial or functional outcomes. An early study by Noelker and Harel (1978) identified predictors of well-being and survival among 125 long-term care residents of 14 NHs. Regression models found that residents' who had ‘met their desire for visitors’ were more likely to report higher life satisfaction ($B = .21$, $p < .05$). Greene and Monahan (1982) also examined whether family visits to NH residents affected psychosocial well-being. A random sample of 28 NHs and 298 residents within these facilities were included. Staff members were surveyed on a variety of dimensions, and subsequent empirical models found that frequency of NH visits was negatively related to residents' psychosocial impairment ($p < .05$). This early work hinted at the important role of family and the family context in accounting for key outcomes among NH residents, offering descriptive support to later longitudinal research.

Work by Lewis, Kane, Cretin, and Clark (1985) determined predictors of immediate and long-term discharge from NHs. Five-hundred and sixty-three patients discharged from 24 NHs in southern California were followed from 1980 to 1982 retrospectively. In addition to a variety of functional indicators, information on visits (coded as 0 = no; 1 = yes) was obtained from nursing notes. Residents who received visitors were more likely to discharge from a NH alive ($B = .55$, $p < .05$). Subsequent work by Penrod and colleagues (2000; see above) attempted to determine whether informal care provided to residents during the 2 weeks following admission to NHs influenced discharge over a 6-week period. Caregivers providing the greatest informal assistance (i.e., more than 35 hours of care per week) were most likely to discharge their loved ones from a NH (odds ratio = 7.23; $p = .01$). The findings suggest that informal care may positively affect the quality of care residents receive in long-term care environments, possibly leading to discharge to the community. However, a potential (and more parsimonious) explanation for these results is that due to the availability of a family member, there is an increased likelihood for discharge to the community. As there is an implicit bias in much of the family involvement literature to focus on long-term care residents with an available family member, the experiences of those residents without family members or other informal supports remains unexplored and a key area for future research (see below).

Research by Kiely, Simon, Jones, and Morris (2000) examined the empirical relationship between NH resident social engagement and mortality over a 1721-day follow-up period. A total of 927 residents from a Boston NH were included. A six-item scale of social engagement developed by Mor and colleagues (1995) was used, and data on other important covariates were derived from MDS assessments. Those with higher scores on the social engagement scale were less likely to die during the course of the follow-up (risk ratio = 2.78, $p = .0001$). Although limited to one facility and residents who could communicate, the long follow-up period and large sample offer persuasive results linking residents' social integration with important outcomes. Another large-scale study by Zimmerman and associates (2002) included 2,015 new admissions from 59 randomly sampled NHs in Maryland, U.S. In addition to a wide range of other factors, percentage of facility visitors per every 100 beds was significantly associated with a slightly lower risk of infection (relative risk = .99) and hospitalization for infection (relative risk = .90) among NH residents in the analysis.

Interventions Designed to Facilitate Family Involvement

Various interventions have attempted to facilitate family involvement and improve quality of staff-family relationships. Although a number of strategies exist, ranging from support groups to family councils, most of these interventions have not been evaluated in a scientific manner that incorporate control groups or administer measurement conducive to evaluation (e.g., Cox & Ephross, 1989; Fabisewski & Howell, 1986; Greenfield, 1984; Hansen, Patterson, & Wilson, 1988; Helphand & Porter, 1982; Hepburn et al., 1997; Linsk et al., 1988; Palmer, 1991; Peak, 2000; Safford, 1980; Sancier, 1984; Shulman & Mandel, 1988; Van Meter & Johnson, 1985). The few programs that were subject to scientific evaluation are discussed below.

