Early dementia diagnosis and the risk of suicide and euthanasia

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Abstract

Background: Diagnosis of dementia is occurring earlier, and much research concerns the identification of predementia states and the hunt for biomarkers of Alzheimer’s disease. Reports of suicidal behavior and requests for euthanasia in persons with dementia may be increasing.

Methods: We performed a selective literature review of suicide risk in persons with dementia and the ethical issues associated with euthanasia in this population.

Results: In the absence of any effective treatments for Alzheimer’s disease or other types of dementia, there is already evidence that persons with mild cognitive change and early dementia are at risk of suicidal behavior, often in the context of comorbid depression. The ensuing clinical, ethical, and legal dilemmas associated with physician-assisted suicide and euthanasia in the context of dementia are a subject of intense debate. By analogy, the preclinical and early diagnoses of Huntington’s disease are associated with an increased risk of suicidal behavior. Thus there is the potential for a preclinical and early diagnosis of Alzheimer’s disease (through biomarkers, neuroimaging, and clinical assessment) to result in increased suicide risk and requests for physician-assisted suicide.

Conclusions: Although dementia specialists have long recognized the importance of a sensitive approach to conveying bad news to patients and families and the possibility of depressive reactions, suicidal behavior has not been regarded as a likely outcome. Such preconceptions will need to change, and protocols to monitor and manage suicide risk will need to be developed for this population.

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1. Introduction

Over the last few decades, the community and professional knowledge of dementia has increased worldwide through medical education and public-awareness campaigns sponsored by government agencies and organizations such as Alzheimer Associations. One key message has been the importance of early diagnosis and the distinction of dementia from normal aging. Although still debated, there is also a move toward diagnostic truth-telling with the person with dementia\textsuperscript{1,2}. The advent of cholinesterase-inhibitor therapy for Alzheimer’s disease in the late 1990s provided a further incentive for early diagnosis. One consequence of early diagnosis for persons with dementia is the likelihood that they will be competent with regard to certain decisions, or have some insight at the time of diagnosis.

Although early diagnosis has many benefits, especially with regard to autonomy, it also brings challenges to those with retained insight. They must adjust emotionally to a condition that, given the limits of available therapies, will result in loss of mental competence, assuming the person survives long enough. Although most persons with dementia appear to make this adjustment without seriously contemplating hastened death, some do consider it. Examples include suicidal ideation and behavior in the context of depression during the adjustment period, and later “rational suicide” before significant deterioration occurs, assisted suicide, and advance directives that incorporate instructions about euthanasia for end-of-life care.

We sought to review all of the relevant empirical literature on suicidal behavior (including rational suicide and assisted suicide) and euthanasia in dementia, in the context of increased
community awareness, early diagnosis, and the prospect of a preclinical diagnosis of dementia. We acknowledge that this is not a systematic review, and although we aimed to consider different viewpoints, especially on ethical issues, as with all selective reviews, there is always the possibility of bias when interpreting the literature. The model of the effects of preclinical and early diagnosis of Huntington’s disease upon suicide risk and euthanasia is also examined. Finally, we offer recommendations for the identification and management of persons with dementia who are contemplating suicide or euthanasia, and for the further research required in the area.

2. Early and preclinical diagnosis of dementia

The preclinical diagnosis of dementia and of Alzheimer’s disease in particular may become a reality. Public concern, or even Alzheimer-phobia, is already evident, at least in developed countries. Yet the early diagnosis of dementia can be challenging, and is often delayed. General practitioners were reported as missing up to 91% of mild cases [3]. A European survey reported that the gap between first symptoms and diagnosis varied between 10 and 32 months across 10 countries [4]. The modal age of diagnosis of dementia in the early 80s reflects a balance between an exponential increase in incidence with age and a declining population with very old age. In younger people, the diagnosis is often delayed even longer [5]. Traditionally, a diagnosis is based on clinical history, especially that of an informant, clinical examination, a basic or more detailed neuropsychological assessment, and confirmatory investigations, mostly directed at excluding other causes of cognitive impairment.

