

Suicide in dementia: 9-year national clinical survey in England and Wales

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Background

Knowledge of suicide in people with dementia is limited to small case series.

Aims

To describe behavioural, clinical and care characteristics of people with dementia who died by suicide.

Method

All dementia cases (n=118) from a 9-year national clinical survey of suicides in England and Wales (n=11512) were compared with age- and gender-matched non-dementia cases (control group) (n=492) by conditional logistic regression.

Results

The most common method of suicide in patients with dementia was self-poisoning, followed by drowning and

hanging, the latter being less frequent than in controls. In contrast to controls, significantly fewer suicides occurred within 1 year of diagnosis in patients with dementia. Patients with dementia were also less likely to have a history of self-harm, psychiatric symptoms and previous psychiatric admissions

Conclusions

Known indicators of suicide risk are found less frequently in dementia suicide cases than non-dementia suicide cases. Further research should clarify whether suicide in dementia is a response to worsening dementia or an underappreciation of psychiatric symptoms by clinicians.

Declaration on interest

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Prevention of suicide is a priority for health services. Historically, older age has been shown to be a risk factor for suicide. Over the past 15 years, suicide rates have fallen in some high-income countries, particularly in older age groups. However, the world population is aging and the study of suicide in older age remains important. Previous research suggests that suicide in older people is associated with depression, comorbid physical illnesses and substance misuse. Description

Dementia is one of the major healthcare problems in later life, affecting 24 million people worldwide.⁷ Although high rates of psychiatric symptoms during the course of illness have been reported,⁸ the risk of suicide in people with dementia is generally considered low.^{9,10} Empirical data on suicide in dementia are scarce and primarily based on case reports (e.g. Rhode *et al*¹¹). In a recent summary of those case reports, it has been suggested that early stage of dementia, male gender, high educational level, professional occupation, retention of insight, depressive features post-dating the onset of dementia, suicidal ideation and access to firearms might be risk factors for completed suicide in dementia.⁹ Furthermore, some studies have reported significantly more Alzheimer's pathology in the brains of older suicide victims compared with age- and gender-matched controls who died naturally,¹² although findings have not been consistent.¹³

The National Confidential Inquiry into Suicide and Homicide by People with Mental Illness collects data on all those who die by suicide within 12 months of last contact with mental health services of the National Health Service (NHS) in the UK. 14 It currently holds data on 11512 people aged 10 years and above who died by suicide in the period April 1996 to December 2004 and offers a unique opportunity to examine suicide in dementia in more detail. Our objectives were to describe the behavioural, clinical and care characteristics of patients with dementia who died by suicide, and to compare them with age- and gendermatched controls who died by suicide and who did not have clinical diagnosis of dementia.

Methods

The study was carried out as part of the National Confidential Inquiry into Suicide and Homicide by People with Mental Illness (the Inquiry),¹⁴ a complete national clinical sample of all people that had been in contact with mental health services in the 12 months prior to their death by suicide. The Inquiry has research ethics approval (South Manchester Research Ethics Committee ERP/96/2771) and approval under Section 60 of the Health and Social Care Act to process patient-identifiable data without consent. The data collection on suicides involved three stages: (a) collection of a comprehensive national sample, irrespective of mental health history; (b) identification of people in the sample who had been in contact with mental health services in the 12 months before death; and (c) collection of clinical data about these individuals. Data collection has been described in detail elsewhere, ¹⁵ and is summarised below.

Comprehensive national sample

Information on all deaths in England and Wales receiving a suicide or an open verdict at coroner's inquest was obtained from the Office for National Statistics. The cases presented here consist of suicides registered by the Office for National Statistics from 1 April 1996 until 31 December 2004. In the first 3 years of the study, this information was cross-checked against equivalent data from health authorities in England and Wales; inconsistencies were rare. Open verdicts, recorded as deaths from undetermined external cause, are often reached in cases of suicide in the UK. Open verdicts are conventionally included in research on suicide and in official suicide statistics. ^{16–18} In this study, we adopted this convention and included open (ICD–10 codes Y10–Y34, excluding Y33.9 (verdict pending) and Y87.2 (sequelae of events of

undetermined intent)) as well as suicide (ICD-10 Codes X60-X84 and Y87.0) verdicts. ¹⁹

