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ORIGINAL RESEARCH: EMPIRICAL RESEARCH –  
QUANTITATIVE

## Older persons with dementia at risk for institutionalization in eight European countries: a cross-sectional study on the perceptions of informal caregivers and healthcare professionals

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### Abstract

**Aims.** To explore the perceptions of informal caregivers and healthcare professionals regarding potential reasons for the institutionalization of older persons with dementia in eight European countries.

**Background.** Healthcare professionals may have an important role in facilitating informal caregivers' decision-making regarding institutionalization. Little is known about the perceptions of informal caregivers and healthcare professionals prior to institutionalization.

**Design.** Cross-sectional survey in eight European countries (November 2010–January 2012).

**Methods.** Healthcare professionals reported why they clinically judged persons with dementia at risk for institutionalization. Informal caregivers reported potential reasons from their perspectives. Answers were openly coded and categorized. Variation between informal caregivers and healthcare professionals was investigated (agreement on at least one potential reason per case/proportion of maximum attainable kappa).

**Results.** Judgements of healthcare professionals and informal caregivers on 1160 persons with dementia were included. A total of 22 categories emerged. Approximately 90% of informal caregivers reported potential reasons. In 41% of the cases, informal caregivers and healthcare professionals agreed on at least one reason. Discrepancy was high for potential reasons related to caregiver burden. For the most frequent categories (caregiver burden, caregiver unable to provide care, neuropsychiatric symptoms, overall deterioration, care dependency), 24–41% of the attainable kappa was achieved. Differences between countries

*continued on page 2*

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emerged indicating more favourable agreement in Finland, Sweden and Estonia and lowest agreement in England and Spain.

**Conclusion.** Agreement between healthcare professionals and informal caregivers on potential reasons for institutionalization was low-to-moderate. Healthcare professionals are challenged to develop a detailed understanding of the perspectives and perceived burden of informal caregivers.

**Keywords:** caregivers, decision-making, dementia, home care, institutionalization, long-term care, nursing homes

#### Why is this research needed?

- Healthcare professionals may play a decisive role in supporting informal caregivers' decision-making regarding the institutionalization of older persons with dementia.
- Better understanding of the perceptions of informal caregivers and healthcare professionals prior to institutionalization is required to develop appropriate supporting strategies.

#### What are the key findings?

- Overall, the most frequently perceived potential reasons for institutionalization are: caregiver burden; caregiver unable to provide care; neuropsychiatric symptoms; overall deterioration; and general care dependency of the persons with dementia.
- The agreement between informal caregivers and healthcare professionals was low-to-moderate and not consistent across countries.
- In all countries, the variation between the perceptions of informal caregivers and healthcare professionals was high regarding caregiver burden.

#### How should the findings be used to influence practice/research and or education?

- Healthcare professionals should be aware that their perceived reasons for potential institutionalization may significantly differ from informal caregivers' perspectives, in particular with regard to caregiver burden.
- Health professionals should be trained to initiate and promote open discussions with informal caregivers about decision-making in the institutionalization of a person with dementia.
- Reasons why informal caregivers and healthcare professionals differ regarding their judgments on potential reasons for institutionalization remain to be investigated; country comparisons should consider cultural and health/social care system-related aspects.

## Introduction

Informal caregivers feel great responsibility towards their relative with dementia. Hence, the decision to move to an institutional long-term care (ILTC) facility is a difficult one for informal caregivers (Livingston *et al.* 2010), although the extent to which they are involved in the decision-making process varies (Graneheim *et al.* 2014). Healthcare profes-

sionals' (HCP) guidance in decision-making is perceived as supportive, and these professionals should offer careful reflections about relinquishing care and hence may reduce feelings of guilt. (Lundh *et al.* 2000, Caron *et al.* 2006, Couture *et al.* 2012, Ducharme *et al.* 2012, Graneheim *et al.* 2014). Little is known about whether informal caregivers and HCP experience the need for institutionalization in the same way (Lundh *et al.* 2000, Caron *et al.* 2006). It is unclear whether

these two groups perceive comparable reasons for potentially admitting the person with dementia to an ILTC facility.

## Background

Healthcare systems throughout Europe support the concept of ‘aging in place’ (OECD 1994) and therefore employ policies to enable older persons to live at home for as long as possible (Moïse *et al.* 2004). As a consequence, long-term care is more often provided at home than in ILTC (Damiani *et al.* 2011). The latter is usually considered by informal caregivers to be a last resort (Ryan & Scullion 2000, Ryan 2002). However, relinquishing care to ILTC may become necessary at a certain point, for example, in an advanced stage of dementia. A systematic review revealed an admission rate of persons with dementia to ILTC ranging from 20% in the first year after diagnosis up to 50% after 5 years (Luppa *et al.* 2008).