The arrival of medications for the treatment of Alzheimer’s disease (AD) and the better management of affected people and their families heralded a new interest in dementia. The explosion of awareness about dementia and the arrival of baby boomers into late middle age, accompanied by their experience of seeing aging parents with dementia and their own concerns for themselves, led to increased requests for earlier and earlier diagnoses and presymptomatic testing to determine one’s risk for developing dementia. In parallel with these developments were discoveries in genes, biomarkers, and neuroimaging, and refinements in neuropsychology, that have the potential to answer these requests, along with the advent of a predementia diagnosis, i.e., mild cognitive impairment (MCI), which in patients presenting at specialty clinics “converts” to dementia at a rate of about 10% to 15% per year [6].

In the last 15 years, a number of genes were identified as causing or increasing the risk of AD. Mutations on the presenilin genes on chromosome 14 or 1 and on the amyloid precursor protein gene on chromosome 21 cause autosomal-dominant familial AD [7]. Affected persons from these families are rare, accounting for less than 1% of all cases of AD, but such cases are especially tragic because the symptoms become typically apparent in patients’ 40s or 50s, usually after they have started their families. However, for the majority of persons with AD, there is no reliable genetic predictor of the development of dementia. Although persons with one copy of the apolipoprotein E ε4 gene have between two to five times the risk of AD (compared with those who do not carry the ε4 gene), and ε4 ε4 homozygotes have a 10-fold or more increased risk of AD, the positive predictive value of ApoE testing in the general population is low, and consensus conferences have been uniform in stating that predictive genetic testing is insufficiently accurate for presymptomatic testing [7,8]. With a few exceptions, including Huntington’s disease and the linkage of frontotemporal dementia with Parkinson’s disease with a mutation on chromosome 17, genetic markers for other dementias are even less developed.

More recent developments in the identification of biological markers for AD appear more fruitful. Biomarkers include the measurement of levels of total tau protein and phosphorylated tau protein, of Aβ40 and Aβ42 in cerebrospinal fluid, and of Aβ40 and Aβ42 and other proteins in the blood [9]. By using a combination of concentrations of cerebrospinal fluid levels of Aβ42 and total tau for AD versus control subjects, high sensitivities (85% to 94%) and specificities (83% to 100%) can be achieved [10]. Kits are available commercially, without advice about counseling, to allow wide-scale bio-testing.

Early diagnosis or prediagnosis with neuroimaging has evolved from serial quantitative magnetic resonance imaging to determine rates of hippocampal atrophy, to static and serial functional magnetic resonance imaging and positron emission tomography scans using activation tasks, to positron emission tomography scans using Pittsburgh B compound and newer ligands to display amyloid plaques in vivo [9]. Follow-up studies are emerging, and indicate that people who are Pittsburgh B-positive with subjective and objective memory complaints have a high rate of developing AD over 18 months of follow-up [11].

Against this background, Dubois et al. recommended new criteria for the diagnosis of AD, based on a combination of biomarkers and neuroimaging [9]. This raises ethical issues about presymptomatic diagnoses, about diagnosing MCI, and about the reactions of patients who undergo such testing. Individuals concerned about whether they are destined to develop AD can now arrange for predictive testing, even though they have no symptoms. They could then find out whether they are susceptible to developing AD, even though the probability is uncertain, i.e., there are false positives and false negatives. Further, even if testing demonstrates a high risk, the times to onset of symptoms and decline to a dependent state are also inexact. Perhaps the most imprecise prediction involves whether quality of life will be compromised by the development of AD, at least in early and middle stages.

3. The meaning of dementia

3.1. “The worried well” and philosophical discourses about “obligatory suicide”

With increasing patient education and awareness has come a fear of illnesses such as dementia. The fear of
developing AD in particular is highly salient, by virtue of the wide dissemination of scientific knowledge about AD and awareness concerning prominent public figures with AD [12]. As suggested by Hertogh, “Many people, especially the elderly, are fearful of becoming demented and generally the disease is viewed upon as a humiliating affliction, affecting self and personality” [13].