Identification of mental health service contact and collection of clinical data

Identifying details on each individual who had died by suicide were submitted to the main hospital and community NHS trusts who provided mental health services to people living in the deceased's district of residence. When NHS records showed that contact had occurred in the 12 months before the suicide, the person became an 'Inquiry case'. For each Inquiry case, the consultant psychiatrist was sent a questionnaire and asked to complete it based on their knowledge of the patient, psychiatry case notes, and in discussion with other members of the mental health team. The questionnaire consisted of sections covering social/demographic characteristics, clinical history, details of suicide, aspects of care, details of final contact with mental health services and clinicians' views on suicide prevention. Clinicians were asked for an ICD-10 primary diagnosis and also any ICD-10 secondary diagnoses. ¹⁹ The social and clinical items reflected many of the most frequently reported risk factors for suicide. The majority of items were factual but some (for example, adherence to treatment) were based on the judgements of clinicians.

Identification of patients with dementia and selection of controls

Based on the information provided by the responsible consultant psychiatrist, we identified all patients with an ICD–10 diagnosis of dementia. A total of 118 patients with dementia were identified. For each individual with dementia, we extracted four gendermatched suicide cases of patients without a diagnosis of dementia (controls) nearest in age to the dementia patients (n=472). This selection was masked, i.e. we were unaware of the behavioural, clinical and care characteristics of these controls. All controls were individually matched for gender and 462/472 (98%) for age within 2 years of the index case (3-year difference for seven cases, 5-year difference for two cases and 6-year difference for one case).

Statistical analysis

All data are presented as absolute numbers and percentages within groups. If an item of information was not known for a case, the case was removed from the analysis of that item; the denominator in all estimates is therefore the number of valid cases for the item. Differences between cases and controls were tested by univariate conditional logistic regression analyses, using Intercooled Stata 9.0 for Windows. As the study was mainly exploratory, main findings are presented as odds ratios (OR) including 95% confidence intervals (CI). Acknowledging heterogeneity in the cases of dementia, we also performed subgroup analyses. The following subgroups were defined: (a) patients with dementia aged 65 years and over; and (b) all dementia cases excluding those in which the individual had a comorbid diagnosis of alcohol dependence and/ or schizophrenia and other delusional disorders. Dementia associated with alcohol dependence or schizophrenia and related disorders is thought to be qualitatively different from dementia in older people caused by neurodegenerative and/or cerebrovascular processes (e.g. Alzheimer's disease, vascular dementia and dementia with Lewy bodies).²⁰ Patients with dementia under the age of 65 years were not selected for subgroup analyses as we anticipated small numbers.

Results

Over the 9-year study period, the Inquiry received notifications of $45\,012$ deaths by suicide, including $30\,794$ (68%) cases in which the coroner's verdict was suicide and $14\,218$ (32%) open verdicts or deaths from undetermined cause. Of these, $11\,733$ (26.1%) were confirmed to have been in contact with mental health services in the year prior to death. Completed questionnaires were received for $11\,512$ cases, a response rate of 98.1%. In $11\,141$ cases (97.9% of the $11\,375$ cases that included data on primary diagnosis), a psychiatric diagnosis was recorded. In 118 (1.1%) of these cases, the individuals had received a clinical diagnosis of dementia from their psychiatrist and 72 (61%) had received an open verdict. As expected this was a higher proportion of open verdicts than in the control sample (n=131, 28%).

Behavioural, clinical and care characteristics of the dementia group

The 118 patients who had died by suicide and had a clinical diagnosis of dementia had a median age of 75 years (range 32–95) and 63 (53%) were male. The sample was predominantly White, including only 5 (4%) individuals from an ethnic minority group. Furthermore, 36 (32%) individuals were married and 58 (49%) lived alone at the time of suicide.

