International Psychogeriatrics (2015), 27:10, 1601–1611 © International Psychogeriatric Association 2015
doi:10.1017/S1041610215000629

REVIEW

Suicidal behavior and assisted suicide in dementia

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ABSTRACT

Background: Concerns about suicide risk in people with dementia have been increasing in recent years along with a discourse about rational suicide and assisted suicide.

Methods: A systematic narrative literature review of suicidal behavior and assisted suicide in persons with dementia.

Results: Most studies that have examined the spectrum of suicidal ideation, attempted suicide and suicide in dementia have methodological limitations but the overall suicide risk does not appear to be increased. When suicidal behavior does occur, common themes include the presence of psychiatric comorbidity, mainly depression; occurrence early in the dementia course with preserved insight and capacity; and an increased risk in younger people. The emerging discourse on rational and assisted suicide has been spurred by early and pre-symptomatic diagnosis and poses a number of ethical challenges for clinicians including the role of proxy decision-makers.

Conclusions: Although dementia might not confer a significant overall risk for suicidal behavior, clinicians still need to consider the potential for suicide in vulnerable individuals particularly early in the dementia course.

Key words: suicide, dementia, euthanasia

Introduction

Historically, people with dementia have not been regarded as being at an increased risk of suicide and have been excluded from consideration for assisted suicide. In both circumstances, this has largely been attributed to the loss of competence and insight due to the dementia. In recent years, concerns have been raised that the risk of suicidal behavior might be increased in early dementia. Further, a discourse has emerged about people with dementia having the right to access information for rational pre-emptive suicide in early dementia and assisted suicide in more severe dementia.

The combination of better community and professional awareness of dementia, early dementia diagnosis, and the move towards diagnostic truth-telling means that it is now more likely that the person with dementia has insight into their condition and is competent to make decisions about their life at the time of diagnosis (Draper *et al.*, 2010). While this brings many benefits to the person with dementia with regards to autonomy, it also brings emotional challenges that are perhaps greater for those with retained insight. They have to adjust to a diagnosis that is incurable, that will most likely result in their loss of mental competence, and which carries a significant stigma in society. With the prospect of pre-symptomatic diagnosis of Alzheimer's disease through biomarkers getting closer and the baby boomer generation reaching late life, the number of people in this situation is going to rapidly increase. Most people with dementia appear to make this adjustment without seriously contemplating hastened death, but some do consider it.

This review paper examines the range of suicidal behavior that occurs in the course of dementia including suicidal ideation, attempted suicide, suicide, and indirect self-destructive behavior in residential care. It also considers the ethical issues of rational suicide and assisted suicide for people with dementia including the use of advance directives that incorporate instructions about euthanasia by proxy for end-of-life care. Systematic reviews and book chapters on suicidal behavior and assisted suicide in dementia were supplemented by a search of English-language articles from Medline,

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https://doi.org/10.1017/S1041610215000629 Published online by Cambridge University Press

PsycInfo, and Embase databases using keywords (suicide, deliberate self-harm, suicide ideation, attempted suicide, assisted suicide, euthanasia dementia, Alzheimer's disease).

Suicidal ideation

There is surprisingly little published data on the prevalence of suicidal ideation in people with mild cognitive impairment (MCI) or dementia. Numerous studies have reported behavioral and psychological symptoms of dementia (BPSD) using standardized instruments that include items on suicidal ideation (e.g. Neuropsychiatric Inventory (NPI), Cornell Scale for Depression in Dementia (CSDD)), but these items are rarely reported. Furthermore, available studies are difficult to compare due to the use of either self- or observer-reports, small and often select sample sizes, differing definitions, varying timeframes, and a failure to specify the stage or type of dementia.

