

Postprint version : 1.0
Journal website : www.journals.sagepub.com
Pubmed link : <https://pubmed.ncbi.nlm.nih.gov/36710420/>
DOI : 10.1177/07334648231153722

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What facilitates or hampers living at home with advanced dementia until the end of life? A qualitative study using retrospective interviews among family caregivers, general practitioners, and case managers

Loes M. de Jong¹, Anneke L. Francke^{1,2}, G´e Donker¹, Susanne van den Buuse³, Iris van der Heide¹

¹ Netherlands Institute for Health Services Research (Nivel), Utrecht, Netherlands

² Department of Public and Occupational Health, Amsterdam Public Health Research Institute, VU University, Amsterdam, Netherlands

³ Alzheimer Netherlands, Amersfoort, Netherlands

Abstract

This study provides insight into circumstances that facilitate or hamper living at home with advanced dementia until the end of life. Interviews were held with 11 bereaved family caregivers, two general practitioners, and nine case managers, related to a total of 12 persons with advanced dementia who had recently died. Persons with dementia who lived at home until the end of life often had family caregivers that received timely support from professionals and their social network. In the cases where the person with dementia could not live at home until the end of life, safety issues, severely challenging behavior, and high care dependency of the person with dementia played key roles. Case management and a continuous process of advance care planning will improve the chance that the end-of-life setting is in accordance with the key values and needs of both the person with dementia and family caregivers.

What this paper adds

- New insight into circumstances that facilitate or hamper living at home until the end of life with advanced dementia from the point of view of family caregivers, GPs, and case managers.
- In particular, insight on perspectives regarding safety issues of living at home until the end of life, how these can be overcome, or eventually are a reason for nursing home admission.
- As well as on how the acceptance of certain safety risks by family caregivers, such as the risk of falling, can contribute to living at home with advanced dementia until the end of life.

Applications of study findings

- The findings provide input for advance care planning for persons with dementia.
- The findings can help healthcare professionals to offer end-of-life care that is in accordance with the key values and needs of both the person with dementia and family caregivers.
- The study provides examples on how a close interaction between case managers, GPs, and family caregivers can contribute to offering care that is in line with the wishes of persons with dementia and to positive experiences with the care process among family caregivers.

Introduction

The majority of people prefer to live at home until the end of life (e.g., De Roo et al., 2014), including people with dementia (van der Steen et al., 2016). In particular, persons with advanced dementia can become seriously distressed when moving away from home (Gozalo et al., 2011). In accordance with the preference of most people, international healthcare policy is oriented toward providing care at home for as long as possible (World Health Organization, 2015).

In line with this, attention for end-of-life care at home has increased over the past years. As end-of-life care at home often involves a family caregiver, ways on how to support family caregivers, who face a variety of challenges, or involve them in the care process is an important angle of studies on end-of-life care at home (Michaels et al., 2022). The availability of health care professionals that address the needs of family caregivers was found to be one of the key makers of optimum end-of-life care for persons living at home (Butler et al., 2022).

When it comes to end-of-life care for persons with dementia, most research has been performed in institutional settings (O'Connor et al., 2022). One of the conclusions of a recent review is that further research is necessary to identify the key components of care that enable people with dementia to stay at home as long as possible (O'Connor et al., 2022).

Although healthcare policies prioritize remaining at home as long as possible, and persons with dementia favor in-home care (Wammes et al., 2021), only a small percentage of people with dementia do live at home until the end of life. Badrakalimuthu and Barclay (2013) found that in studies published before 2013, dying at home with dementia was rare (3–5% in England, Scotland, Wales and the Netherlands, and 11% in Belgium). For the Netherlands, there are more recent percentages: 9% of the people with dementia who died in 2019, died at home. In the Netherlands, a nursing home or other long-term care facility is the most common place of death for people with dementia (81%), while deaths in a hospital are relatively rare in this group (8%) (van der Heide et al., 2021).

These figures raise the question why so few people with dementia die at home. Mogan and colleagues (2018) performed a narrative review of studies of the facilitators and challenges in ensuring good end-of-life care at home for people with dementia. Based on their review of three qualitative and four quantitative studies, Mogan et al. identified the following facilitators: support

from healthcare professionals, family caregivers' resilience and extended social networks, adequate medication and symptom management, and appropriate equipment and opportunities to make adaptations to the home environment. The challenges they identified were issues with professional services and the decline in the physical or mental health of the person with dementia. The latter often led to admission to a long-term care facility.

