

QUALITATIVE PAPER

The paradoxes experienced by informal caregivers of people with dementia during the transition from home to a nursing home

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Abstract

Background: The transition from home to a nursing home is a common care process experienced by older persons with dementia and their informal caregivers. This transition process is often experienced as fragmented and is paired with negative outcomes for both older persons (e.g. mortality) and informal caregivers (e.g. grief). Due to the central role that informal caregivers play, it is crucial to capture their experiences throughout all phases of the transition.

Methods: A secondary data analysis was conducted using an interpretative phenomenological design. A total of 24 informal caregivers of older persons with dementia, moving to a nursing home, participated in in-depth interviews. Data were collected between February 2018 and July 2018 in the Netherlands. Data were analysed using Interpretative Phenomenological Analysis.

Results: The transition experiences are characterised by three paradoxes: (i) contradicting emotions during the transition process; (ii) the need for a timely transition versus the need to postpone the transition process and (iii) the need for involvement versus the need for distance. All paradoxes are influenced by the healthcare system.

Conclusions: The identified paradoxes show the impact of the healthcare system and the importance of timely planning/preparing for this transition on the experiences of informal caregivers. In addition, it provides healthcare professionals insight into the thought processes of informal caregivers. Future research can use these paradoxes as a foundation to develop innovations aiming to improve the transition process from home to a nursing home for informal caregivers and, consequently, older persons.

Keywords: transitional care, nursing homes, older persons with dementia and informal caregivers, older people, qualitative

Key Points

- Informal caregivers avoid a nursing home admission prospectively but prefer a timely care plan retrospectively.
 - At the nursing home, informal caregivers experience an internal struggle between remaining involved and keeping their distance.
 - Informal caregivers experience conflicting emotions during the transition from home to a nursing home.
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Introduction

Nursing home admission is a common care transition, especially for older persons diagnosed with dementia. In Europe, about 80% of nursing home residents are diagnosed with dementia [1–3]. The transition from home to a nursing home can be divided into three phases: pre-, mid- and post-transition [4]. The pre-transition phase commences when a nursing home move is discussed for the first time and the phase is terminated when the decision for nursing home admission is made [5–8]. The mid-transition phase focuses on the preparation for the move as the older person receives a place on a nursing home waiting list. The phase ends when the older person resides at the nursing home [7–9]. Lastly, the post-transition phase starts after the move and it includes the time for the older person and informal caregivers to accept and adjust to the new living situation [5, 7–9]. In the Netherlands, the possibility to move into a nursing home is based on a standardised need assessment carried out by a government agency while following the older persons' and informal caregivers' wishes.

The World Health Organization encourages that the needs and preferences of older persons are prioritised during the transition process, as this is a very complex and emotionally challenging process [10–13]. However, the majority of future nursing home residents are diagnosed with dementia. Therefore, their informal caregivers will often take on a more active and central role during the transition process [14, 15]. Often, informal caregivers tend to postpone nursing home admission until the older person is no longer safe at home and they or other informal caregivers are mentally and physically drained [6, 12, 16–19]. This can cause a crisis to unfold, possibly leading to urgent, uncoordinated and fragmented transitions, which in turn can lead to outcomes that are even more negative for both older persons (e.g. mortality and morbidity) and informal caregivers (e.g. higher mortality due to grief) [18, 20–23]. Despite these negative emotions, studies indicate that a nursing home admission can also reduce the burden for informal caregivers [24–26].

Some studies have focused on describing the experiences and needs of informal caregivers [4, 5, 7, 11, 18, 19, 27, 28]. Nevertheless, the majority of these studies either examined only the period before the transition or after the transition. A description of the entire transition process (pre-, mid- and post-transition), as experienced by informal caregivers is missing from the literature [10–12]. Moreover, a comprehensive understanding of why informal caregivers experience transitional care as being very complex, and the thoughts, emotions and perceptions of informal caregivers during this transition are still unknown.

