

The occurrence and persistence of thoughts of suicide, self-harm and death in family caregivers of people with dementia: a longitudinal data analysis over 2 years

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Objective: Family caregivers of people with dementia often report high levels of stress and depression, but little is known about those who contemplate suicide or self-harm. This study explores thoughts of suicide, self-harm and death in dementia caregivers and investigates the characteristics that distinguish them from those without such thoughts.

Methods: Data were collected every 3 months, for 24 months, from 192 family caregivers of people with dementia living in the Netherlands. Caregivers did not have a clinical depression or anxiety disorder at baseline. Suicide-related thoughts were measured with an item from the Mini International Neuropsychiatric Interview, a diagnostic instrument for DSM-IV mental disorders. Fisher exact, analysis of variance or Kruskal–Wallis tests compared the characteristics of caregivers who had contemplated suicide with two comparison groups.

Results: Within 24 months, 76 caregivers reported symptoms of a potential depression and were further assessed for suicidal thoughts. Nine carers (11.8%, 4.7% of the total sample) reported suicidal thoughts with three of those at multiple points. Caregivers with suicidal thoughts had more severe depressive and anxious symptoms, had a lower sense of competence and mastery, felt less happy and experienced more health problems, less family support and more feelings of loneliness than caregivers who had not.

Conclusion: Suicidal thoughts are present in dementia caregivers and can persist across the care trajectory. Various psychological and social characteristics significantly distinguish caregivers with suicidal thoughts from those without. More research is needed to enable the identification of high-risk caregivers and provide an evidence base for the development of preventive strategies and interventions.

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Introduction

In the coming decades, the number of people with dementia is expected to increase substantially (WHO 2012), and alongside this, the demand for family care will also increase. The majority of care for people with dementia is provided at home by family members (Bosanquet *et al.*, 1997; Johnson *et al.*, 2000), which can be very challenging and burdensome. Family caregivers often report high levels of stress (Etters *et al.*, 2008), have higher rates of depression and anxiety

(e.g. Cooper *et al.*, 2007; Joling *et al.*, 2010) and experience worse physical health than non-caregivers (Vitaliano *et al.*, 2003).

Recent research also suggests that caregivers may be a high-risk group for suicide. A study of more than 500 Australian caregivers reported that 16% had contemplated suicide more than once in the previous year, and of those, approximately one-fifth said they were likely to attempt suicide in the future (O'Dwyer *et al.*, 2016). Although that study identified rates of suicidal ideation in caregivers more than four times

those of the general population, much remains to be understood about suicidality in caregivers, particularly whether these rates are consistent across cultures and countries. In Australia, for example, following the 1996 Port Arthur Massacre, there are strict gun control laws (McPhedran and Baker 2008). Differences in these and other social, cultural and political factors, such as the availability of and access to supportive resources, may influence the rate of suicidal thoughts and behaviours in caregivers in other places. Furthermore, the Australian research was cross-sectional, so it is not known how caregivers experience suicidal ideation over time.

A more comprehensive understanding of suicide-related thoughts in this population, and the identification of caregivers at highest risk, will aid in the development of targeted suicide prevention strategies and ensure that timely and effective support is provided to support the well-being of dementia caregivers. Estimates of suicidality in international caregiver samples, preferably over time, are needed to determine the extent to which the Australian findings are generalizable and could create further understanding of the role of cultural, social and political factors in suicidal thinking and behaviour. For example, research on caregivers in countries with comprehensive care and support services, and fewer remote and isolated areas, such as the Netherlands, could strengthen understanding of how, when and why carers contemplate suicide.

The aim of this study was to explore the occurrence and persistence of thoughts of suicide, self-harm and death in a sample of Dutch family caregivers during 2 years of follow-up and to compare the characteristics of caregivers who had and had not experienced thoughts of suicide, self-harm and death. In the interests of brevity, we further refer to these as suicidal thoughts.

Methods

Design and setting

Data from the Family Meetings study (FAME) were used. The design of the FAME study has been described elsewhere (Joling *et al.*, 2008; Joling *et al.*, 2012a). In summary, FAME tested the (cost-)effectiveness of a family meetings intervention aimed at preventing the onset of mental disorders in family caregivers of people with dementia in the Netherlands. Dyads of family caregivers and their relatives with dementia were recruited from memory clinics ($n = 91$), services delivering case management ($n = 79$), general

practices, home care settings and meeting centres for people with dementia and their caregivers ($n = 22$). No significant or clinically relevant effects of the family meetings intervention were found (Joling *et al.*, 2012a; Joling *et al.*, 2012b). Therefore, we combined the data from the intervention and control conditions for the current study.