The perspective of healthcare professionals was not considered in the studies that were reviewed by Mogan and colleagues. However, GPs and case managers in particular are often involved in the coordination and delivery of care for home-dwelling people with dementia, and therefore their views on remaining at home until the end of life with advanced dementia may add valuable insights. Although the review of Mogan and colleagues (2018) could identify studies reflecting the perspectives of family caregivers, these studies are also still scarce. Moreover, the review of Mogan and colleagues primarily focused on factors associated with good end-of-life care rather than considering what facilitates or hampers living at home until the end of life with advanced dementia. Hence, Mogan and colleagues recommended further research to obtain a better understanding of the challenges and facilitators regarding living at home until the end of life.

Therefore, the present study aims to provide insight into the views of bereaved family caregivers, GPs, and case managers on factors and circumstances that help meet the wish of people with advanced dementia to remain at home until the end of life.

Method

Recruitment and Sample

This qualitative study, using retrospective interviews, reconstructs cases of recently deceased persons who had advanced dementia. For each case, we aimed to interview a bereaved family caregiver and the GP or case manager who had been most involved in the care for the person with dementia. It was however not a strict requirement that for each case both a family caregiver and a GP or case manager agreed to participate, as there are cases in which there is no family caregiver or GP or case manager involved. The case manager could be a specialized dementia case manager or a community nurse who had the case manager role.

Cases were eligible for the study if the person with dementia meets the following criteria:

- Initially wanted to stay at home until the end of life, and their primary family caregiver(s) wanted this.
- Had advanced dementia when they died. The advanced stage was derived from the fact the person needed 24 hours of care a day at the end of life as a consequence of the dementia.
- Had died not less than 2 months and not more than 1.5 years prior to the interview.
- Had died in a nursing home and the nursing home admission had taken place in the last 6 months of life, or if 24 hours of care a day was needed as a consequence
- of the dementia before admission.

The family caregivers, GPs, and case managers of the persons with dementia were recruited in multiple ways between April 2020 and June 2021. Firstly, GPs and case managers within the professional networks of the authors were asked if they knew cases that fitted the eligibility criteria. If so, they were requested to contact the family caregiver and ask permission to be approached by the principle researchers (LdJ or IvdH). Given the sensitivity of the subject, family caregivers were approached only if their relative had died more than 2 months ago.

Secondly, family caregivers that were member of a nationwide research panel of family caregivers hosted by Alzheimer Netherlands were invited by email to participate in our study, in case they met

the eligibility criteria. When eligible, they were then asked to approach the GP or dementia case manager of their relative to ask whether the GP or case manager was also willing to be interviewed.

Thirdly, recruitment took place through an open call on the online fora of two home-care organizations in the Netherlands. The call was directed at specialized dementia case managers as well as community nurses who had the role of case manager. When an eligible case manager or community nurse was willing to be interviewed, (s)he was asked to contact the family caregiver for an invitation to participate in an interview as well.

Finally, snowball sampling via the interviewed GPs and case managers was used to recruit more cases for the study

Data collection

All participants first received written and verbal information on the purpose of the study and on their right of withdrawing at any time. The participants provided informed consent in writing before their participation in the interviews.

Individual, semi-structured interviews were held between April 2020 and June 2021 by the first author (junior researcher, registered community nurse, and health scientist) or last author (senior researcher and humanities graduate). One interview was held by two interviewers (LdJ and SvdB). All interviewers were trained in performing qualitative interviews. See COREQ checklist for details on the personal characteristics of the research team.

The interviews with family caregivers were intended to be held at their place of preference, as this facilitates trust and engagement (Green & Thorogood, 2018). The first three interviews were indeed held at the home of the family caregiver. However, due to the COVID-19 pandemic, the subsequent interviews were held via telephone. See COREQ checklist for details on the duration of the interviews.

A topic list with questions was used to guide the interviews. Topics included experiences with receiving/providing professional care and with family care at the end of life, perceived safety in the home, decision-making about moving to a nursing home, and whether views on the desirability of staying at home until the end of life changed in the course of the dementia trajectory. Broad open questions were used to encourage interviewees to talk about their own experiences and views.