A smaller-scale study by Anderson, Hobson, Steiner, and Rodel (1992) determined if family involvement in the delivery and planning of care would have positive effects on NH residents with dementia. The study was conducted at a VAMC unit in the Midwestern U.S. and included 12 subjects with dementia and their family members. Six participants were randomized to an experimental condition and 6 to a control. Two registered nurses contacted family members in the experimental group and requested a meeting designed to jointly develop care plans, identify resident interests, and address concerns. At the end of 12 weeks, the nurse and family members met to evaluate the experience. Family members reported better relations with the resident and indicated that the resident responded more favorably to family visits. Also, medications were more likely to be reduced for residents in the experimental condition. The findings highlight the potential of family-staff interventions to facilitate communication. A particular strength of this study was including a control group as part of its experimental design, which helped to highlight the benefits of the program.

The Family Involvement in Care (FIC) program was designed to negotiate and establish partnerships and cooperative role behaviors between family caregivers of cognitively impaired NH residents and staff members (Maas et al., 2000). The components of the FIC included family orientation and education sessions, as well as the negotiation, formation, and evaluation of partnership agreements between family and staff. NHs were grouped in pairs according to size and ownership type; one facility in the pair was randomly selected to receive the FIC. The intervention targeted family members' involvement and adaptation to placement as well as staff relationships with family members and overall job satisfaction. Effects of the intervention were evaluated for family members of residents with Alzheimer' disease and staff in 14 NH special care units (7 experimental, 7 control) in Iowa, U.S. A nine-month trial of the FIC was completed for each family member, including 2 pretests in months 1 and 3 and three posttests at months 5, 7 and 8. Staff were measured at baseline and every 6 months thereafter. Two hundred family members agreed to be contacted of the 371 that offered consent; 99 family members completed the entire 9-month evaluation. Providing physical care and consideration of the relative increased for family members in the FIC. In addition, feelings of loss decreased for family members in the FIC. Strength of partnership ratings between family members and staff were also higher in the FIC (all findings reported at the $p < .05$ level). The FIC evaluation demonstrates the potential benefits of structured interventions for improving family involvement.

The Partners in Caregiving (PIC) program developed by Pillemer et al. (1998) is designed to intervene not only on the part of family members (e.g., councils or support groups), but also to engage staff and administrators to effectively change facility policies. The PIC consists of two workshop series (one for nurses and nursing assistants; one for family members) that include various components such as training in communication and listening skills, group discussions, and similar exercises. Both family members and staff were assessed during the course of the PIC to determine the effects of the intervention on family involvement, relationships between families and staff, and staff job satisfaction. Preliminary evaluations in New York (U.S.) NHs suggested high satisfaction among family members and staff. Extension and replication of the initial evaluation included 932 relatives and 655 staff members recruited from 20 NHs in the central New York (U.S.) region (Pillemer et al., 2002). Two representative units from ten of the facilities were selected and randomly assigned to a treatment or control condition, and family members of residents and staff were recruited from these units. In order to reduce the potential effects of contamination, 10 additional facilities were randomly selected as ‘pure’ control sites. Randomization ensured adequate statistical comparability between the treatment and control conditions. After 6 months, 683 family members and 450 staff remained in the study (interviews were administered at baseline, 2 months, and 6 months). Significant treatment effects were found over the 2- and 6-month intervals; both families and staff in the PIC showed improved attitudes toward each other ($p < .05$), families of residents with dementia reported less conflict with staff ($p < .01$), and staff were less likely to quit during the course of the intervention ($p < .05$). The findings suggest that the PIC may serve as an effective method to reduce family-staff conflict in NHs. Treatment effects did appear to weaken from the 2- to 6-month time interval.

Discussion

While prior research has adequately emphasized that family involvement exists in NHs, inquiries in other areas (e.g., family involvement and resident outcomes) are relatively scant. Moreover, most interventions designed to facilitate family involvement in residential settings have not been subject to rigorous evaluation. For these reasons, we provide recommendations to refine the research and practice of family involvement in residential long-term care.

