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***Reasons for Institutionalization of People with Dementia: Informal Caregiver Reports from Eight European Countries***

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Reasons to institutionalize dementia patients

### **Abstract**

#### Objectives:

To explore reasons for institutionalization of people with dementia according to informal caregivers as well as variation in reasons between countries.

#### Design:

An explorative cross-sectional study was conducted in eight European countries.

#### Setting:

Per country a minimum of three long-term care facilities, offering care and accommodation as a package, participated in this study. Participating countries were selected to represent different geographic areas in Europe.

#### Participants:

Of the 791 informal caregivers involved in the RightTimePlaceCare project of people with dementia who were recently admitted to a long-term care facility, 786 were included for this study.

#### Measurements:

As part of a semi-structured interview, informal caregivers were asked the main reason for institutionalization in an open-ended question. Answers were categorized according to a conventional coding approach. All reasons were then quantified and tested.

#### Results:

Mainly patient related reasons were stated, such as neuropsychiatric symptoms (25%), care dependency (24%) and cognition (19%). Neuropsychiatric symptoms were among the most often mentioned reasons in the majority of countries. Beside patient related reasons, caregiver burden and the inability of the informal caregiver to care for the patient were stated as reasons (both 15%). Further analyses showed countries differ significantly in reasons according to informal caregivers. Additionally, reasons were analysed for spouses and child-caregivers, showing that spouses more often stated reasons related to themselves compared to child-caregivers.

#### Conclusion:

Multiple reasons contribute to the institutionalization for people with dementia, with several factors that may influence why there were country differences. Variation in the organization of dementia care and cultural aspects, or the relationship between the informal caregiver and person with dementia may be factors influencing the reasons. Because of a wide variation in reasons between countries, no one-size-fits-all approach can be offered to guide informal caregivers when facing the possibility of institutionalization of the person with dementia.

### Introduction

The process of institutionalizing a relative with dementia can be considered one of the most difficult aspects in the so called informal caregiver career.<sup>1, 2</sup> Informal caregivers may experience adverse effects when confronted with treatment decisions for others.<sup>3</sup> Feelings of guilt, doubt, sadness, failure and betrayal (of marital commitment) are reported by informal caregivers of people with dementia in circumstances of decision making, such as the need for institutional long-term care.<sup>3-6</sup> The percentage of people with dementia being admitted to institutional long-term care differs between countries, which might in part be explained by country differences in the organization of dementia care. Care systems across Europe vary, e.g. in structure, financing, and services provided.<sup>7-9</sup> Furthermore no exact overall number on admission rate is available for Europe. However, with an ever increasing number of people suffering from dementia in Europe -from 9.95 million in 2010 estimated to rise to 18.65 million in 2050-<sup>10</sup> the number of informal caregivers facing the institutionalization of a person with dementia will increase as well.

Since informal caregivers have an important voice in the process of admitting their relative with dementia to institutional long-term care,<sup>1, 11</sup> they are a valuable source of information regarding reasons for institutionalization. However, cross-country information on the reasons for institutionalization of people with dementia from the perspective of the informal caregiver is lacking. Knowing that the institutionalization of a loved one impacts the informal caregiver, it seems necessary to offer tailored and need-driven guidance during the transition process from homecare to institutional long-term care. By offering support to informal caregivers during this process the likelihood of suitable and timely institutionalization could be increased,<sup>12</sup> and consequently the best possible care in the most suitable setting is provided. Current knowledge regarding reasons for institutionalization is mainly derived from studies on predictors of institutionalization, based on the results of standardized instruments.<sup>13-16</sup> More insight is needed regarding the perspective of the informal caregiver in order to understand their experiences and anticipate institutionalization to complement our current knowledge.

Only some evidence is available on what informal caregivers consider reasons for institutionalization.<sup>12, 17</sup> An US study offered informal caregivers of veterans with dementia (n=572) five predefined answers to indicate their reasons for institutionalizing their relative with dementia. The most frequently chosen answers were: insufficient caring skills and health problems of the informal caregiver. Difficult patient behavior was the third most selected reason.<sup>12</sup> As part of a French study (n=109), only 45% of the caregivers indicated a specific reason for institutionalization, such as: increased dependency of the patient, patient behavior and the health of the informal caregiver. Besides focusing on a specific group of patients, offering pre-defined answer possibilities or small sample sizes, these studies only focus on national data and lack an international perspective.<sup>17</sup>

With existing variation between countries in culture, healthcare systems, family obligations to care and admission rates for people with dementia to institutional long-term care, differences in reasons for institutionalization can be expected. However, possible variation between countries in reasons for institutionalization according to informal

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caregivers has not yet been explored. Since informal caregivers are important in the decision-making, exploring reasons for institutionalization according to them offers a valuable starting point for developing guidance during this difficult period. This study is part of the RightTimePlaceCare project, designed to improve dementia care across Europe with a specific focus on the transition from home-care to institutional long-term care.<sup>18</sup> The current study aims to: 1) explore reasons for the institutionalization of people with dementia, according to informal caregivers; 2) explore variation in reasons between eight European countries.