Therefore, the research question is: what are the experiences of informal caregivers of older persons with dementia during all phases of the transition from home to a nursing home? To answer this question, interview data from a large-scale research project DEDICATED, into palliative care for

people with dementia, was used. The DEDICATED project aimed to examine the collaboration between healthcare professionals interprofessionally and together with informal caregivers, both intra- and transmural, as experienced by informal caregivers during the palliative care process in the Netherlands.

Methods

Study design

A secondary data analysis study was conducted using an interpretative phenomenological design. This design was chosen as it allows the identification of the personal lived experiences of informal caregivers during the transition from home to a nursing home [29]. This study was reported according to Standards for Reporting Qualitative Research to ensure rigor [30].

Participants and setting

Nurses employed from the three partner organisations in the DEDICATED project identified participants, using a purposive sampling technique [31]. The recruitment was based on a predetermined list of inclusion criteria provided to the nurses. Participants with varying characteristics, such as gender, age and level of education and years residing in the nursing home, were recruited. Participants were included in the study if: (i) they were informal caregivers whose partner/loved one received care at the partner nursing home organisation; (ii) the person with dementia was 65 years of age or older and had made the transition to a nursing home and (iii) the older person had died between 6 weeks and 6 months ago. A significant amount of participants was approached, as the researchers needed a heterogeneous sample of participants. These sampling methods were chosen to accommodate the aim of the original study.

Informal caregivers matching the inclusion criteria were asked to participate by a healthcare professional. If they agreed, the researchers from the DEDICATED project contacted potential participants, and a face-to-face meeting was scheduled. Participants were free to choose where the interviews took place, either at their residence, a university building or one of the participating care organisations.

Participants provided written informed consent before starting the interviews. The Medical Ethics Committee of Zuyderland confirmed that the rules of Medical Research involving Human Subjects Acts were not applicable (registration number METCZ20180026).

Data collection

Semi-structured, face-to-face interviews were conducted between February 2018 and July 2018. A topic list was designed based on existing literature and guidelines [32–34]. The topic list consisted of four themes relevant to the DEDICATED project: (i) symptom management; (ii) interprofessional collaboration; (iii) collaboration between

home and nursing home care and (iv) end-of-life communication (Supplementary Material A1). This study focused on capturing the experiences of informal caregivers concerning the transition to a nursing home mentioned most extensively in the third topic. Two researchers (Sascha R. Bolt and Sabine Pieters) from the DEDICATED project conducted the interviews together. One interviewer asked the questions. The 2nd interviewer noted relevant observations and asked additional questions when necessary. Both researchers received training on conducting interviews. Moreover, both were experts on dementia and palliative care. All interviews started by obtaining the demographic characteristics of participants. The interview ended by asking participants if they had additional comments. The interviews were recorded using an audio recorder or mobile phone.

Data analysis

The demographic factors were descriptively analysed. The recorded interviews were transcribed according to the clean-read verbatim method. Only the fragments focusing on transitional care were analysed in this study. The Interpretative Phenomenological Analysis method was used. It consisted of three consecutive steps: (1) develop a list of significant statements, 2) develop themes and 3) writing the essence [35]. The first step was developing a list of statements related to transitional care. Each of these statements was given a code. Examples of codes were ‘feeling like imprisoning a loved one’ or ‘relief due to unsustainability at home’. The codes used were closely related to the words of the participants. The codes analysed in the first step were then clustered leading to the development of themes, such as ‘negative transition feelings’ or ‘positive transition feelings’. Initially, the themes seemed contradictory to one another. However, upon further analysis, the authors found a common mechanism that linked the different themes to one another. These links were defined as paradoxes. A paradox entails a statement or opinion that seems contradictory as it contains opposite facts or characteristics [36]. For example, codes related to the theme of both ‘negative transition feelings’ and ‘positive transition feelings’ were found in almost all transcripts. This indicates that informal caregivers felt conflicted during the transition period, leading to paradoxical emotions. The different steps were realised consecutively and iteratively throughout the whole analysis [37, 38].

