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Re-Imagining 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 RLTC, the COVID-19 pandemic has magnified the need to determine how families can remain most effectively involved in the lives of residents. This paper 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 re-imagine, family involvement in RLTC.

Brief summary:

This article reviews current research and offers recommendations to better integrate family members in residential long-term care, an issue that COVID-19 has starkly demonstrated as crucial.

Keywords

Family caregiving; Nursing homes; Assisted living; Long-term care

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.”[1] 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 (RLTC) settings such as nursing homes (NH) or

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assisted living communities. The tension in how family involvement in RLTC 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 RLTC settings was to severely restrict family visitation; such measures were implemented by state departments of health in the U.S. However, facility lockdowns and visitor restrictions have raised serious concerns among families and staff about the social deprivation experienced by many residents.

This paper 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 re-imagine, family involvement in RLTC. 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 RLTC, 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 RLTC

Prior and more recent reviews of family involvement in RLTC[2-6] have emphasized that although the nature of family caregiving may change considerably with the entry of a relative to a 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 RLTC, 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 RLTC, we conducted an updated search of the literature. From January, 2007 (the date of publication of our last literature search)[3] to November 2021, we searched the MEDLINE, PSYCINFO, and EMBASE databases to identify recent research on family involvement in RLTC. The following keywords were utilized 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 a 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 1st 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.

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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.[6,8-11] 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/achievement when maintaining family relationships. Families can also ensure care quality while honoring filial responsibilities.[12,13] Moreover, the sense of "home" in a 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 (i.e., 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, Miller (2019) identified the following barriers to family visits in RLTC: psychological issues, health concerns, impaired staff-member relationships, employment/financial impediments, prolonged travel time to the facility, and lack of access to transportation.[16,17] 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,[see 2,3 for reviews] recent mixed methods studies have found that more frequent nursing home 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 dementia family caregivers 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,

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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 (e.g., 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 (i.e., "informal contacts"), individualized and responsive care, and communication with family members.[43-45] During care conferences, the use of scripts (e.g., e.g., 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/emergency departments to NHs.[47] A German study indicated that although close to ⅔ of relatives/legal guardians are informed about transfers from hospitals to NHs, only about 1 in 5 were actually involved in such decisions.[5]

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Reviews of qualitative research of family members' involvement in relatives' transfer decisions from NHs to hospitals 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.[23,48]

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 during the decision to admit a relative to a RLTC setting.[24,49,50] Similarly, qualitative research on family members' perceptions of hospital to skilled nursing facility transfers 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 due to 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.[4,54,55] 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 that their relative was treated with dignity or respect and more likely to indicate "unwanted" decisions were made during their relative's end-of-life care.[56] Taking part in care planning during a relative's end-of-life in RLTC also appears to enhance family members' feelings of involvement during this health transition.[57] An analysis of family involvement during a relative's final month of life in RLTC found that the majority of family members were involved with monitoring and managing their relative's care as well as helping with meals, while 40% provided personal care. Caregivers who indicated strain in their roles were slightly more likely to remain involved in the final month of a relative's life in RLTC.[58] Negative experiences related to end-of-life dementia care in NHs as reported by family members include neglect (lack of information, inaccessibility or disinterest on the part of care staff) and lack of respect (insensitivity, noncompliance).[59] Nursing home staff emphasized increased family involvement as a priority when enhancing end-of-life care for residents.[60]

Incorporation of the roles and expectations of residents, staff, and family members are key features of effective advanced care planning in NHs.[61] Indeed, lack of family involvement has been cited as a barrier to effective advanced care planning for skilled nursing facility

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residents.[62,63] Reviews of existing studies suggest a complex and variable process of family involvement in advanced care planning or other decisions in RLTC settings.[62,64-67]

Optimizing family involvement in RLTC.