Empirical research to date has largely ignored the various roles family members play in the lives of institutionalized loved ones. For example, quantitative studies either analyze visits only or utilize task-based approaches based on ADL and IADL measures to determine range, and in some cases frequency, of family involvement. However, as qualitative research has made clear (e.g., Bowers, 1988; Duncan & Morgan, 1994; Kelley et al., 1999; Rowles & High, 1996), family members roles' extend beyond the provision of personal and instrumental care to encompass assistance that is designed to preserve the identity and quality of life of loved ones. Quantitative research that builds on ADL and IADL task-based measurements and assesses more socioemotional forms of help is needed to fully describe family roles in residential long-term care.

The literature also tends to assume that increased family involvement is positive and leads to quality of life and quality of care for residents. Relative to other research on family involvement, few studies exist that directly test this assertion. Prior work suggests that family involvement and increased social engagement leads to positive psychosocial outcomes (Greene & Monahan, 1982; Noelker & Harel, 1978), discharge to the community (Lewis et al., 1985; Penrod et al., 2000), and decreased mortality, infection, and hospitalization on the part of residents (Kiely et al., 2000; Zimmerman et al., 2002). Most of these studies solely examine family visits or ADL/IADL care provided and do not ascertain how other dimensions of family involvement (e.g., socioemotional support, advocacy) may affect residents. Given the multidimensional nature of family involvement and quality of life (e.g., Kane, 2001), future research must direct greater attention to the potentially complex associations between family involvement and various domains of resident outcomes.

The majority of research on family involvement tends to use cross-sectional designs to address questions of interest. These studies assume a static, retrospective approach to examining family involvement in long-term care environments. For example, negative correlations between NH resident length of stay and family visits suggest that the longer relatives remain in NHs, the less likely family members visit. In contrast, prospective longitudinal research has found that many families continue to remain involved in the lives of institutionalized loved ones (e.g., Aneshensel et al., 1995; Spasoff et al., 1978). Additional prospective research that includes larger, more representative samples and examines types of involvement in addition to visits will significantly add to our understanding of how family involvement shifts and changes over time.

Further refinement of the literature will occur if family involvement is explored in contexts beyond the NH. Most research inquiries have examined family visits and involvement in nursing facilities; while such settings provide the majority of residential long-term care to older adults, other venues have begun to emerge that are beginning to serve an increased number of clients (e.g., ASLs, FCHs). Future work that builds on past research and determines the role and importance of family involvement in these settings will help to advance the literature. Moreover, few studies examine family involvement among residents of diverse ethnic origin (for an exception, see Kolb, 2000). As in community caregiving (e.g., Dilworth-Anderson, 2001), family involvement within diverse ethnic or racial contexts may operate in a qualitatively different manner when compared to Caucasian residents. The process of family care and integration in these contexts will offer a fuller picture of the placement experience for all families.

Attrition in resident, family, or staff samples is often an unavoidable challenge facing investigators who longitudinally describe family involvement in residential long-term care or evaluate family-based interventions. Nonetheless, the empirical effects of participant drop-out (whether due to death or loss-to-follow-up) can bias final results. As recommended by Kane and others (Stark, Kane, Kane, & Finch, 1995), several conservative approaches can be included to counteract the effects of attrition bias in long-term care samples. For example, in addition to a model of participants who remain in the analysis, parallel models that include those residents who both remain in the study over time as well as those who exit (in NHs, reason for exit will most often be due to death; e.g., Gaugler & Kane, 2001) can be considered. Residents who die are assigned the lowest values on measures of importance, such as functional status, family involvement, and psychosocial well-being. Although this approach may be overly conservative, it certainly can address the potentially negative effects of attrition due to death in an evaluation analysis. As recommended by Heckman and others (Berk, 1983; Heckman, 1979; Miller & Wright, 1995), several empirical approaches can also be incorporated to counteract the effects of attrition bias in longitudinal evaluations, such as the Heckman two-stage approach (Heckman, 1979). The Heckman adjustment essentially involves modeling the ‘decision’ to leave a longitudinal evaluation and then using information about each person's likelihood of exiting the study (i.e., the Mills ratio) to correct for selective attrition bias in subsequent analytical models.

