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**Title:**

Where should nurses in community-based dementia care focus to facilitate aging in place.

A qualitative study to assess 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.

**Keywords:** Aging-in-place, community-dwelling, dementia, focus groups, nurses, practical problems

# 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>10</sup> <sup>9</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 (sociodemographic and relationship characteristics of patients and caregivers), needs variables (primary stressors such as severity of dementia, functional impairment and 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 the 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 two hours. All interviews were audio recorded with verbal consent of all participants. The interviews were led by experienced moderators (two authors [insert initials] and one other researcher) who are doctorally-prepared researchers in gerontology, assisted by one or two observers (one author [insert initials] 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 [insert initials] and one other researcher) into themes indicating the problem domains, keeping in mind the clusters made during the focus group interviews. They discussed the clusters to reach consensus about the themes (subsequently described as problem domains). Based on the audio files, literal transcripts were made for each focus group session. The interview texts were analyzed according to the principles of qualitative content analysis.<sup>19</sup> The first author [insert initials] read the entire interview text several times and highlighted passages where the interviewees expressed their opinion about the problem domains, as previously defined. All information provided about one problem domain was first summarized using condensation, which means shortening the text but preserving the essence<sup>19</sup> for each individual interview. Subsequently, the condensed descriptions of the problem domains of all interviews were combined into one overall MS Word document. The information about the problem domains was reviewed, and content-related categories were formulated by the first author and discussed amongst the co-authors to reach consensus.

To strengthen the trustworthiness of the study, different measures were taken to meet the criteria of credibility, dependability, confirmability, and transferability, based on the framework of Lincoln and Lubba.<sup>20</sup> Since choosing participants with various experiences can lead to a richer description of the topic under consideration and therefore increase the credibility of the results,<sup>19</sup> a purposive sampling method was used to include various perspectives of stakeholders playing a central role in community-based dementia care. Moreover, the main problem domains were derived from the sticky notes and clustered by two pairs of researchers, who subsequently reached consensus about the problem domains. This procedure was followed by a member check where the main results were presented and discussed with a sample of former participants of focus group type A (N=5) to further improve the credibility and dependability of the results.<sup>20</sup> To enhance dependability, the procedures followed in this study were meticulously described, and the same topic list was used for all focus group interviews. To increase the confirmability, which means ensuring the objectivity of the data,<sup>21</sup> the moderator summarized the main results at the end of each focus group interview and encouraged the participants to critically reflect on the results and correct or add information where necessary. Detailed descriptions of the findings backed with literal quotes from all six focus groups are provided in order to increase the transferability<sup>19</sup> all results presented in this article were substantiated with literal quotes from all six focus groups in this article.

### **Ethical considerations**

The study protocol was approved by the medical ethics committee of Atrium-Orbis-Zuyd (14-N-95). Information about the aim of the study and the expected burden of the focus group session was provided to all participants in advance, either by email or post. Participation in the interviews was strictly voluntary for all participants. Before the start of each interview, oral consent to contribute to the study was given by all participants. Additional written informed consent was obtained from representatives from interest groups and informal caregivers.



## Results

A total of 43 participants took part in the six focus group interviews. Table 1 provides information about the composition of the focus groups and socio-demographic characteristics of the participants.

[Insert Table 1 here]

### **Practical problems in daily life preventing people with dementia from living at home**

The participants came up with a variety of practical problems in daily life, such as problems due to insufficient food and fluid intake, wandering, or absence of a person who can detect risks and intervene in case of emergency. The participants initially reported that defining the three most important problems was challenging. In their opinion, the problems in daily life are highly determined by the individual situation, and a combination of problems may lead to a situation in which living at home may become impossible. However, when asking them to write down what first came to their minds, comparable problems within all groups were described, which could be categorized into common “problem domains”: problems due to decreased self-reliance, safety-related problems, informal care/social network-related problems, behavioral problems, formal care-related problems, and cognitive decline. Those problem domains were also confirmed during the member check.

In the following paragraphs, the practical problems mentioned by the participants are described for each problem domain, starting with the most often described problem domains, followed by the less frequently mentioned problems. Table 2 provides an overview of the practical problems described within the problem domains, supported by quotations from the participants. The codes assigned to the quotes stand for FG (focus group), followed by two numbers, with the first indicating the number of the focus group (1–6) and the second indicating the number assigned to the individual participant.

[Insert Table 2 here]

### **Decreased self-reliance of the person with dementia**

The first problem domain consistently described during all six focus group interviews was problems regarding decreased self-reliance of the person with dementia, meaning that people with dementia lost their ability to conduct, plan, and decide about normal activities of daily living (ADL) during the course of a day. A frequently described problem preventing people with dementia from living at home was decreased ability to conduct basic ADL (especially eating, drinking, washing, mobility and transfers).