Community studies that have reported on the relationship between cognitive impairment and suicidal ideation have not adequately determined the type of cognitive disorder present, with most studies using brief cognitive screening tools such as the Mini-Mental State Examination (MMSE), and so it is unclear whether the participants would meet diagnostic criteria for MCI or dementia. No consistent relationship between suicidal ideation and cognition has been reported. A study of 539 American homecare recipients aged 65 years and over reported no relationship with cognition as measured by MMSE (Raue *et al.*, 2007). Two community studies, each with over 900 older people, reported higher rates of the "wish to die" in Australia (Jorm *et al.*, 1995) or suicidal thoughts in Sweden (Forsell *et al.*, 1997) in cognitively impaired participants, but once depression was controlled for in each study, cognitive impairment was no longer a significant factor. In contrast, a study of over 15,000 older primary-care patients without dementia in the USA found that cognitive impairment measured by the Short Orientation Memory Concentration Test was associated with both passive ("better off dead") and active ("thoughts of hurting self") suicidal ideation in the previous two weeks, even when taking distress into account (Ayalon *et al.*, 2007).

In studies of people with dementia, observer-reported rates of suicidal ideation are higher than those from self-reports, but few studies have reported both rates from the same sample. Rubin and Kinscherf (1989), using an unspecified timeframe, reported on 68 persons with mild Alzheimer-type dementia and found that only one (2%) had self-reported suicidal thoughts, while in contrast caregivers reported that ten (15%) had suicidal thoughts. Studies based on observer (usually caregiver) reports include a multicenter study on the development of the Behavior Rating Scale for CERAD involving 303 persons with probable Alzheimer's disease ranging in severity from very mild to severe in which about 25% had expressed the "wish to die" in the previous month (Tariot *et al.*, 1995). Factor analysis of the scale showed that the "wish to die" was included in a factor with other depressive features. A study of 505 nursing home residents with dementia ($n = 484$) or cognitive impairment as rated by Abbreviated Mental Test Scale (AMTS) ($n = 21$) used reports from nursing staff and found that 1.8% expressed verbal suicidal ideation at least weekly and that a further 9.5% did so less than weekly (Draper *et al.*, 2003a).

Two memory clinic studies provide data on self-reported suicidal ideation. In an Australian study of 221 patients with dementia, 5.4% felt life was not worth living, 3% "wished to die" or had thoughts of death, 0.9% had suicidal ideas, and none had made suicide attempts in the previous week (Draper *et al.*, 1998). Suicidal ideation was associated with depression but not with the presence of insight into memory loss. An American study involving 90 patients with Alzheimer's disease found that 10% reported "life is not worth living" and hopelessness was more prominent in those with greater awareness of cognitive deficits or with anxiety and depression (Harwood and Sultzer, 2002). Given the association of suicidal ideation with depression, it is surprising that few studies of depression in dementia report this symptom. One study of depression in mild-moderate dementia reported that suicidal thoughts occurred in 45% of patients with Research Diagnostic Criteria (RDC) major depression ($n = 31$) and 12% with RDC minor depression ($n = 34$) in the previous week based on ratings from the CSDD (Ballard *et al.*, 1996).

Few studies have examined whether suicidal ideation is more likely in any particular type of dementia with one memory clinic study finding an association of suicidal ideation with Alzheimer's disease (Draper *et al.*, 1998) and another with mixed Alzheimer/vascular dementia (Rao *et al.*, 1997). There is, however, strong evidence that suicidal behavior across the spectrum is prominent in Huntington's disease. Suicidal ideation was examined in 4,171 individuals in the Huntington Study Group database. The peak periods for suicidal ideation were in the period immediately before an individual received a formal diagnosis when they had "possible Huntington's disease"

https://doi.org/10.1017/S1041610215000629 Published online by Cambridge University Press

(23.5%) and 21.6% in stage 2 of the disease when independence was diminishing (Paulsen *et al.*, 2005). Psychiatric comorbidity including depression, anxiety, alcohol, and drug abuse are predictive of suicidal ideation in people with Huntington's disease (Wetzel *et al.*, 2011). A study that compared mutation carriers with non-carriers found that 20% of carriers that were free from suicidal ideation at baseline had suicidal ideation two years later compared with no non-carriers. Clinical DSM IV depression, depressed mood and use of antidepressants were predictive of suicidal ideation with baseline depression the only significant longitudinal predictor of suicidal ideation (Huber *et al.*, 2012). Suicidality was not related to the stage of the disease.