Results of this study could have important clinical implications, offering knowledge to be used for the development of guidance programs to support informal caregivers across Europe during that last period at home prior to the institutionalization of the person with dementia.

### Methods

#### Design

Embedded in the RightTimePlaceCare project,<sup>19</sup> an explorative cross-sectional study was conducted in eight countries: England, Estonia, Finland, France, Germany, the Netherlands, Spain and Sweden.

#### Sample

As part of the RightTimePlaceCare project, dyads were recruited consisting of people with dementia who were recently admitted to long-term nursing care facilities and their main informal caregiver.<sup>19</sup> Possible participants were identified by the long-term care facilities through their administration of new admissions. The study population for this study comprised the informal caregivers of each dyad. In order to target a similar population in all eight countries, the following inclusion and exclusion criteria and pre-defined definitions of terms were set.

*Informal caregivers:* All main informal caregivers were eligible for this study, provided they were involved in the care of a person with dementia who 1) had a formal diagnosis of dementia as determined by an expert assessment; 2) had a score of 24 or less on the Standardized Mini Mental State Examination (S-MMSE) 3) been newly admitted to a long-term nursing care facility, living there at least one month and no longer than three months and 4) had an informal caregiver that visited at least twice a month. Informal caregivers of people with dementia admitted only for a limited period of time, such as rehabilitation or respite care, with the intention of moving back home were excluded.

*Long-term care facilities:* In this study a long-term care facility was defined as a place of collective living where care and accommodation is provided as a package by a public agency, non-profit or private company.<sup>20, 21</sup> Each country had to include at least three different long-term care facilities as to achieve some within country variation in the recruited sample.

#### Procedure

##### *Data collection*

Data were collected between November 2010 and January 2012. Prior to data collection ethical approval was obtained in each country to conduct the study. Before each individual interview, written informed consent was obtained from informal caregivers.

During a comprehensive structured face-to-face interview a specific open ended question regarding the institutionalization was posed. Informal caregivers were asked: *Please state the main reason for institutionalization.* Informal caregivers also answered socio-demographic related questions.

The interviews were performed by trained interviewers with at least a Bachelors-degree in health or social care<sup>19</sup> and were guided by a written manual. Interviewers were instructed to prompt respondents by asking further questions, in order to get to the main reason for institutionalizing their relative to a long-term care facility.

### *Data processing*

During the interviews answers were noted in the native language. Subsequently, answers were translated into English to enable comparative analysis across countries. As instructed for this study, the translations were performed by no more than two researchers per country to assure consistency in wording and use of terms in the translated answers.<sup>22</sup>

### *Coding and analysis*

The coding procedure for this study was an iterative process during which several points of analysis, testing, evaluation and adaptations took place. Both a bottom-up (building from the data), and top-down approach (relying on literature) were used during this process.<sup>23</sup> Figure 1 shows an overview of the steps taken.

First, a pilot was performed in order to establish feasibility of the planned procedure for this study. Two researchers from Germany and two from the Netherlands independently categorized 5% of the dataset of both countries and discussed their findings, resulting in an initial version of a codebook. This codebook was created using conventional content analysis,<sup>23</sup> an open coding approach in which the categories are derived from the data at hand without preconceived categories.

After the pilot, conventional content analysis was used again to create a second version of the codebook based on 20% of the complete dataset. The codebook contained an overview of main categories covering reasons for institutionalization clustered per theme. If possible and appropriate, main categories were further specified into sub-categories. For this process two researchers from the Netherlands independently categorized the selected cases using an open coding approach. The individual categorization was then discussed by the two Dutch researchers, and in case of disagreement, the rationale of the coding was negotiated until consensus was reached. The decisions made during these discussions were recorded in a manual, which was part of the codebook. Finally, a literature search on reasons for institutionalization according to informal caregivers was performed afterwards to ensure no known reasons for institutionalization were missing in this version of the codebook. Based on this search one sub-category was added to the codebook. The complete dataset was then categorized anew with the final codebook.