The decision to permanently place a relative in an ILTC facility has been described as one of the most difficult decisions during the care-giving process (Ryan 2002, Sury *et al.* 2013) and the final decision is often protracted (Caron *et al.* 2006). Informal caregivers of persons with dementia often feel unprepared and lonely when they have to make a decision about relinquishing care (Graneheim *et al.* 2014). They avoid making the decision on their own, seeking endorsement by relatives and HCP (Butcher *et al.* 2001, Strang *et al.* 2006). Therefore, HCP may have an important role in initiating and facilitating the decision-making process (Couture *et al.* 2012). Support by HCP may be particularly relevant in legitimizing and de-stigmatizing the decision (Ryan 2002, Caron *et al.* 2006).

After the decision has been made, informal caregivers may experience conflicted feelings of guilt, failure, sadness and relief and they often regret their decision (Graneheim *et al.* 2014, Sury *et al.* 2013). Decisions made by HCP without the full participation of informal caregivers appear to increase negative feelings and induce new feelings such as treachery (Lundh *et al.* 2000, Caron *et al.* 2006). However, if the decision for admission is supported by all relevant persons involved in the caregiving, informal caregivers experience more balanced feelings (Lundh *et al.* 2000, Butcher *et al.* 2001, Graneheim *et al.* 2014). Hence, decision-making may be considerably alleviated if HCP and informal caregivers share the same opinion (Caron *et al.* 2006). However, informal caregivers also appreciate different views (Livingston *et al.* 2010) and an exchange of perspectives may also contribute to enhanced decision-making (Couture *et al.* 2012). Thus, the decision-making process should be carefully initiated and supported by HCP and professional

guidance is warranted (Lundh *et al.* 2000, Butcher *et al.* 2001, Caron & Bowers 2003, Caron *et al.* 2006, Couture *et al.* 2012, Graneheim *et al.* 2014).

Few studies from Europe address the institutionalization of persons with dementia, especially with those prior to admission to ILTC. Varying healthcare structures throughout Europe may influence how the decision on institutionalization is made. Institutionalization rates considerably differ across Europe (Vellas *et al.* 2012), as do the reasons for institutionalization reported by informal caregivers (Afram *et al.* 2014). Retrospective data collection was the most frequently employed design in exploring reasons for institutionalization (Thomas *et al.* 2004, Buhr *et al.* 2006, Afram *et al.* 2014).

Little is known about the perspectives of informal caregivers of persons with dementia immediately prior to institutionalization. The aspects of caregiving that are perceived as potential reasons leading to ILTC admission are not well understood. Moreover, there is a lack of studies investigating the perspectives of both informal caregivers and HCP, respectively.

An increased understanding of the phase preceding the institutionalization of persons with dementia is required. This knowledge is prerequisite for the development of strategies that could enable HCP to support the decision-making process of informal caregivers.

## The study

### Aim

This study aimed to explore informal caregivers’ and HCPs’ perceptions of potential reasons for the institutionalization of older persons with dementia (and the variation therein) in eight European countries.

### Design

The study was nested into the European 7th framework research project *RightTimePlaceCare* (Meyer *et al.* 2012). A comprehensive cross-sectional survey was carried out in England (ENG), Estonia (EE), Finland (FI), France (FR), Germany (DE), the Netherlands (NL), Spain (ES) and Sweden (SE). Two types of dyads consisting of older persons with dementia and their main informal caregivers were interviewed using a comprehensive set of questions. The first group of persons with dementia was recently admitted to ILTC; the second group lived at home, but was at risk for institutionalization. Further details of the study protocol are published elsewhere (Verbeek *et al.* 2012). As part of the interview, the informal caregivers of the first group

retrospectively reported on reasons for institutionalization. The results have been reported recently (Afram *et al.* 2014). In the second group (the arm of the study reported here), informal caregivers described reasons that they perceived could potentially lead to institutionalization.

## Participants

The participants of this study were the main informal caregivers of persons with dementia who lived at home (living in the same household or visiting the person with dementia at least twice per month). Inclusion criteria on the part of the persons with dementia were age  $\geq 65$  years, diagnosed with dementia, Mini-Mental-State Examination (Molloy *et al.* 1991)  $\leq 24$  points, no primary psychiatric disease or Korsakoff syndrome and the receipt of any type of professional home care (Verbeek *et al.* 2012).

For participation, a HCP involved in the care must have clinically judged the person with dementia to be at risk for admission to ILTC within the next 6 months (irrespective of whether an admission actually took place). The clinical judgment was performed without predefined categories and could have been provided by either a single HCP or a professional team. Because we aimed to include the best-informed HCP, informants belonged to different professional groups depending on the country-specific health and social care delivery structures.