Deliberate self-harm (DSH) and attempted suicide

With increasing age, DSH is more likely to represent a failed suicide attempt (Draper, 2010). Two systematic reviews that covered the published studies of attempted suicide and DSH in older people from 1985 to 2004 found that most studies reported less than 10% of patients had a primary diagnosis of dementia (Draper, 1996; Chan *et al.*, 2007). Higher rates of dementia appear in studies that report psychiatric comorbidity (Sendbuehler and Goldstein, 1977; Draper, 1994; Schmid *et al.*, 1994; Osvath *et al.*, 2005). Where clinical details are provided, the majority of suicide attempts by people with dementia have psychiatric comorbidity, which mainly involves depression and/or psychosis (Batchelor and Napier, 1953; O'Neal *et al.*, 1956; Sendbuehler and Goldstein, 1977; Draper, 1994; Schmid *et al.*, 1994; Osvath *et al.*, 2005; Tsai *et al.*, 2007).

Two studies from the past decade are illustrative. A Hungarian study of psychiatric inpatients aged 65 years and over compared 62 patients admitted with suicide attempt with other older inpatients; of the 22 suicide attempts with dementia, 50% had comorbid depression, 18% an adjustment disorder, and 27% had no psychiatric comorbidity. Multivariate analyses indicated that depression rather than cognitive impairment predicted suicidal behavior (Osvath *et al.*, 2005). A case series of seven people from Taiwan admitted after a suicide attempt, reported that delusions (theft, persecution, jealousy) were the primary cause in each case and that "significant clinical depression" was present in only three cases, although the Hamilton Depression Rating Scale scores indicate that a further three patients scored in the mild depression range of 10 to 14 (Tsai *et al.*, 2007).

Although the systematic reviews comment that cognitive impairment is usually mild (Draper, 1996; Chan *et al.*, 2007), the two studies that have objectively quantified cognition report MMSE scores in the mild to moderate range (14–24) (Osvath *et al.*, 2005; Tsai *et al.*, 2007). There are also reports that more impulsive suicide attempts are found in patients with frontal impairment (Pierce, 1987; Draper, 1994; Rosenberg and Rosse, 2003), but there have not been any structured assessments of frontal function in older suicide attempters with cognitive impairment.

Few studies have documented the types of dementia. Schmid *et al.* (1994) reported that of their 25 dementia patients, 76% had vascular dementia and 24% had Alzheimer's disease, while vascular dementia, Alzheimer's disease, and Lewy body dementia were represented in the small case series from Taiwan (Tsai *et al.*, 2007). A ten year retrospective analysis from Israel reported that 7.4% of all elderly inpatients diagnosed with Alzheimer's disease were admitted following suicide attempts (Barak and Aizenberg, 2002). Another retrospective study reported the possible increased risk of the suicide attempts in people with semantic dementia compared with Alzheimer's disease (Sabodash *et al.*, 2013), with a case report indicating that suicide attempts were related to disturbances in perceiving "future self" that contributed to a decreased sense of being human due to being unable to imagine doing things in the future that had been done in the past (Hsiao *et al.*, 2013).

Despite dementia being reported in older people who repeatedly self-harm, there is no evidence that dementia or cognitive impairment increases the risk of repetition (Pierce, 1996; De Leo *et al.*, 2002; Lebret *et al.*, 2006).

The overall quality of research on DSH and attempted suicide in older people is poor with most studies being retrospective, selective and underpowered, and few being prospective and longitudinal (Draper, 2010). In addition, few studies give adequate details about the patients with dementia and while it seems that most people with dementia have comorbid psychiatric disorders, other details including the type of dementia, cognitive profile and psychological stressors are lacking. Although it is plausible that cognitive impairment might interfere with the planning and execution of high lethality suicidal behavior, there is only an anecdotal evidence to support this. Nearly all studies have been drawn from mental health service samples and thus it is unclear whether they are representative of all DSH, as it is likely that some patients are managed in primary and residential care without involving a mental health review.

