Special Article

Reimagining Family Involvement in Residential Long-Term Care

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Abstract

Although descriptions of family involvement in residential long-term care (RLTC) are available in the scientific literature, how family involvement is optimized in nursing homes or assisted living settings remains underexplored. During the facility lockdowns and visitor restrictions of the COVID-19 pandemic, residents experienced social deprivation that may have resulted in significant and adverse health outcomes. As with so many other critical issues in RTLC, the COVID-19 pandemic has magnified the need to determine how families can remain most effectively involved in the lives of residents. This article seeks to better understand the state of the science of family involvement in RTLC and how the COVID-19 pandemic has expedited the need to revisit, and reimagine, family involvement in RLTC.

Keywords:
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Long-term care is defined as “an array of informal (unpaid) and formal (paid) community-based and residential services offered to those with chronic conditions and/or functional limitations over time.” Long-term care is not necessarily arranged across a linear continuum but is dynamic and interactive in terms of the services delivered and the environment where these services are received. One scenario that features the overlap, and in some instances tension, between formal and informal long-term care provision is family involvement in residential long-term care (RTLC) settings such as nursing homes (NHs) or assisted living communities. The tension in how family involvement in RTLC is optimized has, like so many other critical issues, been magnified and exacerbated throughout the COVID-19 pandemic. One of the primary methods to reduce community transmission of COVID-19 within RTLC settings was to severely restrict family visitation; such measures were implemented by state departments of health in the United States. However, facility lockdowns and visitor restrictions have raised serious concerns among families and staff about the social deprivation experienced by many residents.

This article seeks to better understand the state of the science of family involvement in RLTC and how the COVID-19 pandemic has expedited the need to revisit, and reimagine, family involvement in RTLC. To address this concern, we present research, practice, and policy recommendations based on a review of recent scientific literature and, in particular, highlight those issues related to family involvement that emerged during the COVID-19 pandemic. We demonstrate how families are involved in RTLC; how such involvement is linked to family, resident, and quality of care outcomes; how family involvement can be optimized in RTLC; and how COVID-19 necessitated a reimagining of family involvement. The recommendations provided herein are practical and positioned for ready implementation in RTLC in order to more fully integrate families’ in NHs, assisted living communities, or similar environments.

Recent Literature on Family Involvement in RTLC

Prior and more recent reviews of family involvement in RTLC2–6 have emphasized that although the nature of family caregiving may change considerably with the entry of a relative to an NH or assisted living setting, it by no means ends. In general, family members’ roles may change or adapt following the admission of a relative to RTLC, but families continue to visit, advocate for, and in some instances offer personal and/or instrumental assistance.7 Much of the prior research on family involvement in NHs describes visits and types of family involvement.2 In order to better characterize the state of the science of family involvement in RTLC, we conducted an updated search of the literature. From January 2007 (the date of publication of our last literature search)7 to November 2021, we searched the MEDLINE, PsycINFO, and EMBASE databases to identify recent research on family involvement in RTLC. The following keywords were used and combined: family involvement, nursing homes, assisted living, and residential...
long-term care. Single studies or literature reviews that considered any aspect of family involvement during or following a relative’s admission to an RLTC setting were considered.

A total of 106 abstracts were identified and 81 individual studies were reviewed and, where appropriate, their findings were synthesized for this updated review. Additional references in the first author’s personal library were also included and integrated into the review. Following a review of abstracts and full-text articles by the first author, the studies were categorized in terms of their focus on family involvement in RLTC. These categories included (1) types and domains of family involvement; (2) family involvement and outcomes; (3) family-staff relationships; (4) family involvement, RLTC, and key transitions; (5) optimizing family involvement in RLTC; and (6) the potentially transformative effects of COVID-19. Studies relevant to these categories are summarized in the section below.

Types and Domains of Family Involvement

Several recent studies have explored domains of family involvement in RLTC. Reviews and concept analyses of family involvement in RLTC have identified several themes that describe the family involvement process: relationship building with care staff, negotiating with care staff, professional support of staff, management of expectations and the role of families, collaborative engagement with staff, and provision of personal and therapeutic care.8–11 Families also address key unmet care needs for relatives in RLTC.7 Residents perceive family involvement as a “blessing” and indicate a sense of competence and achievement when maintaining family relationships. Families can also ensure care quality while honoring filial responsibilities.12,13 Moreover, the sense of “home” in an NH as perceived by residents, family members, and staff includes robust family involvement.14 Mixed methods analyses have indicated that families tend to increase involvement during short-term (ie, less than 3 months) stays and when a relative’s health requires greater attention. Spouses and women are more likely to visit, provide personal care, or engage in family-staff communication, whereas families in rural areas report less family involvement.15 In a review of the literature, Miller16 identified the following barriers to family visits in RLTC: psychological issues, health concerns, impaired staff-member relationships, employment and financial impediments, prolonged travel time to the facility, and lack of access to transportation.17 Other qualitative studies have examined the NH as a power structure that influences how families remain involved in the lives of relatives over time.18

