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To cite this article: Cecilia Holmstrand, Ingalill Rahm Hallberg, Kai Saks, Helena Leino-Kilpi, Anna Renom Guiteras, Hilde Verbeek, Adelaida Zabalegui, Caroline Sutcliffe & Connie Lethin (2020): Associated factors of suicidal ideation among older persons with dementia living at home in eight European countries, *Aging & Mental Health*, DOI: [10.1080/13607863.2020.1745143](https://doi.org/10.1080/13607863.2020.1745143)

To link to this article: <https://doi.org/10.1080/13607863.2020.1745143>



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Published online: 30 Mar 2020.



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Associated factors of suicidal ideation among older persons with dementia living at home in eight European countries

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ABSTRACT

Objectives: This study aimed to investigate the occurrence of suicidal ideation and associated factors in older persons with dementia living at home in eight European countries, and its association with quality of life. Furthermore, changes in suicidal ideation over time were investigated.

Methods: This cohort study ($n = 1,223$) was part of the European “RightTimePlaceCare” project conducted in 2010–2013. Participating countries were Estonia, Finland, France, Germany, the Netherlands, Spain, Sweden and the United Kingdom. Baseline and follow-up data were analysed using bivariate and multivariate logistic regression.

Results: The occurrence of suicidal ideation in the participating countries varied between 6% and 24%. Factors significantly ($p < 0.0018$) associated with suicidal ideation using bivariate analysis were: nationality, depressive symptoms, delusions, hallucinations, agitation, anxiety, apathy, disinhibition, irritability, night-time behaviour disturbances, anxiolytics and anti-dementia medication. In the multivariate regression analysis, country of origin, moderate stage of the dementia, depressive and delusional symptoms, and anti-dementia medication were significantly associated with suicidal ideation ($p < 0.05$). Over time, suicidal ideation decreased from severe to mild or became absent in 54% of the persons with dementia.

Conclusion: It is essential that professionals identify older persons with dementia and suicidal ideation and depressive and other psychological symptoms in order to give them appropriate treatment and provide relief for their informal caregivers. We emphasize the importance of identifying suicidal ideation, irrespective of depressive symptoms, and specifically of paying attention to persons with moderate dementia. Living with the informal caregiver seems to be associated with staying stable without suicidal ideation.

ARTICLE HISTORY

Received 8 November 2019
Accepted 15 March 2020

KEYWORDS

Dementia; depression;
home care; older people;
suicidal ideation

Introduction

Suicide, suicidal behaviour and suicidal ideation are serious problems worldwide (World Health Organization, 2014). High age and mental disorders are important risk factors for suicide. Results concerning suicidality among persons with dementia are diverse and, to our knowledge, sparse. One review concluded that suicidal ideation in persons with cognitive decline is deficiently studied (Draper, 2015).

In one longitudinal study, hospital-diagnosed dementia was associated with an elevated suicide risk among older adults, which remained significant when controlling for mood disorders (Erlangsen, Zarit, & Conwell, 2008). However, several studies have not identified dementia diagnosis in general as a risk factor for suicide (Conwell, Duberstein, & Caine, 2002; Harwood, Hawton, Hope, & Jacoby, 2000; Haw, Harwood, & Hawton, 2009; Waern et al., 2002). Others report that suicide and suicidal behaviour is

more common in the early stages of the disease when the person has preserved insight and capacity (Draper, Peisah, Snowdon, & Brodaty, 2010; Ferris et al., 1999; Haw et al., 2009; Lim, Rubin, Coats, & Morris, 2005), relatively soon after diagnosis (Erlangsen et al., 2008; Seyfried, Kales, Ignacio, Conwell, & Valenstein, 2011) and in early-onset disease (Erlangsen et al., 2008). In a review, Alzheimer's disease (AD) was found to be associated with a moderate risk of suicide (Serafini et al., 2016).

The association between dementia diseases and suicide ideation has been reported to be almost completely mediated by depression and anxiety (Borges, Acosta, & Sosa, 2015) and the dementia disease itself has been stated to be of importance only with lower severity of dementia. An earlier study conducted in community residents aged >81 years showed an association between suicidal thinking and depression, as well as between suicidal thinking and

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mixed AD/multi-infarct dementia (Rao, Dening, Brayne, & Huppert, 1997). The occurrence of a comorbid depressive disorder has been reported to affect 10–50% of persons with AD (Ballard, Bannister, Solis, Oyeboode, & Wilcock, 1996; Wragg & Jeste, 1989; Zubenko et al., 2003). Psychiatric disorders and suicidal behaviour have been studied across dementia subtypes, and the highest prevalence of suicidal ideation, plans and/or attempts was found in frontotemporal dementia, followed by vascular dementia (VaD) (Lai, Kaup, Yaffe, & Byers, 2018). A Japanese study reporting suicidal ideation in about 10% of 634 outpatients with dementia (Koyama et al., 2015), showed that patients with suicidal ideation had a higher rate of behavioural and psychological symptoms of dementia (BPSD). Besides depression/dysphoria, the findings particularly showed high delusion, agitation/aggression, and anxiety severity. Therefore, the risk of suicide, suicidal behaviour and suicidal ideation in persons with dementia may vary depending on type and stage of dementia, as well as on presence of a comorbid mental disorder.