Study sample

Caregivers were eligible if they were the primary family caregiver of a relative with a clinical diagnosis of dementia living at home at intake. As the aim of the FAME study was to prevent caregivers from developing a mental disorder, caregivers were excluded when they met the criteria for a clinically significant depressive or anxiety disorder ($n = 7$) as measured with the Mini International Neuropsychiatric Interview (MINI) (Sheehan, *et al.* 1998), a short, structured and validated diagnostic tool used to diagnose DSM-IV disorders. A total of 192 family caregivers met the inclusion criteria and participated in the study. These caregivers were assessed with the MINI every 3 months, for 24 months. If they screened positive on the two initial screening questions for major depression included in the MINI, they were further assessed for suicidal thoughts. For the current analysis, these data were used to create three groups: group A, caregivers who had depressive symptoms and reported suicidal thoughts; group B, caregivers who had depressive symptoms but did not report suicidal thoughts; and group C, caregivers who did not have depressive symptoms and so were not screened for suicidal thoughts.

Ethics

The Medical Ethics Committee of the VU University Medical Centre approved the study protocol. Written informed consent was obtained from all participants. When suicidal thoughts were reported, the researcher supported the participant to consult their general practitioner and provided help with this if required.

Measures

Suicidal thoughts. Suicidal thoughts were assessed with the question 'Over the past two weeks, did you repeatedly consider hurting yourself, feel suicidal, or wish that you were dead?' This item was included in the major depression episode module of the MINI

(Sheehan *et al.*, 1998). The MINI is widely used in research and clinical practice to screen for psychiatric illness. If one of the two screening questions for a depressive episode is triggered in this interview instrument, the participant is asked about the presence of seven additional symptoms, including thoughts of suicide, self-harm and death.

Descriptive characteristics. A variety of background demographic, clinical and psychological characteristics of the caregivers and their relative with dementia, as well as social and contextual characteristics, were measured at baseline. Measurement instruments, scale ranges and used cut-off points are shown in Table 2.

- *Caregiver background characteristics* included age, gender, educational level, relationship to the person with dementia (spouse or other relative) and being religious (yes/no).
- *Clinical and psychological characteristics of the caregiver* included the severity of depressive and anxious symptoms, assessed with, respectively, the Centre for Epidemiologic Studies Depression Scale (Radloff 1977) and Hospital Anxiety and Depression Scale—Anxiety (Zigmond and Snaith 1983); subjective health problems; and self-esteem measured with two subscales of the Caregiver Reaction Assessment (CRA) (Given *et al.*, 1992). Sense of mastery and sense of competence to care for the care recipient were assessed, respectively, with the Pearlin Mastery Scale (Pearlin and Schooler 1978) and the Short Sense of Competence Questionnaire (Vernooij-Dassen *et al.*, 1999).
- *Characteristics of the caregiving context and social aspects* included cohabiting status, the length of time for which caregivers had taken care of their spouse, the period that the person with dementia could be left alone and receipt of case management services (yes/no). Care burden was measured with a single self-rated burden question (van Exel *et al.*, 2004). Three dimensions of care burden as measured with the CRA assessed the extent to which caregiving interrupts usual daily activities ('disrupted schedule'), financial problems and lack of family support for the caregiver (Given *et al.*, 1992). Feelings of loneliness were measured with the de Jong Gierveld loneliness scale (de Jong Gierveld and Kamphuis 1985).
- *Background characteristics of the person with dementia* included the type of dementia, years since clinical diagnosis and level of cognitive functioning as measured with the Mini-Mental State Examination (Folstein *et al.*, 1975).

Statistical analyses

We investigated baseline similarity in the characteristics of dropouts and completers by performing logistic regression analysis. The presence of suicidal thoughts was calculated as the number of caregivers who reported these thoughts at any point during the 24 months. As nursing home admission or death of the person with dementia during the study could have influenced the presence of suicidal thoughts in caregivers, the occurrence of these events was compared between the three groups with Fisher's exact test, which is appropriate when data are unequally distributed among the cells of the contingency table. Next, baseline characteristics among the three groups of caregivers were compared using Fisher's exact test for categorical variables, and analysis of variance for continuous variables, or Kruskal–Wallis tests if continuous baseline variables were skewed. In the case of an overall statistically significant difference between the groups, post-hoc analyses were carried out to confirm where the differences occurred between groups. Analyses of variance were followed by a Bonferroni post-hoc analysis and Kruskal–Wallis tests by the Mann–Whitney *U* test with a Bonferroni adjustment to correct for multiple comparisons. Statistical significance was considered as two-tailed $p < 0.05$ for all tests, except for the Bonferroni correction for which the significance level was set to $\alpha = 0.0167$. All analyses were conducted with the SPSS software program (version 22.0).