## Data collection

Data collection took place between November 2010–January 2012. Organizations delivering care at home or community care services (or comparable healthcare services) were contacted in each country. HCP referred older persons with dementia and their informal caregivers who were willing to participate in the study. HCP were predominately Registered Nurses but also social workers or general practitioners. They were working in different health/social care settings, e.g. nursing home care organizations or day-care centres. In France, the participants were recruited by physicians in a large geriatric hospital. HCP were asked to specify why, according to their clinical judgment, the person with dementia was at risk of institutionalization. The potential reasons from their perspectives were recorded prior to the interview with the informal caregiver.

Trained interviewers (holding at least a Bachelor's degree) performed structured face-to-face interviews with the informal caregivers. Data on quality of life, quality of care as well as social, economic and health-related aspects of the informal caregiver and the person with dementia were collected

(Verbeek *et al.* 2012). A specific open-ended question directed at the informal caregivers was embedded in these interviews: In which situation do you think it might be necessary for the care recipient to move to an ILTC facility? The interviewers were instructed to report the answers as verbatim as possible. Background characteristics of the informal caregivers (gender, age, relation to the person with dementia, employment status, living situation) were also assessed.

## Ethical considerations

Each country obtained ethical approval from the responsible country-specific legal authorities. National regulations and standards were followed, as were the country-specific requirements regarding consent procedures. Informal caregivers gave written informed consent.

## Data analysis

### *Content analysis using an open coding procedure*

Answers in the native language were translated to English. To ensure consistency, translations were performed by one or two researchers per country. The reasons given by HCP and informal caregivers as to why admission to ILTC might be necessary were categorized applying an iterative coding procedure. First, two Dutch and two German researchers independently categorized the same 5% from the material of both countries. An open coding approach was applied and the categories were developed from the data without preconceived concepts (Hsieh & Shannon 2005). Only minor deviations appeared and were discussed between the four researchers.

The two Dutch researchers consecutively applied the initial coding scheme to 20% of the complete material from all countries using a conventional content analysis (Hsieh & Shannon 2005). If necessary, a category was modified or further specified into sub-categories. The entire material was then categorized using the agreed final coding scheme. During the coding process, the categories were sorted into global themes. Modifications, the refining of definitions or merging of (sub-) categories were possible throughout the entire coding procedure. To ensure a clear and reproducible approach, coding decisions and rationales were documented in a manual describing all (sub-) categories. One of the two researchers categorized the dataset of a country to avoid deviations in categories due to country-specific translation styles or expressions (Polit & Beck 2011).

### *Quantitative analysis*

We investigated whether informal caregivers of older persons with dementia and HCP in eight EU countries agree in their

perceptions of potential reasons for institutionalization. A stepwise analysis was performed. We explored: (1) whether the informal caregivers and HCP perceived a potential reason for institutionalization in the same situation; (2) the agreement between the informal caregivers and HCP and examined whether both groups agree on at least one potential reason per case; (3) we further compared the most frequently perceived reasons and reported variation between informal caregivers and HCP; (4) in a last step, we explored the agreement between informal caregivers and HCP for the most frequently perceived reasons. Absolute positive agreement and Cohen's kappa ( $\kappa$ ) were calculated (Cohen 1960). Possible influence on kappa should be taken into account while judging its magnitude (Sim & Wright 2005, Vach 2005). Bias between raters (the extent to which the raters disagree on the proportion of positive judgements) and the prevalence of categories may affect the interpretation of kappa values (Sim & Wright 2005). In accordance with the literature-based recommendation, the maximum attainable kappa ( $\kappa_m$ ) was calculated to address these factors and to improve the interpretation (Sim & Wright 2005, Miranda-Castillo *et al.* 2013). The  $\kappa_m$  is particularly useful for the comparison of different observers because it considers the extent to which the raters' ability to agree is constrained by pre-existing factors (Sim & Wright 2005). The reference value is the proportion of the maximum possible agreement ( $\kappa/\kappa_m$ ) that was actually achieved. According to a benchmark provided in a similar study, we considered a proportion of  $\kappa/\kappa_m \geq 0.6$  as an indicator of good agreement (Miranda-Castillo *et al.* 2013). Country differences were considered for all steps of the analysis. For significance testing of the sample differences between countries,  $\chi^2$  was used. Statistical analyses were performed with IBM Statistical Package for the Social Science for Windows (Version 20.0; IBM Corp, Armonk, NY, USA).

### Validity and reliability of the open coding procedure

Before coding the entire material, two validation procedures were employed. First, the quality and reliability of translations from the native language to English were checked. Second, the final coding scheme was tested in terms of inter-coder agreement between the two Dutch researchers.

For the first procedure, one researcher from each country reviewed a randomly selected overview of 20% of the respective countries' data. The first 10% of the material contained the original answers in the native language and was translated to English once more. These new translations were then categorized by the two Dutch researchers and compared with the categorization based on the first translations. An overall agreement of 83% was reached.