Non-fatal suicidal behaviour has been reported to decrease with age, but suicide rates rise with increased age, thus suicide in older people does not seldom occur without any previous suicidal behaviour (Conwell et al., 1998; De Leo, Padoani, et al., 2001; Scocco & De Leo, 2002). This indicates the importance of paying attention to suicidal communication in the older population, such as suicidal ideation (De Leo, Hickey, Neulinger, & Cantor, 2001).

Older people who report suicidal ideation more frequently have psychiatric symptoms or disorders, mostly of a depressive character (Draper, 2014; Fassberg et al., 2019; Kim, Ha, Yu, Park, & Ryu, 2014; Kiosses, Szanto, & Alexopoulos, 2014; O'Connell, Chin, Cunningham, & Lawlor, 2004; Rurup, Deeg, Poppelaars, Kerkhof, & Onwuteaka-Philipsen, 2011; Scocco & De Leo, 2002). A previous study concerning older people without cognitive decline presented a positive correlation between depression and suicidal ideation, as well as between low QoL and suicidal ideation (Ponte, Almeida, & Fernandes, 2014). In a community sample, thwarted belongingness, perceived burdensomeness and hopelessness, according to Joiner's Interpersonal Theory of Suicide (Joiner, 2005; Van Orden et al., 2010), were all significant in predicting suicide ideation in older adults in their 60s (Christensen, Batterham, Soubelet, & Mackinnon, 2013), indicating that circumstances in the later part of life could be important in the suicidal process. In a review, limited social connectedness was found to be associated with suicidal ideation, non-fatal suicidal behaviour and suicide in later life (Fassberg et al., 2012). Furthermore, differences in area-level socio-economic disadvantage may influence suicidal behaviours in Europe (Cairns, Graham, & Bamba, 2017). In a register study including European countries, national attitudes towards older people were found to influence elderly suicide mortality (Yur'yev et al., 2010).

However, older people seem less prone to communicate suicide intent (De Leo, Hickey, et al., 2001; Scocco & De Leo, 2002). Persons of higher age in an exposed life situation regarding their physical and mental health, possibly with feelings of no longer belonging in the society, may not express suicide ideation unless specifically prompted.

Furthermore, culture may affect how openly suicide ideation is discussed and how people react to suicidal ideation communicated by others (An, Cruwys, Lee, & Chang, 2019).

In summary, reduced cognitive and physical capacity for making suicide attempts, and for completing suicide, may underestimate the severity of mental health problems and reduced QoL in persons with dementia, thus highlighting the need for research on suicidal ideation in this group of people.

To our knowledge, studies of suicidal ideation and associated factors, including the association with QoL, in larger populations of persons with dementia living at home are still sparse. Increased knowledge in this field may be essential for professionals to make appropriate interventions for persons with dementia as well as for their informal caregivers. The overall aim of this study was to investigate the occurrence of suicidal ideation in older persons with dementia living at home, proxy-reported by their informal caregivers, in eight European countries. Specific aims were to investigate factors associated with suicidal ideation, such as demographics, physical and mental health, type and stage of dementia, QoL, and psychotropic medication, and, furthermore, and to investigate changes in suicidal ideation over time using 3-month follow-up data.

Methods

Study context

This cohort study was part of the European "RightTimePlaceCare (RTPC)" project (the EU 7th Framework Programme for Research, contract number 24 21 53) conducted in 2010–2013. The RTPC project included eight participating countries: Estonia, Finland, France, Germany, the Netherlands, Spain, Sweden and the United Kingdom. The overall aim of the RTPC project was to describe the health care services for European citizens with dementia and their informal caregivers and to develop best practice strategies for transition from professional home care to institutional long-term care facilities. The present study followed the same procedures and methods used by the RTPC project without modification (Verbeek et al., 2012) and data were collected at baseline and at 3 months for a follow-up.

Participants

Community-living persons with dementia and their informal caregivers were recruited by the RTPC project, in total 1,223 dyads (Estonia $n = 172$, Finland $n = 182$, France $n = 175$, Germany $n = 116$, the Netherlands $n = 177$, Spain $n = 174$, Sweden $n = 146$, and the United Kingdom $n = 81$). Inclusion criteria for persons with dementia were age ≥ 65 years, a primary diagnosis of dementia and a Standardized Mini-Mental State Examination (SMMSE) score of ≤ 24 (Molloy, Alemayehu, & Roberts, 1991). A further criterion was living at home with support from health care or social services and deemed by a professional caregiver responsible for their care, a registered nurse or general practitioner, to be at risk of moving to a nursing home within 6 months. The informal caregiver had to be visiting

the person with dementia at least twice a month. A contact person, who could be from different health care disciplines, with knowledge about persons with dementia contacted potential participants. The contact person informed the person with dementia and their informal caregiver about the study and the interviews, and asked for permission for the researchers to contact them.