Results

Study sample

Participants were recruited from November 2007 to November 2009. Caregivers were on average 69.5 years old (standard deviation (SD) 10.4), and 70.3% were female. Almost all caregivers (94.3%) were caring for a spouse with dementia. The people with dementia were on average 75 years old (SD 8.9), quite recently diagnosed with dementia (mean 1.1 years, SD 1.2) and mostly had mild levels of cognitive impairments (mean mini-mental state examination score 21.6, SD 5.3). Over the 24 months, 37 (19.3%) of the caregivers were lost to follow-up. None of the baseline variables were significantly associated with dropout. Also, there was no significant difference in the number of dropouts among the three groups of caregivers.

Presence of suicidal thoughts

Across the 24 months, 76 of the 192 caregivers (39.6%) reported symptoms of a potential major depression and were further assessed for suicidal thoughts. Of those, nine people (11.8%, 4.7% of the total sample) reported such thoughts. Three of those reported experiencing suicidal thoughts at multiple time points (Table 1). In most cases ($n = 7$), these thoughts were reported in the second follow-up year.

During the study, 55 people with dementia were admitted to a long-term care facility and 27 died (14 of those after admission to long-term care). Within the group of nine caregivers who reported suicidal thoughts, four were caring for a person with dementia who was admitted to a long-term care facility (compared with 19/67 and 32/116 in groups B and C, respectively) and one was caring for a person with dementia who died after admission (compared with 10/67 and 16/116 in groups B and C, respectively). Two caregivers reported suicidal thoughts before their relative was admitted to long-term care, one reported them after admission and one after the death of their relative (who had been admitted to long-term care prior to death; Table 1). There was no significant difference between the three groups with regard to the number of admissions ($p = 0.56$) and deaths ($p = 0.94$).

Differences in characteristics of caregivers with and without suicidal thoughts

Background characteristics of the caregivers who reported suicidal thoughts (group A), as well as the characteristics of the people they cared for, were comparable with those of the other two groups of caregivers who did not report suicidal thoughts (group B) or were not further assessed as they screened

negative for clinically significant depressive symptoms (group C) (Table 2). With regard to their clinical and psychological characteristics, group A presented more severe depressive symptoms, had a lower sense of competence and mastery, experienced more health problems and felt less happy than groups B and C. Also, caregivers in group A reported more severe symptoms of anxiety than caregivers from group C (Table 2). Examination of the caregiving and social context showed that caregivers who reported suicidal thoughts (group A) experienced less family support and more feelings of loneliness than the other groups.

Discussion

To our knowledge, this is the first longitudinal study of suicidal thoughts in dementia caregivers and the first study of thoughts of self-harm in this population. About one in eight caregivers who were assessed reported suicidal thoughts, with one-third of those reporting thoughts at multiple points over the 24-month follow-up. Although differences in measurement make direct comparison difficult, these findings are broadly consistent with previous Australian research, which reported suicidal thoughts in one of six dementia caregivers (O'Dwyer *et al.*, 2016), as well as with research that has documented elevated rates of suicide-related thoughts and behaviours in mixed samples of caregivers in Australia and the UK (O'Dwyer *et al.*, 2014; Stansfeld *et al.*, 2014) and AIDS caregivers in Africa and America (Rosengard and Folkman 1997; Skeen *et al.*, 2014). This suggests that the experience of suicidal ideation and related thoughts may be a phenomenon among caregivers that transcends cultural, political and social boundaries.

The data reported here may, however, underestimate the rate of suicidal thoughts in Dutch family

Table 1 Frequency and timing of suicidal ideation in the nine caregivers over 2 years' follow-up

Caregiver	Months after baseline								Time that the person with dementia	
	3	6	9	12	15	18	21	24	Was admitted	Died
A		•	•	•	•	•	•		Between 15 and 18 months	
B								•		
C				•	•					
D								•		
E								•		
F	•								Between 12 and 15 months	
G						•			Between 6 and 9 months	Between 9 and 12 months
H								•		
I								•	Between 15 and 18 months	

• indicates reported suicidal thoughts on a sub-item of the MINI International Neuropsychiatric Interview (Sheehan *et al.*, 1998).