Data Analysis

The interview data were analyzed in a cyclic iterative process of “data collection – analysis – new data collection,” until data saturation was achieved (Guest et al., 2006). This meant that each family caregiver or healthcare professional interview transcript was analyzed before the next interview took place.

The transcripts were analyzed, by following the steps of thematic analysis (Clarke & Braun, 2014): (1) familiarizing themselves with the data; (2) generating initial codes; (3) searching for themes; (4) reviewing themes; (5) defining and naming themes; and (6) reporting.

All interview transcripts were analyzed by the first author (LdJ), while the first half of the transcripts were also analysed independently by at least one of the other authors (AF, GD, and SvdB). Since the analyses of the first half of the transcripts showed no major discrepancies between coders and consensus was reached about the codes and main themes, the second half of the transcripts were analyzed by the first author and read by at least one other author to ensure no new subthemes were missed.

The outcomes of the analyses were discussed with all authors in (at least monthly) team meetings that included the following: (a) reaching consensus on codes and main themes derived from the transcripts; (b) identifying topics that were considered important to include in upcoming interviews; and (c) examining whether data saturation had been reached.

After all the transcripts were analyzed, team meetings were held to reach consensus about the main overall themes and discuss how these relate to each other.

Results

Background Characteristics of the Cases and Persons Interviewed

As Table 1 shows, a total of 12 cases were included in the study. For these twelve cases, a total of eleven bereaved family caregivers, two GPs and nine case managers were interviewed. Of the nine case managers, six were specialized dementia case managers and three were community nurses with a case management role. For the readability, both the specialized case managers and the community nurses with a case management role are referred to hereafter as “case manager.”

[Table 1]

In five of the twelve cases, the person with dementia stayed at home until the end of life. In three of these five cases, the person lived with a family caregiver. In another case the person lived alone, but with the support of a family caregiver, while one person lived alone and had no family who cared for her. In the latter case, only the case manager was interviewed.

Out of the seven cases where the person eventually moved to a nursing home, five people with dementia lived with their partner and two people lived alone before the nursing home admission. In these two cases, a son-in-law or a daughter was the primary caregiver.

Factors and Circumstances That Facilitated Living at Home Until the End of Life

The interviews relating to cases in which the wish to remain at home was met revealed five main factors and circumstances that were interactively important in helping the person with dementia remain at home (Figure 1). In the following section, the factors and circumstances that were perceived to facilitate living at home until the end of life will be outlined. Quotes to illustrate each of the factors can be found in Table 2.

Some of these factors and circumstances, such as support from professionals, were also often present in cases in which the person with dementia was eventually admitted to a nursing home. However, in those cases, severely challenging behavior, unsafe situations, and the increasing care dependency of the person with dementia resulted in an increasing care burden for the family caregiver, and consequently changing views on the desirability and feasibility of staying at home. The changing views of the primary family caregiver ultimately led to a nursing home admission (see Figure 2).

Resilience of the Family Caregivers. Having sufficient resilience

was crucial in particular for caregivers who lived with the person with dementia, according to both the family caregivers themselves and the professionals interviewed. They often did not mention resilience explicitly, but referred to their resilience as “being able to cope” and “being able to keep up” the care. GPs and case managers felt that their assessment of the family caregiver’s resilience was key to whether they supported the decision to let the person with dementia stay at home. In another case involving a woman who lived alone, the caregiver tasks were performed not just by her children but also by a self-directing home care team and her neighbors. In combination, the care professionals, children, and neighbors formed a resilient team that allowed the woman to continue living at home even though she had advanced dementia and lived alone.

Support From a Case Manager, GP, and/or Home Care Nurses.

In four of the five cases in which the person with dementia stayed at home, the interviewees said that the support of a case manager, GP, and/or home care staff was of key importance in helping the family caregivers keep up their care tasks for so long.

[Figure 1]

The care professionals assisted the person with dementia and the primary caregiver, in accordance with their needs and wishes. In particular, the GP or case manager helped work out how to organize and carry out the care, checked whether the need for support had changed over the course of the illness, and sometimes arranged care too. This was important for the family caregivers as they found arranging the care, for example, day care, cost a great deal of energy. Some family caregivers said they “really couldn’t cope with that as well.” Case managers said that their support helped the family caregivers to accept the use of more professional care and assistance, which reduced the burden for the family caregivers and let them keep up their care tasks for longer.