Online Table DS1 describes behavioural, clinical and care characteristics of the dementia group as a whole, and by predefined subgroups. For 91 (80%) of the group, the last contact with services was routine or non-urgent, and for 57 (50%) it occurred in patients' homes. A care-coordinator was allocated in 84 (81%) cases and 47 (40%) individuals were on an enhanced care programme approach (a form of enhanced aftercare indicative of clinical complexity and involvement of at least two members of a multidisciplinary team with different professional backgrounds, usually a community psychiatry nurse and a psychiatrist). The time between last contact and the suicide was less than 1 week for 50 (44%) individuals, and less than 24 h for 18 (16%). A further 29 (25%) individuals had their last contact between 1 and 4 weeks before suicide, 13 (11%) between 5 and 13 weeks, and 23 (20%) more than 3 months before. Evidence of psychiatric symptoms at the last contact was noted for 41 (35%) individuals, most often depressive illness (n=18, 16%), hopelessness (n=10, 9%) and delusions or hallucinations (n=8, 7%). In four patients (4%) suicidal ideation was recorded at the last contact. A deterioration in physical health was noted for 27 (24%) patients.

A total of 26 individuals who had died by suicide and had a diagnosis of dementia were aged below 65 years, and half of this younger subgroup (n=13, 50%) had a history of alcohol and/or drug misuse, including 6 (23%) with a diagnosis of alcohol dependence. As shown in online Table DS1, this subgroup had more involved psychiatric histories and received more intense psychiatric care.

Method of suicide

Similar to the control group, self-poisoning was the most common method of suicide in the dementia group, accounting for almost a third of deaths (Table 1). The substance used was highly variable, most often being analgesics (n=12: paracetamol, n=4; codeine-containing preparations and other opiate analgesics, n=4; other analgesics, n=4), psychotropic drugs (n=4, all different classes), or other poisons such as weed killer (n=4). All other substances were used only once. After self-poisoning, drowning (19%) and hanging (17%) were the second and third most

Table 1 Method of suicide in patients with dementia compared with controls													
Cause of death	Dementia group (n=118) ^a n (%)	Control group (n=472) ^a n (%)			Dementia subgroup statistics ^b								
			Main statistics		Age > 65 years (n=92)		Excluding patients with comorbid schizophrenia and alcohol dependence (<i>n</i> =90)						
			OR (95% CI)	Р	OR (95% CI)	Р	OR (95% CI)	Р					
Self-poisoning	30 (28)	153 (33)	0.88 (0.54-1.42)	0.60	0.59 (0.32–1.09)	0.091							
Drowning	21 (19)	54 (12)	1.55 (0.90–2.69)	0.12									
Hanging	19 (17)	142 (30)	0.45 (0.26-0.78)	0.005			0.55 (0.30-1.02)	0.058					
Jumping (height/moving vehicle)	9 (8)	26 (6)	0.90 (0.43–1.86)	0.77									
Suffocation	6 (6)	35 (8)	0.75 (0.30–1.88)	0.49									
Cutting or stabbing	5 (5)	12 (3)	1.51 (0.54–4.25)	0.43									
Other ^c	27 (23)	30 (6)											

common methods of suicide among patients in the dementia group. The main analysis showed that hanging was used significantly less often by those in the dementia group compared with controls. Three suicides in the dementia group were part of a suicide pact.

Comparison with the non-dementia group

Patients with dementia who died by suicide were compared with their matched controls on all variables presented in online Table DS1. All demographic characteristics were similar for those in the dementia group and their age- and gender-matched controls (P>0.43). In Table 2, behavioural, clinical and care variables that were significantly different in patients with dementia and their controls are presented. With respect to psychiatric history, patients with dementia less often died by suicide within 1 year of diagnosis, were less often prescribed antidepressants, and were less likely to have a history of self-harm. Although the main analysis suggests that patients with dementia were more likely to have a history of violence (12% ν . 6%, P=0.018), the difference was quite small and was not replicated in the two subgroup analyses (Table 2). In line with these findings, patients with dementia had fewer psychiatric admissions and were also less likely to die by suicide while psychiatric in-patients. Significantly fewer psychiatric symptoms were reported during the last contact with a mental health service professional in patients with dementia compared

