Risk of suicide in patients with dementia: a case study


Abstract
Evidence indicates that the risk of attempted suicide is a significant issue among people with dementia, however there is a lack of information to guide professional practice. This article uses a case study to reflect on the risk management strategies and ethics of suicide and assisted suicide in relation to a specific patient with dementia. It analyses recommendations aimed at improving the lived experience of people with dementia and those involved in their care, including providing patients with a formal diagnosis as early as possible.

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Approximately 800,000 people in the UK have dementia, many of whom are under 65 years (Alzheimer’s Society 2013a). This figure is set to increase to 1.4 million in the next 30 years (Alzheimer’s Society 2007). The emotional and financial burden of dementia on patients and their families is significant, and with an increasing number of people with the condition, the quality of care provided by healthcare professionals and the experience of people with dementia and their families might be affected. Erlangsen et al (2008) identified an increased risk of suicidal behaviour among patients with dementia within the first three months following diagnosis. This increased risk poses a challenge for healthcare professionals because they not only need to manage symptoms of dementia, but also need to monitor and manage suicide risk in these patients. Risk management in dementia can result in a safety first approach to care practices, which may be disempowering for people with dementia (Clarke et al 2009). Therefore, new ways of managing dementia need to be developed.

Aetiology and pathophysiology
The term dementia describes symptoms that occur when the brain is affected by specific diseases and conditions. Symptoms include decline in memory, reasoning and communication skills, and a gradual loss of ability to carry out daily activities (Alzheimer’s Society 2007). Symptoms vary, and at least two of the following mental functions must be impaired significantly for a person to be considered to have dementia (Alzheimer’s Association 2013):
- Memory, affecting ability to perform everyday activities.
- Communication and language.
- Ability to focus and pay attention.
- Reasoning and judgement.
- Visual perception.

Alzheimer’s disease, caused by structural and chemical changes in the brain, is the most common type of dementia. Vascular dementia is caused by problems with oxygen supply to the brain following stroke or small vessel disease. Vascular dementia progresses in a similar way to Alzheimer’s disease, but progression is often stepped rather than gradual, with sudden mental decline when the person experiences another stroke (Alzheimer’s Society 2013b).

While most changes in the brain that cause dementia are permanent and progressive, thinking and memory impairment caused by depression, side effects of medication, excess consumption of alcohol, thyroid problems and vitamin deficiencies may improve when these
Art & science dementia care

Case study
Mary (pseudonym), a 58-year-old widow with two adult children and a history of chronic obstructive pulmonary disease (COPD) related to smoking, had not experienced any acute episodes of COPD since she had given up smoking two years before, and her COPD symptoms remained well controlled.

She began to experience memory problems, which within six months had affected her ability to perform everyday activities. Initially, she thought stress and depression, following her husband’s death the year before, were affecting her memory. Her symptoms worsened and with family support, she arranged an appointment with the GP.

The GP performed comprehensive testing and referred Mary to a neurology specialist. Memory testing, a magnetic resonance imaging scan and a period of monitoring and assessment led to a diagnosis of vascular dementia with possible Alzheimer’s disease 14 months later. A community care assessment was undertaken by community-based professionals, using a patient-centred approach to understand Mary’s needs, wishes, hopes and fears. Home and day care services were put in place to help meet her needs, maintain her independence and pursue her goals. However, Mary did not take the diagnosis of dementia well and expressed suicidal ideation. This was a conventional reaction in the circumstances, and therefore Mary was not considered at high risk of suicide.

The first few months after diagnosis were difficult for Mary, and she could not visualise a future that offered an appealing quality of life. She felt a burden to her family and friends, and anticipated that she would be unable to enjoy activities such as looking after her grandchildren or even remember how to make a cup of tea. This resulted in an acute episode of COPD, and she reasoned that her best and only course of action was to take her own life. Four months after diagnosis, Mary’s increasing depression and frustration manifested in a calculated attempt at ending her own life before significant cognitive deterioration had occurred.

