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Letters to the Editor

The Need to Consider Relocations WITHIN Long-Term Care



To the Editor:

The RELOCARE (relocations in long-term care) consortium aims to raise awareness of the topic of relocations in long-term care. Some older people living in a long-term care facility experiences (involuntary) relocations. Relocations in long-term care are complex and can have a large impact on older people and their family caregivers. Furthermore, relocations are expected to occur more often in the future because of the larger culture change within long-term care, in which radical changes in physical, social, and organizational care environments are being implemented to facilitate person-centered care and support.^{1–3} When implementing these changes in the long-term care environment, relocations are necessary. Groups of residents who already live in a long-term care facility are being relocated to different facilities due to redesign, or individual residents move to a long-term care facility that is more in line with their increasing care needs and preferences. Relocations generally consist of 3 phases: the anticipatory phase, the actual relocation, and the “settling-in/adaptation” phase.^{4,5}

Meeting care needs during these phases is related to the integration, coordination, and continuity of care. These changes should be accompanied with innovative approaches that improve relocation processes. However, knowledge on how to facilitate relocations in long-term care is still scarce. It is known that residents living in long-term care facilities regularly relocate, although specific numbers are lacking. Current studies addressing relocations mainly focus on the transition from home to a long-term-care facility,⁶ or relocations from and to the hospital⁷ indicating a general knowledge gap on the topic of relocations within long-term care (within a location, or from one location to another). Based on current literature, the RELOCARE consortium highlights several knowledge gaps.

What Are the Current Knowledge Gaps?

A first specific knowledge gap is related to the impact and consequences of relocations. Relocations might be associated with a decline in life satisfaction and feelings of grief and loss of personhood.⁸ Furthermore, an increased risk of hospital admission, or a decline in functional health, such as problems with activities of daily living and an increase in stress, illness, and fall rates have been reported.^{8,9} However, the initial stressors associated with relocations are time limited and relocations ultimately also may show beneficial effects on neuropsychiatric symptoms (ie,

depression), mortality, and independence.¹⁰ Research on the effects of relocations on health and well-being of residents and family is scarce. Furthermore, it is unclear how the various reasons for relocating residents impact their outcomes. For example, involuntary relocations are associated with more dissatisfaction in residents and family members compared with voluntary relocations.⁵

A second specific knowledge gap is related to initiatives to improve the process and outcomes of relocations. Some initiatives (interventions and guidelines) exist that aim to improve way finding, behavioral skills, positive cognitions, and aiding adjustment to the new locations.^{11–15} The scarce evidence from these first studies show that it appears to be beneficial when residents are able to consider what they will gain and/or lose when relocating. For instance, when residents realize that their care needs are considered and that they are able to continue purposeful activities at the new living facility, this is expected to facilitate adaptation. In addition, being able to maintain their interpersonal connections and relationships might contribute to a better relocation.^{16,17} Nevertheless, although these studies mention favorable outcomes such as an increase in active-outgoing behavior, or positive trends in resourcefulness, and relocation adjustment, the evidence is still very preliminary and more research is needed on what is needed to improve the relocation process and outcomes. It is unclear which components of the relocation process should be altered to contribute to positive outcomes.

A third specific knowledge gap is related to whether relocations to innovative facilities are experienced differently by older people and their informal caregivers, and whether these relocations differ in terms of their effects compared with relocations to regular long-term care facilities. Long-term care organizations increasingly design innovative care concepts as alternative for traditional nursing homes, as part of the larger culture change movement.^{1–3} Examples include green houses, dementia villages, green care farms, and several community models. Radical changes in the physical, social, and organizational care environment are being implemented. This means that changes in the physical environment are used as a prerequisite to facilitate changes in the social and organizational environment (eg, the environment allows people to live their lives in a self-determined manner, using principles of a person-environment fit, using smart technologies, creating partnership between residents).^{1,18} It is possible that these kind of innovative care concepts influence how relocations are experienced.