Three different researchers analysed the data together (L.G., A.B. and E.dV.). Two researchers had extensive experience with qualitative research (A.B. and E.dV.), and one researcher was an expert on the subject (L.G.). The quality of this analysis was ensured in several ways. First, investigator triangulation was adopted as three researchers analysed the data separately, followed by a discussion to reduce decision bias [39]. Moreover, these researchers reflected on their backgrounds and their knowledge of the subject and how this could interfere with data analysis. Uncertainties regarding possible bias were discussed within the research team. Finally, peer debriefings were held on multiple

Table 1. Participant characteristics

Age, mean (range)	62 (44–85)
Gender, number (%)	
Male	7 (29%)
Female	17 (71%)
Connection to the older person with dementia, number (%)	
Son (in-law) or daughter (in-law)	18 (75%)
Brother (in-law) or sister (in-law)	1 (4%)
Niece or nephew	2 (8%)
(ex-) Partner	2 (8%)
A friend	1 (4%)
Highest level of education, number (%)	
Preparatory secondary vocational education	7 (29%)
Senior secondary vocational education and training	7 (29%)
Senior general secondary education and university preparatory education	4 (17%)
Bachelor or Master level	6 (25%)
Length of stay at the nursing home, number (%)	
0–6 months	7 (29%)
7–12 months	2 (8%)
1–2 years	9 (38%)
2–5 years	6 (25%)

occasions to discuss the preliminary and final results within the research team.

Results

Sample characteristics

In total, 24 interviews were conducted, lasting for 94 min on average (range: 66–139 min). The loved ones of the informal caregivers had passed away at the time of the interview. The length between nursing home admission and the interviews varied significantly. Data saturation was reached as the final interviews did not lead to additional codes or significant changes in the results. Participants were on average 62 years old. The majority of participants were women ($n = 17$) and daughters, however, we tried to obtain heterogeneity for educational background and age group. The place before the transition to the nursing home varied—16 older persons moved from home or another nursing home and eight moved from the hospital ($n = 2$) or another care facility ($n = 6$).

Key findings

Informal caregivers experienced the older person’s transition to a nursing home as a complex care process characterised by paradoxes. The term paradoxes were used as the informal caregivers describe ostensibly, seemingly contradicting needs and emotions when relaying their transition experiences (Figure 1). Three overarching paradoxes were identified: (i) contradicting emotions during the transition process; (ii) the need for a timely transition process versus the need to postpone the transition process and (iii) the need to be involved versus the need for distance from care responsibilities. These paradoxes are influenced by how the healthcare