In some of the cases, the case manager, GP, and/or home care staff went further in the support they gave than would be expected given their normal professional duties and working hours. The clearest example of this is the case concerning a woman who remained living at home until the end of life but received no help from relatives. In this example, the case manager and nursing staff in a self-directing home care team took on tasks, such as get groceries and preparing and giving food, that were not part of their professional duties. In addition, they visited the woman extremely frequently. Actually, they gave a lot of help that was not reimbursed by the health insurer and that in other cases was given by family members.

However, not all of the family caregivers received support from professionals. In one case, the husband of a woman who stayed at home until the end of life was dissatisfied with the assistance from the GP and decided to take care of his wife by himself. In another case, a daughter decided to carry on doing as much as she could herself rather than involving home care professionals, as her mother was calmer then.

Day Care and Planned Takeover of the Family Caregiver’s Care Tasks.

In some of the cases, day care and the planned temporary takeover of care tasks (respite care) seemed to be important in letting family caregivers keep up their task. Day care often took the form of a number of mornings or afternoons a week with organized activities outside the home. The planned takeover of care tasks involved another relative, a paid carer, or a volunteer taking over the care tasks in the home at fixed times once a week or more.

Various family caregivers reported that the day care and planned takeover of care tasks allowed them to get their breath back as it meant they had some time for social contacts, hobbies, work, or doing the grocery shopping.

However, day care was not used in all the cases where it was possible for the person with dementia to remain at home. Moreover, sometimes admission to a nursing home proved necessary in cases where there was day care and/or the planned takeover of care tasks. This suggests that day care and having scheduled “breaks” are not in themselves sufficient. Here too, these are interacting factors (see Figure 1) that can affect the resilience of the family caregivers.

Support From the Wider Social Network.

Support from other relatives, friends, and/or neighbors is another interacting factor that can affect the resilience of family caregivers and consequently whether the person with dementia can remain living at home. Family caregivers who enjoy the support of a social network feel they are not facing the task alone.

In the case of the woman with dementia who lived alone, the neighbors played a key role in addition to the professionals in the self-directing home care team. They “kept an eye on” the person with dementia and offered help where necessary.

There were two cases where the person was able to continue living at home even though there was little support from a broader social network. The lack of this form of support was however felt to be a problem in these cases.

[Table 2]

[Figure 2]

Safety and the Acceptance of Safety Risks.

A safe home environment also seemed to be a factor in determining whether someone could continue to live at home. Family caregivers and professionals mentioned aspects such as having no stairs, the possibility of shutting of the gas, and installing a height-adjustable bed. Staying at home also required the acceptance of certain safety risks by family caregivers and the professionals concerned, for example, based on an acknowledgment that falls can also occur in nursing homes.

Factors and Circumstances That Hampered Living at

Home Until the End of Life

In the cases where living at home until the end of life was not possible, this was often because of unsafe situations, extreme levels of care dependency, or because the person with dementia increasingly exhibited severely challenging behavior, which all led to a very high care burden for the family caregivers (Figure 2).

All cases where the person with dementia was admitted to a nursing home involved multiple interacting factors that led to a change in views on the feasibility of the person with dementia being able to stay in their own home. In the sections below, we discuss the factors and circumstances that the interviewees thought were behind that change in the views. Quotes to illustrate each of the factors can be found in Table 2.

Very High Level of Care Dependency and Care Burden

Caregivers who looked after a partner felt that as the dementia worsened, their partner required increasingly intensive care, which placed a heavy burden on them, both physically and mentally. This made them gradually revise their ideas about the feasibility of looking after their partner at home until the end of life. In one of the cases, the partner–caregiver suffered such severe physical complaints that she was unable to continue caring for her husband and required care herself. As a result, she and the case manager concluded that it was no longer possible for the man to be cared for in their home.

Family caregivers who had to combine the care for their relative with a job and the care for other family members also found the task increasingly wearing.