A study of 97 healthy older adults aged 50 to 85 years, self-referred for a free community memory screen, found that such a fear is particularly pronounced in individuals with personal AD experience (usually in relation to family members), those who are younger, those who report more depression, and those with more negative aging stereotypes, although AD experience moderated the relationship between perceived AD threat and these other variables [12].

What many of the elderly fear most are the effects of dementia on independence and competence. The stereotyping of old age as a state of resignation has been challenged in society, and older people increasingly want to remain in control of their lives and identity [14]. Indeed, a hypothetical Kantian philosophical argument for “morally obligatory suicide” has been put forward on the basis of the inherent loss of dignity, rationality, moral agency, and selfhood associated with dementia [15].

3.2. The impact of diagnosis and the lived experience of dementia

People fear being diagnosed with dementia, and many doctors fear the consequences of frank disclosure [1]. Carpenter et al., however, found that disclosure of a dementia diagnosis did not usually prompt a catastrophic emotional reaction [2]. Rather, it provided some relief, including a substantial reduction of anxiety, after an explanation for symptoms was provided and a treatment plan was developed. In an exploratory study of 30 patients within 1 week of a dementia diagnosis, patients exhibited a range of emotional responses that could be divided into three broad categories: responses suggesting a lack of insight or an active denial of the diagnosis; grief reactions/emotional crisis related to the experience of actual or anticipated losses associated with dementia; and positive coping responses to maximize the disease outcome [16]. Participants went through stages of emotional response to their diagnosis, ranging from not noticing symptoms and denial to disclosure, shock, crisis, confirmation, and adaptation or disorganization. For some, the emotional adjustment is so overwhelming that suicide ensues within months of diagnosis [17].

Clearly, diagnosis has different meanings for different people, and they experience a range of possible reactions, although lack of insight and denial are probably the most common reactions. Rabins suggested that perhaps 60% of people with AD are unaware that they have a problem, and remain unconvinced of any problem when they are diagnosed as having dementia [18]. Many people do not flinch when a diagnosis of dementia is rendered, although some are conscious of the negative stigmatization associated with AD, and prefer to be told they have vascular dementia or Lewy-body disease.

3.3. The lived experience of dementia

As Hertogh et al. cautioned, “Fear is always a bad counselor” [14]. The lived experience of dementia differs from the imagined experience. Although the impact of dementia and the experience of loss and negative emotions cannot be denied, a literature review of the personal experiences of patients living with dementia found “no solid support to the widespread assumption that dementia is necessarily a dreadful state of suffering” [19]. Rather, many sufferers do not bear the disease passively, and use a range of coping strategies (both problem-solving and emotion-orientated) to deal with the challenges it imposes. Important, the strategies of denial, avoidance, minimization, and normalization, whether they are interpreted as emotion-focused coping strategies or as an intrinsic part of the disease biology, are common and clearly protective in terms of the impact of the disease [18,19].

Many people with dementia do not suffer as a result of the condition that they previously feared, and often seem to accept or adjust to a situation that they formerly despised [13]. People with dementia have more positive appraisals of their lives, roles, and relationships than might be expected, and are able to enjoy human interactions and mental and physical activity, even as the disease progresses [18,20]. Furthermore, quality of life is not necessarily influenced by severity of dementia or activities of daily living, and up to 67% of people with mild to moderate dementia report a very good or good quality of life [20,21].

Post argued against these “benign images” of AD that underestimate the anxiety and behavioral difficulties associated with the disease, and that are based on reports of patients with dementia who are living in the “pure present,” and do not appear to be experiencing pain: “The fear is less that of pain than of loss of self, a condition of such indignity in the minds of some that life would not be worth living” [22].

The prevalence of depression and anxiety in dementia cannot be ignored. One study reported a 77% cumulative 5-year-period prevalence of depression among incident cases of dementia (29% at baseline, and 40% to 47% at subsequent yearly intervals), whereas 14% of 408 subjects at baseline and 24% to 32% at subsequent yearly intervals experienced anxiety [23].