Data collection

Data were collected through face-to-face interviews at baseline and after 3 months for a follow-up. The interviews were conducted by professionals in health or social care or by medical/nursing/social care students with practical experience and at least a Bachelor's degree. Sociodemographic data were collected for the person with dementia and the informal caregiver regarding age, gender, and living situation with an informal caregiver and their relationship to each other. The person with dementia answered questions regarding cognition and QoL. The informal caregiver answered questions about the person with dementia including questions concerning type of dementia; comorbidity; and QoL. Furthermore, questions about depression; neuropsychiatric symptoms; presence of pain; and pharmacological treatment were asked. Regarding pharmacological treatment, either the informal caregiver or professionals responded. To investigate pharmacological treatment, information such as dosage per day; route of administration; and "Anatomical Therapeutic Chemical Classification (ATC)" code was collected. The use of psychotropics was recorded, as follows: antipsychotics (ATC N05A); anxiolytics (ATC N05B); sedatives (ATC N05C); antidepressants (ATC N06A); and anti-dementia medication (acetylcholinesterase inhibitors and memantine) (ATC N06D). Regarding follow-up interviews, formal caregivers answered the questions about the person with dementia if this person had moved to a nursing home.

Measurements

Data collection was conducted using the following standardized instruments: the Neuropsychiatric Inventory Questionnaire (NPI-Q) (Cummings et al., 1994); the SMMSE (Molloy et al., 1991); the Cornell Scale for Depression in Dementia (CSDD) (Alexopoulos, Abrams, Young, & Shamoian, 1988); the Charlson Comorbidity Index (CCI) (Charlson, Pompei, Ales, & MacKenzie, 1987); and the Quality of Life in Alzheimer's Disease (QoL-AD) scale (Logsdon, Gibbons, McCurry, & Teri, 1999). For a detailed description of each instrument, see Verbeek et al. (2012). The CSDD was used to record the presence of depressive symptoms in five separate domains (Alexopoulos et al., 1988). Mean score was imputed if no more than three items were missing; no total score was calculated if more than three items were missing. The term "suicidal ideation" includes different levels of the suicidal process, according to the CSDD (Alexopoulos et al., 1988). The domain ideational disturbance comprises the item "suicide" including the subitems "feels that life is not worth living"; "has suicidal wishes"; and "makes suicide attempts". The item "suicide" has a response alternative on a 3-point scale where 0 = absent; 1 = mild or intermittent; and 2 = severe.

In this study, the term "suicidal ideation" was used when reporting values of 1 or 2 (mild or severe).

For the descriptive results (not in the logistic regression analysis), we dichotomized the total CSDD score into "no depression" (= 0) and "depression" (= 1), with a conventional cut-off of ≥ 12 to detect probable significant depressive symptomatology (Alexopoulos et al., 1988). The authors are well aware that this does not meet the criteria for a clinical diagnosis. For the logistic regression analyses at baseline, the dependent variable "suicidal ideation" was created from the CSDD responses "feels that life is not worth living"; "suicidal wishes"; or "makes suicide attempts", dichotomized into 0 = "absent" and 1 = "mild or intermittent or severe".

To investigate, change and stability at follow-up, comparisons between baseline and follow-up were made regarding values of the subitem suicidal ideation in CSDD, creating the dichotomized groups "stable" with no suicidal ideation (yes = 1, no = 0), "persisting" (yes = 1, no = 0), "newly developed" (yes = 1, no = 0) and "improved" (yes = 1, no = 0). The values were categorized as stable = baseline 0 and follow-up 0; persisting = baseline 1 and follow-up 1, baseline 1 and follow-up 2, baseline 2 and follow-up 2; newly developed = baseline 0 and follow-up 1, baseline 0 and follow-up 2; improved = baseline 1 and follow-up 0, baseline 2 and follow-up 0, baseline 2 and follow-up 1.

Analysis

For the independent variable "stage of dementia", the SMMSE score was divided into 1 = "mild" (20–24), 2 = "moderate" (10–19) and 3 = "severe" (0–9) (Monroe & Carter, 2012). Bivariate regression analysis was performed for factors associated with the item "suicide" at baseline. As 28 separate analyses were intended to be conducted in the bivariate regression analysis, adjustments were performed using Bonferroni correction; therefore, in this analysis $p \leq 0.0018$ was regarded as statistically significant. Backward stepwise multivariate regression analysis was performed for associated factors at baseline (presented in Table 1) and $p \leq 0.05$ was regarded as statistically significant. Multi-collinearity was tested for in all regression analyses, and none was found. To control the changes, over time, in suicidal ideation in the overall group of persons with suicidal ideation, information from the 3-month follow-up was used. For the analyses, SPSS, version 26.0 (IBM Corp., Armonk, NY, USA), was used.

Ethical considerations

The International Epidemiological Association (IEA)'s guidelines for good practice in epidemiological research (The International Epidemiological Association, 2007) and the declaration of Helsinki guidelines (World Medical Association Inc, 2009) were followed in the RTPC project. Each participating country obtained ethical approval from their own legal authority and permission for data collection was obtained for each country. Written informed consent was obtained from the participants of the RTPC project. Persons with dementia who were unable to sign the informed consent were asked to assent, and the informal

Table 1. Bivariate regression analysis for factors associated with/not associated with suicidal ideation.