Adult children and their partners who did not live in the same home as the person with dementia also experienced a very high level of care dependency and associated care burden. They had the feeling that as family caregivers they had to be available and reachable 24 hours a day. The family caregivers found this—in combination with the unsafe situations that could arise when their relative was alone—too much of a burden. They gradually came to realize that admission to a nursing home would be better.

Acute, Unexpected Situations

In some cases, an acute, unexpected situation arose that was the final straw, for example, when a family caregiver broke an arm or the person with dementia had to be admitted to hospital urgently. The following quote is from a man who reached the conclusion after his wife was admitted to a hospital with pneumonia that a return home was not a feasible option.

Severely Challenging Behavior and Unsafe Situations

Often, the ever-increasing burden of care and the eventual admission to a nursing home were due to the severely challenging behaviour of the person with dementia. Behavioral problems played a role in all the cases that ended in admission to a nursing home. Restlessness at night was very common, and this meant the partner caregiver was often disturbed in their sleep.

Wandering around lost in the neighborhood, running away, agitation, and occasionally aggression were also reported. In some cases, the challenging behavior included deep suspicion and constantly hiding objects.

The serious behavioral problems of the person with dementia sometimes led to unsafe situations or at the very least a feeling that the situation was not safe. The caregivers sometimes felt unsafe when the person with dementia behaved aggressively. Getting lost and running away constituted unsafe situations for the person with dementia.

Changing Views Resulting in a Decision to Have the Person With Dementia Admitted to a Nursing Home

Over the course of time, the primary caregivers in the cases that ended in admission to a nursing home changed their views on the feasibility of keeping their relative at home. The change in views on the matter sometimes happened quickly, prompted by an acute situation such as a fall or hospital admission. The person with dementia often had no say anymore in the final decision to have them admitted to a nursing home due to their cognitive and communicative limitations.

The case of the man who developed dementia from around the age of 50 was an exception in that respect. The man did not initially agree with his wife's opinion that remaining at home until the end was no longer a realistic option. The case manager had an important supportive role in involving the man and the rest of the family in the decision-making. The case manager came up with ideas for possible nursing homes (including small-scale units) and accompanied the couple when they went to view potential nursing home locations. In the months before the admission, the case manager also had individual conversations with the man in question, his wife, and their children about what they thought was important for the future. As a result, the entire family was involved in the final decision to have the man admitted to a nursing home, a decision that the wife and case manager still feel was right.

In the other cases, the patient's dementia had advanced to such an extent that they no longer had any say in the decision to admit them. In some of these cases, the GP or case manager had initiated discussions at an earlier stage about the possibility of admission to a nursing home if staying at home was no longer feasible. But those conversations could be tricky because people were not yet able to see that it might become too difficult for the person with dementia to remain at home.

Discussion

Sufficient resilience on the part of the primary caregiver seems crucial in enabling persons with dementia to remain at home until the end of life. In our study, the family caregiver often did not use the term resilience, but referred to it as "being able to cope with the situation" and "being able to keep up care for my relative" the care. This fits well with wellknown definitions of resilience like "a range of care partners' capacities to navigate challenging situations throughout the dementia care

trajectory and may enable them to meet both personal and care recipients' needs" (Gaugler et al., 2007).

Sufficient and timely support seems important in boosting the resilience of family caregivers: support from the GP, case managers, home care professionals, and from the extended social network. Also, day care and the planned takeover of family care tasks (respite care) were in some cases very important for the primary caregiver to stay resilient and to fulfil the wish that the relative with dementia remains at home. Other qualitative interview studies also point to the importance of additional support and forms of respite care for the resilience of family caregivers (e.g., Roberts & Struckmeyer, 2018).

However, our study also shows that some family caregivers were resilient without receiving professional support or without making use of day care or planned take-over care. This seems to illustrate that resilience is a multidimensional phenomenon that can be both a personal trait as well as an outcome or process positively affected by support from others, as is also described by Zhou et al. (2021). Zhou and colleagues also pointed to the need for healthcare professionals to assess and promote family caregivers' resilience, for example, within a process of care planning (Zhou et al., 2021).

The facilitators described in our study partly overlap with the facilitators of good end-of-life dementia care as described in the international review of Mogan et al. (2018): support from professionals and from the caregiver's own social network contributes to good end-of-life care and also helps meet a wish to remain at home with advanced dementia.