Minor deviations in translations did not lead to meaningful category deviations. Another 10% of the respective country's material contained the English translations and attributed categories. To assess the agreement credibility, the researchers of each country were asked whether they agreed with the assigned categories (Graneheim & Lundman 2004). The overall agreement was 94%.

For the second procedure, the inter-coder agreement was assessed based on 20% of the data. The Jaccard coefficient was chosen because this measure takes only positive answers into account and discards agreement regarding the absence of categories (Popping 1983). The Jaccard coefficient for both coders ranged from 0.86–0.94, indicating a high positive accordance between the coders.

## Results

### Sample characteristics

A total of 1223 informal caregivers of older persons with dementia participated in the study. Due to missing or unclear answers from informal caregivers (which could not be coded) or missing clinical judgments of the HCP, 63 cases were excluded. Thus, 1160 complete cases were eligible for the analysis.

The characteristics of the informal caregivers are displayed in Table 1. The informal caregivers were predominantly women (ranging from 66% in Sweden and England to 78% in Germany). There were more spouse caregivers in England, the Netherlands, Sweden and Spain, while more children were interviewed in Finland, France, Germany and Estonia. Approximately 30% of the sample in Estonia consisted of other types of caregivers (e.g. friends, siblings, children in law). The mean caregiver age was 64.4 years. The majority of caregivers lived together with the person with dementia (ranging from 46% in Finland to 87% in Spain).

### Results of the content analysis

For both groups (HCP and informal caregivers) and in all countries, comparable categories were identified and a list of 22 categories was created. Each category and the total number of cases with assigned categories are displayed in Table 2. The categories were sorted into three global themes: perceived reasons related to older persons with dementia ( $n = 14$  categories); perceived reasons related to informal caregivers ( $n = 2$  categories); and perceived contextual reasons ( $n = 6$  categories).

The majority of the categories were related to older persons with dementia. The theme 'caregiver-related reasons'



**Table 1** Characteristics of main informal caregivers per country.

	ENG ( <i>n</i> = 80)	EE ( <i>n</i> = 171)	FI ( <i>n</i> = 173)	FR ( <i>n</i> = 174)	DE ( <i>n</i> = 113)	NL ( <i>n</i> = 176)	ES ( <i>n</i> = 169)	SE ( <i>n</i> = 104)	Total ( <i>n</i> = 1160)
Women	53 (66.3)	131 (76.6)	101 (58.4)	119 (68.4)	88 (77.9)	117 (66.5)	121 (71.6)	69 (66.4)	799 (68.9)*
Mean age (SD), years	65.3 (12.3)	56.9 (13.5)	65.5 (12.6)	63.3 (12.8)	62.6 (12.0)	66.2 (13.0)	66.4 (13.8)	72.2 (12.1)	64.4 (13.4)**
Paid job	23 (28.8)	96 (56.1)	57 (33.0)	57 (32.8)	47 (41.6)	55 (31.3)	54 (32.0)	26 (25.0)	415 (35.8)**
Married/with partner	71 (88.8)	99 (57.9)	136 (78.6)	131 (75.3)	83 (73.5)	162 (92.1)	121 (71.6)	91 (87.5)	894 (77.1)**
Living with person with dementia	54 (67.5)	123 (71.9)	80 (46.2)	87 (50.0)	64 (56.6)	101 (57.4)	147 (87.0)	70 (67.3)	726 (62.6)**
Relation to person with dementia									
Spouse	40 (50)	26 (15.2)	64 (37.0)	59 (33.9)	40 (35.4)	91 (51.7)	82 (48.5)	69 (66.4)	471 (40.6)**
Child	32 (40)	95 (55.6)	92 (53.2)	103 (59.2)	55 (48.7)	68 (38.6)	62 (36.7)	27 (26.0)	534 (46.0)**
Other	8 (10)	50 (29.2)	17 (9.8)	12 (6.9)	18 (15.9)	17 (9.7)	25 (14.8)	7 (6.7)	154 (13.3)**

ENG, England; EE, Estonia; FI, Finland; FR, France; DE, Germany; NL, the Netherlands; ES, Spain; SE, Sweden.

Significant differences between countries: \**P* < 0.05, \*\**P* < 0.01. Values are absolute numbers (percentages) if not stated otherwise.

covered ‘caregiver burden’ and ‘caregiver unable to provide care’. ‘Caregiver burden’ described the type of answer that clearly referred to perceived burden or overstrain. ‘Caregiver unable to provide care’ referred to another type of answer that emphasized reasons such as the age or physical health status of the informal caregiver. Overall, ‘perceived reasons related to older persons with dementia’ and ‘informal caregivers’ were more frequently mentioned compared with perceived ‘contextual reasons’.