Table 2 Differences in characteristics at baseline between caregivers who had experienced suicidal thoughts (A), caregivers who had not (B) and caregivers without depressive symptoms who were not assessed for suicidal ideation (C)

	Group A Suicidal thoughts (n = 9)	Group B No suicidal thoughts (n = 67)	Group C Not assessed (n = 116)	Test statistic (F ^a , H ^c)	p	Post-hoc analysis
Caregiver background characteristics						
Age, mean years (SD) ^a	72.9 (10.4)	69.6 (9.5)	69.1 (10.9)	0.6	0.58	
Female gender, n (%) ^b	7 (77.8)	53 (79.1)	75 (64.7)	4.4	0.12	
Educational level, n (%) ^b				4.0	<0.01*	B ≠ C
Lower	2 (22.2)	31 (46.3)	29 (25.0)			
Secondary	5 (55.6)	23 (34.3)	39 (33.6)			
Higher	1 (11.1)	13 (19.4)	47 (40.5)			
Spouse of person with dementia, n (%) ^b	9 (100.0)	66 (98.5)	109 (94.0)	1.9	0.42	
Religious, n (%) ^b	2 (22.2)	38 (56.7)	58 (50.0)	3.8	0.14	
Caregiver clinical and psychological characteristics, mean (SD)						
Depressive symptoms (CES-D, 0–60) ^c	23.3 (5.8)	14.2 (7.5)	9.0 (6.3)	34.1	<0.01*	A > B; A > C; B > C
Anxious symptoms (HADS-A, 0–21) ^c	9.5 (2.9)	6.6 (3.5)	4.5 (3.0)	24.6	<0.01*	A > C; B > C
Sense of competence, SSCQ (7–35) ^a	23.4 (3.8)	24.0 (5.4)	27.3 (4.4)	11.3	<0.01*	B < C
Mastery, Pearlin Mastery scale (7–35) ^a	19.6 (4.2)	23.2 (3.8)	25.2 (3.8)	12.4	<0.01*	A < B; A < C; B < C
How happy do you feel at the moment? (0–100) ^c	47.9 (21.5)	68.1 (13.0)	71.4 (11.6)	16.0	<0.01*	A < B; A < C
Caregiver burden (CRA subscales)						
Health problems (4–20) ^a	13.6 (2.3)	11.0 (2.7)	9.4 (2.9)	13.4	<0.01*	A > B; A > C; B > C
Self-esteem (7–35) ^a	25.3 (2.5)	26.2 (3.9)	27.4 (3.3)	3.8	0.03*	C > B
Social and contextual characteristics						
Cohabiting with the person with dementia, n (%) ^b	9 (100.0)	67 (100.0)	108 (93.1)	5.1	0.09	
Length of time for which caregivers had taken care, n (%) ^b				2.4	0.67	
Less than 1 year	3 (33.3)	9 (13.4)	16 (13.8)			
1 to 4 years	4 (44.4)	35 (52.2)	64 (55.2)			
More than 4 years	1 (11.1)	10 (14.9)	21 (18.1)			
Can you leave your relative alone?, n (%) ^b				9.3	0.13	
Not at all	2 (22.2)	11 (16.4)	8 (6.9)			
Maximum of 2 h	2 (22.2)	18 (26.9)	31 (26.7)			
For half a day	3 (33.3)	11 (16.4)	35 (30.2)			
For more than half a day	2 (22.2)	27 (40.3)	41 (35.3)			
Use of case management services, n (%) ^b	3 (33.3)	34 (50.7)	42 (36.2)	3.9	0.14	
Caregiver burden (CRA subscales), mean (SD)						
Disrupted schedule (5–25) ^a	17.3 (3.9)	15.8 (4.2)	15.1 (4.1)	1.4	0.25	
Financial problems (3–15) ^a	7.1 (2.4)	6.7 (1.9)	6.3 (1.6)	2.0	0.14	
Lack of family support (5–25) ^a	16.8 (2.9)	12.9 (3.9)	12.0 (3.9)	6.3	<0.01*	A > B; A > C
Self-rated burden scale (0–100), mean (SD) ^a	58.9 (21.9)	54.8 (21.0)	42.2 (22.3)	8.3	<0.01*	B > C
Loneliness (0–1), Jong Gierveld scale, mean (SD) ^c	9.4 (1.3)	4.9 (3.4)	3.6 (2.8)	22.6	<0.01*	A > B; A > C; B > C