Persons with dementia living at home	Suicidal ideation				
	Not expr. SI total <i>n</i> = 997	Expr. SI total <i>n</i> = 166	OR	95% CI	<i>p</i> -value*
Participating countries, <i>n</i> (%)					0.001
Sweden (reference)	113 (11)	30 (18)			
Finland	152 (15)	25 (15)	0.620	0.346–1.111	0.108
The Netherlands	134 (13)	39 (24)	1.096	0.640–1.877	0.738
Germany	97 (10)	12 (7)	0.466	0.226–0.960	0.038
Estonia	135 (14)	22 (13)	0.614	0.335–1.123	0.113
France	154 (15)	17 (10)	0.416	0.219–0.791	0.007
Spain	149 (15)	11 (7)	0.278	0.134–0.579	0.001
The United Kingdom	63 (7)	10 (6)	0.598	0.274–1.303	0.196
Age, years; median (Q1; Q3)	83 (79; 87)	82 (78; 87)	0.983	0.959–1.008	0.186
Female gender, %	626 (63)	106 (64)	1.047	0.744–1.474	0.792
Living with informal caregiver	612 (61)	104 (63)	1.052	0.750–1.478	0.768
Dementia diagnosis, <i>n</i> (%)					0.513
AD (reference)	545 (55)	84 (51)			
AD/VaD	62 (6)	9 (6)	0.942	0.451–1.966	0.873
VaD	151 (15)	35 (21)	1.504	0.975–2.320	0.065
Frontotemporal dementia	5 (1)	1 (1)	2.591	0.150–11.244	0.813
Lewy body dementia	18 (2)	5 (3)	1.802	0.652–4.983	0.256
Not otherwise specified	162 (16)	23 (14)	0.921	0.562–1.509	0.744
Other	46 (5)	8 (5)	1.128	0.515–2.474	0.763
Cognition (SMMSE), median (Q1; Q3), 0–30	15 (10; 20)	15 (12; 19)	1.007	0.980–1.035	0.604
Stage of dementia (SMMSE), 0–30, <i>n</i> (%)					0.017
Mild (20–24) (reference)	234 (27)	32 (23)			
Moderate (10–19)	430 (49)	87 (62)	1.480	0.957–2.287	0.078
Severe (0–9)	210 (24)	22 (16)	0.766	0.432–1.360	0.363
Comorbidity (CCI), median (Q1; Q3), 0–37	2 (1; 3)	2 (1; 3)	1.055	0.942–1.183	0.354
Quality of life (QoL-AD, proxy), 13–52	34 (30; 38)	32 (28; 36)	0.957	0.927–0.988	0.007
Depression in dementia (CSDD), 0–36**	6 (3; 10)	12 (8; 17)	1.149	1.116–1.182	<0.001
Neuropsychiatric Inventory (NPI)***					
Delusions, <i>n</i> (%)	325 (33)	94 (57)	2.691	1.927–3.760	<0.001
Hallucinations	281 (28)	69 (42)	1.800	1.283–2.524	0.001
Agitation	470 (47)	116 (70)	2.587	1.815–3.686	<0.001
Depression	443 (45)	132 (80)	4.803	3.228–7.145	<0.001
Anxiety	420 (42)	104 (63)	2.296	1.637–3.222	<0.001
Euphoria	106 (11)	21 (13)	1.217	0.738–2.007	0.441
Apathy	623 (63)	136 (82)	2.678	1.767–4.058	<0.001
Disinhibition	265 (27)	71 (43)	2.106	1.500–2.957	<0.001
Irritability	416 (42)	111 (67)	2.836	2.001–4.020	<0.001
Motor disturbance	353 (36)	78 (47)	1.628	1.168–2.269	0.004
Night-time behaviour disturbances	386 (39)	92 (57)	2.057	1.470–2.878	<0.001
Eating disturbances	305 (31)	68 (41)	1.565	1.117–2.193	0.009
Pain, presence of, yes/no	484 (49)	101 (61)	1.631	1.166–2.281	0.004
Antipsychotics (ATC N05A)	328 (33)	59 (36)	1.125	0.797–1.587	0.504
Anxiolytics (ATC N05B)	198 (20)	53 (32)	1.893	1.318–2.717	0.001
Sedatives (ATC N05C)	151 (15)	28 (17)	1.137	0.731–1.768	0.569
Antidepressants (ATC N06A)	287 (29)	58 (35)	1.329	0.939–1.880	0.109
Anti-dementia medication (ATC N06D)	482 (48)	123 (74)	3.056	2.114–4.419	<0.001

AD = Alzheimer's disease; ATC = Anatomical Therapeutic Chemical Classification (code); CCI = Charlson Comorbidity Index; CI = confidence interval; CSDD = Cornell Scale for Depression in Dementia; expr. = expressed; NPI = Neuropsychiatric Inventory; OR = odds ratio; SMMSE = Standardized Mini-Mental State Examination; QoL-AD = Quality of Life in Alzheimer's Disease scale; Q1 = first quartile; Q3 = third quartile; ref = reference; SI = suicidal ideation; VaD = vascular dementia.