Findings from the Collaborative Studies of Long-Term Care revealed that although frequency of family visits do not differ for cognitively impaired RLTC residents, family members of cognitively impaired residents were more likely to engage in care-related activities during visits.19 In addition, most family members of NH residents report remaining very involved in the behavioral management of their relatives, although fewer than a quarter of family members were engaged in the prescription process of antipsychotic medications.20 Relatives who require greater assistance and residents’ ability to remember family visits were associated with more frequent and longer visits on the part of family members in NHs.21

Family Involvement and Outcomes

Similar to earlier research,2,21 recent mixed methods studies have found that more frequent NH visits by family members are associated with greater quality of life on the part of residents.22 Although more regular family involvement such as visits and provision of personal care was associated with lower perceived resident quality of life on the part of family members in one study, regular communication with staff attenuated this association.23,24 Less frequent family visits were found to be predictive of greater behavioral and psychological disturbances among residents with dementia over a 1-year period.25

Other studies have examined family caregiver outcomes following a relative’s admission to RLTC. For example, in several studies family caregivers of patients with dementia report statistically and clinically significant reductions in burden and depression following care recipients’ institutionalization.26,27 However, additional research has found that close to half of dementia caregivers experience guilt directed from other family members, RLTC staff, or care recipients; qualitative data from the same mixed methods study posited that the decision to move a relative to RLTC and a perceived lack of involvement seemed to drive increased feelings of guilt.28 Family involvement has also been linked to quality of care in RLTC.29 For example, family assistance during mealtimes is associated with quality of feeding assistance along with other indices of quality of care.30,31 Among family members of institutionalized Veterans, those who indicate a greater sense of community in their relative’s RLTC also report less conflict with staff as well as greater family adjustment to a relative’s placement.32

Family-Staff Relationships

Most family caregivers of relatives with advanced dementia who live in NHs indicate moderate to high trust in care professionals (eg, physicians, nurses, and nurses’ aides), and such trust is positively associated with family members’ perceptions of family-staff communication as well as satisfaction with care.33 Similarly, the majority of family members feel a sense of congruence between perceived importance of and opportunities for effective interactions with RLTC staff,34 although primary needs as rated by residents, staff, and family members often differ.35 Qualitative research has revealed that families note significant changes in health which they then communicate to staff, and effective staff-family communication/relationships can help facilitate quality of care in NHs.36,37 Family involvement across NHs and assisted living facilities has been reported as similar, and although little conflict with staff is reported, improvements in staff-family relationships and better-defined family roles in RLTC are needed.38 In general, positive family-staff relationships are those based on trusting communication, clear family/staff roles, and family-centered approaches to care for people living in RLTC; barriers include staff turnover, lack of staff time, and lack of information provided to families.39,40 Ethnographic and other studies have also explored how the care “triad” consisting of nursing staff, residents, and family members are effectively navigated to enhance the care provided to residents with dementia.41,42

Additional research has examined family members’ perceptions of communication and interactions with staff in NHs. Positive family members’ perceptions of the NH are associated with family engagement on the part of facility staff, including “demonstrations of care” that go beyond routine service delivery (ie, “informal contacts”), individualized and responsive care, and communication with family members.43–45 During care conferences, the use of scripts (eg, predetermined agendas and inflexible ordering of issues to be discussed; “clinical” reporting of relatives’ health status) contributes to communication challenges and lack of family involvement/integration in NHs.46

Family Involvement, RLTC, and Key Transitions

Several recent research efforts have examined family involvement in RLTC during specific transitions, such as transfer from hospitals to NHs and vice versa as well as end-of-life care. For example, family members generally have variable involvement in decisions regarding relatives’ transfers from hospitals and emergency departments to NHs.47 A German study indicated that although close to two-thirds of relatives and legal guardians are informed about transfers from hospitals to NHs, only about 1 in 5 were actually involved in such decisions.48
Reviews of qualitative research of family members’ involvement in relatives’ transfer decisions from NHs have found heterogeneous participation in decision making, although discussions between family members and care providers regarding transfers often take place. Tensions between family members and care professionals occur when family members perceive their relatives’ needs are not being met. Although qualitative research emphasizes the important roles (advocacy) of families in the NH to hospital transition, to-date family involvement in this key transition is not robustly considered in current interventions that aim to reduce hospitalization.46,48