## Results of the quantitative analysis

### *Potential reasons for institutionalization*

The vast majority of informal caregivers were able to verbalize at least one potential reason for the institutionalization of persons with dementia who had been judged to be at risk for institutionalization by HCP. Only 6.6% of the informal caregivers (76/1160) did not mention a potential reason, and 45 of them stated that they had never thought about institutionalization and could therefore not answer the question. Eighteen caregivers clearly excluded institutional care as a future option or did not want to think about it at that moment. Eight informal caregivers stated explicitly that there was currently no need for admission and five reported that the person with dementia was already registered on a waiting list, but did not specify the reason why. Approximately 25% (43/174) of the informal caregivers in France did not answer this question, whereas the percentages ranged from 8% (13/169) in Spain to 0% in Estonia and Sweden.

Hence, informal caregivers reported at least one potential reason for institutionalization in approximately 93% (1084/1160) of the cases. Approximately 57% (666/1160) of the informal caregivers reported a single potential reason, 26% (306/1160) reported two and 10% (112/1160) reported three or more potential reasons. HCP specified their clinical judgments by reporting one potential reason in 58% (667/1160), two potential reasons in 28% (332/1160) and three or more potential reasons in 14% (161/1160) of the cases.

### *Agreement on case level*

Informal caregivers and HCP agreed on at least one perceived reason in 41% (479/1160) of all cases. In the Netherlands and France, the level of agreement was comparable with the average (37% and 44%, respectively). The agreement between informal caregivers and HCP on at least one perceived reason was slightly higher in Germany (47%), Sweden (50%), Estonia (52%) and Finland (53%), while it was lower in England (34%) and considerably lower in Spain (15%).

### *Most frequently perceived reasons*

Overall, informal caregivers in particular (but also HCP) more often mentioned ‘potential reasons related to persons with dementia than related to informal caregivers’ (Table 2). The most frequently perceived potential reasons for institutionalization per case were related to the categories ‘caregiver burden’, ‘caregiver unable to provide care’ and ‘neuropsychiatric symptoms’, ‘overall deterioration’ and ‘general care dependency’ of the persons with dementia.

**Table 2** Global themes and associated categories.

Category	Description	Identified by healthcare professionals ( <i>n</i> )	Identified by informal caregivers ( <i>n</i> )	Number of cases in category ( <i>n</i> )*
<i>Theme 1: Perceived reasons related to older people with dementia</i>		716	764	931
Neuropsychiatric symptoms	Neuropsychiatric symptoms and behaviour that is challenging to the informal caregiver (e.g., wandering, agitation, aggressiveness)	204	205	325
Overall deterioration	Decline in the condition of the person with dementia; not specified	185	129	266
General care dependency	General inability of the person with dementia to manage activities of daily living at home	132	181	266
Cognitive symptoms	Symptoms of cognitive decline/impairment	125	138	221
Mobility	Loss or decline of mobility (e.g., bedridden)	53	135	158
Health problems	Physical or mental health problems	76	99	155
Endangerment	Self-endangerment or endangerment to others	78	99	148
Accidental fall	Falls	42	28	59
Staying alone not possible	Inability of person with dementia to stay/live/be alone	27	21	45
Need for structure	Requires supervision, structure or guidance at home	25	10	33
Loneliness	Descriptions of loneliness or isolation of the person with dementia	20	11	28
Cannot manage at home	Unspecific descriptions in which the situation at home cannot be managed by the person with dementia	13	9	21
Feelings of insecurity	Descriptions of feelings of insecurity of the person with dementia	5	0	5
In case of acute crisis	Acute crisis of person with dementia	1	2	2
<i>Theme 2: Perceived reasons related to informal caregivers</i>		645	433	744
Caregiver burden	Physical and/or emotional caregiver burden caused by the care giving situation	453	160	510
Caregiver unable to provide care	Inability of the informal caregiver to maintain care at home (e.g., due to the age or health condition of the informal caregiver)	235	285	419
<i>Theme 3: Perceived contextual reasons</i>		96	64	145
Insufficient formal support	Formal support at home provided by healthcare professionals described as insufficient	58	45	95
Care relation	Reasons due to problems within care relations /relationships between all persons involved	16	6	21
Disease acceptance/insight	Problems with understanding/accepting dementia disease	14	1	14
Weak social network	Weak social network and support	13	0	13
Recommended or decided by others	Recommendation made by others (healthcare professionals or compulsory)	2	8	10
Environmental factors	Reasons due to living conditions and physical environment	4	5	7

\*Multiple categories were possible per case (*n* = 1160).