Our study, however, also described cases where the wish to let the patient remain at home was not fulfilled. Several intertwined and interacting factors were at the root of this: severely challenging behavior, unsafe situations, and high care dependency, leading in some cases to overburdened family carers and a changing viewpoint on the feasibility of letting the person with dementia remain at home. The extent to which these factors are of significance in individual cases also varies.

However, it is clear that the resilience of family caregivers as well as timely support from professionals and people from family caregivers' social network plays a key role. Case management was important in most of the cases where the person with dementia remained at home. This is in line with a survey study among more than 3500 family caregivers in the Netherlands, in which 61% reported that for them case management was the most important form of professional support in letting their relative with dementia remain at home as long as possible (van der Heide et al., 2020).

As also shown in our study, views on the feasibility and desirability of remaining at home could change. This is one of the reasons why regular advance care planning discussions initiated by the case manager or GP who coordinates the care are important. The international consensus paper on dementia care at the end of life states that "Advance care planning is a process, and plans should be revisited with patient and family on a regular basis and following any significant change in health condition" (van der Steen et al., 2014).

In the cases in our study where the decision was ultimately taken to admit the person with dementia to a nursing home, none of the interviewed family evaluated the stay in the nursing home negatively and they still perceived the admission as necessary in relieving their excessive care burden. This is in line with interviews in an international cohort study in eight European countries: after the transition to a residential care facility, family caregivers of people with dementia experienced a statistically significant decrease in burden and distress (Bleijlevens et al., 2015).

So far, a relatively underexposed research theme concerns the perceptions of family caregivers and healthcare professionals regarding safety issues. We found that a safe home environment, such as having no stairs, might contribute to staying at home. However, not only "objective" safety but certainly also the extent to which those involved are prepared to accept safety risks (e.g., risks of falls) is associated with remaining at home. This finding adds to findings of previous research, in

which safety predominantly was related to interventions or circumstances that could enhance the “objective” safety of persons with dementia living at home (e.g., Gettel et al., 2021).

The current study has also added value since we explored both perspectives of family carers and those from care professionals. Although our initial aim was to interview for each case a family caregiver and a GP or case manager, it turned out that there was a case in which no family caregiver was involved and in another case no healthcare professional was intensively involved, even though remaining at home until the end of life was realized. We consider these interviews an enrichment as they shed a nuanced light on what enables living at home until the end of life with advanced dementia. At the same time, more research on living at home until the end of life without either a family caregiver or a healthcare professional might be relevant as we had little data on these particular cases, given that it was not the focus of the current study.

A limitation of our study is that we know very little on how the persons with dementia experienced remaining at home or an admission in a nursing home, given their initial wish to remain at home.

Another limitation is that our recruitment strategies were partly through care professionals and partly through family caregivers. This had the disadvantage that especially those who had positive experiences with (family) caregivers might have been inclined to participate. However, by also using an open call as a recruitment strategy, we were able to recruit participants who had less good experiences as well.

A third limitation is that almost all interviews had to be conducted by telephone (instead of face-to-face) because of the COVID-19 pandemic. The pandemic also impacted the experiences of the family caregivers and healthcare professionals. For instance, in one case a family caregiver expressed that caregiving had intensified because professional home care was no longer or very limitedly available. One other interviewee (a professional) expressed that it had affected the decision for admission in a nursing home because day care was no longer available, having a huge impact on the family caregiver.

Conclusions and Recommendations

This study indicates that actions that enhance the resilience of family caregivers, case management, and a continuous process of advance care planning will improve the chance that the end-of-life setting is in accordance with the key values and needs of both the person with dementia and family caregivers. Good communication between patient, family, and professionals is of key importance in this regard. Also, care organizations and health care insurers have to allocate GPs, case managers, and community nurses' sufficient time to provide advice and care to persons with dementia who wish to live at home until the end of their lives. A recommendation for future research is to explore the perspectives of persons with dementia regarding the choice for a nursing home admission at the end of their life, in order to obtain a better understanding of how care (settings) could meet the needs of persons with dementia.

Acknowledgments

We thank all the family caregivers and healthcare professionals who participated in this study for sharing their experiences and Stoffels-Hornsta for providing financial support for this study.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This study is supported by Stichting Stoffels-Hornstra.