Other reviews of residents’ relocation from NHs have implied that communication challenges often hinder effective family involvement, although families attempt to and remain involved in various ways.47–49,50 Similarly, qualitative research on family members’ perceptions of hospital to skilled nursing facility transfer has described that such events are rushed and family members generally feel unprepared during this key transition.51 For example, during a relative’s hospital discharge family members often report that they only receive a list of skilled nursing facility names from discharge planners during a truncated planning process; hospital staff had little to no involvement during the hospital to skilled nursing facility transition even though it posed considerable stress to family members.52 In instances when NHs were closed because of care deficiencies, NH staff and supervisors noted a lack of family involvement as complicating the involuntary relocation process of residents.53

Syntheses of qualitative research have highlighted family members’ perceptions of end-of-life care for relatives in NHs. Quality end-of-life care includes integrated basic and spiritual care, respect of end-of-life preferences of residents; continuity of care; and communication and partnership building with family members to facilitate familial support and decision-making involvement.47,49,54 However, a study from Sweden suggested that when compared to other end-of-life care settings, those with relatives in NHs are less likely to report receiving a list of skilled nursing facility names from discharge planners during a truncated planning process; hospital staff had little to no involvement during the hospital to skilled nursing facility transition even though it posed considerable stress to family members.55 In instances when NHs were closed because of care deficiencies, NH staff and supervisors noted a lack of family involvement as complicating the involuntary relocation process of residents.53

The Tragic and Potentially Transformative Effects of COVID-19

The length of the COVID-19 pandemic and long-term care organizations’ continued imposition of visiting restrictions resulted in reports of residents’ “failure to thrive” owing to lack of meaningful social interactions in RLTC settings as well as criticism that classifying family members simply as “visitors” was a disservice to their crucial role in maintaining the well-being of their relatives in RLTC.70 Recent qualitative research70 found that visiting restrictions caused substantial stress for family caregivers as they disrupted regular care routines, limited families’ opportunities for social engagement with residents, and interfered with regular monitoring of their relative’s well-being. Family members worried about their relative passing away without their family nearby to provide comfort and companionship at the end of life. Many family members also noticed a decline in their relatives’ physical and mental health because of social isolation and felt that facilities overly prioritized infection control at the expense of residents’ social and emotional well-being.80

Implications for Practice, Policy, and/or Research

In considering our updated review of the scientific literature, the heightened challenges COVID-19 has posed for families of relatives in RLTC, and recommendations recently set forth in the context of COVID-19 (see below), multiple practice, policy, and research recommendations emerged. Table 1 summarizes these recommendations to reimagine family involvement in RLTC. They include recommendations to (1) enhance communication and achieve family-centered care (practice), (2) incorporate family as a policy driver and adhere to existing visiting recommendations (policy), and (3) focus on under-studied sociodemographic contexts, advance measurement, examine transitions to and from RLTC, develop interventions, incorporate a triadic family-staff-resident lens, and adopt a longitudinal perspective on family involvement in RLTC (research; see above).

Expert panels and similar approaches have yielded guidelines on COVID-19 management in NHs and other RLTC settings, and several of these recommendations offer practice and policy guidance as to appropriate family involvement. For example, a Delphi study of experts generated consensus recommendations to guide NH visits during the COVID-19 pandemic. Following a review of state and federal guidelines, the Delphi panel identified 5 strong recommendations to
guide visitors in residential care: “(1) maintain strong infection prevention and control precautions, (2) facilitate indoor and outdoor visits, (3) allow limited physical contact with appropriate precautions, (4) assess individual residents’ care preferences and level of risk tolerance, and (5) dedicate an essential caregiver and extend the definition of compassionate care visits to include care that promotes tolerance, and (5) dedicate an essential caregiver and extend the definition of compassionate care visits to include care that promotes social context is necessary to create a true participation in RLTC in times of emergency. Thus, families often expressed frustration and concern about infection prevention policies that did not make sense to them, such as not requiring staff to be vaccinated, family members remaining restricted from visiting even after a negative COVID-19 test, and limiting visitors to only 1 essential caregiver in cases where multiple family members provided significant care. Integrating families in the decision-making process could allow for discussions of such concerns and for the identification of solutions in collaborative fashion. Similarly, involving family members in decisions about facility policies beyond the context of COVID-19 is necessary to ensure that policies optimally meet residents’ and families’ needs.