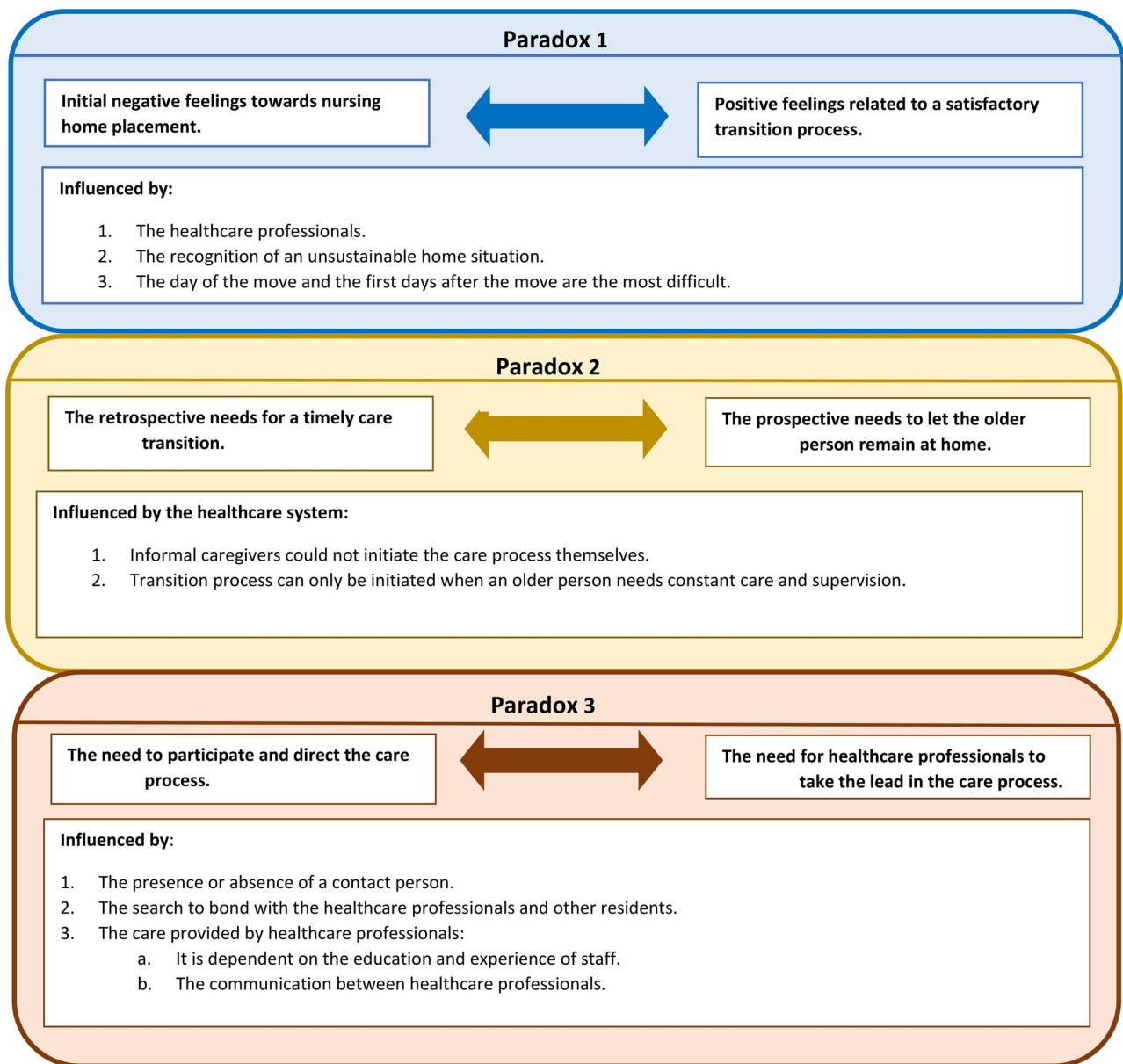


Figure 1. Three paradoxes as experienced by the informal caregivers.

system is organised and by how the healthcare professionals provide care.

Contradicting emotions during the transition process

The first paradox describes the initial negative feelings associated with nursing home placement, which is a paradox to the feelings of relief and acceptance related to a positive transitional care process afterward.

Initially, the participants indicated that the transition from home to a nursing home was a very emotionally challenging process. The majority of informal caregivers described the process of admitting their loved ones with negative emotions. They described it as a very difficult and painful process. Some informal caregivers even described it as imprisoning those they cared for.

(Daughter, 62, interview: Z1.04) [‘I feel incredibly guilty and I said, under false pretences, we are going to have a nice sit down in the cosy living room . . . sitting down, and later on she will be imprisoned here, yes . . .’.]

Paradoxical to the informal caregivers’ predominately negative associations with transitional care, more than half of the participants also identified clear positive experiences throughout this process, such as feelings of relief and acceptance after nursing home admission. This was especially true for informal caregivers who described positive experiences related to the practical and emotional support offered by healthcare professionals.

(Daughter, 60, interview: e1.07) [‘On the one side, it is positive, a bit of safety that you know . . . She had been there for a year and a half because my father could no longer support her. It gave us a sense of security, and it resolved the reciprocal conflicts that we had’.]

Moreover, the interviews showed that the emotions related to this transition process were strongly influenced by three factors. Firstly, the care provided by the healthcare professionals had the strongest influence on the experiences of informal caregivers. Negative emotions were pronounced even stronger when the care process itself was experienced as being insufficient and/or when the move felt very sudden and/or the informal caregivers did not receive any (emotional) support from healthcare professionals. One informal caregiver even spoke about the guilt she felt after being advised by healthcare professionals to prepare the transition process behind her back.