In order to achieve person-centered care throughout the multiple and complex transitions that often occur for older persons, communication with family members and inclusion of families in healthcare decisions and care planning is viewed as optimal.[68] Literature reviews as well as singular interventions suggest multiple approaches to facilitating family involvement in RLTC. Existing interventions focus on creating family-staff partnerships;[69,70] incorporating family members into formal care decisions; and providing psychoeducational support to family members. In general, the state of the science in promoting family involvement in long-term care remains limited, with little information available on intervention mechanisms/components that could foster family inclusion in the care of people living with dementia.[71] Valid and reliable measures of family participation in RLTC is another area requiring scientific development to better inform the effects of family involvement interventions.[72] One large, high quality group-randomized trial evaluated an intervention (Family Matters) that facilitated families' meaningful roles in NHs and assisted living and found that the intervention decreased family burden and improved resident quality of life but also increased guilt and family members' sense of conflict.[73] Other smaller scale interventions have examined the feasibility, acceptability, and preliminary benefits of various strategies to improve family visits/involvement as well as leverage the involvement of family members to enhance intervention delivery in RLTC. These efforts include individualized music programs,[74] a family life review approach to facilitate families' transitions to assisted living,[75] a group-based psychosocial and spiritual program to enhance person-centered care and quality of life for residents with dementia,[76] three dimensional printing of cherished objects,[77] and embedded sensor systems.[78] *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" due 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.[79] Recent qualitative research[80] 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 (see below), multiple practice, policy and research recommendations emerged. Table 1 summarizes these recommendations to re-imagine

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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 understudied 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 five 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 psychosocial well-being of residents."[81, p. 1759] Similar conclusions were made for assisted living settings, with the added recommendations of improving integration with other services/resources to enhance advance care planning discussions and improve clinical care delivery; both ideally feature active involvement of family members.[82]

Our research with family caregivers in the wake of the COVID-19 pandemic generated several recommendations that could be implemented to improve residents' and families' experiences with caring for a relative in RLTC.[80] Communication between families and RLTC staff emerged as a critical determinant of families' experiences during the pandemic. When facilities provided proactive, frequent, detailed information about residents' status and needs, families felt reassured and confident. Where communication was lacking, families felt uninformed, anxious, and fearful. Beyond the COVID-19 context, timely, proactive communication from RLTC staff – especially in times of transition or precipitous changes in residents' health status – may substantially ease families' anxiety and facilitate planning and care coordination. As demonstrated prior to the pandemic, a strong emphasis on RLTC residents' social context is necessary to create a true "neighborhood" that features robust staff and family involvement.[83]

The COVID-19 pandemic emphasized the need to involve families in policy decision-making processes. Families often expressed frustration 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 one essential caregiver in cases where multiple family members provided substantial care.[80] 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.

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In the face of the excessive infection and mortality rates among residents in RTLC settings throughout the pandemic, state officials in the U.S. 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 and family members' voices in RLTC decision making.[84-86]

Frank (2021)[86] 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, due 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 (2021) thus presents an alternative, "hybrid" model of family involvement in RLTC where family members, residents, and direct care staff would co-develop policies (i.e., 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.[86] Frank also emphasizes that in addition to policy development, this "representational governance" model should include the appraisal of new evidence to update policies and the evaluation of implemented policies via robust, stakeholder engagement strategies. As noted in various recommendations related to the re-imagining 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 family members, in contrast to many current regulatory indicators of quality in RLTC (which often overemphasize resident safety at the cost of other measures of well-being/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 healthcare, families generally are not acknowledged as key components of care planning or other key decision-making processes in RTLC.[87] 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, feel alone, and facilities potentially overemphasize resident safety. Prior[88] 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 towards more representative governance models, the likelihood of innovative approaches to re-imagine family involvement and improve resident well-being will remain elusive.

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Table 1.

Research, Practice, and Policy Recommendations to Reimagine Family Involvement in Residential Long-Term Care.

Recommendation	Details
Practice	
Enhance communication	• Ensure that communication from healthcare 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 as well during key transitions to or from RLTC settings • Discourage scripts (e.g., 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/implement governance structures that allow family design of actual care processes and policies in RLTC – Participatory representation – Hybrid model (co-develop policies and partner with families to propose and advocate for policies where necessary)
Follow visitation recommendations	• Adhere to visitation recommendations and family involvement in anti-microbial stewardship as outlined in recent *JAMDA* publications[81,82] and others[89]
Research	
Focus on understudied sociodemographic contexts	• Conduct research that better captures the family involvement process in rural and other understudied sociodemographic contexts
Advance measurement	• Continue to test valid and reliable measures of family participation in RLTC
Transitions to and from RLTC	• Conduct ongoing descriptive research on family involvement in transitions to and from RLTC with the goal of advancing interventions to help families and RLTCs improve and better navigate these transitions, including: – Advanced care planning; – Transfer from hospital/emergency room to RLTC and vice versa; – End of life care; and

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Recommendation	Details
	– Admission to RLTC
Intervention development	• Incorporate family members in the design and evaluation of interventions that improve quality of care and quality of life in RLTC
Triadic focus	• Apply methodologies to better understand the resident-family-staff triad 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

NOTE: RLTC: residential long-term care; *JAMDA: Journal of the American Medical Directors Association*