An additional conceptual limitation in family involvement research is its general focus on a ‘primary’ family member. The primary family member generally refers to the one relative who remains most involved in the life of a resident following institutionalization (Maas et al., 2000). As the community-based caregiving literature has noted, there is usually one ‘primary’ caregiver who provides the bulk of assistance to a disabled elderly relative (Aneshensel et al., 1995; Cantor, 1983). However, other studies have emphasized that multiple family members within diverse family structures provide assistance to chronically impaired older adults, illustrating the complexity of the family caregiving process (Dilworth-Anderson, 2001; Gaugler et al., 2000b; Schoenberg, Amey, Stoller, & Mundoon, 2003; Tennstedt, McKinlay, & Sullivan, 1989). To date, research that has focused on family involvement following institutionalization has not recognized this complexity. The dynamics of family structure, in terms of number of involved family members, their roles in involvement, and their interactions with facility staff must be taken into account in both qualitative and quantitative research. In addition, implementing a broader focus on family context may enhance the effectiveness of family interventions. Recognizing the multiple configurations of families may help to refine and facilitate staff-family care plans and relationships, and in some cases could prove integral to the successful involvement of not only a primary family member, but also the entire family.

In contrast, some residents in a variety of long-term care settings have no family members at all, which complicates the interpretation of the findings in prior family involvement research. For example, findings suggest that families with relatives who live closer to residents are more likely to visit when compared to family members who do not. However, these results often do not take into account those residents without family members, which adds considerable complexity to the role and potential influence of family involvement in residential long-term care. To date, it remains unknown how the lack of family members among older adults in residential long-term care affects key outcomes. Future research that recognizes and includes residents without family members or other social supports would add considerably to the family involvement literature and provide key information on how external social support influences older persons in residential long-term care.

Descriptive studies on family involvement following placement are helpful in laying a foundation of basic knowledge on decision-making, coping, and adjustment of families to the NH experience. However, the literature remains relatively atheoretical; conceptual models are needed to determine the antecedents and ramifications of family involvement in residential long-term care. Such models would be useful in guiding both descriptive efforts as well as developing interventions with the goal of facilitating family involvement. For example, Figure 1 illustrates a potential model of family involvement in residential long-term care that captures elements of family caregiving prior to placement (i.e., the stress process; see Aneshensel et al., 1995) as well as descriptive quantitative and qualitative findings on the types and ramifications of family involvement. Specifically, the stress process model takes a multidimensional and comprehensive approach in describing how caregiving can become problematic during preplacement, and highlights various precursors and outcomes including the sociodemographic context of care, emotional and psychological reactions to care demands, and psychosocial resources that can mitigate negative outcomes related to stress. In addition to incorporating elements of the stress process, the conceptual model in Figure 1 considers the results of prior research in documenting the potential types of involvement among multiple family members in residential long-term care, their antecedents (e.g., aspects of the residential setting, sociodemographic context of family and resident, resident functional status), and potential outcomes among an array of stakeholders (i.e., family, staff, residents, and facilities). An important component of the model is its emphasis on time; family-resident relationships have their genesis in lives prior to placement (Kelley et al., 1999), and these in addition to prospective events must be considered when analyzing the placement experience for families.

Until recently, many interventions designed to improve family involvement and family/staff relationships have not been subject to scientific evaluation; few evaluations utilize randomized, ‘intention to treat’ designs (see Hollis & Campbell, 1999; Montori & Guyatt, 2001) where treatment and control participants are randomly assigned prior to the intervention allowing for more thorough assessment of program effectiveness. Although a few interventions use fairly rigorous evaluation designs when determining efficacy (e.g., Anderson et al., 1992; Maas et al., 2000; Pillemer et al., 2002), these programs have been implemented in singular facilities or regions only. Given the diversity in resident populations that likely exist in different facilities and regions, successful programs must be administered and evaluated at multiple sites. Finally, more rigorous attempts to determine the effectiveness of singular approaches or compare various strategies are needed to assist practitioners and other stakeholders identify those programs that would be most beneficial in their given facilities.