4. Advance directives, euthanasia, and rational suicide

4.1. Advance directives for euthanasia

Given the aforementioned fear of dementia, it is not surprising that in countries where euthanasia or physician-assisted suicide is legal, a growing number of people are drawing up advance directives or living wills in which they express the wish to terminate their lives if they develop dementia. Yet in countries where euthanasia is illegal, clinical
experience and anecdotal reports suggest that people are making covert arrangements for some form of assisted suicide in the event of being diagnosed with dementia.

Advance directives are controversial and fraught with difficulties in the context of dementia. Advance directives rely on the concept of patient autonomy, i.e., the authority of the former competent self to govern the welfare of the later, noncompetent self [24]. Critics of advance directives highlight the constraints of being able to imagine ourselves with different abilities, needs, and preferences in radically different circumstances, and the difficulties in projecting decisions to future states or personal identities of selves that may have changed because of physical or mental changes [25]. This concern would be heightened if effective treatments of dementia were developed.

Degrazia argued that people sometimes cannot grasp in detail the circumstances in which advance directives will apply, and there can be major changes in values and preferences between the time when persons complete their directive and when it comes into effect [26]. This led Degrazia [26] to propose that the predementia person and the same person with dementia are “literally” two different people, and that any advance directive made by the predementia person is effectively directed to someone else.

Furthermore, if the directive includes choosing a proxy, this can result in proxies projecting their own values onto various possible future circumstances when they have to make decisions for the person creating the advance directive [26]. This can be quite problematic because caregivers, especially when burdened by care, have a tendency to report lower scores on quality of life than the patients themselves [13].

4.2. Euthanasia and physician-assisted suicide

Physician-assisted suicide (PAS) or active (i.e., not passive, which includes decisions to forgo life-saving treatment) euthanasia is defined as the active and intentional termination of a patient’s life at the explicit request of a patient. Although such practices remain very controversial and frankly illegal in most countries, the law is very liberal in Belgium, Switzerland, The Netherlands, and certain states of America, such as Oregon [27]. In The Netherlands, where the Euthanasia Act was adopted in 2002, 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 [13]. According to Hertogh [13] and Hertogh et al. [14], few experts in the field believe that patients with dementia satisfy these criteria, and interestingly, there has been a striking lack of requests for assisted suicide made by people actually suffering from dementia. Recently, Hertogh speculated that the two principal reasons for this lack of requests comprise: 1) the uncertainty about whether patients with advanced dementia truly experience the suffering that they had once feared, and 2) a lack of shared understanding and reciprocity in advanced dementia between doctor and patient that renders euthanasia morally inconceivable, even in the presence of an advance euthanasia directive [28].

To date, there are four known cases of PAS in patients with early dementia, who were, according to their doctor, competent at the time of the request, and who were deemed to be suffering unbearably. All were relatively young, suffered atypical symptoms, and had uncommon courses of illnesses [14]. These cases provoked much debate about the determination of competence to choose euthanasia in dementia. Attempts to operationalize such criteria were based on generic capacity criteria:

- The ability to communicate a choice;
- Factual understanding of the issues;
- An appreciation of one’s situation and the consequences; and
- An ability to rationally manipulate information.

However, there is a lack of consensus in terms of standards that are used to determine competence, and the threshold varies with clinicians and (not surprisingly) their ethical stance. In a study of 456 forensic psychiatrists in the United States, 78% recommended a very stringent standard of competence [29].

Although caution in moving toward PAS in dementia has been advocated, arguments about the injustice of precluding patients with dementia from self-determination and access to PAS have also been put forward [22].

4.3. Rational suicide

The first person to die using Dr. Kevorkian’s “suicide machine” was a 54-year-old woman with early AD, who was said to have persuaded him that her decision was rational and the result of long and careful reflection. There has been much debate about what can be termed “rational suicide.” Many physicians agree that the decision of a terminally ill patient to shorten the period of suffering before death can be rational [30], with the caveat that the desire for death in such patients is closely associated with clinical depression in most cases [31]. Rabins suggested that about 1% to 2% of people who die by suicide “fulfill the rationality criterion” [18].