https://doi.org/10.1017/S1041610215000629 Published online by Cambridge University Press

Suicide

A systematic review concluded that the overall risk of suicide in persons with dementia is low (Haw *et al.*, 2009). A meta-analysis of the suicide risk of common mental disorders found that dementia had a lower than expected standardized mortality ratio due to suicide, although the methodological limitations of the studies reviewed meant that they were largely restricted to patients of moderate and severe dementia, where impaired competence might be protective (Harris and Barraclough, 1997). Psychological autopsy studies of suicide rely on the retrospective reports of close contacts of the person who died including health professionals, medical and other records such as coroner's and police files. Undiagnosed early dementia can easily be unrecognized in such investigations. Depression is the major risk factor for the suicide in late life and depressive symptoms are common early symptoms of dementia and might obscure the underlying cognitive disorder resulting in major depression being the only recorded diagnosis (Conwell *et al.*, 2002; Draper *et al.*, 2010).

There have been three large case register studies of suicide in dementia. A nationwide longitudinal study from Denmark using register data found hospital-diagnosed dementia was associated with an elevated risk of suicide particularly in those aged 50–69 years where the relative risk was 8.5 in men and 10.8 in women. In those aged 70 years and over, the relative risk was 4.7 in men and 3.4 in women (Erlangsen *et al.*, 2008). The relative risk was highest within six months of diagnosis (13.5 in men, 13.7 in women), but in men the risk was particularly high within three months of diagnosis where 26% died. However, 39% died by suicide more than three years after diagnosis. Controlling for mood disorders reduced but did not eliminate the increased risk (Erlangsen *et al.*, 2008). Some limitations of the study include the possibility of delirium being misdiagnosed as dementia in a general hospital setting and the likelihood that other mental comorbidity, apart from depression, was not controlled for in the 65% diagnosed during psychiatric hospitalization.

The second study involved data from a nine-year national clinical survey of all suicides in England and Wales (around 45,000) of which 26.1% had been in contact with mental health services in the year before death (Purandare *et al.*, 2009). Of those that had been in contact with a mental health service, 118 had a dementia diagnosis and these were compared with age- and gender-matched patients without dementia ($n = 492$) by conditional logistic regression. Psychiatric comorbidity was present in 69% of the dementia patients, particularly depressive illness (36%), alcohol dependence (14%), and schizophrenia/delusional disorder (10%). Forty-four per cent had a history of self-harm. Only 14% had been diagnosed in the previous year. Twenty-two per cent of the dementia patients were under the age of 65 years, much higher than would be expected by age distribution of people with dementia, and these had a higher rate of psychiatric comorbidity, particularly alcohol dependence and psychoses, and history of psychiatric admissions. Although comparisons with controls indicated that the dementia patients had a lower rate of psychiatric hospitalization, psychiatric symptoms and a history of self-harm, this is not surprising given that the controls were people that had been in recent contact with a mental health service (Purandare *et al.*, 2009).

A cohort study of a national sample of nearly 300,000 Department of Veterans Affairs patients in the USA aged 60 years and over that were diagnosed with dementia included 241 (0.09%) who died by suicide (Seyfried *et al.*, 2011). Seventy-five percent of the suicide deaths occurred within two years of diagnosis. Using multivariate logistic regression, a history of psychiatric hospitalization, diagnosis of depression, and prescription fills of antidepressant or anxiolytic medication were associated with increased risk of suicide.

The findings of frequent psychiatric comorbidity with dementia, particularly depression, are echoed in some psychological autopsy studies. The San Diego suicide study found mental comorbidity present in five out of seven suicide cases with dementia (Carney *et al.*, 1994), while Snowdon and Baume (2002) identified 15 patients of possible or probable dementia from Coroner's files, of which 13 were considered to be depressed at the time of death and dementia was thought to be the main precipitant in eight.