On the other hand, healthcare professionals could also positively influence the transition experience. For example, if the informal caregiver felt supported by healthcare professionals and experienced that the older person was included in the decision-making process. The latter was not always feasible due to the older person's dementia or their unwillingness to move to a nursing home.

(Daughter-in-law, 55, interview: V1.05) [‘If I recognize that, yes, she has a central position and we are going for it, we are really striving for comfort and quality, yeah, you know, that is very soothing’.]

Despite the practical support offered by healthcare professionals to navigate through the different care organisations, the majority of informal caregivers indicated that healthcare professionals, although much needed, did not offer emotional support. Moreover, more than two-thirds of the informal caregivers had to prepare the older persons (emotionally) for the upcoming transition themselves.

(Wife, 75, interview: Z1.06) [‘Because were you ever prepared for this? No, not at all, I thought: what is happening now ... it was a real shock, yes’.]

Secondly, most participants recognised the dangerous home situation for older persons and their feelings of worry and burn-out. They acknowledged that the former home situation was no longer homely and nursing home admission was inevitable. This was especially true for the five informal caregivers whose loved ones understood their illness or were positive about moving into a nursing home. When the older person acknowledged it was no longer safe to live at home and indicated to appreciate the secure environment of a nursing home, the participants themselves were more positive and accepted a move to a nursing home.

(Brother, 85, interview: Z1.05) [‘I thought she will be fine there. And she agreed. That was of course very nice for me, that she liked it there herself. Otherwise, it would have been a bit more difficult of course ... I always left there feeling satisfied’.]

Finally, the interviews showed that negative emotions regarding the transition (e.g. feelings of guilt and grief) were often related to the day of the move and the first days after the move. It was noticeable that the majority of informal caregivers coped with this emotional challenge by focusing on re-establishing routine and homeliness for the older person. This continuation of their lives seemed just as important for the informal caregiver's well-being as for the older person's

adjustment to a new living situation [40]. More specifically, for informal caregivers, it was paramount that their loved ones had a place that looked like home. Furniture from their previous residence was brought in to let the older person feel at home. Additionally, all informal caregivers indicated the importance of continuing routines and habits once the older person resided at the nursing home. Different examples were given, such as the importance of religion, eating habits and care provision. If these habits were broken, informal caregivers often stepped up ensuring the proceedings of their routines.

(Daughter, 59, interview: e1.04) [‘So, I asked them like, wouldn't you be able to place his chair on the ward as it can be tilted. He really can't get out of his chair and they said: yeah, we could do that. And then another person said no, we have asked, but it is not allowed regarding the safety regulations ... then maybe he would have been more comfortable in comparison to the wheelchair which was closed off and which he hated. Then, he would have felt more at home, I think’.]

The need for a timely transition process versus the need to postpone the transition process

The second paradox showed that, at the moment of the transition, informal caregivers postponed a nursing home admission for as long as possible. In contrast, when looking back, informal caregivers would have preferred a timely transition plan. This shows the paradox between retrospective and prospective needs.

By analysing the interviews, it became clear that informal caregivers would have preferred sufficient time to prepare for the transition process. More specifically, about one-fourth of the informal caregivers specifically indicated the need for a timely organised care process, where sufficient time was taken to recognise, address and discuss a possible transition with family and, if possible, with the older persons as well. Moreover, about three-fourths of informal caregivers had a clear idea of what an ideal nursing home would look like. Around half of the informal caregivers focused on location (e.g. a familiar neighbourhood for the older person) or the context of the nursing home (e.g. easy access to the outdoors). They would have preferred more time to visit some nursing homes to allow for careful consideration.

(Daughter, 67, interview: V1.09) [‘She had to be admitted within 14 days, at the first place available. It was absolutely horrible’.]

However, the actions of the informal caregivers, at the time of transition, showed that they aimed at keeping the older persons home for as long as possible. The negative emotions associated with a nursing home admission made informal caregivers postpone a nursing home admission and thus avoid transitional care until the home situation was unsustainable and dangerous.