(Continues)

Table 2. (Continued)

	Group A Suicidal thoughts (n = 9)	Group B No suicidal thoughts (n = 67)	Group C Not assessed (n = 116)	Test statistic (F ^a , H ^b)	p	Post-hoc analysis
Person with dementia background characteristics						
Age, mean years (SD) ^a	76.4 (9.7)	73.9 (8.9)	75.1 (8.8)	0.5	0.59	
Female gender, n (%) ^b	2 (22.2)	14 (20.9)	46 (39.7)	7.2	0.02*	B < C
Type of dementia, n (%) ^b				0.3	0.88	
Alzheimer dementia	6 (66.7)	38 (56.7)	66 (56.9)			
Other or not specified	3 (33.3)	29 (43.3)	50 (43.1)			
Years since clinical diagnosis of dementia, mean (SD) ^c	2.0 (2.7)	1.2 (1.2)	1.1 (1.1)	2.5	0.29	
Cognitive impairment, MMSE score (0–30), mean (SD) ^a	21.6 (4.1)	20.5 (5.8)	22.2 (4.9)	2.2	0.12	

More positive scores are underlined.

SD, standard deviation; CES-D, Center for Epidemiologic Studies Depression scale; HADS-A, Hospital Anxiety and Depression Scale—Anxiety; SSCQ, Short Sense of Competence Questionnaire; CRA, Caregiver Reaction Assessment; MMSE, Mini-Mental State Examination.

^aAnalysis of variance with 2 degrees of freedom.

^bFisher's exact test.

^cKruskal–Wallis test with two degrees of freedom.

*Statistically significant.

caregivers. In the current study, caregivers who screened negative for clinically significant depressive symptoms were not asked about suicide-related thoughts. Some carers may experience suicidal thoughts as a crisis response or as part of a rational decision-making process (O'Dwyer *et al.*, 2013), rather than as a consequence of mental illness, so the number of caregivers reporting suicidal thoughts may have been higher if all participants had been assessed. On the other hand, we found a consistent pattern across the groups in relation to the baseline measures, with caregivers who had contemplated suicide presenting most severe values, followed by the caregivers who had depressive symptoms but did not report suicidal thoughts and the caregivers who did not have depressive symptoms and so were not screened for suicidal thoughts. This may suggest that it is unlikely that a large number of persons with suicidal thoughts were missed in caregivers who were not assessed.

The fact that our sample comprised people caring for family members who had, overall, been relatively recently diagnosed with dementia and had mild levels of cognitive impairment might also have influenced the rate of suicidal thoughts. Suicidal thoughts may be more common in people who have been caring for longer and/or are caring for a person with more severe cognitive impairment, although our study did not show significant differences between the caregivers with and without suicidal thoughts in relation to these features. Nevertheless, research that includes a diverse range of caregivers and assesses suicidal thoughts independent of mental illness would be recommended to determine the true rate of suicide-related thoughts and behaviours in family caregivers.

The longitudinal nature of the current study represents a unique contribution to the caregiver literature, documenting for the first time suicide-related thoughts in family caregivers that persist or recur over time, including after admission or death of their relative. These findings extend previous cross-sectional research that found comparable rates of suicidal ideation between people caring for a family member with dementia in the community, people caring for a family member with dementia who had moved into long-term care and caregivers who were recently bereaved (O'Dwyer *et al.*, 2016), and highlight the importance of supporting caregivers through and beyond transitions into long-term care or death. The results provide a rationale for the use of longitudinal research methods in future studies of suicidality and self-harm in family caregivers. Qualitative research methods would also allow for a more nuanced understanding of the influence of role transitions on these thoughts.

A wide variety of characteristics spanning a number of different domains were available in the dataset to examine differences between caregivers with suicidal thoughts and the two comparison groups. Although the small sample size prevented the use of multivariate statistics, the clinical, psychological and social differences between caregivers who had contemplated suicide and caregivers who had not are largely consistent with previous research (O'Dwyer *et al.*, 2013; O'Dwyer *et al.*, 2014; Rosengard and Folkman 1997; Skeen *et al.*, 2014) and highlight areas where prevention and intervention efforts might be targeted.