Mary was admitted to a local hospital for symptomatic relief of COPD following a deliberate overdose of oral morphine and lorazepam. She expressed her disappointment at her lack of success in the suicide attempt stating ‘I couldn’t even do that properly’. During her six-week hospital admission Mary made a request for physician-assisted suicide and enquired about advance decisions and euthanasia for end of life care. No further suicide attempts were made, but she considered assisted suicide as an option. Mary was discharged home with a plan of care, including referral for an outpatient assessment by a dedicated community mental health centre.

Mary appeared to live contentedly in the community for a further eight months before experiencing severe physical and cognitive decline. She was readmitted to hospital for end of life care and received all essential nursing and medical care, to maintain comfort and dignity, including sedation. However, in accordance with her advance decision Mary was not given nasogastric feeding or cardiopulmonary resuscitation.

Diagnosis disclosure
Carpenter and Dave (2004) found that a diagnosis of dementia does not usually prompt a ‘catastrophic emotional reaction’. However, people experience a range of possible reactions, and diagnosis has different meanings for different people. From the perspective of the person with dementia, adjusting emotionally to a condition resulting in loss of mental competence can be the greatest difficulty as he or she has to deal with the prospect of loss of self-esteem, social status, roles and function.

Smith and Beattie (2001) highlighted the benefits of receiving an early dementia diagnosis, including increased autonomy, opportunities for future care planning and sharing the diagnosis with others. Factors that influence coping strategies include people’s perceptions of ageing, their current health, and their previous experience and understanding of dementia (Manthorpe et al 2011). Other factors that influence coping strategies include the need for clinicians to gauge accurately the amount of information to disclose. Evidence suggests that specialists rather than GPs are better placed to deliver a precise diagnosis and explain dementia, and have more time to provide information, particularly in relation to prognosis and the ability to deal with the emotional aspects of receiving the diagnosis, in a sensitive manner (Bamford et al 2004). Aminzadeh et al (2007) noted that disclosure of a dementia diagnosis can have negative effects such as an expectation of progressive decline and derangement leading to a self-fulfilling prophecy, whereby the person is discredited because of the disease. Alternatively, non-disclosure or a vague or possible diagnosis was also identified as confusing, upsetting or difficult to interpret.

Although many patients with dementia are not given a formal diagnosis, patients and carers value the opportunity to obtain information about
Suicidal ideation

Carpenter and Dave (2004) confirmed that most people with dementia appear to make the adjustment from diagnosis to acceptance fairly well, attempting to manage their reactions to diagnosis and changes in their social identity. However, some people express suicidal ideation and behaviour because of clinical depression and anxiety during the adjustment period following diagnosis (Manthorpe et al 2011). Therefore, it is important to identify patients with dementia who are at increased risk of suicide and provide timely treatment, as well as recognising that controlling mood disorders reduces, but does not necessarily eliminate the risk of suicide (Erlangsen et al 2008).

In the case study, Mary had expressed suicidal ideation, but she was not considered to be at high risk of suicide. If the correct and appropriate protocols had been in place and implemented immediately, with strategies to improve her sense of dignity, such as Living Well with Dementia (Department of Health (DH) 2009) and Living and Dying Well (Scottish Government 2008), Mary may not have attempted to end her life. Similarly, if risk assessment frameworks had been employed, involving suicide awareness alerts and counselling, with explicit perspectives of practitioners, patients with dementia and their families, Mary may have felt reassured and supported, and some of the issues she experienced may have been resolved (DH 2009).