(Son, 63, interview: Z1.02) [‘She then went home where she had to cross a very busy road. She would say: those cars will stop for me. However, we realized something needed to happen’.]

The majority of informal caregivers waited too long to commence the admission process. They were mentally exhausted

and/or the older person was no longer safe. However, this often led to an unsustainable home situation, requiring an immediate admission, which led to a hastened care transition. The older person and informal caregivers were no longer able to prepare for this challenging process. This led one-third of the informal caregivers to feel like the transition process was unexpected and hastened. They indicated feeling overloaded with tasks/information and they did not have the time or space to mentally process the upcoming move.

(Daughter, 59, interview: e1.10) [‘On Wednesday going to your mother and you sit with her and then your mother is being told that yes, you will be moving on Friday. Then, you have to support your mother and arrange everything, you have to start packing right away, arranging things and you don’t even have, you don’t even have the chance to adequately prepare yourself or straightening things out, this is lacking yes . . . that should have been prepared better, yes’.]

Moreover, the few people who started the transition process on-time were impeded by an inefficient healthcare system, which influenced the transition experiences. Firstly, it was almost impossible for informal caregivers to initiate this care process themselves. Five informal caregivers felt that they were not taken seriously when addressing the need for transition, and once informal caregivers started contacting the responsible healthcare professionals, it was often a lengthy process. They indicated that they had to almost beg, insist and use strong language. One informal caregiver even used a family friend to start up the transition process. Another informal caregiver was advised by healthcare professionals to keep calling, repeatedly, to the responsible care organisations.

(Daughter, 44, interview: V1.10) [‘Interviewer: But how did you organize the transfer? Participant: . . . I made use of favouritism, what I mean is, in the nursing home works a girl who lives in our village and my aunt suggested, yeah, try to get in via her’.]

Secondly, in the Netherlands, older persons are only allowed to be put on a nursing home waiting list when they require 24-h support and care. However, by the time the older person had reached this stage, the informal caregiver often felt burned out and a nursing home admission was required urgently.

(Daughter, 59, interview: e1.04) [‘However, the GP is much more focused on the medical aspect of care and he had all the medications, and then one time he had a TIA. It is waiting for the big blow, so to speak but that’s how it was told to us. Interviewer: Yes, yes, until the requirements are there to take another step into care. Participant: Yes’.]

The need to be involved versus the need for distance from care responsibilities

The final paradox focuses on the internal struggle of informal caregivers, especially once the older person is residing at the nursing home. On the one hand, they wanted to be involved and monitor the care process, as they did at home. While, at the same time, they recognised their limitations and chose a nursing home when the care became too burdensome.

More than three-quarters of the participants felt the need to remain involved in the life of the older person after moving

to the nursing home. They indicated a need to participate and help direct the care process. They strived to form some kind of partnership with healthcare professionals. In this partnership, informal caregivers wanted to be acknowledged as a caregiver while searching for their new role in the nursing home.

(Daughter-in-law, 55, interview: V1.05) [‘My husband said at a certain moment: Gosh, don’t worry so much, she now lives over there and you need to let go, and I felt something was not right, I can’t let go when something isn’t right’.]

Although almost all informal caregivers indicated they wanted to remain involved in the life of their loved ones, about half of them stated a need to alleviate the care burden. Some informal caregivers felt they were still burdened with care tasks, taking on care responsibilities normally executed by healthcare professionals. Four participants said it was their job to lead the healthcare professionals and felt they needed to resolve any issues that arose. While preferably, informal caregivers did not want to direct the care process. They wanted to trust the expertise and experience of the healthcare professionals at the nursing home. Therefore, three-quarters of the informal caregivers indicated the importance of a contact person, as an influencing factor. Preferably, informal caregivers want to be introduced to him/her before or on the day of the move, and ideally, it was the same person throughout their stay at the nursing home. Eleven participants described the main responsibilities of these contact persons—to keep in contact with the informal caregiver and be available.