ORCID iD

Iris van der Heide  <https://orcid.org/0000-0002-9709-7261>

Supplemental Material

Supplemental material for this article is available online.

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Tables and figures

Table 1. Background Characteristics of the People With Dementia, the Family Caregivers, and the Healthcare Professionals That Were Interviewed.

| Cases of People With Advanced Dementia Who Remained at Home Until the End of Life | | | | |
|-----------------------------------------------------------------------------------|--------------------------------------------|------------------|--------------------------------------|-----------------------------------------------------------|
| Case # | Gender and Age of the Person With Dementia | Living Situation | Primary Family Caregiver Interviewed | Professional Interviewed |
| 1 | F, 80 | With spouse | Spouse | None, we were not able to recruit a professional involved |
| 2 | F, 75 | With spouse | Spouse | Specialized case manager |
| 3 | F, 87 | With daughter | Daughter | GP |
| 4 | F, 89 | Alone | — | Community nurse with case management role |
| 5 | F, 95 | Alone | Son | Community nurse with case management role |

| Cases of People With Advanced Dementia Eventually Admitted to a Nursing Home | | | | |
|------------------------------------------------------------------------------|--------------------------------------------|----------------------------------------------------|--------------------------------------|-------------------------------------------|
| Case # | Gender and Age of the Person With Dementia | Living Situation Before the Nursing Home Admission | Primary Family Caregiver Interviewed | Professional Interviewed |
| 6 | F, 86 | With spouse | Spouse | GP |
| 7 | M, 75 | With spouse | Spouse | Specialized case manager |
| 8 | F, 98 | Alone | Son-in-law | Specialized case manager |
| 9 | F, 94 | Alone | Daughter | Specialized case manager |
| 10 | F, 94 | With spouse | Spouse | Community nurse with case management role |
| 11 | M, 54 | With family | Spouse | Specialized case manager |
| 12 | M, 90 | With spouse | Son | Specialized case manager |

Figure 1. Factors and circumstances enabling living at home until the end of life.

