

# **The transition from home to a nursing home: the perspectives of older persons, informal caregivers, and healthcare professionals.**

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## **Key highlights (4):**

- The transition from home to a nursing home can be defined by three phases: the pre-transition, mid-transition and post-transition phase.
- Older persons and informal caregivers need information, support, time, support and a partnership with the healthcare professional throughout the transition process.
- Informal caregivers experience paradoxical emotions during the transition from home to a nursing home. Their prospective and retrospective needs differ. Additionally, they look for a balance between their need for distance versus the need to remain involved.
- Older persons living with dementia fear the idea of having to move to a nursing home. Their future care wishes are to remain autonomous individuals who are in contact with others.

## **Introduction**

The transition from home to a nursing home is common for older persons living with dementia and informal caregivers. The transition can generally be described as having three phases. First is the pre-transition phase. This is the time to make a transition decision and choose a nursing home. The mid-transition phase is the time that the older person waits on the waiting list for a place in a nursing home. This phase ends when the older person resides in the nursing home. Finally, in the post-

transition phase, both the older person and the informal caregiver adapt and adjust to the new living situation [1].

Despite being an often-reoccurring care process, many care transitions are fragmented, leading to negative outcomes for all involved [2]. For older persons, it can lead to medication-associated events, fall injuries, and even mortality. Informal caregivers, who often play a central role during this care process, can be burdened with feelings of sadness and failure. Healthcare professionals can experience burnout as a result of duplication of services. The latter can have financial implications for the general healthcare system.

To improve this care process and avoid negative outcomes, interventions must be implemented that consider the needs and perspectives of those involved. Currently, Interventions to improve this care process are scarce. Moreover, most interventions focus on the post-transition phase. This is unfortunate as research has shown that the pre- and mid-transition phase experiences can significantly impact the experiences during the post-transition phase [3].

Therefore, we aimed to improve the transition from home to a nursing home by understanding the perspectives of older people living with dementia, informal caregivers, and healthcare professionals. This research project is part of TRANS-SENIOR, a European-funded research network.

### **Identifying needs and interventions**

This research project was started by identifying the needs of older persons and informal caregivers during the transition from home to a nursing home. A literature review was conducted. The review identified studies that focused on the experiences of older persons and/or informal caregivers during the care transition. Based on these experiences, the research team identified a list of needs. These needs were analyzed, leading to the TRANSCIT-model. It is an abbreviation for TRANSition

Support, Communication, Information, and Time. The model identifies the four key components and the need for a partnership throughout the transition process [1].

Additionally, we conducted a scoping review to identify existing interventions to improve the care process [4]. The study identified 17 studies describing 13 distinct interventions. The interventions consisted of five single-component and eight multi-component interventions. The single-component interventions were smaller, focused interventions. The multi-component interventions were longer interventions with multiple sessions. In general, only one intervention included the entire transition process. The majority of studies focused only on the post-transition phase. Moreover, when comparing the interventions with the TRANSCIT-model, the results showed that none of the interventions considered the key needs. The interventions also only focused on one or two participants rather than looking at the entire care triad of older persons, informal caregivers, and healthcare professionals [4].

### **Perspectives of family and older persons with dementia**

To understand the identified needs, a qualitative, interpretative study was conducted [3]. We interviewed informal caregivers, who played an important role during the transitional care process of a loved one, to understand their perspectives. The results showed that informal caregivers identified three paradoxes. The first paradox was the initial negative emotions versus positive emotions of relief and acceptance. These emotions were strongly influenced by the healthcare system. Specifically, if the informal caregivers received the necessary support during the move, more positive emotions were expressed. Especially, the day of the move and the first days after the move were associated with negative emotions. The second paradox was the retrospective need for a timely care process versus the prospective need to avoid the transition. This meant that informal care avoided the transition process until the home situation was no longer safe and they were burned out. However, when looking back on their experiences, they would have liked to have a timely planned and organized care process. The third paradox focused on the need for distance versus the need to remain involved. Where the informal caregivers struggled to find a

balance between being involved in the life of the older person while also keeping some distance and trusting the care that was provided [3].

Finally, interviews were conducted to get an understanding of the perspectives of older persons living with dementia regarding a possible move to a nursing home. The results indicated that most older persons feared moving to a nursing home; they associated it with loss. Moreover, the potential, future nursing home resident wished to remain autonomous and in contact with others. They defined autonomy as the wish for respect regarding preferences and choices while remaining independent. Individuality was seen as personalized care and the possibility of continuing hobbies and routines. Moreover, the older persons wanted to hold on to their social contacts by remaining close to friends and family.

### **Future directions**

What is currently lacking is knowledge based on a prospective insight of older people's and their caregivers' experiences throughout the transition journey. Previous studies indicate a gap between needing and accepting help, and caregivers often reflect differently regarding previous decisions retrospectively [5]. Therefore, we are conducting patient journeys at the moment. Here, the researcher follows older persons, informal caregivers, and healthcare professionals throughout the transitional care journey from living at home to moving to a nursing home. The study's goal is to better understand the prospective experiences of the participants and their perspectives throughout the transition process. Data are collected through interviews and informal conversations. Results are expected by the end of this year.

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