(Ex-husband, 72, interview: V1.04) [‘Participant: One contact person and whom that is, even if it is a carpenter . . . Yes, I mean, if you go to the store and you can’t find a certain product then you also go to the person wearing a blouse or jacket, then I think, oh that person I can see. And that person then has a boss to whom he/she has to answer. That is not my problem, is it?’]

The search for that balance, between being involved and keeping some distance, was strongly influenced by the other residents residing at the nursing home and perceived care provision. More specifically, about one-third of informal caregivers indicated having difficulties accepting the new home, if other residents were more cognitively impaired compared with their loved ones. They had more difficulties leaving the older person alone. This could be related to the older persons themselves feeling less comfortable and experiencing more difficulties adapting to the new living situation. Moreover, if informal caregivers felt dissatisfied with the care provided, they tended to monitor care more closely. This dissatisfaction was, according to informal caregivers, often related to absenteeism and lack of educated staff. Informal caregivers often criticised the lack of personnel. Two participants specifically indicated the difference between highly educated staff compared with staff in training, which caused a decrease in the quality of care. Moreover, informal caregivers often felt that communication with and between healthcare professionals was lacking. This made some informal caregivers intervene in this care process and take on the role of intermediary in the communication

process. Informal caregivers defined good communication as being open and honest. They wanted to be able to express their experiences of care with the healthcare professionals, and they felt they should be able and time should be made to ask questions. However, half of the participants noticed an inconsistency or a lack of communication between staff which, according to them, led to incomplete care provision.

(Daughter, 61, interview: V1.12) [‘Everyone should be on the same level of understanding. And that did not happen and then you noticed that everyone who worked there is an individual with their approach, which I understand. However, there should be a certain, yes, equality, a sort of, yeah, basis I would call it, which should be the same for everyone . . . And I missed this, certainly at the beginning’.]

Discussion

This study aimed to capture the experiences of informal caregivers of older persons with dementia throughout the transition process from home to moving into a nursing home. These experiences were characterised by the presence of three paradoxes: (i) contradicting emotions during the transition process; (ii) the need for a timely transition process versus the avoidance of transitional care altogether and (iii) the need to be involved versus the need for distance from care responsibilities. These paradoxes were influenced by the healthcare system, such as the inability to become familiar with a nursing home before receiving an official nursing home placement indication.

This study defined the transition from home to a nursing home as paradoxical. These paradoxes not only narrate the experiences but also provide a deeper understanding of the reasoning of informal caregivers during this process. It showed how fragile this care process is, identifying a fine line between an optimal and fragmented care transition. To illustrate, while informal caregivers need time to accept the need for a transition, a simple delay at the start of the transition process can lead to a crisis admission. The study by Boots *et al.* (2015) identified that informal caregivers of persons with early stage dementia had difficulty accepting help from healthcare professionals, while in a later dementia stage they would have appreciated the offered help.

Our results indicate that overall negative feelings associated with moving into a nursing home can be alleviated by a successful care transition. This is supported by the literature stating that the choices and steps made in the pre-transition phase strongly influence the experiences in the post-transition phase (e.g. good information about different nursing homes enables informal caregivers and older persons to choose a nursing home that fits their needs) [7, 19]. Additionally, different transitional care studies have emphasised the influence of healthcare professionals on the transitional care experiences of informal caregivers [5, 7, 11, 19, 41]. However, the importance of the social environment and the support of fellow informal caregivers, although strongly present in other studies [5–7, 9, 19, 41, 42], was not clearly stated by the participants in this study. This can be related to the focus of the interviews, which concentrated more on the

relationship between the informal caregiver and healthcare professionals.

Furthermore, we identified a clear mismatch between retrospective needs for a timely transition process versus the prospective desire of informal caregivers to enable the older person with dementia to remain at home for as long as possible. This paradox provides a possible explanation as to why care transitions are often associated with a crisis and critical events (e.g. hospitalisation) [7, 19, 42]. This highlights the importance of the nursing home placement occurring at the right time [6, 24].