Differences between the judgments of informal caregivers and HCP emerged, which were most striking for the category ‘caregiver burden’. HCP assessed ‘caregiver burden’ to be a potential reason for admission to an ILTC facility in approximately 39% of the cases, whereas

informal caregivers mentioned their own burden in only 14% of the cases. In all countries, ‘caregiver burden’ was more frequently mentioned by HCP than by informal caregivers. The lowest difference in this was shown for Estonia (28% vs. 22%). ‘Caregiver burden’ was twice to



three-fold as frequently reported by HCP than by informal caregivers in France (20% vs. 10%), Sweden (47% vs. 22%), England (34% vs. 15%), the Netherlands (45% vs. 18%) and Finland (26% vs. 9%). This difference between informal caregivers and HCP was larger in Germany (43% vs. 9%); the most distinct difference was revealed in Spain: HCP assessed 'caregiver burden' in 72% of the cases, but only 10% of the informal caregivers mentioned their own 'burden' as a potential reason for relinquishing care to ILTC.

'Caregiver unable to provide care' was more frequently reported by informal caregivers than HCP in England (30% vs. 10%), Spain (32% vs. 15%), Finland (26% vs. 13%), Sweden (33% vs. 24%) and Estonia (29% vs. 22%). The distribution was reversed in France (6% vs. 27%) and nearly equal in Germany (40% vs. 35%) and the Netherlands (12% vs. 17%).

Deviations between the informal caregivers and HCP regarding the perceived reason related to the older persons with dementia – 'neuropsychiatric symptoms', 'overall deterioration & general care dependency' – were marginal and ranged from 11–18% of the cases.

#### *Level of agreement on the most frequently perceived reasons*

The overall agreement between the informal caregivers and HCP was notably low (Table 3). The absolute positive agreement for the most frequently cited reasons ranged from 18–26%. The proportion of the maximum possible agreement ( $\kappa/\kappa_m$ ) ranged from 0.24–0.42, indicating that only 24–41% of the maximum possible agreement was reached per category. However, in Finland, Estonia, France and Sweden, the proportion of the maximum possible agreement tended to be better in comparison with the remaining countries. Finnish informal caregivers and HCP even reached good agreement with regard to 'caregiver-related reasons' ( $\kappa/\kappa_m = 0.71$  and 0.64). The lowest proportions of the maximum possible agreement were achieved in Spain ( $\kappa/\kappa_m = 0.03$ –0.34) and England ( $\kappa/\kappa_m = 0.06$ –0.12).

## Discussion

We analysed the judgements of HCP and informal caregivers regarding 1160 older persons with dementia from eight European countries. The vast majority of respective informal caregivers were able to report reasons for a potential admission. Only approximately 7% of the informal caregivers did not answer the question or even excluded ILTC as a future care option. This figure was considerably higher in France (25%) compared with the remaining countries (0–8%).

In 41% of the cases, informal caregivers and HCP agreed on at least one perceived reason. The agreement was slightly higher in Germany, Sweden, Estonia and Finland (approximately 50%), but clearly lower in England and Spain (34% and 15%). Overall, the most frequently perceived potential reasons belonged to the categories 'caregiver burden' and 'caregiver unable to provide care' and to the categories related to the person with dementia: 'neuropsychiatric symptoms', 'overall deterioration' and 'general care dependency'. The variation between the perceptions of informal caregivers and HCP was most striking for potential reasons related to the category 'caregiver burden'. Potential reasons in this category were clearly more frequently mentioned by HCP than by informal caregivers in all countries, but especially in Spain, Germany and the Netherlands. The proportion of maximum possible agreement in reasons related to the most frequent categories was low to moderate. Slightly better agreement was revealed in Finland, Estonia, France and Sweden and the lowest proportions of maximum attainable agreement were measured in Spain and England.

To the best of our knowledge, this is the first study investigating the perceptions of informal caregivers of older persons with dementia and HCP on potential reasons for admission to ILTC and their agreement therein.

Notably, informal caregivers more frequently reported 'potential reasons related to persons with dementia' than potential reasons related to their own. This finding is in accordance with the results by Afram *et al.* (2014) investigating the postadmission phase in the RightTimePlaceCare study and retrospectively exploring reasons for institutionalization. The diversity of the derived categories describing the 'potential reason related to the persons with dementia' underlines the complexity of symptoms and conditions. Potential reasons reported by informal caregivers and HCP correspond with reported risk factors for institutionalization and the revealed aspects were not surprising (Buhr *et al.* 2006, Lupp *et al.* 2008, Gaugler *et al.* 2009).

Remarkably, the majority of informal caregivers in all countries were able to answer the question about possible admission. Hence, our findings suggest that initiating discussions about ILTC appears to be feasible, although informal caregivers perceived this question as difficult and requiring some time to answer; the interviewers occasionally had to ask a second time. It remains open whether informal caregivers perceived the need for admission to ILTC to be as urgent as the HCP (within 6 months), which may have contributed to the low agreement.