Approaches to care

There are several pharmacological and non-pharmacological approaches to the care of people with dementia who may be at increased risk of suicide. The administration of psychotrophic and sedative medications such as risperidone and lormetazepam should be restricted in patients with dementia as they can have a negative effect on cognitive functioning and may lead to further deterioration (Mitchell 2013). Fluoxetine, a selective serotonin re-uptake inhibitor, can be administered to improve mood and reduce the benign image of dementia – ‘a humiliating affliction’ and ‘a dreadful state of suffering’ leading to loss of self and personality (Draper et al 2010) – and anxiety in patients with dementia (British National Formulary (BNF) 2011). Galantamine can be prescribed to increase cholinergic functioning by targeting the acetyl cholinesterase inhibition responsible for cognitive impairment in Alzheimer’s disease (BNF 2011). Fluoxetine inhibits liver enzymes and galantamine is metabolised in the liver, so liver enzymes and possible adverse effects, such as toxicity and hyper-toxicity, need to be monitored (Mitchell 2013).

Non-pharmacological approaches to the management of dementia include interpersonal therapy, aromatherapy, validation and music therapy. Promoting contentment and positivity, and overlapping with Kitwood’s (2001) person-centred approach, interpersonal therapy examines an individual’s distress within an interpersonal context by using a specific framework in which distress is conceptualised through one of four domains: interpersonal disputes, personality difficulties, bereavement, transitions and life events (Weissman et al 2000).

Following clinical judgement and risk assessment, a care plan was formulated to maximise Mary’s quality of life and reduce symptoms of depression. Regular consultations with Mary were organised to determine the effects of dementia on her feelings and behaviour. Healthcare staff liaised with her family to find practical strategies to address concerns, as well as preventing her from harming herself. Ward management strategies focused on the future, emphasising the physical domain of risk and safeguarding alerts, while an individual approach to risk and dementia was taken by healthcare professionals (Bouch and Marshall 2005).

A risk-benefit analysis can be performed that considers the wellbeing and autonomy of the patient as well as the need for protection from harm (DH 2010). This is an example of positive risk taking, practised on the ward as part of a ‘risk enablement’ strategy.

Best practice

The VIPS (value, individual needs, perspective of service user, social environment) framework (Box 1) developed by Brooker (2007), using Kitwood’s (2001) theoretical approach to underpin professional practice, helps healthcare professionals assess strengths and weaknesses with regard to providing person-centred dementia care. This framework aims to help healthcare professionals assess strengths and weaknesses with regard to providing person-centred dementia care.
for example valuing people with dementia and those who care for them, treating people as individuals, and looking at the world from the perspective of the person with dementia. For each element of the VIPS framework, reflection on organisational performance is undertaken to devise an action plan to improve dementia care.

Relevant to inpatients and part of Living Well with Dementia (DH 2009), the Butterfly Scheme is used in many hospital wards as an example of best practice in dementia care (Royal College of Nursing (RCN) 2013). Developed by a carer, the Butterfly Scheme is a way of sharing carer expertise and insight with staff who take over that care in hospital, which helps to develop their dementia care skills. It is an opt-in scheme that uses skills-based education. Continuing the practice of excellence in dementia palliation, end of life care strategies can work to ensure appropriate use of care pathways and plans, ensuring ethical issues such as the provision of symptomatic relief to alleviate pain and distress avoid being confused with euthanasia (Tuckey and Slowther 2009). In Mary’s case, these strategies and attitudes were applied to her end of life care pathway, thereby inspiring those caring for her to provide ongoing, compassionate care within the legal requirements (Knowles 2012).

**Risk management**

Nurses can feel uncomfortable when a patient requests to die (RCN 2011). RCN (2011) guidance indicates the importance of debating issues related to end of life care for people with dementia as openly as possible. The Nursing and Midwifery Council (NMC) (2008) instructs nurses to ‘make the care of people your first concern, treating them as individuals and respecting their dignity’, and states that nurses should protect and promote the wellbeing of patients, families and carers and the wider community, while acting lawfully and managing risk. In the desire to promote choice, rights, independence, capacity, and balance positive risk against organisational factors (resources, litigation, guidelines and support) and physical risks (self-harm, neglect, falls, exploitation by others and absconding), good practice should involve acceptance that risks can never be eliminated completely (DH 2010).