Our results showed an internal dialogue of informal caregivers struggling to remain a part of the lives of older persons while simultaneously letting go of the caregivers’ responsibilities. Previous studies have indicated the difficulty for informal caregivers to distance themselves from their caregiver roles and take on new roles once in the nursing home [5, 6, 27, 43, 44]. These new roles were described as those of an advocate, quality controller and representative [9, 19, 43]. This is in line with the current study, which identified the need for informal caregivers to remain involved, assure continuity of care and re-establish previous routines [9, 11, 19, 43].

Finally, all paradoxes were influenced by the operationalisation of the healthcare system and whether healthcare professionals offered support (practical and emotional). More specifically, in some countries practical matters (e.g. financial burden) may significantly influence the transition process, possibly influencing the paradoxical experiences. However, in the Netherlands, the government finances nursing homes, decreasing the financial burden of informal caregivers and thus its impact on the transition experiences. Moreover, the need for support as expressed by informal caregivers indicates the importance of a partnership with the healthcare professionals, preferably led by a contact person appointed on the day of the move. This was also confirmed by Groenvynck *et al.* (2020) [4] who indicated the overall need of older persons and informal caregivers was to form a partnership during the transition process.

Implications for research and practice

The results show that the transition from home to a nursing home is more than relocating. They identify the complexity of transitional care and signify the need for improvement. However, the question should be raised if such an improvement is possible. The paradoxes, as described by the informal caregivers, are mostly internal conflicts related to the emotional gravity of the care transition [10–12]. This could mean that optimal transitional care simply should recognise and tie into these. Therefore, future research should enable healthcare professionals to support informal caregivers in managing these paradoxes. Moreover, the relation of these paradoxes to the current healthcare system should be defined. It is paramount to understand the ability of healthcare professionals and policymakers to improve the transition process.

Further insight into these existing paradoxes is important for both healthcare professionals and informal caregivers. For informal caregivers, it can be motivating to start planning this care transition on time, and it can prepare them for this upcoming care process. For healthcare professionals, it can provide insight into the thought processes of informal caregivers. This can help healthcare professionals to better support informal caregivers. For both of them, it can create awareness of the current gaps within the healthcare system [27, 45]. Moreover, the paradoxical feelings identified by the participants were found throughout all phases of the transition process (pre-, mid- and post-transition). This can be confirmed by previous research that indicated that the needs of informal caregivers are constant throughout the entire transition process [4, 5]. Future research should define the relationship between the paradoxes and the three transition phases as it would allow for more focused care innovations. Finally, throughout the analysis of the interviews, it became clear how strongly the identified paradoxes are interwoven with one another. One example hereof is how the negative emotions associated with the transition process led informal caregivers to postpone nursing home admission, which in turn led to negative transitional care experiences, followed by a need to more closely control the care environment. Future research should focus on further defining and analysing these interwoven paradoxes. This can be done by relaying these findings to the informal caregiver.

Limitations

Some limitations of the study should be considered. Firstly, the data collection was a secondary data analysis, part of the DEDICATED project focusing on palliative care. Therefore, data collection was started after the older person had passed away at the nursing home and a significant amount of time had passed between the interview and the transition. For six participants, the transition thus occurred >2 years ago. This retrospective research may have led to recall bias that might have influenced the results. Alternatively, the time between the transition and the interviews may have allowed informal caregivers to rationalise their transition process, possibly providing a more distant recollection of the transitional care process. Secondly, some older persons were admitted to a hospital or resided at a different care setting before making the transition to a nursing home. This may have led to different care experiences. However, although the transition pathways were different, the researchers did not find clear differences regarding the identified paradoxes.

Conclusion

The transition process, as experienced by informal caregivers, is defined by three paradoxes. They indicate the fragility of this transitional care process. Therefore, future research should focus on further defining these paradoxes and their

link with the care system to determine if the transition from home to a nursing home can be optimised.

Supplementary Data: Supplementary data mentioned in the text are available to subscribers in *Age and Ageing* online.

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