In the face of the excessive infection and mortality rates among residents in RLTC settings throughout the pandemic, state officials in the United States and facility ownership were the principal decision makers when initiating restrictive lockdown procedures. Families were often and remain uninvolved or peripheral to such decisions. Despite the existence of resident self-determination via the 1987 federal Patient Self-Determination Act, the pandemic has significantly attenuated residents’ voices in favor of what Vervaecke, Meisner, Kusmaul, Frank, and others deem “compassionate ageism,” or a paternalistic approach that has further eroded residents’ voices in RLTC decision making.85

Frank87 outlines several alternative RLTC governance models that could better integrate and thus optimize family involvement. One model that would potentially empower families and residents in RLTC is participatory representation, where families and/or residents are actively involved in developing and implementing policies. However, owing to the need for government approval to authorize key changes owing to the need for government approval to authorize key changes in the regulation of many RLTC settings such as NHs, this model is likely not feasible. Frank thus presents an alternative, “hybrid” model of family involvement in RLTC where family members, residents, and direct care staff would codevelop policies (ie, participatory), but then would actively partner with RLTC administrators to propose the policy and, if necessary, provide petitionary representation (p. 4) to ensure it becomes law. At that point, families would have responsibility along with RLTC administration to implement the policy.85

Frank also emphasizes that in addition to policy development, this “representational governance” model should include the appraisal of new evidence to update and evaluate implemented policies via robust, stakeholder engagement strategies. As noted in various recommendations related to the reimagining of RLTC following the COVID-19 pandemic, the representational governance model would help to inform the inclusion of outcome measures that matter the most to residents and

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<th>Research, Practice, and Policy Recommendations to Reimagine Family Involvement in Residential Long-Term Care</th>
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| **Practice** | **Enhance communication**
- Ensure that communication from health care professionals and direct care staff is transparent, accurate, and timely to ensure effective family partnership in key care decisions
- Establish communication mechanisms so that family members can report changes in a relative’s health status to the professional care team
| **Achieve family-centered care**
- Develop strategies to fully incorporate family members as part of care teams both in RLTC and during key transitions to or from RLTC settings
- Discourage scripts (eg, predetermined and inflexible agendas; use of clinical jargon) when meeting with families to ensure that care and services are more effectively person and family centered |
| **Policy** | **Family as policy driver**
- Move beyond the family council and develop and implement governance structures that allow family design of actual care processes and policies in RLTC
  - Participatory representation
  - Hybrid model (coderevelop policies and partner with families to propose and advocate for policies where necessary)
| **Follow visitation recommendations**
- Adhere to visitation recommendations and family involvement in antimicrobial stewardship as outlined in recent JAMDA publications51,52 and others11 |
| **Research** | **Focus on understudied sociodemographic contexts**
- Conduct research that better captures the family involvement process in rural and other understudied sociodemographic contexts |
| **Advance measurement** | **Transitions to and from RLTC**
- Continue to test valid and reliable measures of family participation in RLTC
  - Advance care planning;
  - Transfer from hospital or emergency department to RLTC and vice versa;
  - End-of-life care; and
  - Admission to RLTC |
| **Intervention development** | **Triadic focus**
- Incorporate family members in the design and evaluation of interventions that improve quality of care and quality of life in RLTC
| **Longitudinal perspective** | **Conduct longitudinal analyses of change in family involvement to inform the timing and content of interventions**
- Continue to examine how changes in family involvement are predictive of key family, staff, and resident outcomes in RLTC |
family members, in contrast to many current regulatory indicators of quality in RLTC (which often prioritize resident safety at the cost of other measures of well-being and quality of life). One could argue that a representational governance model may have resulted in more feasible visiting policies during the COVID-19 pandemic rather than the total lockdown approach that emphasized survival over quality of life.

Like other aspects of health care, families generally are not acknowledged as key components of care planning or other key decision-making processes in RLTC. This is a systemic issue in how RLTC is incentivized to provide care. COVID-19 starkly demonstrated the crucial role of families in the well-being of residents, and that quality of life as well as personhood is challenging to maintain in RLTC settings when residents are socially isolated and feel alone. Prior\textsuperscript{29} and current interventions to enhance and potentially optimize family involvement in RLTC are available. However, if the structure of regulation and care delivery in RLTC are not shifted toward more representative governance models, the likelihood of innovative approaches to reimagine family involvement and improve resident well-being will remain elusive.

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References


74. Dassa A. “Opening our time capsule”-creating an individualized music and other memory cues database to promote communication between spouses and people with dementia during visits to a nursing home. Front Med (Lausanne) 2018;5:215.