Given that Mary was identified as being at risk of suicide, having certain dynamic risk factors including suicidal ideation and intent, health professionals sought to balance risk management and risk enablement by promoting freedom and independence while undertaking observation and supervision. Finding a description of risk that avoids associating risk with danger is achieved by using the ‘balancing risks’ approach (Bouch and Marshall 2005). The principle underpinning this approach is that all risk can never be eliminated, and that good practice should acknowledge different risks result in different outcomes instead of trying to eliminate them (Dixon and Oyebode 2007).

The issue of eliminating risk caused conflict between Mary’s family and healthcare staff. With knowledge of their relative, family members’ perceptions of risk were focused on the present, demanding that staff take extreme measures to ensure that Mary could not attempt to take her life again. All staff had undergone applied suicide intervention skills training and skills-based training on risk management to understand the behavioural, physiological and psychological effect of her diagnosis and related suicide risk (NHS Health Scotland 2013). A risk-benefit analysis considering the wellbeing and autonomy of the patient as well as the need for protection and reduction from harm was performed (Chisholm and Ford 2004). Giving people choice and control in their lives involves some element of risk and healthcare staff can sometimes face tensions between balancing risks and opportunities for individuals and their duty to care for individuals deemed to be ‘vulnerable’ (Taylor 2006). Mary’s care plan sought to maximise her quality of life and enjoyment through managing acceptable risk and enhancing safety (DH 2010).

A specialist multiprofessional community mental health team used an assertive outreach model of care at Level 3 (high intensity community based services) to support Mary. She was supported during the most difficult period after the suicide attempt, her symptoms of depression and anxiety were stabilised, and further planning was carried out with her family (Katikireddi and Cloud 2008). Enhanced care at Level 4 (medically monitored non-residential service) was planned for when she would require longer term inpatient care.

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**BOX 1**

**VIPS framework**

V: a value base that asserts the absolute value of all human lives regardless of age or cognitive ability.

I: an individualised approach, recognising uniqueness.

P: understanding the world from the perspective of the service user (personhood).

S: providing a social environment that supports psychological needs.

(Brooker 2007)
Advance care planning
Legislation such as the Mental Capacity Act 2005 and the Adult Support and Protection (Scotland) Act 2007 supports those at risk of harm and identifies continuous assessment as part of the long-term management plan (NHS National End of Life Care Programme 2011). Mary was given assistance in planning for future decision making. Because of her COPD Mary required intermittent oxygen therapy to alleviate symptoms of breathlessness. However, she stipulated an advance decision to refuse cardiopulmonary resuscitation and nasogastric feeding. These wishes were acknowledged and recorded in her care plan for end of life care. Details of her requests for euthanasia were also recorded.

Euthanasia versus palliation
The term euthanasia refers to intentional termination of a person’s life to relieve pain and distress (Sanson et al 1998). Most descriptions of euthanasia imply that the person has requested death. Euthanasia is unlawful under the terms of the Suicide Act 1961 and carries a maximum penalty of 14 years’ imprisonment (NHS Choices 2013). Patients cannot use an advance decision to demand a specific treatment or request unlawful help to die (RCN 2011). The UK law draws a distinction between actively causing or assisting an individual to die and withdrawing or withholding life-sustaining treatment. The RCN (2011) recognises that there is a clear difference between end of life decisions taken as part of palliative care advance care planning and acting to end life. The core ethical principle in the doctrine of the ‘double effect’ focuses on the intent of the action, with a moral distinction between acting with the intent to bring about death and performing an act where death is a foreseen but unintended consequence (Tuckey and Slowther 2009). To date, campaigns to legalise euthanasia in the UK have been unsuccessful. However, voluntary and involuntary euthanasia is practised without safeguards in the UK (Wilkes 2011).

Beauchamp and Childress (2009) offered an ethical framework whereby nurses have respect for the autonomy, beneficence, non-maleficence and justice of patients while practising professionally within the context of national laws (NMC 2008, RCN 2011). Mary had indicated her interest in euthanasia. By listening carefully and reflecting sensitively and professionally, denoting seriousness, compassion and caring, the legal position in the UK was made clear to Mary (RCN 2011).