We did not find a relationship between the presence of suicidal thoughts and the use of case management services. More work is required, however, to better determine the influence of social, cultural and political factors. The use of standardized measures of suicidal thoughts across international studies would enable clearer comparisons of rates and risk factors across cultures, while qualitative studies can provide greater insight into the influence of specific factors such as firearm access, and different health and social care systems.

Although this study makes a significant contribution to the caregiver literature, some limitations must be acknowledged. First, data on previous mental health problems, suicide-related thoughts and behaviours and the presence of other major stressful life events prior to becoming a caregiver were not collected in the current study but are important. Russo *et al.*, (1995) found that caregivers with a psychiatric history prior to the onset of their spouses' Alzheimer's disease were significantly more likely to experience an episode of a major depression or generalized anxiety disorder after the dementia onset than caregivers without a psychiatric history (Russo *et al.*, 1995). As there is also evidence that depression predicts suicide ideation (but not suicide plans or attempts among those with ideation) (Nock *et al.*, 2010), it could be likely that prior severe mental health problems will be related to the presence of suicidal thoughts.

Grief and bereavement experiences of dementia caregivers could be other interesting factors to examine in relation to suicidal thoughts. Recent reviews have concluded that family carers' grief before and after the death of the person with dementia is still only superficially understood (Arruda and Paun 2016; Chan *et al.*, 2013) but offer some evidence for the relation between complicated grief symptoms after the death of a relative and a variety of negative health outcomes including suicidal ideation (Prigerson *et al.*, 1997). Also, several studies have found that caregiver depression increases with anticipatory grief and suggested that what appears to be clinical depression may actually

be a grief reaction (Chan *et al.*, 2013). More insight in such factors could be used to identify dementia caregivers who may need support during the grieving period to prevent the development of subsequent complicated grief and mental problems. Measuring these variables in future studies would strengthen understanding of suicidal phenomena in caregiving populations and facilitate the development of targeted intervention and prevention efforts.

As mentioned earlier in the discussion, owing to the small number of cases, we were not able to use multivariate analyses and adjust for potential confounders when examining the relation between suicidal thoughts and the characteristics of the caregiver, person with dementia and context. Although the demographics of the groups did not statistically differ, caregivers with suicidal thoughts were older and caregivers seemed to be not evenly distributed across educational levels between groups. If related to suicidal ideation, future larger studies may want to adjust for such factors in the analyses.

Furthermore, in the current study, thoughts of suicide, thoughts of self-harm and thoughts of death were grouped together. Although generally considered to be part of the spectrum of suicidal phenomena (O'Dwyer *et al.*, 2014; Rurup *et al.*, 2011; Scocco and De Leo 2002; Silverman *et al.*, 2007; Thomas *et al.*, 2002), thoughts of self-harm and thoughts of death are not synonymous with thoughts of suicide, and more research is required to understand the differences and similarities between caregivers who contemplate suicide, caregivers who contemplate self-harm and caregivers who think about death.

In this study, we did not examine whether any of the caregivers had attempted suicide or engaged in self-harm. Although thoughts of suicide and self-harm are a necessary precursor to suicide attempts and acts of harm, they are not a guarantee. Research that includes measures of self-harm and suicide attempts is needed to clarify the proportion of caregivers who progress from ideation to action.

Conclusion and implications

Our study showed that, over the course of 2 years, a number of people caring for a relative with dementia 'repeatedly' considered hurting themselves, felt suicidal or wished they were dead. The majority of these thoughts appeared during the second year of the study and persisted for a longer period of time in some caregivers. This underlines the vulnerability of family caregivers and the need to find effective strategies to support people

providing substantial amounts of care over a long period of time for a relative with dementia. To derive a deeper understanding of how, when and why caregivers contemplate suicide, and whether transitions into a nursing home, or the death of the person with dementia increase the risk of suicidal ideation, prospective, longitudinal studies that begin at diagnosis and track over time are needed. These insights could help practitioners be more aware of high-risk situations and more precisely determine the time to intervene.

Conflict of interest

None declared.

Key points

- Some family caregivers of people with dementia experience thoughts of suicide and self-harm that persist over time.
- A range of psychological and social characteristics distinguish caregivers who experience thoughts of suicide and self-harm from those who do not.
- Studies with large representative caregiver samples are needed to identify high-risk groups for suicide and enable targeted prevention efforts.

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