There are limited data on the type of dementia. Erlangsen *et al.* (2008) found that women, but not men, had a significantly higher risk of suicide in Alzheimer's disease compared with vascular dementia in the Danish case register study. There are possible biological mechanisms for suicide risk to be increased in Alzheimer's disease, as early neuropathological changes often occur in the limbic system and it has been suggested that mood changes or other emotional symptoms may precede detectable cognitive decline and make patients more vulnerable to suicidal behavior (Rubio *et al.*, 2001). Two neuropathological studies have had conflicting results about Alzheimer's pathology in suicide, with one study finding an overrepresentation of severe Alzheimer's disease pathology and the other finding no differences compared with controls (Rubio *et al.*,

https://doi.org/10.1017/S1041610215000629 Published online by Cambridge University Press

2001; Peisah *et al.*, 2007). A recent retrospective study raised concerns about suicide risk in semantic dementia with two suicide deaths in a case series of 25 demonstrating a higher rate than in 111 age-matched patients of early-onset Alzheimer's disease (Sabodash *et al.*, 2013).

The higher prevalence of depression in vascular dementia than in Alzheimer's disease provides theoretical support for the possibility of increased suicide risk (Ballard *et al.*, 1996); however the limited data available does not show this. A Japanese study of 241 vascular dementia patients diagnosed in hospital, reported that only four (1.7%) subsequently died by suicide, all had mild dementia and most were depressed (Ito *et al.*, 2002, cited in Haw *et al.*, 2009).

Suicide has long been recognized as being more common in Huntington's disease than in the general population with one meta-analysis estimating that the risk is three times that expected (Harris and Barraclough, 1997). A study from Hungary that examined 396 deaths of people with Huntington's disease reported that 10.1% were due to suicide (Baliko *et al.*, 2004); while in the USA 7.3% of 2,793 deaths on a national Huntington's disease register were due to suicide (Di Maio *et al.*, 1993). Suicide risk is reported to be increased early in the course of Huntington's disease when there are minimal symptoms but suicide can occur later as well (Farrer 1986; Di Maio *et al.*, 1993; Baliko *et al.*, 2004). What is missing from the Huntington's research is standardized information about the degree of cognitive impairment before suicide; it is not clear what proportion of suicide deaths in Huntington's disease occur in people that meet criteria for dementia. A similar situation exists with HIV-related dementia where there have been only case reports of suicide (Alfonso and Cohen, 1994). While there is an evidence of increased suicide risk in individuals with HIV/AIDS, the quality of research is poor and it is unclear what level of cognitive impairment is present (Komiti *et al.*, 2001).

There are many gaps in the suicide data particularly relating to the type of dementia and the circumstances surrounding the suicides in which there is no identified psychiatric comorbidity. However, the evidence suggests that apart from one study (Erlangsen *et al.*, 2008) the overall suicide risk does not appear to be increased. Whether this will change as early dementia diagnosis becomes more common is unclear.

There are common themes across the spectrum of suicidal ideation, attempted suicide and suicide in dementia. First, there is an usually psychiatric comorbidity present, mainly, but not limited to, depression. Second, suicidal behavior mainly occurs in early dementia, often within three months of diagnosis, and might be associated with preserved awareness and insight into declining cognition as well as the ability to perform planned actions (Margo and Finkel, 1990; Lim *et al.*, 2005). Third, there appears to be an increased risk in younger people with dementia, which might partially reflect higher rates of comorbid depression and difficulties in adjusting to the diagnosis.

Self-injury and indirect self-destructive behavior in residential care

In residential care, high rates of BPSD have been well documented and these tend to increase with dementia severity (Brodaty *et al.*, 2001; Zuidema *et al.*, 2007). Depression is common with one study of 319 nursing home residents with dementia reporting that 43% were depressed as measured by the CSDD and that the presence of depression was associated with other BPSD as measured by the NPI, particularly anxiety, agitation and irritability (Prado-Jean *et al.*, 2010).

Some BPSD include various types of overt self-injurious behavior, such as self-cutting and pica, for which the intent might be difficult to determine due to the resident's level of cognitive function. Self-injurious behaviors may range in intent from wishing to die (DSH), to gambling with death, non-lethal but intentional self-harm, through to unintentional (accidental) harm. Indirect self-destructive behavior (ISDB) has been defined as "an act of omission or commission that causes self-harm leading indirectly, over time, to the patient's death" (Conwell *et al.*, 1996) and has been most frequently described in war veterans and older people in long-term residential care (Nelson and Farberow, 1982; Draper *et al.*, 2002). Examples of ISDB that might be related to DSH include refusal to eat or drink and medication refusal.