Legalising euthanasia may result in a lack of respect for human life, while patients consider it because of guilt about the burden imposed on family members or carers (Sanson et al 1998). Some carers could take advantage of decision making being motivated to make independent arbitrary decisions for monetary gain. Mary’s family knew that the time may come when they would have to make decisions on her behalf. However, there would be no conflict of interest, as her wishes, apart from her desire to end her life, would be respected and acted on.

Several countries and some American states have legalised euthanasia under certain conditions. Public acceptance of euthanasia continues to increase and emphasises the importance of understanding people’s constructs of unbearable pain and distress, the factors that lead them to ask for help to die, their hopes for a good death and their fears of abuse (Hendry et al 2013).

Pro-choice campaigners and organisations argue for legislation permitting euthanasia on the grounds of respect for autonomy. At the centre of notions such as the ‘right to die’ and the ‘right to die with dignity’ is the issue of self-control, assuming the absolute right to choose to avoid experiencing an extremely poor quality of life (Sanson et al 1998). Evidence suggests that ideas of compassion in dying are often presented as ethical reasons to justify euthanasia in terminally ill patients with dementia, and are the rhetoric of social and political interests (Alvargonzález 2012). Other pro-choice arguments suggest that healthcare costs could be reduced because expensive medical procedures and the use of advanced technology would not then be necessary (Sanson et al 1998).

Dutch law on euthanasia breaches the Universal Declaration of Human Rights because of the risk it poses to the rights of safety and integrity for each person’s life (Pereira 2011). The United Nations expressed concern that the system may fail in detecting and preventing situations whereby people could be subjected to unjustified pressure to access or provide euthanasia and could circumvent safeguards that are in place (Pereira 2011).

Discussion
Mary was given autonomy and choice throughout her care trajectory, but these are values with limits. The fact that her suicidal tendencies were not identified initially is perhaps an understandable and forgivable error. However, it is important that healthcare professionals recognise the increased risk of suicide through use of risk assessment frameworks and ensure that discrepancies between the perspectives of healthcare professionals and patients are understood.

If the appropriate protocols such as risk enablement had been in place and implemented
immediately, with strategies to improve Mary’s sense of dignity, she may not have attempted to end her life (DH 2009, RCN 2013). Similarly, the Five Wishes (Aging with Dignity 2013) advanced care planning document encourages the individual to consider the following:
- Who you want to make healthcare decisions for you when you cannot make them.
- The kind of medical treatment you want or do not want.
- How comfortable you want to be.
- How you want people to treat you.
- What you want your loved ones to know.

This information enables healthcare professionals to structure important conversations about end of life care. The hospice model of care (NHS Choices 2012), the process of ensuring that all people die as they would wish (Scottish Government 2008) and the Preferred Priorities for Care (NHS Improving Quality 2013) are frameworks and pathways that could work well in dementia care (Nuffield Council on Bioethics 2009). Irrespective of individual values and beliefs, the healthcare professional’s responsibility is to offer ongoing support and care that acts within the parameters of the law (RCN 2011).

References
Euthanasia eliminates the burden of dementia that society faces, but it does not enhance the potential growth through sensitive communication, deep concern and intimacy that caring for patients with dementia can allow (Hughes and Dove 2004).

Conclusion

As the number of people with dementia increases, the need for specialist care from the point of diagnosis is apparent. There are, as yet, few consistent protocols and guidelines on how this could be achieved. Evidence indicates that the risk of attempted suicide is a significant issue among people with dementia, however there is a lack of information to guide professional practice. Euthanasia and attempted suicide among these individuals would diminish with effective management, provision of public and professional education about dementia, and adoption of a person-centred approach to dementia care.

It is important that healthcare professionals work towards fulfilling the wishes of the person with dementia by giving him or her the opportunity to die with dignity rather than have the person pursue death on request.