Missing cases at baseline *n* = 60.

Underlining of values indicates a positive result, e.g. 0–36.

**p* < 0.0018 was regarded as significant; significant *p*-values are marked in bold.

**CSDD without item 16, suicidal ideation.

***Each item calculated separately.

caregiver signed the informed consent for them, if agreed (Verbeek et al., 2012).

Results

Based on CSDD scores, we included 1,163 persons with dementia from the total sample of 1,223, of whom 166 (14%) had expressed suicidal ideation in the previous week, according to the informal caregiver as a proxy: 119 (10% of the total sample) to a mild or intermittent extent (hereafter referred to as "mild") and 47 (4%) to a severe extent. Among persons with dementia, 1,090 completed the total CSDD. Of the 284 (26%) with CDSS score ≥ 12 , altogether 61 (21% of this group) had mild suicidal ideation, and 34 (12%) had severe suicidal ideation. Among persons without

expressed symptoms of "depression", suicidal ideation was reported in 58 out of 807 cases (7%). In persons with mild dementia, 32/266 (12%) had suicidal ideation; compared with 87/517 (17%) with moderate dementia, and 22/232 (9%) with severe dementia. At diagnosis at baseline, suicidal ideation (mild or severe) was most common in persons with Lewy body dementia (5/23, 22%), and second most common in VaD (35/186, 19%).

In the bivariate analysis in Table 1, nationality and depressive symptoms (according to the CSDD) were associated with suicidal ideation. All items in the NPI were positively associated with suicidal ideation, except for euphoria, motor disturbance and eating disturbances. This was also valid for anxiolytics and anti-dementia medication. Among the group of persons with dementia and suicidal ideation, 61% had pain, mostly of moderate or severe grade.

Table 2. Multivariate regression analysis for factors associated with/not associated with suicidal ideation.

Associated factors of suicidal ideation				
	Adjusted R ² *	OR	95% CI	p-value**
Participating countries	0.284			<0.001
Sweden (reference)				
Finland		2.843	0.967–8.356	0.057
The Netherlands		1.752	0.595–5.160	0.309
Germany		2.828	0.989–8.087	0.052
Estonia		0.872	0.264–2.874	0.822
France		0.943	0.312–2.852	0.918
Spain		0.733	0.258–2.596	0.733
The United Kingdom		0.484	0.196–2.162	0.484
Stage of dementia (SMMSE), 0–30				0.008
Mild (20–24) (reference)				
Moderate (10–19)		1.705	1.017–2.858	0.043
Severe (0–9)		0.769	0.394–1.503	0.442
Neuropsychiatric symptoms (NPI)***				
Delusion		1.853	1.215–2.826	0.004
Depression		3.056	1.885–4.954	< 0.001
Anti-dementia medication		2.034	1.266–3.269	0.003
Depression (CSDD), total score 0–36****		1.121	1.078–1.165	< 0.001

CI = confidence interval; CSDD = Depression Scale in Dementia; NPI = Neuropsychiatric Inventory; OR = odds ratio; SMMSE = Standardized Mini-Mental State Examination.

*Nagelkerke R square.

** $p < 0.05$ was regarded as significant; significant p-values are marked in bold. Underlining of values indicates a positive result, e.g. 0–36.

***Each item calculated separately.

****CSDD without item 16 (suicidal ideation).

In the multivariate regression analysis (Table 2), nationality and dementia stage were significantly associated with suicidal ideation, and specifically the moderate stage had a positive association with suicidal ideation. Delusion and depression, according to the NPI, depression (CSDD) total score, and anti-dementia medication were also positively associated with suicidal ideation.

Regarding stability of and changes in suicidal ideation over time (3 months) in the overall group of persons with dementia participating in the RTPC study, 773 (63%) persons remained stable without suicidal ideation, 56 (5%) had newly developed suicidal ideation, 45 (4%) had persisting suicidal ideation, and 89 (7%) had improved to less or absent suicidal ideation. Missing data for the item from baseline to follow-up were 235 (19%) and 24 (2%) had no comparable data from baseline. In the bivariate regression analysis, living with the informal caregiver were significantly associated with staying stable without suicidal ideation (Table 3) and negatively associated to newly developed suicidal ideation. Furthermore, depressive symptoms was positively associated with persisting suicidal ideation and to develop suicidal ideation.

Discussion

The results of this study of persons with dementia living at home in eight European countries showed that the occurrence of suicidal ideation was 14%, as proxy-reported by the informal caregiver, and changed over time. This occurrence is lower than that reported in a previous study, by Shah et al., in which self-reported prevalence of “feels that life is not worth living” and “suicidal ideation” was 38% and 29%, respectively, in persons with dementia (Shah et al., 1998). Our figure is higher than the findings by Koyama et al., of 10.1% reported by proxy (Koyama et al., 2015), and Draper et al. where self-reported prevalence of “... feels that life is not worth living” was 5.4%, “wished to die or had thoughts of death” 3.2% and “suicide ideations or gestures” 0.9% (Draper, MacCuspie-Moore, & Brodaty,

1998). Our results are close to the results of Rubin and Kinscherf, who found “suicidal thoughts”, as reported by proxy, in 15% of participants (Rubin & Kinscherf, 1989). These results could be compared to the frequency found in older people in general. Borges et al. (2015) found self-reported suicide ideation in 4.2% and Almeida et al. (2012) reported “thoughts about killing oneself” in 4.8% in a community sample with a 2-week time frame. Previous results, together with the results of this study, indicate that suicidal ideation in persons with dementia is not negligible, and seems to occur more often than in older people in general.