Cause of death		Controls (<i>n</i> =472) ^a <i>n</i> (%)			Dementia subgroup statistics ^b					
	All dementia cases (n=118) ^a n (%)		Main statistics		Age > 65 years (n=92)		Excluding patients with comorbid schizophrenia ar alcohol dependence (n=90)			
			OR (95% CI)	Р	OR (95% CI)	Р	OR (95% CI)	Р		
sychiatric history										
Duration of primary										
diagnosis <1 year	16 (14)	134 (31)	0.34 (0.20–0.61)	< 0.001			0.31 (0.16–0.59)	< 0.00		
Duration of primary	44 (05)	104 (14)	0.40.40.44.4.04	0.007	0.50 (0.04 0.00)	0.040	0.50 (0.05, 0.00)	0.0		
diagnosis >5 years	41 (35)	191 (44)	0.68 (0.44–1.06)	0.087	0.53 (0.31–0.99)	0.019	0.59 (0.35–0.99)	0.0		
Previous psychiatric admissions	63 (54)	337 (72)	0.43 (0.27–0.67)	<0.001	0.35 (0.21–0.57)	< 0.001	0.35 (0.21–0.58)	< 0.0		
History of self-harm	50 (44)	265 (58)	0.43 (0.27–0.07)		0.42 (0.26–0.69)		0.55 (0.34–0.89)	0.0		
History of violence	14 (12)	28 (6)	2.47 (1.17–5.20)	0.018	0.42 (0.20 0.07)	< 0.001	0.00 (0.04 0.07)	0.0		
History of alcohol misuse	22 (19)	75 (16)	1.14 (0.66–1.96)	0.64			0.29 (0.10-0.83)	0.0		
Clinical care										
In-patient at time of suicide	7 (6)	56 (12)	0.41 (0.18-0.93)	0.033	0.31 (0.11-0.89)	0.030	0.33 (0.11-0.96)	0.0		
Antidepressant prescribed	37 (47)	280 (71)	0.36 (0.22-0.60)	< 0.001	0.26 (0.15-0.46)	< 0.001	0.39 (0.22-0.68)	0.0		
Under care of old age										
psychiatry	60 (76)	233 (67)	4.41 (1.39–14.0)	0.012	3.08 (0.99–9.64)	0.053	5.37 (1.42–20.3)	0.0		
ast contact with services										
Within 7 days of death	50 (44)	260 (55)	0.55 (0.37–0.84)	0.005	0.44 (0.27–0.70)	0.001	0.54 (0.33–0.87)	0.0		
Psychiatric symptoms	(0.00)	0.40.400								
noted	41 (35)	269 (57)	0.59 (0.39–0.90)	< 0.001	0.40 (0.25–0.65)	< 0.001	0.41 (0.25–0.66)	< 0.0		

a. The denominator in all estimates is the number of valid cases for each item.
b. To improve readability, only OR (95% CI) reported with a P<0.10.
c. To prevent the possibility of individuals being identified, all methods used by fewer than three patients in the dementia group are not described (examples include the use of firearms, burning, electrocution, etc.).

with their matched controls, of which emotional problems (31% ν . 16%, P=0.002) and depressive symptoms (40% ν . 16%, P<0.001) reached statistical significance. Life events within 3 months prior to suicide were evaluated systematically in 14 different categories (e.g. interpersonal problems with significant others, financial problems, victim of violence). The frequency of all different life events was similar in patients with dementia and controls, including 'own physical health problems' which was the most often reported life event in both groups (15% ν . 17%, P=0.82).

Discussion

This paper describes a complete national sample of people with dementia who died by suicide while in the care, or having recently been in the care, of mental health services in England and Wales, a geographical area including over 55 million citizens. These cases comprise only 1% (equivalent to 13.5 deaths per year) of the full 9-year sample of people who died by suicide within 12 months of contact with mental health services. This number may be considered to be low given that about 550 000 people in England and Wales are suffering from dementia;²¹ however, we only included individuals who had been seen by specialist mental health services in the 12 months before death. Over a fifth of suicide cases in the dementia group were aged below 65 years, an age group in which the prevalence of dementia is rare (<0.5%) compared with people aged over 65 years (in whom the prevalence increases sharply from 1.5% in those aged 65-70 years to 24.8% in those aged over 85 years). This finding indicates a high proportional risk of suicide in younger patients with dementia compared with older patients with dementia, although this might also suggest that younger patients with dementia are more likely to be in contact with specialist services than their older counterparts. Detailed inspection of this younger age group showed high levels of psychiatric comorbidity and long-standing psychiatric problems.

