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## Feature Article

## Facilitating aging in place: A qualitative study of practical problems preventing people with dementia from living at home

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## ABSTRACT

Although the majority of people with dementia wish to age in place, they are particularly susceptible to nursing home admission. Nurses can play an important role in detecting practical problems people with dementia and their informal caregivers are facing and in advising them on various ways to manage these problems at home. Six focus group interviews ( $n = 43$ ) with formal and informal caregivers and experts in the field of assistive technology were conducted to gain insight into the most important practical problems preventing people with dementia from living at home. Problems within three domains were consistently described as most important: informal caregiver/social network-related problems (e.g. high load of care responsibility), safety-related problems (e.g. fall risk, wandering), and decreased self-reliance (e.g. problems regarding self-care, lack of day structure). To facilitate aging in place and/or to delay institutionalization, nurses in community-based dementia care should focus on assessing problems within those three domains and offer potential solutions.

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## Introduction

## Background

The number of people suffering from dementia is increasing worldwide.<sup>1,2</sup> Currently, about 260,000 people with dementia live in the Netherlands,<sup>3</sup> and about 70% of them are living at home supported by informal and formal caregivers.<sup>4</sup> Formal community-based dementia care in the Netherlands basically consists of care providers such as general practitioners, home care organizations, day-care centers, and care coordinators (e.g. dementia case managers).<sup>5</sup> Since dementia is a progressive disease characterized by cognitive and functional decline, it makes people increasingly dependent on support<sup>2</sup> and particularly susceptible to nursing home admission.<sup>6</sup> At the same time, the expected preference of the

majority of people with dementia is to live at home as long as possible,<sup>1,7</sup> which is also a common policy aim of many Western countries.<sup>1,8</sup>

During the last years the policy concerning the eligibility for publicly funded professional long-term care in the Netherlands has changed significantly.<sup>9,10</sup> Where in the past people were widely supported by publicly funded professional care either at home or in long-term care facilities, people now need to live as long as possible in their own home environment. Moreover, the social network of a care dependent person is expected to fulfill as much care tasks as possible before publicly funded care can be requested.<sup>9, 10</sup> These changes put new responsibilities on informal caregivers and ask for new solutions to delay or even prevent nursing home admission.

To delay nursing home admission of people with dementia it is necessary to have insight into the factors which prevent people with dementia from living at home. General predictors of nursing home admission of people with dementia have already been extensively studied, and the results are, to a large extent, summarized in two systematic reviews by Gaugler et al<sup>11</sup> and Luppá et al.<sup>12</sup> According to Luppá et al<sup>12</sup> the predictors can be categorized into predisposing variables (socio-demographic and relationship characteristics of patients and caregivers), needs variables (primary stressors such as severity of dementia, functional impairment and

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caregiving hours and secondary stressors such as caregiver burden or life satisfaction) and enabling variables (personal and social resources and community-based care). A recent European study<sup>13</sup> showed that caregiver burden and dependency in activities of daily life, are the most consistent factors predicting a nursing home admission for people with dementia. In order to support people with dementia and to delay or even prevent institutionalization it is necessary to focus on potentially modifiable predictors such as caregiver burden or ADL dependencies. Consequently, this theoretical knowledge needs to be operationalized into concrete solutions to delay or even prevent institutionalization of people with dementia. To tailor (innovative) solutions first deeper insight into the underlying practical problems (daily struggles) people with dementia and their caregivers are experiencing in the daily life which prevent them from living at home is needed.

Professionals can play an important role in advising people with dementia and their informal caregivers on possible solutions and care options<sup>14</sup> as people with dementia and their informal caregivers might not be aware of available and quickly evolving (technological) solutions.<sup>15</sup> In community-based dementia care nurses in the function of district nurse or and case manager often fulfill this advisory role. Hence, nurses need to have insight into most important practical problems people with dementia and their informal caregivers are experiencing, that prevent them from living at home. Those problems should be addressed first in an attempt to delay or prevent nursing home admission.