Clarke drew attention to potential confusion about what is “rational” and what is “understandable” suicide [32]. An analysis of data relating to 210 consecutive suicides of older people in Sydney led to the consensus that in 24%, their decision to kill themselves was understandable [33]. To them, life was unbearable as a result of pain, discomfort, or handicap, and/or they were imposing an excessive burden on the persons closest to them. Most were depressed about their physical condition, so that their decisions, although understandable, may well not have been rational, because depression exerts effects on judgment.

In general, it is believed that those who have severe dementia are rarely able to initiate or carry out the act of killing
themselves. Some might therefore consider it “rational” for people with less advanced dementia to take their own lives even if their quality of life is good, in the knowledge that in due course (maybe not for some years) they will become much more disabled and will then lack the capacity to effect their own suicide. Arguing against Cooley’s declaration that the soon-to-be-demented have a moral duty to commit suicide [15], Rabins pointed out that many persons with dementia continue to have meaningful lives and a degree of moral agency, even when dementia has devastated their cognitive capacities [18]: “Even in end-stage dementia, moral agency, broadly defined as maintaining a role in the family in spite of cognitive devastation, is often present, and dignity is a characteristic of many of those who die from late-stage disease.” He commented that the claim that suicide is an autonomous, self-directed act primarily affecting only the individual who performs the act is often false. One of the basic criteria of acting rationally is the ability to foresee the consequences of planned actions. Rabins noted that family and friends are often permanently and grievously damaged when a loved one or close acquaintance dies by suicide, whether or not there was a “good reason” [18].

Philosophers and ethicists have debated the rights and wrongs of self-killing. Margaret Battin, an American professor of philosophy, declared that rational suicide “represents one of the fullest forms of expression of one’s autonomy. It is the right of people to shape the ends of their lives” [34]. Although suggesting that no human acts are ever wholly rational, she had earlier defined rational suicide in terms of being able to reason, having a realistic worldview, possessing adequate information, and acting in accordance with one’s own fundamental interests [35]. Maris argued that suicide derives from one’s inability or refusal to accept the terms of the human condition [36]. Prado condoned “preemptive” suicide, to avoid demeaning decline and needless suffering [37].

It could be argued that narcissism is commonly the determinant of whether persons can accept and adapt to cognitive and physical decline, and indeed to the effects of old age. Whether early dementia should be accepted as “an unremittingly hopeless condition” (one of the three criteria used by Werth and Cobia to define rational suicide) is questionable [38], but may be affected by personality issues as well as cultural and religious beliefs. What appears to be irrational for some is considered quite rational in other cultural contexts [35]. Although there is compelling evidence that depression commonly drives a seemingly rational wish to self-destruct, it can be accepted that some individuals have entrenched attitudes and beliefs that, for them, make suicide in the face of cognitive decline appear rational. The morality of such an action taken by someone who is not mentally ill can be debated elsewhere.

5. Completed suicide and suicide risk in dementia

Until recently, most research, including psychological autopsy studies of suicide in late life, supported the view that the risk of suicidal behavior is low in persons with dementia [39,40]. Further, 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, and the authors speculated that impaired competence might be protective. They noted that this may not be the case in early dementia [41], a view supported by case reports suggesting that early dementia may be associated with increased suicide risk [42,43].

Barak and Aizenberg observed that suicide attempts were not rare in elderly patients with AD, especially among those with higher levels of daily functioning [44]. Their 10-year retrospective analysis reported that 7.4% of all elderly inpatients diagnosed with AD were admitted after suicide attempts. Although it is plausible that cognitive impairment might interfere with the planning and execution of high-lethality suicidal behavior, only anecdotal evidence supports this. Nevertheless, two systematic reviews of attempted suicide in late life stressed that the majority of cases associated with dementia had comorbid depression, which indicates the clinical importance of identifying and treating such patients [40,45].

Others emphasized the risk associated with features of the earlier stages of the disease, such as preserved awareness and insight into declining cognition, and the ability to perform planned actions [42,43]. It is this potentially lethal combination of insight with ability to perform the act of suicide that may put people in these early stages of the disease at risk.