The stability of and changes in suicidal ideation over time may depend on the trajectory of the dementia disease, the person’s mental state or other temporary factors. In this study, we investigated stability of and changes of suicidal ideation over time in the overall group of participants, and found that a majority were stable without suicidal ideation. Furthermore, the proportion of participants with persisting or newly developed suicidal ideation was closed to proportion of participants that had improved. Living with a caregiver or not was a significant factor to being stable without suicidal ideation, or getting newly developed suicidal ideation, respectively. Depressive symptoms according to NPI at baseline were strongly associated to preserved or increased suicidal ideation, confirming this variable as the most significant factor of suicidal ideation in the study population. To our knowledge, suicidal ideation over time is sparsely investigated in either people with dementia or older people in general. One longitudinal study investigated the course of depressive symptoms using the CSDD and demographic and clinical variables and found that the likelihood of present mood symptoms of “suicidal ideation”, “pessimism” and “delusions” was lower at every subsequent follow-up assessment (over 74 months). This persisted after adjusting for the severity of dementia (Borza et al., 2015).

Expressing the wish to die in old adults may differ between countries because of culture (An et al., 2019) and attitudes to death (Bonnewyn, Shah, Bruffaerts, &

Table 3. Bivariate regression analysis for factors at baseline associated with/not associated with stability over time in the overall group of persons with dementia.

	Stability of suicidal ideation over time, <i>n</i> = 1223			
	Stable without* <i>n</i> = 773 OR; <i>p</i> -value**	Persisting <i>n</i> = 45 OR; <i>p</i> -value**	Newly developed <i>n</i> = 56 OR; <i>p</i> -value**	Improved <i>n</i> = 89 OR; <i>p</i> -value**
Persons with dementia living at home				
Age, years	0.995; 0.589	0.984; 0.470	0.990; 0.614	0.980; 0.222
Gender	1.029; 0.829	0.793; 0.451	0.973; 0.923	1.298; 0.271
Living with informal caregiver	1.369; 0.013	1.175; 0.610	0.585; 0.050	1.067; 0.803
Cognition (SMMSE) 0–30	0.987; 0.203	1.046; 0.087	1.051; 0.039	1.011; 0.562
Dementia diagnosis				
AD (reference)	– ; 0.107	– ; 0.591	– ; 0.219	– ; 0.974
AD/ VaD	1.075; 0.785	0.826; 0.799	1.149; 0.824	1.182; 0.711
VaD	1.386; 0.054	1.713; 0.155	1.565; 0.230	1.073; 0.819
Frontotemporal dementia	1.579; 0.552	0.000; 0.999	4.340; 0.182	2.135; 0.487
Lewy Body dementia	2.488; 0.029	2.591; 0.216	2.367; 0.261	1.164; 0.840
Not otherwise specified	1.343; 0.084	0.770; 0.603	1.295; 0.518	0.863; 0.661
Other	1.562; 0.121	1.676; 0.414	3.255; 0.014	1.307; 0.587
Stage of dementia, (SMMSE) 0–30				
Mild, (20–24) (reference)	– ; 0.574	– ; 0.068	– ; 0.268	– ; 0.022
Moderate, (10–19)	1.186; 0.296	0.970; 0.987	1.067; 0.846	1.787; 0.8057
Severe, (0–9)	1.145; 0.478	0.244; 0.029	0.536; 0.186	0.796; 0.576
Quality of life (QoL-AD), 13–52	0.924; <0.001	1.013; 0.654	0.549; 0.983	0.975; 0.289
Depression (NPI, severity), 1–3	2.248; <0.001	6.240; <0.001	4.053; <0.001	2.176; 0.001
Depression in dementia (CSDD), 0–36***	1.098; <0.001	1.113; <0.001	1.014; 0.552	1.113; <0.001

AD = Alzheimer's disease; NPI = Neuropsychiatric Inventory; OR = odds ratio; SMMSE = Standardized Mini-Mental State Examination; QoL-AD = Quality of Life in Alzheimer's Disease scale; VaD = vascular dementia.

*Persons with dementia remaining stable with no suicidal ideation.

***p* < 0.05 was regarded as significant; significant *p*-values are marked in bold. Underlining of values indicates a positive result, e.g. 0–30.