The high proportion of French informal caregivers who failed to provide an answer to the question may be due to a different recruiting procedure rather than to cultural differ-

**Table 3** Level of agreement on the most frequent categories (overall and per country).

	Caregiver burden			Caregiver inability to care			Neuropsychiatric symptoms			Overall deterioration			Care dependency		
	pa <sup>†</sup> (%)	κ <sup>‡</sup>	κ/κ <sub>m</sub> <sup>§</sup>	pa (%)	κ	κ <sub>m</sub>	κ/κ <sub>m</sub>	pa (%)	κ	κ <sub>m</sub>	κ/κ <sub>m</sub>	pa (%)	κ	κ <sub>m</sub>	κ/κ <sub>m</sub>
Total	103/510 (20.2)	0.17*	0.40	0.42	0.40	0.42	0.88	0.24	83/325 (25.5)	0.28*	0.28	48/266 (18.1)	0.20*	0.80	0.25
ENG	5/34 (11.6)	0.06	0.52	0.12	0.04	0.11	0.41	0.11	5/36 (13.9)	−0.02	#	2/21 (9.5)	0.04	0.75	0.06
EE	19/64 (29.7)	0.23*	0.83	0.35	0.42*	0.52	0.82	0.52	4/18 (22.2)	0.33*	0.62	4/16 (25.0)	0.37*	0.68	0.54
FI	11/49 (22.5)	0.27*	0.43	0.64	0.43*	0.71	0.61	0.71	27/66 (40.9)	0.43*	0.78	10/64 (15.6)	0.12	0.48	0.25
FR	11/41 (26.8)	0.34*	0.60	0.56	0.12*	0.31	0.38	0.38	26/59 (44.1)	0.49*	0.92	17/58 (29.3)	0.30*	0.98	0.31
DE	6/53 (11.3)	0.07	0.23	0.29	0.17	0.89	0.19	0.19	5/29 (17.2)	0.17	1.0	8/40 (20.0)	0.15	0.95	0.16
NL	20/91 (22.0)	0.14*	0.41	0.35	0.10	0.82	0.12	0.12	13/73 (17.8)	0.08	0.74	0/21 (0.0)	−0.06	#	#
ES	13/124 (10.5)	0.03	0.08	0.34	0.03	0.54	0.06	0.06	1/26 (3.9)	0.01	0.49	1/17 (5.9)	0.07	0.65	0.10
SE	18/54 (33.3)	0.29*	0.48	0.59	0.27*	0.79	0.35	0.35	2/18 (11.1)	0.12	1.0	6/29 (20.7)	0.23*	0.57	0.41

ENG, England; EE, Estonia; FI, Finland; FR, France; DE, Germany; NL, the Netherlands; ES, Spain; SE, Sweden.

\* $P < 0.05$ .

†Absolute positive agreement (%): cases with agreement/total number of cases with assigned category.

‡Cohen's kappa.

§Maximum attainable kappa.

¶Proportion of maximum attainable agreement.

#Not calculated since observed agreement was smaller than mean-chance agreement.

ences. Participants in France were approached in a geriatric hospital and recruited by physicians, whereas other countries recruited participants via community care services.

Our study revealed distinct variation between the reported potential reasons of informal caregivers and HCP and only low to moderate agreement across countries. Thus, our results are contradictory to recent findings from a study investigating the perception of caregiving needs for persons with dementia; good agreement between the informal caregivers and HCP was reported (Miranda-Castillo *et al.* 2013). However, compared with Miranda-Castillo *et al.*, we did not use a structured questionnaire and the assessment of caregiving needs may be easier than an assessment of potential reasons leading to a future admission to ILTC.

Our study showed variation between the countries. Informal caregivers and HCP in Finland, Estonia and Sweden consistently revealed more agreement in all measures, while participants in England and in Spain consistently revealed the lowest agreement. These differences could be partially influenced by different long-term care structures (Prince *et al.* 2009, 2013). Some countries have a greater availability of structured support, which could result in continuous and closer contact with informal caregivers and persons with dementia. For instance, memory nurses are in place in Finland and act as key contact persons for the persons with dementia and their informal caregivers (Alzheimer Europe 2007, The National Memory Programme 2013). Furthermore, the obligations of families differ across countries. In Estonia, families are legally obliged to care for their relative with dementia (Alzheimer Europe 2007). Therefore, access to an ILTC facility could be limited and only allowed in certain circumstances. Surprisingly, low agreement between informal caregivers and HCP was revealed in England, where community mental health teams are employed and offer a range of interventions in a multi-disciplinary team (Royal College of Psychiatrists and Royal College of Physicians 2006, Tucker *et al.* 2009). A multi-disciplinary and holistic approach incorporating the care of both the people with dementia and their informal caregivers may provide HCP with a wider perspective in identifying the perceived needs of both parties.