Respondents frequently stressed that a lack of ability to conduct the most basic activities, such as eating and drinking, can lead to serious consequences as the following quote shows:

*“What we see a lot in daily care is that people often forget to eat and forget to drink. Consequently, they become malnourished and dehydrated (...).” (FG11)*

Moreover, an inability to conduct higher-order activities/instrumental activities of daily living (IADL), such as housekeeping and medication management, and difficulties regarding financial administration are also considered problems preventing people with dementia from continuing to live at home. Additionally, the participants emphasized that a lack of ability to structure the sequence of daily activities, a lack of meaningful activities, and a disrupted day/night rhythm also threaten the ability of people with dementia to live at home as the following quote indicates:

*“The third (problem), and for me the most important one, is that people lose their day and night rhythm. They lose their feeling for time; consequently, they don’t know when they need to eat and their normal feeling of being hungry is also gone. They don’t drink enough, causing dehydration and-related problems.” (FG210)*

### **Safety-related problems**

The second major problem domain consistently described during all focus group interviews was safety-related problems. These problems include an inability to judge risk and make independent decisions, dangerous situations for people with dementia or their environment, and a lack of safety measures to prevent dangerous situations. One participant (an informal caregiver of a person with dementia) described a dangerous situation as follows:

*“Once, I noticed fire inside my house because the gas was not switched off.” (FG42)*

The participants described additionally various other safety hazards such as improper use of electronic devices, the risk of being mistreated or robbed by strangers entering the house, the risk of falling

incidents, unsafe behaviors in traffic, unsafe handling of finances, and the risk of getting lost outside the house and not being able to find the way back home. Moreover, the risks of health-related problems due to improper medication use, insufficient intake of food and liquids, or wearing clothes that are not appropriate for the temperature were discussed. Another frequently reported problem was the absence of a “supervision function” to detect possible risks for the person with dementia as the following quote shows:

*“Lack of a signaling function at home, thus there is nobody who intervenes when a situations is about to go wrong. (...) To identify risks on time, for example when the gas is switched on.”*

(FG13)

As described earlier, people with dementia can lose their ability to judge risks and to act in a reasonable way to prevent safety hazards. Therefore, they need to be supported in the judgment of risks and regarding interventions in case of emergency. If this “supervisor” is lacking, this might hinder the ability to live at home.

### **Informal care/social network-related problems**

The third problem domain described during all six focus group interviews are informal care/network-related problems. This domain includes problems concerning excessive informal caregiver’s responsibility, the inability of the informal caregiver to properly handle the person with dementia, a lack of availability of informal caregivers, and the loss of social contacts of the person with dementia. Informal caregivers can compensate, to a certain extent, for their deficits in functional abilities and safety judgment. This can be very burdensome for the informal caregivers, especially when the person with dementia requires attention and support 24 hours a day as illustrated by the following quote:

*“If you have time to sleep at night then you (the informal caregivers) are able to handle it, but when it becomes 24 h care, when you need to be alert continuously during the night and you wake up all the time because your partner who is lying next to you starts wandering and wants to leave the house, (...) that is when things get out of hand (...).” (FG46).*

In cases in which the burden exceeds the personal limit of the informal caregiver, the ability of the person with dementia to stay at home can be threatened. Another problem mentioned was that informal caregivers misinterpret the behaviors of the person with dementia. Problems with dealing with

difficult behavior may occur when a caregiver lacks the ability to empathize with the perceptions of the person with dementia. When people know that certain behaviors are a consequence of the disease, it might be easier for them to accept those behaviors. Another frequently described problem is the lack of available informal caregivers as the following quote illustrates:

*“Lack of a safety net regarding informal care. Children are, due to their responsibilities at work, often unable to keep an eye on mom and dad 24 h a day (...) or married couples from which the healthy partner suddenly becomes ill or unable to perform the same tasks as before, then literally the whole world collapses, and we have a huge problem.” (FG35)*

It seems that people who have no informal caregivers at all or who have a small social network, such as when they have no children or the family members live too far away, are less likely to remain living at home. A situation in which an informal caregiver is suddenly unable to provide care due to various reasons (e.g. hospital stay) can also seriously threaten the ability of people with dementia to live at home. Finally, the loss of social contacts was described as a problem hindering the ability of people with dementia to live at home. Loneliness may ensue from a loss of social contacts, the inability to build new social relationships or challenging behavior of the person with dementia.