Programs that appear to exert the greatest impact consider multiple stakeholders when attempting to increase and facilitate family involvement. For example, interventions that incorporate family and staff in collaborative partnerships/contracts have reported efficacy in improving family involvement in some areas (e.g., Anderson et al., 1992; Maas et al., 2000; Pillemer et al., 2002). In addition to assessing the benefits of these programs for family/staff relationships, these interventions could measure potential outcomes for residents, family members, staff, administrators, and the overall facility environment more consistently in order to document the overall ramifications of family/staff partnership programs. In particular, it appears that the success of family involvement interventions depends on the culture of each facility (e.g., Caron et al., 1999). Future evaluations that document the interactive relationship between program implementation and facility environment/culture over time would help practitioners determine whether such approaches are feasible in their respective facilities.

Several tools are available to practitioners that can provide guidelines when developing family intervention strategies in residential long-term care. For example, family life education (FLE), with its demonstrated theoretical and practice foundations, may serve as a useful starting point when implementing family involvement interventions (e.g., Arcus, 1987, 1992; Brubaker &

Roberto, 1992; Thomas & Arcus, 1992). The main objective of FLE is to strengthen and enrich individuals and family well-being; within the residential long-term care context, programs that capitalize on: 1) the continuity of individual and family behaviors (e.g., having facility staff understand the nature and history of family relationships prior to placement); 2) challenges of change for families (learning about how individuals and families have managed stressful situations in the past when developing strategies to improve resident quality of life and quality of care); 3) the multigenerational family (directing programs beyond a ‘primary’ family member and instead involving multiple family members who are likely to visit and remain integrated in the resident's life, such as grandchildren); 4) older persons as resources (utilize families and residents themselves as sources of information to guide individualized care plans and responsibilities); and 5) diversity of older people (programs must recognize that differences in gender and racial/ethnic background necessitate flexible, individually-tailored programs as opposed to a ‘one program fits all’ approach) may result in the most successful outcomes. While each of the different interventions presented above may encompass some of these FLE objectives, new generations of family-based programs in long-term care that comprehensively incorporate FLE guidelines may prove even more effective for facilities, staff, families, and residents.

In addition to FLE, several efforts at nursing home reform also exist which may serve as useful starting points when designing and implementing programs to promote family involvement. Perhaps the most notable is the Eden Alternative (EA). Introduced in a New Berlin, New York (U.S.) NH, the EA aims to improve quality of life for NH residents by creating a more homelike environment that de-emphasizes the traditionally medicalized philosophy of the U.S. nursing home facility. This is primarily accomplished with a systematic introduction of pets, plants, and children. Accompanying these changes are increased programmatic and administrative efforts to empower and engage staff to initiate such changes (Thomas, 1994). While anecdotal research suggests that the EA reduced mortality, drug use, and upper respiratory infections (Thomas, 1996), larger-scale longitudinal studies of the EA provide more equivocal results as to the benefits of the EA on NH resident outcomes or staff turnover, particularly on standardized resident indicators such as those derived from the Minimum Data Set (e.g., Brooke & Drew, 1999; Coleman et al., 2002; Drew & Brooke, 1999; Hinman & Heyl, 2002; Ransom, 1998). Given the psychosocial focus of the EA, few studies have evaluated how the implementation of this model potentially influences or promotes family involvement. Qualitative data implies that families value the implementation of the EA at their relatives' facilities (Drew & Brooke, 1999); however, extensive qualitative or quantitative findings on how programs such as the EA promote family involvement have yet to emerge. Future work that examines the roles of family members within psychosocial reform efforts such as the EA may provide additional insight into how traditional long-term care practice can be modified to enhance the social environments of residents.

A final recommendation, and one aimed at practitioners themselves, is the need for research participation, particularly in studies that attempt to evaluate novel programs designed to enhance family involvement. Although it is a growing area of research, there is little empirical evidence on how family involvement actually affects long-term care residents, or what strategies are most effective in incorporating families into facility life. Understanding how families contribute to resident, staff, and facility outcomes via quality research can lead to important benefits to providers who are actively involved in quality of care and quality of life improvement efforts.