The variation in the perceptions of informal caregivers and HCP was particularly high for the category caregiver burden. Overall and in all countries, 'caregiver burden' was more frequently mentioned by HCP than informal caregivers. Former studies suggest that 'caregiver burden' is a risk factor for the institutionalization of persons with dementia (Luppa *et al.* 2008, Gaugler *et al.* 2009) and early supportive interventions have been requested (Miller *et al.* 2012). However, in our study, only 9% (Finland

and Germany) – 22% (Estonia and Sweden) of informal caregivers described their own burden; this result is in accordance with Afram *et al.* (2014). Informal caregivers may not perceive a burden or simply not name their situation ‘burdensome’, even if ‘burden’ was identified from a professional perspective. The different perceptions regarding burden could also be explained by the emotion-focused coping style of informal caregivers, in particular via avoidance or denial (Kneebone & Martin 2003, Sun *et al.* 2010). Our results suggest that informal caregivers may disregard their personal needs and feelings of burden and solely focus on the person with dementia for which they are caring.

The perceptions of ‘caregiver burden’ varied considerably across countries. The discrepancy between informal caregivers and HCP was most striking in Spain. Social and cultural beliefs appear to strongly impact how informal caregivers perceive caregiving and cope with its associated burdens (Janevic & Connell 2001, Etters *et al.* 2008, Corcoran 2011). In countries with a strong cultural belief that families have to care for a relative with dementia (such as Spain) (Vellas *et al.* 2012), a disregard for their own burden may be pronounced. Interestingly, Spanish informal caregivers retrospectively reported slightly more reasons for institutionalization that were related to themselves, including their own burden (Afram *et al.* 2014).

Our results indicate that informal caregivers and HCP perceive or prioritize different potential reasons for institutionalization. These findings should be highlighted, keeping in mind that HCP referred only those persons with dementia who were judged to be at risk for institutionalization within the next 6 months. Hence, it should be assumed that HCP reported potential reasons that are important in their clinical judgements. Based on their judgements, HCP most likely propose or initiate supportive interventions for informal caregivers and persons with dementia. However, it is obvious that informal caregivers will probably not seek or accept support as long as they do not perceive their own burden as a problem or are not prepared to speak about it. With regard to this issue, our findings could provide further insights into why informal caregivers do not use professional support (Brodsky *et al.* 2005, Robinson *et al.* 2005). In the light of the discrepancy between the perspectives of HCP and informal caregivers, the responsibility of HCP in offering need-tailored counselling and support should be stressed.

### Limitations and strengths

Some limitations of our study should be considered. First, no descriptive information about the HCP was collected.

Different types of HCP contributed to the clinical judgements. Registered Nurses were primarily used, but (depending on the country) social workers and physicians also contributed. Thus, we are not able to determine whether the professional background of the HCP influenced the results. Furthermore, we did not collect any retrospective data about the duration or intensity of the care relationship between informal caregivers and HCP, nor did we collect prospective data over time. Therefore, whether the informal caregivers and HCP already discussed (or would discuss) the possibility of relinquishing care remains unknown. Nevertheless, we can assume that realistic results were generated by choosing a cross-sectional design and relying on the best informed HCP per country, especially because it has been shown that different types of HCP are probably involved in the decision-making process (Couture *et al.* 2012).

Sample size deviated between countries with low participant numbers in England, Sweden and Germany. This could have influenced the kappa values as larger sample sizes are likely to yield more reliable results (Sim & Wright 2005). Data were collected in defined regions of the respective countries as opposed to nationwide. Thus, our findings should be interpreted cautiously because they do not necessarily represent the entire country.

Answers from informal caregivers and HCP were not recorded and could have therefore been influenced by the interviewers’ documentation. Language transfer bias cannot be ruled out because the answers collected across countries had to be translated into English. However, to ensure the quality of the translation process and the open coding procedure, a strict approach was employed with reliability checks and a validation procedure.

### Conclusion

Informal caregivers and HCP differ in their perceptions of potential reasons for the placement of older persons with dementia in an ILTC facility, particularly with regard to caregiver burden. Our findings are relevant because HCP have a decisive role in making decisions regarding institutionalization. Our results may be integrated into the development of appropriate counselling strategies. Good communication skills are required to carefully initiate open discussions about the institutionalization of persons with dementia. HCP should be conscious of their important function as counsellors for informal caregivers who offer valuable reflections of the current care situation but also provide different perspectives about future care options and timing. They can inform the decisions of informal caregivers and should avoid urging them to make unwanted

decisions. Further research is required to investigate the discrepancies between the perceptions of informal caregivers and HCP; this research should focus in particular on the perception of burden. Further studies should consider social and cultural differences as well as different health and social care structures.

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## Conflict of interest

The authors have no conflicts of interest to declare.

## Author contributions

All authors have agreed on the final version and meet at least one of the following criteria [recommended by the ICMJE ([http://www.icmje.org/ethical\\_1author.html](http://www.icmje.org/ethical_1author.html))]:

- substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data;
- drafting the article or revising it critically for important intellectual content.

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## Appendix

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