For the analysis, percentages were calculated of the proportion of informal caregivers stating a certain reason. All reasons within an answer were considered independently and no decision was made by the researchers on what the main reason was in case of multiple reasons in the answer. Analyses were performed on three levels: per theme, per main category and (if applicable) sub-category. This was done for the overall sample, as well as for

the countries individually. In order to determine whether country differences were significant, ANOVA (for continuous data) and  $\chi^2$ -tests (for categorical data) were performed.

[INSERT FIGURE 1]

### Reliability and validity check

Before starting with the implementation of the coding procedure on the entire dataset, a validation procedure was conducted to ensure reliability and validity of the data. The aim of the reliability and validation check was twofold: 1) to ensure the quality and reliability of the translations of the answers in the database from the native language to English and 2) to check or validate the interpretations of the answers by the raters. For this procedure a researcher involved in the RightTimePlaceCare project from each country was contacted. Each researcher was given an overview of 10% of participant ID codes of that country, and was asked to go back to the original answer (in the native language) to translate the answer again into English. The new translations were then categorized, and the categorization of the new translations was compared to the categorization of the translation in the dataset. This step was introduced to ensure that the primary translations in the dataset were reliable translations of the original texts in the native languages. Furthermore, the principal researchers of the interviewing team of each country received an overview of already categorized cases from their own country. Each overview held the English translation of the answer and allotted categories. The researchers were then asked whether they agreed with the allotted categories, confirming agreement credibility.<sup>24</sup> These two procedures showed a confirmation in categorization of respectively 83% and 94%.

The inter-rater reliability for this study was addressed by means of Jaccard coefficients for similarity<sup>25, 26</sup> (ranging from 0.86-0.94, indicating a high accordance between the raters). The Jaccard coefficient was chosen because this measure discards confirmation of absence of the category. Consistency in allotting categories was safeguarded by the decision to have the dataset of each country categorized by one of the two Dutch researchers.<sup>27</sup> All these steps and precautions ensured that the procedure, data and its translations had a sound validity.



## Results

### Sample characteristics

Of the 791 interviews conducted for RightTimePlaceCare, 786 informal caregivers were eligible for this study. Table 1 presents the socio-demographic characteristics of the sample. Informal caregivers were predominantly female (65%), had an average age of just over 61 years and were, for the largest part, a child of the person with dementia (63%). Some variation between the samples of the countries was found, with Sweden having older caregivers, and Estonia having younger caregivers. France deviates from the other countries in the distribution of gender, with equally as many males and females in the sample. In most countries the majority of informal caregivers did not have a paid job (54%), whereas in Estonia and Sweden over half of the caregivers did have a paid job.

[INSERT TABLE 1]

### Reasons for institutionalization

During the interviews, it emerged that the circumstance prompting the transition to institutional long-term care generally consisted of multiple reasons. Informal caregivers often gave several reasons for institutionalization instead of one main reason, with 60% of the sample giving two or more reasons (range: 1-7 reasons within the statement). Along the whole sample 1465 reasons were given, giving an average of 1.9 reasons per informal caregiver (ranging from 1.3 reasons in Spain and France to 2.4 reasons in Finland).

Three themes were identified: 1) patient related reasons; 2) informal caregiver related reasons; and 3) formal care related reasons. All answers given were allotted one of these themes. The majority of informal caregivers (84%) gave one or more patient related reasons, 28% gave one or more informal care related reasons and, formal care related reasons were mentioned by 9% of the informal caregivers. Table 2 provides an overview of the most mentioned reasons per theme for the overall sample and per country. Results show a wide range between the countries when looking at the proportion of caregivers stating a specific reason. On a wider scale, Spanish caregivers often gave a reason related to themselves as a reason for institutionalization (50%), whereas in other countries the caregivers gave notably more reasons related to the person with dementia. In the following sections more in-depth results are described per theme.

[INSERT TABLE 2]

### *Patient related reasons*

The theme 'patient related reasons' consists of 14 main categories: neuropsychiatric symptoms, cognitive symptoms, health problems, overall deterioration, mobility problems, fall incidents, care dependency, inability to manage at home, staying alone not possible, endangerment, loneliness, (feelings of) insecurity, need for supervision/guidance/structure. The five most mentioned categories are described in more detail below.  $\chi^2$ -analyses showed there were significant differences between countries in all mentioned categories (Table 2).