In an Australian study involving 505 residents of 11 nursing homes with a diagnosis of dementia or having an AMTS score of less than 7, on the Harmful Behaviors Scale (HBS) nursing staff reported that 45.8% were refusing to eat or drink, 31.5% were refusing medication, 5.6% were eating foreign objects or drinking toxic liquids and 4.0% were self-cutting with a sharp object; most of these behaviors were occurring less than weekly (Draper *et al.*, 2002, 2003a). Around 25% of the self-cutting was regarded as intentional (Draper *et al.*, 2002). Although no relationship was found between total HBS score and measures of depression or suicidal ideation, around 3.5% of the residents that were refusing food had clinical depression (Draper *et al.*, 2003a). A follow-up study found that the

https://doi.org/10.1017/S1041610215000629 Published online by Cambridge University Press

passive self-harm factor subscale on the HBS which includes refusal to eat or drink and take medication, predicted mortality at one year, none from suicide (Draper *et al.*, 2003b). Residents that scored highly on the passive self-harm factor were also more likely to reside in nursing home environments that were regarded as having a better design for dementia including better security features (Low *et al.*, 2004).

A Dutch cross-sectional study involving 110 nursing home residents with dementia found that 22% had self-injurious behavior in the previous two weeks but no measures of depression or suicidal behavior were recorded (de Jonghe-Rouleau *et al.*, 2005). Self-injurious behavior was modestly related to aimless repetitive behavior and aggression, with benzodiazepines and restraints being frequently used in management.

Research to date has not clearly elucidated the rates of suicidal ideation and DSH in nursing home residents with dementia, at least in part due to the difficulty in obtaining reliable ascertainment of suicidal intent in moderate to severe dementia. In addition, the only reasonable evidence about suicide rates in nursing home residents with dementia found significantly lower rates compared with community dwelling people with dementia (Seyfried *et al.*, 2011). Most self-injurious behavior is subsumed within BPSD rather than a possible expression of suicidal intent. This might be correct but too few studies have posed the question. Similar difficulties exist in applying the construct of ISDB to this population even though there appears to be a small minority of nursing home residents with dementia that refuse to eat in the context of depression and suicidal ideation (Draper *et al.*, 2003a).

Suicide risk in pre-symptomatic and early diagnosis of dementia

In an era that is moving towards pre-symptomatic and early diagnosis utilizing biomarkers and genetic tests, concerns have been raised about the potential for suicidal behavior (Draper *et al.*, 2010). Although concerns were raised that predictive testing in Huntington's disease would increase suicide risk (Farrer, 1986), it is unclear whether this occurred. A worldwide assessment of the impact of predictive testing found that approximately 2% of participants who received a result showed either increased risk or a mutation exhibited suicidal behavior up to four years after the test, with the majority occurring in the first year (Almqvist *et al.*, 1999). The study highlights the importance of providing support, particularly in the first year, for those with positive results. An Australian study reporting a 20-year case series of 518 at-risk patients who applied for predictive testing for Huntington's disease (n = 466) and other neurodegenerative disorders (n = 52) found that there were no recorded suicides (Wedderburn *et al.*, 2013).

It has been suggested that the model used in predictive testing for Huntington's disease should be adopted as a model in other types of dementia including situations where pre-symptomatic diagnosis might occur (Draper *et al.*, 2010). This involves pre-test counseling to explain the risks and benefits of testing, a time lag between the initial visit and provision of results as individuals need time to decide if they want to opt out, and the provision of test results face to face (Hayden, 2003). There are guidelines already in place about the handling of diagnostic disclosure in dementia (Carpenter and Dave, 2004; Foy *et al.*, 2007), and it has been recommended that issues related to suicide risk and management need to be incorporated (Draper *et al.*, 2010). The importance of support and ongoing care particularly in the first year after diagnosis is essential in this context.