### **Behavioral problems**

The fourth problem domain put forward during five focus group interviews is related to the specific behaviors of people with dementia. First, a person with dementia may not be willing to accept care because the person does not see the necessity of help, which can lead to safety hazards. Second, the person with dementia can show certain behaviors, such as aggression, wandering, anxiety which are very burdensome for the person with dementia as well as the informal caregivers to deal with as the following quote indicates:

*“I think that when a person with dementia exhibits certain behavior, especially when there is a partner, and the person with dementia is difficult to handle, difficult to manage, querulant, maybe aggressive, verbally or physically, that this can lead to a situation in which the partner is not able to deal with the situation any longer.” (FG34)*

These examples indicate that it is not the behavior itself that hinders the ability of people with dementia to live at home, but rather the consequences (e.g. safety hazard or increased burden of informal care) of these behaviors.

## **Formal care-related problems**

In five of the six focus group interviews, formal care-related problems were discussed. The problems regarding formal care can be summarized as a lack of availability of care services adapted to the needs of people with dementia/the informal caregivers and inappropriate coordination of care services. With regard to the lack of suitable care services, one respondent mentioned:

*“What I (an informal caregiver) really miss are easily accessible places for people with dementia to stay overnight (...) to give me (the informal caregiver) the possibility to recover, to catch my breath, which would enable me to continue (the informal care) for a while.” (FG44)*

Besides a lack of respite care a lack of day-care facilities that meet the needs of the individual person with dementia who is not interested in mainstream activities (e.g. bingo or singing) was described. With regard to inappropriate coordination of care services, the respondents mentioned that, frequently, several formal care providers are involved in the care of community-dwelling people with dementia and that they are often unaware of each other's work. Moreover, it was described that sometimes too many caregivers are involved, which can have negative consequences on the behavior of people with dementia.

## **Cognitive decline**

Cognitive decline was described less frequently during the focus group interviews (twice in one interview). The respondents described forgetfulness and a lack of ability to recognize things as hindering the ability to live at home.

# **Discussion**

## **Important problem domains preventing people with dementia from living at home**

In the present study, problems within three domains threatening the ability of people with dementia to live at home were described most frequently during all six focus group interviews and can therefore be regarded as the most important ones, namely problems involving decreased self-reliance, safety-related problems, and informal caregiver/social network-related problems. In addition, behavioral problems, formal care-related problems, anxiety, and decreased mobility and cognition were described, but less frequently. Our results of the identified problem domains are supported by the

results of other studies describing problems regarding ADL activities and behavioral difficulties<sup>22</sup> as well as decreased abilities to perform IADL activities.<sup>23</sup> A recent study on causes of crisis situations, defined as situations in which immediate psychiatric interventions are needed by community-dwelling people with dementia, described problems relating to risks and hazards at home, family carer-related problems, problems involving memory and behavior, community services-related problems, physical health problems, and social and environmental changes.<sup>24</sup> Social and environmental changes were not explicitly mentioned as problems that hinder the ability to live at home in the present study; possibly, these factors are more specifically related to a crisis, instead of the ability to live at home.

Our study adds knowledge by identifying that problems in the three domains, decreased self-reliance, safety-related problems, and informal caregiver/social network-related problems, seem to be the most important barriers for aging in place that nurses in community-based dementia care should pay attention to. These problem domains are interrelated since the underlying problem of decreased self-reliance underscores the need for willing and able informal caregivers that can compensate for functional deficits and a lack of meaningful activities, provide structure and prevent risky behavior. Otherwise the person with dementia will experience decreased autonomy, quality of life, and dignity as well as increased risk of hospitalization and institutionalization.<sup>25</sup> The data might indicate that an optimal amount of support exists to enable persons with dementia to prolong living at home. It was described that too many professionals being involved in care can cause coordination problems. While too few informal caregivers being available, may cause a lack of practical and emotional support. In both situations the ability of the person with dementia to live at home might be threatened. Moreover, it needs to be recognized that providing informal care can be very burdensome and can lead to a situation in which the burden exceeds the personal capabilities of the caregivers. Therefore, it is essential to tackle not only problems that people with dementia are experiencing directly but also those problems related to informal caregivers and their social network in order to delay or prevent nursing home admission.