Over the whole sample, 25% (n=200) of caregivers gave at least one neuropsychiatric symptom as a reason for institutionalization. However, when looking at country differences, less than 3% of Estonian caregivers mentioned this category. The most common specified neuropsychiatric symptom was 'wandering/runaway behavior' (36% of caregivers that mention neuropsychiatric symptoms, consequently being approximately 10% of the overall sample). The two other neuropsychiatric symptoms frequently specified were 'agitation/aggression' and 'sleep/nighttime behavior disorders' (each around 19% of those caregivers mentioning a neuropsychiatric symptom). Country analyses show that especially caregivers in England specified wandering, whereas none of the French and Swedish caregivers indicated this symptom. Agitation/aggression was mostly mentioned by French caregivers. Sleep and nighttime behavior was mentioned by none of the Estonian caregivers, whereas about a third of Dutch, Swedish and German caregivers specified this as a reason.

With 24% (n=192), care dependency was the second largest patient related reason for institutionalization. In France, care dependency was mentioned by only 6% of the caregivers, whereas in Finland it was mentioned by 40%. Among 60% (n=115) of caregivers mentioning care dependency a particular (instrumental) activity of daily living task was specified such as eating/drinking, hygiene and incontinence. Finnish caregivers specified care dependency most often (84% of caregivers stating care dependency) and Estonian caregivers specified care dependency the least (26% of caregivers stating care dependency).

Across all countries, 19% (n=149) of informal caregivers mentioned cognitive symptoms as a reason for institutionalization. In the country analyses Spain showed a deviation, with fewer than 2% of Spanish caregivers mentioning cognitive symptoms. On the other hand, around 29% of Dutch and Swedish caregivers considered cognitive symptoms as a reason for institutionalization. Further specification of the answers resulted in 56% of caregivers mentioning cognitive symptoms stating 'disorientation/confusion' as a reason for institutionalization. Subsequently, this sub-category was mentioned so often, that it represents 11% of the overall sample.

Of all caregivers, 14% (n=111) stated health problems of the person with dementia as a reason for institutionalization. In Finland 29% of informal caregivers reported patient health as a reason for institutionalization compared to only 2% of French informal caregivers.

Across the overall sample, 14% (n=107) of all informal caregivers stated fall incidents as a reason for institutionalization. It is notable that in Estonia and Spain, this category was never mentioned.

### *Informal caregiver related reasons*

During analysis, two main categories emerged related to the informal caregiver.

Among all informal caregivers, 15% (n=116), considered burden as the reason for institutionalization. Results of the  $\chi^2$ -analysis for burden showed no significant differences between the countries, indicating burden to be consistently mentioned in all countries (Table 2).

The second category related to informal caregivers is inability to care for the person with dementia, mentioned by 15% (n=115) of the overall sample. Answers in this category included statements such as caregivers not being capable to provide care for the person with dementia anymore due to health problems or lack of caring skills to cover all caring needs of the person with dementia.  $\chi^2$ -analysis showed that there were statistically significant differences between countries (Table 2). Differences between the countries were apparent with none of the French informal caregivers expressing inability to care as a reason for institutionalization. Spanish informal caregivers, on the other hand, mentioned this category in 30% of the caregivers. In total, 35% of caregivers mentioning inability to care specified their own condition, such as own health or physical abilities, being the reason why they were unable to care. Again, variation across countries is present, with 64% of the Finnish caregivers in this main category specifying the condition of the informal caregiver, against 11% of Dutch caregivers mentioning inability to care.

### *Formal care related reasons*

Two categories related to formal care.

Across the countries 6% (n=44) of informal caregivers declared that formal care was not sufficient prior to institutionalization. This category comprised answers such as homecare was not sufficient and home services failed to meet the patient's needs.

When looking at the individual countries Finland, England, Germany and Sweden had the largest percentage of informal caregivers claiming insufficient formal care as a reason for institutionalization (each around 9%). In contrast, less than 1% of the Estonian informal caregivers and none of the Spanish caregivers noted insufficient formal support as a reason for institutionalization.

Throughout the whole sample 3% (n=26) of informal caregivers mentioned that admission was recommended by someone other than themselves. Spanish and English informal caregivers were advised most often (around 7% of the country samples). Among Dutch and Estonian informal caregivers, this category was mentioned the least (under 1%).