Future Research

Figure 1 shows a schematic representation of relocations in long-term care. It shows that relocations have several characteristics that can influence both negative and beneficial consequences of relocations. Furthermore there are approaches to improve relocations that are influenced by the characteristics of the relocations, as well as by characteristics of the approach. These approaches, in turn, influence the consequences of relocations. The figure highlights the areas where more research is needed. The RELOCARE consortium suggests that more research should be

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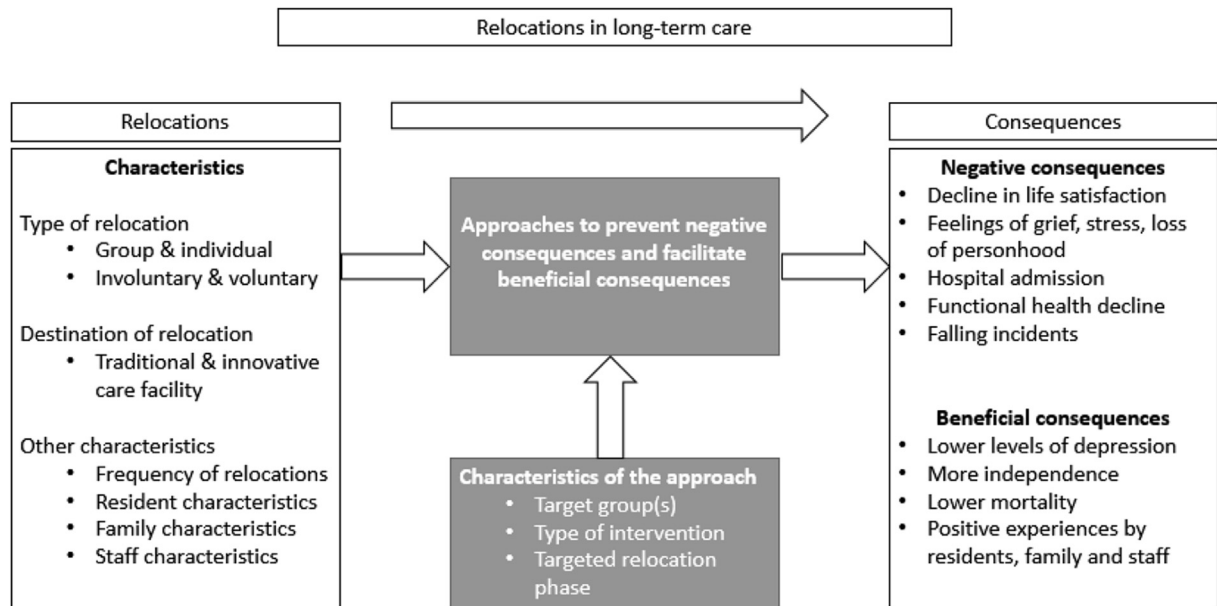


Fig. 1. Schematic representation of relocations in long-term care.

conducted focusing on (1) the characteristics and consequences of relocations within long-term care facilities for residents and their family caregivers; (2) how relocations within long-term care can be improved to maintain quality of life and quality of care; and (3) what the experiences and consequences are for residents and their family caregivers with relocating to innovative long-term care concepts. The RELOCARE consortium conducts research on these questions within the 6 Dutch academic collaborative networks in care for older people.^{19,20}

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- The University Network for the Care Sector Zuid-Holland/Leiden University Medical Center: Prof. Dr. W.P. Achterberg, Dr. M.A.A. Caljouw, D.S.E. Broekharst (MSc)
- The University Network of Elderly Care – UMCG/University of Groningen: Dr. E.G.M. Landeweer, Dr. H.J. Luijendijk, M.C. Schreuder (MSc), Prof. dr. S.U. Zuidema
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- The Academic Collaborative Centre Older Adults – Tranzo/Tilburg University: Prof. dr. K.G. Luijckx, Dr. A. Stoop
- The University Network in care for older people Amsterdam/University of Amsterdam: Dr. W. Groen