### **Implications for practice and research**

Knowledge of the most important problem domains facilitate nurses to target their efforts in early detection so that they can intervene as soon with (innovative) solutions to prevent transfer to nursing homes. To support self-reliance, technological solutions may be employed such as medication

dispensers with a reminder function, tools to apply and remove compression stockings,<sup>26</sup> audible or visual prompts for other ADL activities such as eating or drinking, or specific clocks or agendas for people with dementia to facilitate a daily structure.<sup>27</sup> For safety-related problems, the caregiver can consider GPS tracking devices for people who tend to wander, fall sensors, systems to shut off the gas or water to prevent injuries at home,<sup>27</sup> or lifestyle monitoring to assess deviant behavioral patterns from a distance.<sup>26</sup> Solutions to support informal caregivers are also currently available. Examples of solutions to reduce caregiver burden or to increase caregivers well-being are: adult day care, respite care,<sup>28</sup> educational programs for informal caregivers<sup>29</sup> or internet-based support interventions for informal caregivers.<sup>30</sup>

People with dementia and their informal caregivers are often unaware of the available treatment options for their practical problems.<sup>14</sup> Hence, professionals (e.g. district nurses and case managers) can play an important role in detecting those problems, introducing possible solutions and coordinating these solutions. As one person with dementia is not like the other, each individual might face different combinations of practical problems. Since they might have different resources to compensate for their deficiencies, an individualized approach would be advisable when it comes to assessment of problems and a search for possible solutions. What is considered an optimal solution for one person might not be suitable for another. Moreover, new (technological) solutions are constantly developed and become available for implementation in practice. Thus, it can be challenging for nurses to keep up to date on the available solutions and to choose the right solution for the individual person. In addition, it must be considered that a certain infrastructure is needed to implement more complex technological solutions, such as telecare systems. Therefore, to fulfill their advisory role, nurses need to have detailed information on the solutions and their requirements for implementation. To obtain this information is to access general databases for assistive technology such as EASTIN<sup>31</sup> and AbleData.<sup>32</sup> However, those general databases might not contain all dementia-specific solutions and solutions beyond the scope of assistive technology. An area for further research might be the development and evaluation of a (computerized) decision support tool specifically developed for nurses in community-based dementia care. This might be helpful to facilitate nurses in their advisory role. Such a tool could match possible solutions for specific identified problems.

The aim to detect problems early and to introduce solutions is in line with an international attempt to facilitate people to live well with dementia, which was one of the main themes of the first

international WHO Ministerial Conference on Global Action against Dementia held in 2015. The conference stressed that it is essential to empower people with dementia to participate in society as much as possible.<sup>33</sup> Any effort to empower people with dementia assumes that people have abilities to cope with deficiencies caused by their disease. This is also one of the underlying assumptions of the new definition of health “as the ability to adapt and to self-manage.”<sup>34p.2</sup> One dimension within this definition is social health, which is described as a “dynamic balance between opportunities and limitations, shifting through life and affected by external conditions such as social and environmental challenges.”<sup>34p.2</sup> This underpins the importance of detecting practical problems that people with dementia and their informal caregivers experience, which threaten this balance in daily life, and finding suitable solutions to recover the balance between opportunities and limitations.

### **Considerations and limitations**

First, we included mainly professionals, and we conducted the member check with a selective sample of professionals. However, this was a conscious choice, because professionals with a coordinating function (such as home care nurses and case managers) in community-based dementia care were expected to be a good and reliable source of information about frequently occurring practical problems in daily life. They have experienced many transitions of people with dementia from the home to a nursing home, whereas people with dementia and informal caregivers can only report about their own case. We deliberately included a small group of informal caregivers and patient representatives to validate whether the problems described by them differ considerably from those put forward by the professionals; as this was not the case, we decided to include only this limited number. People with dementia were not included in this study those who had experienced problems threatening their ability to live at home are expected to be in an advanced stage of the disease, in which they could not meaningfully participate in such an interview. Second, the focus of this study was to explore the most important practical problems in daily life by using sticky notes to gather information. This, on the one hand, ensured that every participant got an equal chance to share his/her view during the interview. On the other hand, it might have limited the richness of descriptions of the practical problems because people were forced to write down their ideas in a few words. However, during the interviews, the moderators tried to stimulate the participants to express their opinions in more detail by providing examples where possible. Finally, the participants were asked to



indicate what were, according to them, the most important problems preventing people with dementia from living at home. What is seen as important may be a rather subjective interpretation. However, since certain problems were described consistently throughout the focus groups, it seems that those problems occurred frequently and therefore were regarded as important barriers for living at home. Nevertheless, to validate whether those problems can be generalized to a larger population, a longitudinal cohort study is recommended.

## **Conclusion**

To facilitate aging in place and/or delay institutionalization of people with dementia, nurses in community-based dementia care should focus on detecting problems in the domains of decreased self-reliance, safety-related problems, and informal care/social network-related problems . Moreover, they should be able to advise people with dementia and their informal caregivers on possible solutions to deal with the daily struggles they encounter within these three domains

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