Other suicide studies found that dementia is not uncommon among older suicides. The San Diego Study of Suicide found that in 49 suicides aged ≥60 years, seven (14%) had dementia, but in only two cases was there no mental comorbidity [46]. Snowdon and Baume examined factors that might have been relevant to the suicides of 210 persons aged ≥65 years who died between 1994 and 1998 in Australia [33]. Informants offered histories pointing to possible or probable diagnoses of dementia in 15 (7%) cases. Of these 15 cases, 13 were considered to be depressed at time of death, and dementia was thought to be the main precipitating factor in eight [33]. A case-controlled Swedish study of older persons found that dementia was associated with an increased risk of suicide (odds ratio, 1.5), comparable to that recorded in chronic obstructive lung disease and cardiac insufficiency [47].

A recent nationwide longitudinal study from Denmark, using register data, reported that hospital-diagnosed dementia was associated with an elevated risk of suicide, particularly in those aged 50 to 69 years, where the relative risk was 8.5 in men and 10.8 in women. The risk was higher in the first 3 months after diagnosis, particularly in men, of whom a quarter died in this period. Nonetheless, 39% died by suicide more than 3 years after diagnosis. Controlling for mood disorders reduced but did not eliminate the increased risk [17]. There are a number of limitations to the data. For example, 65% were diagnosed during a psychiatric hospitalization, when another mental comorbidity was
common, and apart from depression, was not controlled for. The possibility in somatic hospitals of delirium misdiagnosed as dementia cannot be excluded.

This discrepancy regarding suicide risk in dementia is likely attributable to a number of factors, some of them methodological, and others related to changes in community awareness and medical practice. Most mental-health data on elderly suicides were derived from psychological autopsy studies that retrospectively constructed, from interviews and case notes, the circumstances surrounding the death, to identify stressors and health concerns. Depression is the major risk factor for suicide in late life, but there are many pathways to depression, and early dementia is one of them [39]. Some studies simply did not record organic disorders, and others listed them as organic brain syndromes or “confusion,” without identifying cases of dementia [48,49]. But even when an effort is made to record dementia diagnoses, it is very difficult to ascertain retrospectively whether early dementia is present if it was not previously diagnosed. Individuals with severe major depression in the context of early dementia may only be listed as having major depression.

In more severe dementia, when impaired competence is a major issue, high rates of indirect and direct self-destructive behavior, in which intentionality is difficult to determine, were recorded in nursing-home residents [50,51]. Passive self-harm behaviors in particular were found to predict mortality [52]. Deaths related to such behavior are unlikely to be recorded as suicides by a coroner or the treating physician, because significant doubt would exist due to an inability to determine intentionality, or link the death to behavior such as passive food refusal.

6. Possible biological determinants of suicide in dementia

The contribution of biological factors to the risk of suicide in dementia remains controversial and little studied. A lifetime history of depression corresponds to increases in AD-related neuropathological changes within the hippocampus, suggesting an interaction between major depression and AD neuropathology [53]. Because the burden of the burden in early AD is borne by the limbic system, mood changes or other emotional symptoms may precede detectable cognitive decline and make subjects more vulnerable to suicidal behavior [54]. Furthermore, elderly subjects with major depression who were apolipoprotein E4 carriers manifested an increased suicide attempt history and worse cognition than depressed subjects who were not apolipoprotein E4 carriers [55].

Two neuropathological studies that investigated these associations between suicide and AD produced conflicting results. One study found an overrepresentation of severe AD pathology [54], and the other found no differences compared with control subjects [56]. Importantly, postmortem tissue availability limited both studies to an examination of the prevalence of AD, yet a small case series comprising a sub-sample of one of the study populations illustrated a range of neurodegenerative pathologies that might underlie suicide in the context of dementia [57].

The risks of suicide and suicidal ideation were reported to be higher in AD than in vascular dementia [17,58]. However, the higher prevalence of depression in vascular dementia than in AD, and the robust epidemiological association between depression and vascular disease, make vascular dementia an important candidate for investigations of pathological correlates of suicide in dementia [57,59].