### *Reasons analyzed by caregiver socio-demographics*

Relationship to the person with dementia also appeared to influence reasons for institutionalization, as shown in table 3. More child-caregivers mentioned care dependency ( $p<0.01$ ), cognitive symptoms ( $p<0.05$ ) and fall incidents ( $p<0.001$ ), compared to spouses. When looking at the countries, cognitive symptoms and fall incidents were consistently mentioned more often by child-caregivers than spouses. In Spain, spouses mentioned care dependency more often than child-caregivers. No significant differences were found between spouses and child-caregivers for neuropsychiatric symptoms and health of the person with dementia.

Explicitly more spouses disclosed reasons related to themselves as a reason for institutionalization compared to child-caregivers ( $p<0.001$ , both the informal caregiver related reasons in this theme combined). However country differences do exist with child-caregivers in Germany and Spain reporting their inability to care slightly more often than spouses.

With regard to formal care, insufficient formal support was noted by relatively more child-caregivers ( $p<0.05$ ), with the exception of English caregivers who show the opposite trend.

No patterns were found for other socio-demographic aspects such as caregiver gender or having children under eighteen in the household.

[INSERT TABLE 3]

## **Discussion**

This study aimed to explore reasons for institutionalization of people with dementia according to informal caregivers within eight European countries. Variations between countries were found in reasons for institutionalization, however overall results showed that caregivers mainly stated reasons related to the person with dementia. This is contrary to some previous research in which more reasons related to informal care came forward.<sup>12</sup> Informal caregivers often stated multiple reasons in their answer showing institutionalization is often a result of a combination of reasons.

Despite the country differences, certain reasons seem to overarch country boundaries, with neuropsychiatric symptoms and care dependency being among the top five reasons in most countries. Neuropsychiatric symptoms seem to be the main reasons across the countries, with the exception of Estonia. This category also overarches the relationship of the informal caregiver to the person with dementia, with both spouses and children often indicating neuropsychiatric symptoms as a reason for institutionalization. Moreover, caregivers report more on active behavior (e.g. wandering, aggression and sleep/nighttime disturbances) compared to inactive behavior (e.g. depression and apathy). The behaviors most mentioned are in accordance with studies linking challenging behavior to caregiver burden.<sup>28</sup>

## Reasons to institutionalize dementia patients

Beside country differences, relationship to the person with dementia also seems to influence reasons for institutionalization. The most distinct difference is caregiver burden, with notably more spouses reporting burden as a reason for institutionalization compared to child-caregivers. This is possibly due to the fact that spouses are also elderly with probably health problems of their own, resulting in feelings of burden. Furthermore, spouses generally live with the person with dementia prior to admission, which might explain a higher burden. Future research is needed to investigate this relationship in more detail.

A similar proportion of caregivers across the countries states caregiver burden as a reason. Whereas many previous studies show caregiver burden to be a strong predictor for institutionalization,<sup>13, 14, 29, 30</sup> only 15% of caregivers actually declare their burden as a reason for institutionalization. This is an interesting result because it may imply that caregivers do not (always) label what is considered 'burden' by formal caregivers as such. Caregivers do, however, often state patient related aspects which are linked to burden such as patient behavior<sup>30</sup> and care needs,<sup>31</sup> possibly indicating a level of specificity in which caregivers implicitly indicate the reasons for their burden. This result might be key in offering formal support to informal caregivers in the home situation especially during sensitive periods, such as the final period in which the person with dementia lives at home. If an informal caregiver does not consider, and therefore not label his/her situation as burdened, formal support should be adapted to match the perception of the informal caregiver and focus on those aspects linked to burden. As described, many differences are apparent between countries. An explanation for variation in reasons could be the variation in the organization of dementia-care across Europe and therewith the availability and accessibility of (home) services to support informal caregivers in meeting the needs of the person with dementia. In Estonia for example, the availability of services is rather low, especially compared to other European countries. Also Estonian legislation states an obligation for family caregivers to care for their relatives.<sup>32</sup> This might to a certain extent explain the results of our study, with Estonian caregivers not stating that many reasons for institutionalization. Along this same line, services may be available or accessible, but still not used by informal caregivers, due to unawareness of these services.<sup>33</sup> Additionally certain evidence suggests that culture shapes the perceptions of caregiver responsibilities.<sup>30</sup> For example, in our sample Spanish caregivers stated relatively more reasons regarding themselves whereas more western and Nordic countries state far more reasons related to the patient. Previous studies suggest that it is more conventional in Southern European countries to expect of family members to care for their elderly compared to the more Nordic and West-European countries.<sup>8, 34</sup> The results in this study also show differences between spouses and child-caregivers. This might be influenced by differences in expectations of caregiving, with spouses being more strongly committed to the care relationship than non-spouses.<sup>35</sup>