***CSDD without item 16 (suicidal ideation).

Demyttenaere, 2016). The results of this study indicated differences between the eight European countries. The Netherlands had the highest proportion of persons with dementia and suicidal ideation, while the lowest proportion was found in Spain. In some countries, dementia is seen as a mental illness, which can enhance stigma (Batsch & Mittleman, 2012), and suicidal ideation might not be an open subject to discuss. It may be assumed that the possibility to decide over one's own life may increase the propensity to communicate suicidal ideation to a relative or caregiver. For example, in the Netherlands, a person experiencing an unbearable and hopeless situation due to a medical condition may request physician-assisted euthanasia (Buiting et al., 2009; de Haan, 2002). Stolz et al. investigated predictors for the development of passive suicide ideation in twelve European countries; and at an individual level they found them to be: female gender, depression, older age, poor health, smaller social network size, loneliness, non-religiosity, and low perceived control (Stolz, Fux, Mayerl, Rasky, & Freidl, 2016). In the same study, about 4% of the total variance was located at the country level and cultural acceptance of suicide, religiosity, and intergenerational cohabitation were associated with the rates of passive suicide ideation. The discrepancy between countries regarding suicidal ideation is likely related to attitudes to suicide, suicidal behaviour and suicidal ideation in various contexts such as community awareness, culture, religion and health care (De Leo & Spathonis, 2003; World Health Organization, 2014). Differences between countries suggest that both detection methods and interventions need to be adjusted to the specific welfare system and context.

Anti-dementia pharmaceuticals are expected to mitigate BPSD, and therefore may be assumed to reduce suicidal ideation. Persons with dementia and reported suicidal ideation in this study more often were on anxiolytics and anti-dementia medication (acetylcholinesterase inhibitors and

memantine). This was unexpected as anti-dementia medication is considered to improve neuropsychiatric symptoms (Finkel, 2004; Huang, Lin, Lane, & Tsai, 2012; Manabe, Ino, Yamanaka, & Kosaka, 2016; Olsen, Poulsen, & Lublin, 2005). One explanation may be that the prescription of these pharmaceuticals may vary depending on the stage of dementia, in favour of the mild and moderate stage. Low severity of dementia has been claimed to represent a risk factor for suicidal ideation (Borges et al., 2015) and suicide (Draper et al., 2010; Ferris et al., 1999; Haw et al., 2009; Lim et al., 2005). An important reason for this may be that the awareness of one's situation and reflective thinking often still occur in an early stage of the disease, which may increase the suicide risk (Draper et al., 2010; Ferris et al., 1999; Harwood & Sultzer, 2002; Lim et al., 2005; Vega, Kishikawa, Ricanati, & Friedland, 2002). However, in two studies, suicide ideation/suicidal thinking was unrelated to the presence of insight into cognitive impairment in AD (Draper et al., 1998) and mixed AD/multi-infarct dementia (Rao et al., 1997). The finding of an association between anxiolytic treatment and suicidal ideation in the present study is in line with the results from a previous study, whose authors found that prescription of anti-anxiety medication was a predictor for suicide in persons with dementia (Seyfried et al., 2011). These findings may indicate more severe BPSDs in those persons.

In this study, the persons with dementia and reported suicidal ideation also had severe neuropsychiatric symptoms (except euphoria, motor disturbance and night-time behaviour disturbances). This is consistent with the results of Koyama et al. (2015). However, only the BPSD delusion and depression, as well as anti-dementia medication, had an independent association with suicidal ideation in the multivariate analysis in this study. In previous studies, depression was an important factor related to suicidal

ideation in dementia (Borges et al., 2015; Draper et al., 1998; Harwood & Sultzer, 2002).

In the present study, 26% of the persons with dementia reached the cut-off for the CSDD total, of ≥ 12 . The CSDD total score was positively associated with suicidal ideation in the bivariate and multiple regression analyses. However, the NPI items “depression” and “agitation” had a stronger association with suicidal ideation. Further, in this study, moderate state of dementia was more strongly associated with suicidal ideation than the mild state. As discussed, mild or early stage of dementia has previously been highlighted as a risk period for suicide and suicidal behaviour (Draper et al., 2010; Ferris et al., 1999; Haw et al., 2009; Lim et al., 2005; Margo & Finkel, 1990; Rohde, Peskind, & Raskind, 1995) and suicide ideation (Borges et al., 2015) in persons with dementia.

Regarding QoL, no association was found in this study between suicidal ideation and proxy-reported QoL. A previous study of older people without cognitive decline found an association between suicidal ideation and poor self-rated QoL (Ponte et al., 2014).

Suicidal ideation may be burdensome, not only for people with dementia, but also for their informal caregivers. In a study assessing behaviour problems in persons with dementia, the items “appears anxious” and “appears sad or depressed” occurred most often (Teri et al., 1992); however, stress reactions from caregivers were strongest for the less frequently reported items “suicidal threats” and “comments about death”. This possibly indicates that suicidal ideation or threats may lead to a higher level of burden for caregivers even if not so common. In another study, caregivers of persons with dementia with suicidal ideation experienced a higher degree of caregiver burden than did caregivers of persons with dementia without suicidal ideation, even after adjusting for BPSD score (Koyama et al., 2015). Experiencing high levels of caregiver burden may also result in poor health-related QoL for the caregiver (Lethin et al., 2018). A systematic review of interventions to prevent suicidal behaviours and reduce suicidal ideation in older people found that primary care or community-based multifaceted intervention programmes may be effective (Okolie, Dennis, Simon Thomas, & John, 2017). Accordingly, identifying suicidal ideation and providing the right care and treatments for the person with dementia may be important for the well-being and health of informal and formal caregivers.