The methods of suicide used by patients with dementia were comparable to those used by controls. Moreover, we did not find differences with respect to the classic risk factors for suicide in later life, such as physical illness and life events. 10 Suicide in dementia, however, was characterised by fewer behavioural and clinical indicators of suicide risk compared with controls in our study, as well as when compared with previous studies on older suicide victims in general.²² The individuals with dementia who died by suicide were significantly less likely to have a history of self-harm or a history of psychiatric admissions. At the last contact prior to suicide, psychiatric symptoms were less likely to be noted in the dementia group than in the control group. It may be that in people with dementia, the cognitions or concerns about the progression of dementia are more important determinants of suicide. Alternatively, psychiatric symptoms, especially depressive symptoms, may be underrecognised in patients with dementia or wrongly attributed to being core symptoms of dementia because of overlap between depression and dementia.²³ This latter explanation is especially relevant as depressive illness is the most important risk factor for suicide in older adults, with a population attributable risk of up to 74%.²⁴ In addition, depressive illness may negatively mediate the effect of physical illness.9

Interestingly, the time since diagnosis in the dementia group was more often between 1 and 5 years compared with patients who had other psychiatric diagnoses, which is in line with results of a retrospective study of suicide in dementia cases admitted to a psychiatric hospital.²⁵ This time period corresponds to the first two-thirds of the disease process, with a median survival time of

10.5 years from onset and 5.7 years from diagnosis, 26 which significantly decreases with advancing age.²⁷ The predominance of suicide in the first half of the dementia process might be explained by significantly less interference of cognitive deficits with the planning and executing of the suicide act at this stage. 28,29 Moreover, depressive symptoms, which may have been underestimated in our sample, predominate the initial stage of the dementia process, whereas the latter stages are more dominated by apathy. 29,30 Importantly, our data show a very low prevalence of suicide in the first 12 months after dementia has been diagnosed. This finding may indicate that disclosure of diagnosis, although it might evoke suicidal thoughts, is not a risk factor as sometimes suggested.³¹ Our results are most consistent with the view that the risk for suicide is highest at the stage of the disease process where patients experience increasing difficulties in daily living activities due to their dementia, but still have a preservation of insight into ongoing and impending cognitive deterioration.³² This point of view contrasts with suicides in other psychiatric disorders in which lack of insight is generally a risk factor for suicide. 15

Study limitations

Although the large size of the database used in this study and high absolute number of dementia suicide cases enhances its inferential value, the findings of this study need to be interpreted in the context of certain methodological issues. First, this study is a survey of the clinical circumstances preceding suicide, and we are unable to make causal inferences. A control group of patients with dementia who had not died by suicide would have been relevant for identification of suicide risk factors specific for dementia. Controls were mental health patients who died by suicide with a diagnosis other than dementia. Therefore, the differences we observed could simply be due to differences between diagnostic groups (rather than differences in suicide risk). As depression (and rarely other psychiatric illnesses) may precede dementia, it is possible that some of the controls may in fact have undiagnosed early dementia.33 This raises the possibility that that observed differences between dementia suicides and the control group of non-dementia suicides may be underestimated. Known risk factors for suicide in later life (i.e. male gender and older age, could not be examined because of matched analyses). 10,34 Second, the generalisability of our findings is limited to patients with dementia in contact with mental health services, most likely patients with dementia with significant behavioural and psychological symptoms. Therefore, suicides in patients with 'uncomplicated' dementia or those who are not receiving treatments to enhance cognition may be under-represented in this sample. Such a bias towards patients with dementia with behavioral difficulties or psychiatric comorbidity make the findings in relation to less symptomatology and comorbidity more remarkable. Moreover, this may also explain the low number of ethnic minorities, as elderly suicide victims from ethnic minorities are less likely to be in contact with psychiatric services.³⁵ Third, the clinicians who provided the information by filling out the study questionnaires were not masked to patient outcome and this may have affected their response to certain questions, for example, the preventability of suicide in their patient. However, this will not affect the comparison between cases and controls, and the accuracy of the Inquiry questionnaire has been shown to be good.14