Certain study limitations must be considered. The first point of importance is the fact that the answers given were not recorded but noted by the interviewer during the interviews. Therefore the results are partly dependent on the

description given by the interviewer, possibly influencing the way in which the answer is categorized, or whether the answer is further specified into a sub-category. The fact that answers had to be translated could be considered a limitation. However, a study on the influence of translation on validity and reliability of qualitative data found that there were no significant differences in the major categories between the translated and original (native) dataset.<sup>22</sup> The precautions taken in this study minimize the effects of translation as much as possible and ensure a sound validity of the data. Also, the systematic approach and analysis of the open ended answers strengthen this study, even though it is not an in-depth qualitative study. Despite being asked for the main reason for admission, informal caregivers often stated multiple reasons within the answer. It would have been interesting to know whether certain reasons weighted more in the decision than others. For this study this distinction could not be made, since no particular inquiry was made about the priority or weight of each reason given. Recall bias has been reported as a possible limitation in studies about past experiences.<sup>36</sup> However, in this study the informal caregivers were interviewed rather quickly after institutionalization (within three months), minimizing recall bias. Finally, caregivers might give answers that are considered socially desirable (for that country/culture). This may possibly result in some caregivers not wanting to admit that the care was too burdensome for them, or caregivers not wanting to 'blame' the persons with dementia, which may influence the answers given. In order to minimize these effects, interviewers were trained to reassure the informal caregivers and emphasize the importance of honest answers. Finally, it is important to note that no pre-admission information on the people with dementia was available, making it impossible to relate the answers given to patient related characteristics. Therefore, country differences as described in this study could be related to differences in the organization of care as well as to differences in patient characteristics between the country samples.

### **Conclusion and implications**

The contributions of this study imply that there is no definitive reason for the institutionalization of a person with dementia, with multiple factors contributing to the decision. The wide variation of reasons found across the countries and between spouses and child-caregivers indicates that several aspects influence the final reason for the institutionalization of the person with dementia. Despite a wide variation of reasons, neuropsychiatric symptoms seem a very important factor. This suggests that interventions focusing on behavioral changes of the people with dementia, and therein especially guiding and supporting informal caregivers to handle these changes, could be beneficial. Since research states that neuropsychiatric symptoms are linked to a higher burden,<sup>30</sup> interventions focusing on educating and guiding informal caregivers on how to handle these symptoms may in turn lower caregiver burden. Likewise, care dependency, which is linked to caregiver burden as well,<sup>31</sup> could possibly be targeted more efficiently. (I)ADL care is among the most time consuming services performed by informal care that could be fulfilled by professional care. This contributes to possible alleviation of caregiver burden.

Our results, furthermore, show that informal caregivers did not report lack of formal care at home as a main reason for institutionalization. This applies to both those countries with a wide range of home-based dementia services available (e.g. the Netherlands) as those with limited services available (e.g. Estonia). The reason could lie in the unawareness of informal caregivers regarding available services, or informal caregivers not wanting to relinquish care.<sup>33, 37</sup> Possible cultural aspects may also influence who, informal caregivers believe, is responsible for delivering dementia care at home. Moreover, an important reason for not mentioning lack of formal care could be that the current range of available services does not meet the needs of informal caregivers. The question whether current services meet the needs of both people with dementia and informal caregivers is of great importance, especially in the light of the 'aging-in-place' agenda that aims to let elderly people live in their own homes as long as possible.<sup>38</sup> Investing in home-care in order to delay or even prevent institutionalization will only be adequate if home-care is adjusted to people's care needs. If available services do not meet care needs and demands, these services will not be used and 'aging in place' will not reach its full potential.

Since informal caregivers have an important voice in the institutionalization of their relative, the importance of tailored guidance by formal care to ease care-transition must be stressed. Particularly, since we have some evidence suggesting that informal caregivers appreciate support offered by formal care during the decision process.<sup>2, 39</sup> By exploring the reasons for institutionalization according to informal caregivers themselves, this study offers some understanding of their reasoning regarding the motives for institutionalization.

The aim across Europe is to aid both patient as well as informal caregiver as best as possible and offer the best possible dementia care. However, because of wide variation of reasons, no one-size-fits-all approach to support can be offered to informal caregivers, emphasizing the need for tailored and need driven guidance, keeping such aspects as culture and relationship to the patient in mind.

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