Assisted suicide and rational suicide

Assisted suicide or active euthanasia is the active and intentional termination of a person's life at their explicit request. The first person to die by assisted suicide using Dr Kevorkian's "suicide machine" in 1989 was a 54-year-old woman, Janet Adkins, who was newly diagnosed with early Alzheimer's disease. Although Kevorkian was charged with murder, the charges were dropped at the preliminary hearing because there were no laws in the jurisdiction (Michigan) outlawing suicide or the medical assistance of it. However, the case raised issues that are still the focus of current ethical and medico-legal debate.

Perhaps the most pertinent issue is the capacity of the person with dementia to provide informed consent. In jurisdictions that allow euthanasia, criteria for legal justification for euthanasia invariably include competence. For example, in the Netherlands euthanasia is legally justified only if the physician is satisfied that the patient's request is voluntary, well-considered, sustained and well-informed, that he or she was fully competent at the time of the request, and that the patient perceives his or her situation in terms of unbearable or hopeless suffering (Hertogh, 2005). There is a lack of consensus about the standards that are used to determine competence and the threshold varies with individual clinicians. A legal test with defined criteria has been proposed for determining capacity to request assisted suicide. The criteria include

https://doi.org/10.1017/S1041610215000629 Published online by Cambridge University Press

the ability to comprehend and retain information regarding their condition and the decision to end their life; the ability to believe the treatment information provided including the prognosis, treatment alternatives, and the information relating to the chosen method of suicide; the ability to weigh the information and reach a decision; the ability to communicate their choices; and that the decision must be free from undue influence (Stewart *et al.*, 2011). Whether anyone with moderate or severe dementia, and even some with mild dementia, could be deemed to be competent by these criteria is debatable.

There is no accurate information about how many people with mild dementia would consider euthanasia while their cognitive impairment remained mild, but experience from the Netherlands would indicate that it is infrequent (Hertogh, 2009). This is likely to be because most people with mild dementia have a quality of life that is acceptable to them. Under the Dutch euthanasia law "unbearable or hopeless suffering" is required and a legal ruling in the Netherlands has determined that mild dementia could theoretically meet that criterion (Booij *et al.*, 2013). This is consistent with the philosophical view that it is "rational" for people with less advanced dementia to take their own lives, even if their quality of life is good, in the knowledge that eventually they will become much more disabled and will lose the capacity to effect their own suicide (Battin, 1984; Prado, 1998). It can be seen as a right to self-determination and autonomy (Post, 1997).

Davis (2013) argued that the move towards pre-symptomatic diagnosis of Alzheimer's disease makes rational suicide a more feasible option for those so inclined. She suggested that the reasons that a person might consider rational suicide included conserve financial assets, to reduce family burden of care, and to allow people to end their lives "with a final chapter that is consonant with the narrative as a whole". More controversially Davis proposed that researchers and clinicians needed to acknowledge the option of pre-emptive suicide and provide information about biomarkers to research participants and patients so that they can make an exit strategy if desired (Davis, 2013). Research protocols for identifying biomarkers in preclinical populations may preclude sharing the information with research participants on the grounds that there are no current treatments that might alter risk. Davis (2013) argues that this disrespects the autonomy of people who might want to use this information to plan their suicide.

There are a number of concerns with this viewpoint. First, it ignores the inability of biomarkers to give accurate prediction of onset of symptomatic disease, quality of life or decision-making capacity (Draper, 2014). This is a particular danger now that there is a wide array of tests directly marketed to consumers that purport to predict dementia risk. None of these tests is specific for dementia hence interpretation of positive findings has to be cautious. Second, it can be argued that from a moral viewpoint, suicide cannot be evaluated solely in terms of personal autonomy as communal values also play a role. Clinicians and researchers have broader ethical responsibilities as the impact of suicide upon families and health professionals can be profound (Sveen and Walby, 2008; Draper *et al.*, 2014). This could be particularly challenging for clinicians working in jurisdictions where euthanasia is permissible.