We used the wider definition of suicide that included both suicide and deaths of undetermined intent. This is the standard definition that is used in official statistics and previous research. Excluding open verdicts may underestimate the number of actual suicide deaths by 50%. ¹⁸ However, the number of open verdicts

was much higher in the dementia group than the control group in this study - why might this be? A study of all suicide and open verdicts over a 10-year period in one coroner's court found that the factors which most reliably distinguished suicide from open verdicts included method of death (hanging and death from car exhaust poisoning more common; drowning and falling from a height less common) and presence of a suicide note. A small study of deaths in individuals aged 65 years found that evidence of suicidal intent, psychiatric history and method of death distinguished suicide and open verdicts.³⁶ In our study, the cases with dementia included a lower proportion of hanging deaths and a higher proportion of drowning deaths than controls. Those with dementia were less likely to have a significant psychiatric history. Individuals with dementia who died by suicide were also presumably less likely than those with other diagnosis who died by suicide to indicate suicidal intent or to write a suicide note, although we did not investigate these factors directly.

Clinical implications

The antecedents and clinical characteristics of patients with dementia who die by suicide differ from age- and gender-matched suicide victims with other psychiatric diagnoses. The low prevalence of suicide in dementia combined with fewer long-standing psychiatric problems, as well as fewer psychiatric symptoms just before death compared with controls, means that identifying people with dementia who are at risk of suicide remains a significant clinical challenge. Patients may be at particular risk 1–5 years after diagnosis; during this period, suicidal thoughts could be openly discussed with patients and their families. This may help improve underrecognition and undertreatment of psychiatric comorbidity such as depression.

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Post-Mortem Recollections of a Medical Lecturer (1836), Charles Lever

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Charles Lever was an Anglo-Irishman who trained in medicine at Trinity College, Dublin, and St Steven's Hospital, but turned to writing in order better to support his family and early gambling habit. This extraordinary tale is purportedly written by a medical lecturer who has had an upsetting morning with the death of a patient but then goes on to give a lecture on insanity. As additional stressors, he is late and finds that the lecture theatre is extremely crowded, that an eminent foreign physician is present, and that he has left behind his main notes. Despite doubts, pauses and even repetitions he begins to warm to his theme, indeed words begin to fall 'with ease and rapidity'; he makes his points boldly and clearly, and easily demolishes theories of the past. Then he begins to think of his childhood, and shows that every case of those who died insane had some characteristic of a previous childhood trait, and develops this idea. He becomes more and more excited, and then full of terror:

'A thought rushed like a meteor flash across my brain, and bursting forth into a loud laugh of hysteric passion, I cried – and I, and I – too, am a maniac . . . a cry of horror burst through the room. I know no more'.

When he comes round, he is in bed, presumably having succumbed to the 'brain fever', common in Victorian novels as the result of extreme stress. He tries to respond to the doctor and sit up, but feels a clammy perspiration, hears a rushing sound, suffers convulsive spasms and falls back again. 'It is over at last', the doctor says.

None the less, consciousness returns, though he is unable to move or speak. He knows he is dead, and wonders if it might be a trance, but knows 'all too well the unerring signs of death'. He is placed in a coffin, and friends gather round. He reflects that the processes of death are slow and that maybe, by the power of will, he can revive. He therefore proceeds, in a methodically medical fashion, 'to think upon those nerves which preside over the action of the heart, their origin, their course, their distribution, their relation, their sympathies'. He wills action, but fails at first, and is full of terror that the coffin is about to be closed. However, a dear friend puts his hand on his heart. Our narrator responds, and breathes once more.

There was a peculiarly Victorian fear of being buried alive which was exploited by a number of writers – for instance, Edgar Allan Poe in his story *The Premature Burial* (1844). The verisimilitude of Lever's tale is unusually enhanced by being told in a well-informed medical way, and indeed apparently had a basis in the author's own experience of a severe illness. The tone and mood, however, are notably 'gothic', and intended to induce horror and terror, as is the description of the descent into apparent madness. All this is most unlike the soothing reports of 'near-death experiences' of our own day.

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