### Aim

Therefore, the aim of this study was to gain deeper insight into the most important practical problems preventing people with dementia from living at home. These insights may inform nurses in community-based dementia care how to target their assessments as well as their advice on possible solutions to delay or prevent institutionalization.

## Material and methods

### Design

A qualitative study using six focus group interviews was conducted to gain insight into the most important practical problems in daily life preventing people with dementia from living at home.

### Sample/participants

A purposive sampling method was applied so that participants were selected who are regarded as particularly knowledgeable about the topic under consideration and can provide relevant information.<sup>16</sup> Therefore, we chose important stakeholders involved in different phases of community-based dementia care. Those stakeholders were divided into three types of focus groups (A, B and C). A total of six focus group interviews were conducted. The size of the individual groups was planned to be between 6 and 11 participants. The first three focus group interviews (type A) consisted of professionals who had a direct role in care coordination for community-dwelling people with dementia (case managers, home care nurses, general practitioners, client advisors of long-term care organizations) ( $n = 23$ ). Those professionals work with community-dwelling people with dementia on a daily basis and have experienced numerous transitions from home to a nursing home. Two focus group interviews (type B) were planned with occupational therapists, experts in the field of assistive technology, suppliers of assistive technology, and a consultant working for a non-profit organization that advises informal

caregivers about their caregiving tasks ( $n = 14$ ). The participants in this group were included because they were expected to have insight into specific practical problems in the daily life of community-dwelling people with dementia, as they are often involved in the process of solving such problems. Finally, one focus group (type C) was composed of informal caregivers of people with dementia and representatives from dementia support groups (who were also informal caregivers) ( $n = 6$ ), as they are the ones actually “co-experiencing” the practical problems in daily life. Informal caregivers were included because they provide, to a large extent, the care for community-dwelling people with dementia. Moreover, evidence shows that they can be considered a reliable source of information on reasons for nursing home admission of people with dementia.<sup>17</sup> All participants were recruited via the Living Lab in Aging and Long-Term Care South Limburg and via a network organization for innovative care and technology located in the south of the Netherlands.

### Data collection

The six focus group interviews were held in September and October 2014. The interviews took place in a meeting room at the university and were planned to last for about 2 h. All interviews were audio recorded with verbal consent of all participants. The interviews were led by experienced moderators (two authors [M.B., M.L.] and one other researcher) who are doctorally-prepared researchers in gerontology, assisted by one or two observers (one author [T.T.L.] and one other researcher). A topic list with two main open-ended questions (1. “What are the most important problems preventing community-dwelling patients with dementia from living at home?” If no informal caregiver-related problems were described initially, the moderator asked the following question: 2. “What are problems informal caregivers experience that threaten the ability of people with dementia to live at home?”) was used to structure the interviews. Prior to the interviews, the participants received information about the aim of the interview as well as the first main question of the topic list via email or mail. To ensure that all participants had an equal chance of expressing their opinion, the focus groups were conducted based on elements of the Metaplan method.<sup>18</sup> According to this method, to visualize and lead group discussions, participants are asked to write down their arguments on cards, which are subsequently jointly clustered. At the start of each focus group interview, all participants were asked to write down on sticky notes what, according to them, were the three most important problems preventing people with dementia from living independently at home. To start the discussion, each member was asked to name the three most important problems. All notes were collected and jointly clustered into categories to get an overview of the problems mentioned and to verify whether important problems were missing. When no new categories emerged, it was assumed that saturation was reached. During the interviews, the observers took field notes. At the end of each interview, the participants were asked to voluntarily complete a socio-demographic questionnaire containing questions about age, gender, and their role in caring for community-dwelling people with dementia.

### Data analysis

The data analysis started with collecting the sticky notes containing the most important problems according to the respondents after each focus group interview. After all interviews were conducted, the sticky notes from all six focus groups were clustered by two pairs of project team members (three authors [T.T.L., M.B., M.L.] and one other researcher) into themes indicating the problem domains, keeping in mind the clusters made

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