Conclusion

Early research on family involvement in residential long-term care focused on debunking the myth that families abandon relatives following NH placement. As an extensive review of the literature suggests, many families continue to visit and provide various forms of assistance to loved ones in residential settings. The reasons why family members remain involved in the lives of relatives following institutionalization are complex; various facility, resident, and family-level variables all appear to account for family involvement. Some work has also linked family involvement to important resident outcomes, such as life satisfaction and early discharge to the community, although relatively few studies have been conducted in this area. The potentially positive effects of family involvement have led to the development and evaluation of various programs that attempt to improve family involvement and family-staff relationships. While the literature has grown considerably over the past three decades, research on other types of residential long-term care settings (e.g., ASLs, FCHs), prospective longitudinal studies, a consideration of the complex dynamics of family structure, and rigorous evaluation of interventions will advance the state of the art. These refinements will assist researchers, practitioners, and policymakers transform medicalized models of institutional care into family-oriented residential settings that emphasize choice, community connection, and quality of life.

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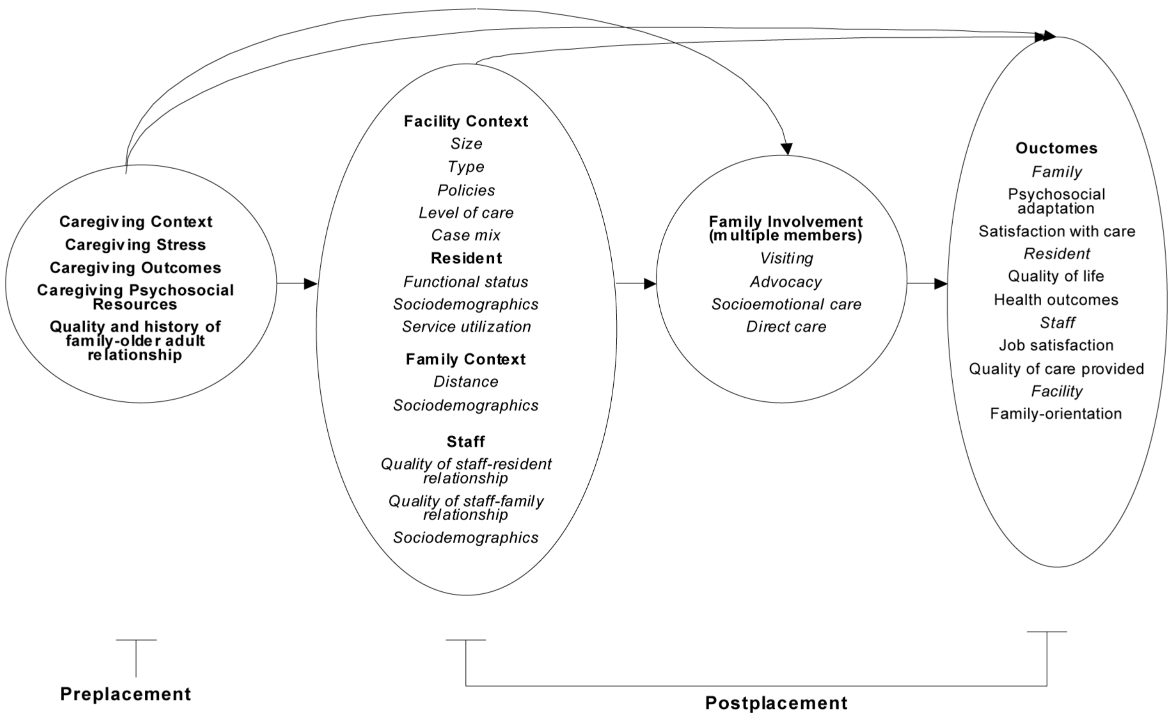

Figure 1.

Conceptual model of family involvement in residential long-term care.