7. Huntington’s disease: A model of presymptomatic diagnosis?

It was suggested that the model used in predictive testing for Huntington’s disease should be adopted as a model for other disorders [60]. Predictive testing for Huntington’s disease commenced in Canada in 1986, initially via linkage analysis showing risk, but later through direct testing for the mutation that confirmed the diagnosis. Before predictive testing was implemented, ethical concerns had been raised about offering a test for presymptomatic diagnosis when no treatment was available. One area of specific concern was the risk of catastrophic outcomes such as suicidal behavior in a population known to be at an approximately three times increased risk of suicide compared with the general population, especially around the age of onset of symptoms in the mid-40s [41,61]. The risk of attempted suicide is also significantly higher, with one study reporting a rate five times higher than in the general population [62].

It is unclear whether predictive testing has resulted in an increase in catastrophic outcomes. A worldwide assessment of the impact of predictive testing on the outcomes of suicide, suicide attempts, and psychiatric hospitalization found that approximately 2% of participants who received a result that showed either increased risk or a mutation exhibited suicidal behavior up to 4 years after the test, with the majority occurring in the first year [61]. Catastrophic outcomes in asymptomatic participants who received an increased risk result mainly occurred in the first year as well [61], though it should be noted that subtle cognitive deficits have been demonstrated in asymptomatic carriers [63]. Increased risk of catastrophic outcomes was noted in participants with a psychiatric history of suicide attempt, psychiatric hospitalization, or treatment by medications for psychological or psychiatric reasons in the previous 5 years [61]. The absence of a comparison group that did not undergo predictive testing makes the results difficult to interpret, but the study highlights the importance of providing support, particularly in the first year, for those with positive results. Interestingly, catastrophic outcomes in some participants who received results showing either reduced risk or exclusion of Huntington’s disease occurred over a year after testing, suggesting the possibility of survivor guilt [61].
8. Recommendations for the management of suicide risk in the presymptomatic and early diagnosis of dementia

There are already rare occasions when genetic testing is used in familial AD, but if the presymptomatic diagnosis of AD and other dementias becomes widely available, the basic model developed for disclosing the genetic risk of Huntington’s disease should be adopted [60]. Pretest counseling is required to explain the risks and benefits of testing. A time lag between the initial visit and provision of results is essential, because 40% abandon testing at this stage, and individuals need time to decide if they want to opt out. Test results should be provided face-to-face.

A number of professional organizations, as well as reviews of opinion and practice, have constructed guidelines or best-practice models for handling diagnostic disclosures in dementia [1,64]. These emphasize the importance of tailoring the process to suit the needs of the patient, using a stepped procedure to ascertain a person’s desire to know, and exploring patient reactions to diagnosis. This gradual disclosure is primarily designed to minimize the possibility of a catastrophic reaction, but should also take into account issues of suicide risk. Persons with dementia who have a past history of depression and/or suicidal behavior may be at particular risk. Involvement of the family with the consent of the person with dementia is desirable, to assist in planning and to provide emotional support.

The content of the disclosure is important. The message should be given in a simple, easily understood manner, with an emphasis that progression is slow, quality of life can be maintained, and symptomatic treatments are available. Realistic hope about the future should be provided regarding the many new potentially effective treatments being researched worldwide. An ongoing commitment to provide regular reviews, with a follow-up appointment for counseling the person with dementia, helps convey the message that the therapist remains committed to the patient’s care, and also allows the therapist to monitor the patient’s reaction to the diagnosis. Early counseling for the family through Alzheimer’s organizations or other courses (e.g., the Living with Memory Loss Program, at http://www.alzheimers.org.au/content.cfm?infopageid=637) is demonstrably effective in reducing stress and improving family members’ coping skills: a less stressed family carer may reduce the emotional impact upon the person with dementia.

9. Conclusions

It is important for clinicians to recognize that there is a risk, albeit small, of suicidal behavior in persons with dementia, particularly in the 3 months after diagnosis, and that this risk will affect a broader range of people if preclinical diagnosis becomes a reality. Clinical practice should reflect such concerns by focusing on the emotional needs of the patient after the diagnosis has been disclosed. Further research is required to determine whether any biological factors associated with AD and other dementias contribute to suicide risk.

References