Strengths and limitations

There were limitations in this study. Firstly, participants in the study were a very specific group of individuals on the margin of care, as they were deemed to require nursing home care within 6 months, and may therefore not represent the whole spectrum of dementia. The suicidal ideation reported by informal or professional caregivers as a proxy for the person with dementia may not reflect actual severity or frequency of suicidal ideation of the person with dementia. It has previously been stated that persons with dementia may under-report and caregivers may over-report symptoms (Gutzmann & Qazi, 2015). Expressed thoughts of suicide reported by informal or professional caregivers may not always correlate to a genuine wish to die, or to genuine suicidal thoughts or plans in persons with dementia.

Secondly, the CSDD was not originally designed for use as a diagnostic instrument for depression in persons with dementia (Alexopoulos et al., 1988). A cut-off of ≥ 7 has elsewhere been associated with clinically significant depression (Kopetz et al., 2000; Korner et al., 2006; Watson, Garrett, Sloane, Gruber-Baldini, & Zimmerman, 2003), but a cut-off of ≥ 9 to ≥ 11 has been suggested as the best cut-off value for depression in persons with dementia (Barca, Engedal, & Selbaek, 2010). Conventionally, a CSDD cut-off of ≥ 12 is used as the threshold to detect probable major depression (Alexopoulos et al., 1988) and was used to detect significant depressive symptoms (“depression”) in this study. A depressive disorder meeting the diagnostic criteria cannot be established in this population.

One of the strengths of this study is the large group of persons with dementia and informal caregivers in Europe. The study included eight different European countries and results at an area level, which may reflect cultural differences between both countries and regions. Another strength of the study is that in a number of cases, the persons with dementia, who might have difficulties in remembering suicidal ideation, had expressed their suicidal thoughts to their informal caregiver. A discrepancy between the occurrence of observer-reported (15%) and self-reported suicidal ideation (2%) was found in a study on people with mild dementia (Rubin & Kinscherf, 1989). The reliability of reported information about suicidal ideation in persons with moderate and severe dementia has been questioned, especially when self-reported (Chappell et al., 2016). In another study, based on cross-sectional interviews from the Clinical Antipsychotic Trials of Intervention Effectiveness-Alzheimer’s Disease (CATIE-AD), asking the person with AD a single question about depression failed to detect most cases, but caregivers identified two-thirds of depression when asked this one question (Watson, Lewis, Moore, & Jeste, 2011). This might indicate that a report by proxy better reflects the true occurrence of suicidal ideation in the person with dementia.

Conclusion

The results of this study are concordant with several studies which found that depression/depressive symptoms in persons with dementia are an essential factor for suicidal ideation. This is important for planning adequate support and care, as well as for detecting clinical depression in need of treatment. Nonetheless, we want to emphasize the importance of observance of expressed suicidal ideation in persons with dementia, irrespective of depressive symptoms, and of not neglecting the moderate stage of dementia. Furthermore, depressive symptoms seem to be important for the persistency of suicidal ideation over time. On the other hand living with a caregiver may possibly be protective against developing such ideation. Professionals need to identify older persons with dementia with suicidal ideation, not only in order to decide their treatment but also to provide support to their informal caregivers. More studies are needed that are country-specific, concerning health care and social service systems as well as community awareness, and cultural background. Further research on suicidal ideation, as well as suicidal behaviour in persons with cognitive decline, is desirable, especially in a broad perspective dealing with various biological,

psychological, social and cultural factors. Longitudinal and intervention studies can improve the knowledge about the course of suicidal ideation over time, and may lead to effective health care and support for persons with dementia and their caregivers.

Acknowledgements

The authors are grateful to all participants of the study for sharing their experiences and information with us. We are also grateful for the statistical advice given by Anna Axmon, Associate Professor, Occupational and Environmental Medicine, Lund University, Lund, Sweden. We acknowledge the RTPC Consortium for developing the study. Collaborators: Meyer G, Stephan A, Renom Guiteras A, Sauerland D, Wübker A, Bremer P, Hamers PH, Afram B, Beerens HC, Bleijlevens MH, Verbeek H, Zwakhalen SM, Ruwaard D, Ambergen T, Hallberg IR, Emilsson UM, Karlsson S, Bokberg C, Lethin C, Challis D, Sutcliffe C, Jolley D, Tucker S, Bowns I, Roe B, Burns A, Leino-Kilpi H, Koskeniemi J, Suhonen R, Viitanen M, Arve S, Stolt M, Hupli M, Saks K, Tiit EM, Leibur J, Raamat K, Armolik A, Toivari TT, Zabalegui A, Navarro M, Cabrera E, Risco E, Alvira C, Farre M, Miguel S, Soto M, Milhet A, Sourdret S, Gillette S, Vellas B.


Disclosure statement

No potential conflict of interest was reported by the authors.

Funding

This work was supported by the EU 7th Framework program for research under grant number 24 21 53. This study was also supported by grants from the Greta and Johan Kocks Foundation and Skåne University Hospitals Foundations.

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