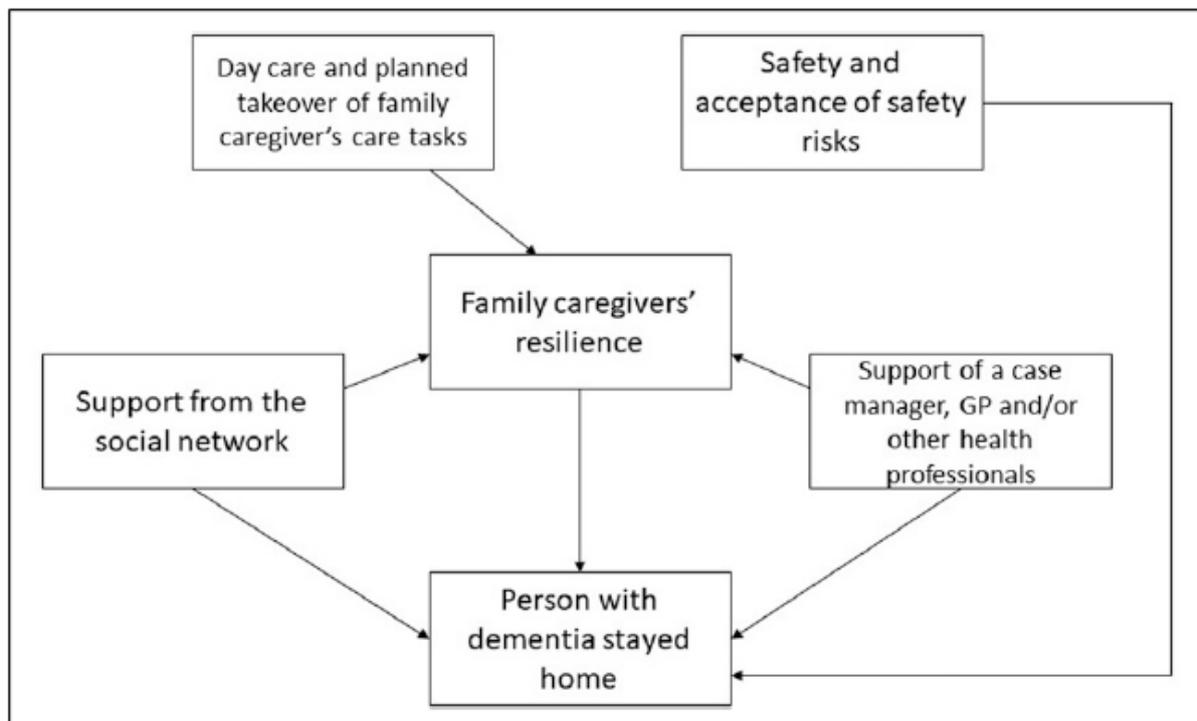


Table 2 Quotes From Interviewees Supporting the Factors That Contribute to or Hamper Living at Home Until the End of Life With Advanced Dementia.

| Factors and Circumstances | Supporting Quotes |
|----------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Factors and circumstances that facilitated living at home until the end of life | |
| Resilience of the family caregivers | "I have seen a lot of situations where I've said 'the home situation is no longer workable'. But I reckon it depends mainly on the caregiver and whether they can cope. [...] And I went all-out to support him, as I thought he would be able to cope." (Case manager in Case No. 2) |
| Support from a case manager, GP, and/or home care nurses | "We thought, well, we accept this situation because she doesn't want it any other way. So what do we need for that? And we kept pushing our boundaries little by little because I ended up doing things that I could see weren't part of my duties." (Case manager in Case No. 4) |
| Day care and planned takeover of the family caregiver's care tasks | "A volunteer came and she was really sweet to my wife. So I could do the shopping, because I had to do all that myself whenever there was a moment. So off I went, to one place and the next." (Family caregiver in Case No. 2) |
| Support from the wider social network | "Well, this informal caregiver, the neighbour who lived opposite did an awful lot for her, you know. [...] And if the neighbour thought 'Hey, where is she? I haven't seen her for a while', she would pop in and sometimes the lady would be lying in the hall or... and then she would call us." (Case manager in Case No. 4) |
| Safety and the acceptance of safety risks | "You don't want someone falling down the stairs or anything like that. If someone falls in their home I see that as very nasty, but it's also something that can happen in a nursing home because you're not watching over them 24 hours a day there either." (Case manager in Case No. 5) |
| Factors and circumstances that hampered living at home until the end of life | |
| Very high level of care dependency and care burden | "Then I went off to my work and my husband was picked up by the care farm van. Then he went to the care farm, my youngest son went to school and I stopped at two thirty, no I mean I stopped at two o'clock because I had care leave. Then I drove home again and I stayed at home until he was brought back. Well, from that point on you had to keep an eye on him constantly, check what he was doing." (Family caregiver in Case No. 11) |
| Acute, unexpected situations | "If you can't do anything anymore and have to be helped by two people every day. [...] She couldn't stand up on her own two feet anymore, for example. She couldn't walk any longer. She hadn't been able to do that for the past few months, the past two to three months. Well, then there was this [the hospital admission] on top of everything else, and it all becomes a bit too much on your own. She couldn't come back home, no." (Family caregiver in Case No. 10) |
| Severely challenging behavior and unsafe situations | "My mother could simply no longer cope with the pressure of my father hiding her things on an increasingly frequent basis and her constantly having to repeat what he needed to do. [...] When he told her the same thing a hundred times, there came a point that she couldn't take it anymore. In particular, it was the getting up in the night, hiding things, continually having to tell him what he should and shouldn't do." (Family caregiver in Case No. 12) "She had a real urge to be moving around and then she would just leave the house. [...] Well at one point she was nowhere to be found, and she was brought back home by the police. After that happened once or twice, we said, 'This can't go on any longer. This isn't safe.' And so she was admitted after all." (GP in Case No. 6) |
| Changing views resulting in a decision to have the person with dementia admitted to a nursing home | "Yes, [the case manager] saw me gradually looking more and more tired every week so, 'How about we visit the Care Farm'. Well, the Care Farm. Yes, he [the person with dementia] thought that was a good idea." (Family caregiver in Case No. 11) "But we also talked about it several times earlier in the process: hey, shouldn't she be put on a waiting list, or how do you feel about that? But he put off having care for her as well for a long time because he really wanted her to stay at home." (Case manager in Case No. 10) |