Others have argued that people with dementia have a moral obligation on Kantian grounds to take their own lives so that they do not become a burden on society (Cooley, 2007), although this view has been the focus of vigorous debate (Rabins, 2007; Sharp, 2012). It is also noteworthy that, at least superficially, nearly 60% of the general public in south-east England agreed with the use of physician-assisted suicide in severe dementia (Williams *et al.*, 2007).

The use of an advance directive for assisted suicide is one approach that has been proposed to allow the competent person, whether or not they have a dementia diagnosis, to make a decision about what they want to happen once they lose their competence. Advance directives in this context are controversial with concerns related to the difficulty that people have in imagining what they will experience when they have different cognitive abilities and what their needs and preferences might be in those circumstances, particularly as people's views about end-of-life decisions can change as illnesses progress. In the extreme, it has been proposed that the pre-dementia person and the same person with dementia could be regarded as two different people and that any advance directive made by the pre-dementia person was effectively directed to someone else (Degrazia, 1999). This concern would be heightened if effective treatments of dementia were developed. This dilemma was highlighted by the case of the mother of American actress Shelley Fabares who had left an advance directive that she wished to kill herself if she were to develop Alzheimer's disease but when that occurred, had forgotten her previous decision (De Leo, 1996). A qualitative study involving people with mild dementia and their carers also demonstrated the difficulties about end-of-life planning in this population and the potential differences between people with dementia and their carers. People with dementia had difficulty

https://doi.org/10.1017/S1041610215000629 Published online by Cambridge University Press

considering their future selves, while carers wanted control at the end-of-life and raised the issues of assisted dying and euthanasia (Dening *et al.*, 2013). These findings are consistent with concerns previously raised by ethicists with the use of a proxy decision-maker to enact an advance directive raising the possibility that proxies might project their own values when faced with such a decision (Degrazia, 1999). There is also the possibility that if the proxy was also the caregiver, the burden of care might influence decision-making (Hertogh, 2005).

These uncertainties about advance directives for euthanasia are perhaps reflected in the extremely low rates of utilization in the Netherlands. A survey of 434 elderly care physicians found that they were never used in incompetent patients and that there were practical difficulties in determining the "unbearableness" of the suffering and choosing the right time to carry out the directive. A crucial factor in the reticence of the physicians was the impossibility of patient–physician communication in advanced dementia, which resulted in a lack of shared understanding and reciprocity between doctor and patient rendering euthanasia morally inconceivable even in the presence of an advance euthanasia directive (Hertogh, 2009; de Boer *et al.*, 2010).

The question has been raised about whether the failure to enact advance euthanasia directives means that more detailed practical guidelines are required (Rurup *et al.*, 2010). The novelist Terry Pratchett, who had been diagnosed with Alzheimer's disease, publicly advocated for assisted suicide to be administered by euthanasia tribunal panels "that would be acting for the good of society as well as that of the applicant" (Pratchett, 2010). Whether such an approach could ever adequately address the moral concerns raised by critics is a matter of ongoing debate.

Conclusions and directions for future research

It should not be surprising that some individuals become suicidal in the context of a life-threatening illness such as dementia and that this is more likely to happen when there is psychiatric comorbidity, in the earlier stages of dementia and particularly in younger people. At present suicide appears to be an uncommon outcome in dementia but the prospect of pre-symptomatic and early diagnosis might change that. The current evidence base on suicidal behaviors in cognitive disorders is limited in quality. Future research needs to explore the evolving death wishes, suicidal ideation, and suicidal behavior of people at risk of dementia or with mild cognitive symptoms in prospective multicenter longitudinal studies, in order to better identify and treat those in distress and reduce suicide risk as well as to understand the evolution of end-of-life wishes that might include euthanasia or assisted suicide. There is also a need to determine whether there are any specific features of cognitive impairment, which could include type of dementia, that are associated with suicide risk.

The challenges of living with dementia can result in some people requesting euthanasia or assisted suicide before the dementia becomes too severe and there needs to be an active public discourse about the moral dilemmas that this poses to society.

Conflicts of interest

None.

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