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Caregiver Respite: An Essential Component of Home- and Community-Based Long-Term Care



To the Editor:

One in 5 US adults (53 million people) provide long-term care to persons who are aging, disabled, and chronically ill.¹ This informal workforce—referred to as *family caregivers*—perform medical tasks, help with activities of daily living, prepare meals, provide transportation, manage finances, coordinate care, and support the psychosocial needs of care recipients living in their homes and in our communities.² The average family caregiver provides 24 hours of direct care per week for about 4.5 years.¹ They are generally unpaid, yet their services do not come for free: caregivers commonly experience care-related declines in their physical, mental, social, and/or financial health.³ The economic value of family caregiving is estimated at nearly \$500 billion annually, an amount that surpasses out-of-pocket and federal spending on long-term care.⁴

Given this, caregiver support is increasingly viewed as an essential component of the long-term services and supports (LTSS) system.⁵ Traditional caregiver support includes education and skills-training interventions, support groups, and respite.⁶ Respite—defined by ARCH National Respite Network and Resource Center as “planned or emergency care provided to a child or adult with special needs in order to provide temporary relief to family caregivers” (www.archrespite.org)—is the most desired and requested caregiver service.^{7,8} There are 3 types of formal respite services: (1) in-home respite agencies, (2) adult day centers, and (3) institutional respite that allows for planned or emergency overnight stays.

When provided consistently and in sufficient doses, respite is associated with positive outcomes for both care recipient and caregiver (eg, reduced hospitalization, delayed institutionalization, reduced caregiver burden).⁹ Yet, 85% of caregivers do not utilize formal respite services,¹ likely because of lengthy waitlists, inability to pay out of pocket, or a general lack of awareness of respite services or their potential benefit. Instead, family caregivers often prefer to use tag-teaming arrangements with friends, families, or neighbors whose occasional assistance provides informal respite to the primary caregiver.

During the COVID-19 pandemic, as businesses shut down and as travel and in-person social interactions became restricted, both formal respite services and informal respite arrangements became inaccessible to caregivers. These disruptions led to increased reports of stress, anxiety, feelings of burden, and social isolation among family caregivers.¹⁰ In fact, the loss of planned respite and an unfulfilled desire for a “short break” was lamented by many caregivers as the greatest challenge of the COVID-19 pandemic, further highlighting the importance of respite as an essential, preventive strategy to help caregivers manage the often relentless 24/7 nature of caregiving responsibilities.

Some formal respite providers quickly pivoted and began offering new types of respite services; for example, adult day centers used video conferencing (eg, Zoom), where care recipients received real-time supervision from an offsite respite provider via an interactive computer screen. Others assembled virtual respite programs or delivered “respite in a box,” which included curated activities to do at home or links to virtual field trips to art museums or recorded concerts.

Caregivers also developed creative solutions, especially when they were granted enhanced flexibility to use their Medicaid home- and community-based services waiver to meet their respite needs; for example, some utilized video-gaming systems to connect with geographically distant family members, and some chose to pay family members to tag-team one another rather than bringing in outside help. These strategies provided diversionary and meaningful activities that temporarily entertained and engaged care recipients, while providing caregivers a break from caregiving responsibilities, even when a physical or formal break was not possible.

Evaluating the effectiveness, usability, and feasibility of these new forms of respite should be a research priority. Results could inform new models of caregiver respite that are more aligned with individual need and choice and less reliant on the narrow definition of respite as a formal service provided to caregivers. These innovations may be particularly useful in light of the ongoing labor shortages plaguing the delivery of traditional LTSS. Although the COVID-19 pandemic severely reduced access to respite, which increased caregiver stress, it also provided some potential innovations that could become more mainstream as we move into a