Ethical practice in dementia care

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Abstract
This article draws on a range of case study examples from dementia care and explains how ethical theory can be applied to enhance professional practice. Ethical concepts are critically examined in this context and tensions between them are explored. The article demonstrates how an established ethical framework can assist with application in practice situations. It also argues that cultivating virtues, such as courage and receptivity, is an essential aspect of providing ethical nursing care for people with dementia.

Aim and intended learning outcomes
This article aims to improve your understanding of the ethics of caring for people living with dementia. It outlines a range of challenging situations in dementia care, explains how ethical theory can be applied to these situations and how you can use this knowledge to reflect on your practice.

After reading this article and completing the time out activities you should be able to:
» Discuss ethical dimensions of dementia care practice.
» Summarise some different approaches to ethical reasoning.
» Apply ethical concepts to practice situations and use an established ethical framework.
» Reflect on ethical responses in your practice.
» Describe how the moral character of healthcare providers is relevant to decision-making.

Relevance to the Code
Nurses are encouraged to apply the four themes of The Code: Professional Standards of Practice and Behaviour for Nurses, Midwives and Nursing Associates to their professional practice (Nursing and Midwifery Council (NMC) 2018). The themes are: prioritise people, practise effectively, preserve safety, and promote professionalism and trust. This article relates to the Code in the following ways:
» Promote professionalism and trust: it discusses the need to act with honesty and integrity, as well as to reflect on the importance of good character and behaviour in nursing practice.

Introduction
Dementia causes a progressive decline in cognition and reduced social or occupational functioning as a result of physical deterioration of the brain. People with the condition may experience language deterioration, poor judgement, impairment in visuospatial skills and memory loss (McFerran and Martin 2014, Stephan and Brayne 2014). As a result, alternative ways to understand the wishes of people with dementia and respond to their needs are needed.

Nursing ethics considers ways that nurses ought to respond to difficult moral situations in their professional context (Holland 2010). These responses are affected by nurses’ ethical reasoning. While some theories focus on upholding moral principles, others seek to improve character or promote good outcomes.

As is explained in this article, these theories can be in tension. In the context of dementia care, nurses and other health professionals strive every day to provide the best possible care. Nevertheless, it can be challenging to find ways to be empathic to the feelings and needs of people with dementia, mainly because the condition gives rise to difficulties in behaviour and communication. Responding appropriately may require an approach that does not depend on direct verbal communication, but in which meaning is sensed (Hughes 2013).

**TIME OUT 1**

Dilemmas in dementia care
Take a moment to think about some of the main ethical issues that may arise in everyday dementia care. If you need some pointers you may wish to download and read the chapter on dilemmas in care from the Nuffield Council on Bioethics (2009) report on ethical issues in dementia care.

**Common ethical challenges in dementia care**

Balancing freedom and risk
In the consultation for its report, the Nuffield Council on Bioethics (NCB) (2009) found that managing risk in a way that respects someone’s freedom caused considerable anxiety for carers. The report stated that (NCB 2009): ‘A balance must be struck between enabling a person to live their life in the way they wish, promoting their well-being, protecting their safety, and protecting the safety and interests of others.’

As the report suggests, what makes it difficult to strike a balance between freedom and risk is that risk can never be eliminated and that eliminating risk can itself cause harm. Risk is part of life and is often necessary for a benefit to occur. If it is managed too intensively, it can result in a poor quality of life.

Nevertheless, in a professional context, the need to keep people safe cannot be overlooked. All risks must be assessed and documented clearly, along with the actions taken to manage them (NMC 2018). Consider case study 1.

**TIME OUT 2**

Freedom and risk
Imagine yourself as the professional responsible for deciding on Margaret’s use of the kitchen. Should access be allowed or prevented? Does Margaret have a right to access the kitchen? If Margaret does use the cooking facilities, is it acceptable to put others at risk? Are there any reasonable solutions that might allow Margaret to use the cooking facilities safely?

A structured approach to solving such dilemmas may involve balancing competing claims in terms of rights, benefits and harms. If there is no compelling solution, however, negotiation and compromise may also be required (Brannelly 2006). This is likely to involve the views of other residents, family and staff as well as taking account of the level of resources that can reasonably be made available.

**Truth-telling**

Another significant ethical issue for dementia care is truth-telling. Studies have found that the telling of lies for therapeutic reasons, usually as a last resort when other strategies have failed, is relatively common in dementia care (Cantone et al 2017, Turner et al 2017).

Telling lies appears to be in direct contravention of the NMC (2018) Code, which states that nurses ‘should act with honesty and integrity at all times’. Arguably, it is disrespectful to lie to a person with dementia and such behaviour would be considered unacceptable with client groups who are not cognitively impaired. Case study 2 outlines the complexity of this issue.

This dilemma highlights an important division in ethics. On the one hand is deontology, the duty to respect human beings as persons, including telling them the truth, regardless of the consequences (Kant 1996).

On the other hand is consequentialism, which is the promotion of positive outcomes, regardless of the action that produces them (Darwall 2003). This is not to argue that any action is acceptable for consequentialist ethics. Some actions are considered wrong because of the overall harm they produce, and rules can be made to forbid such actions based on consequentialist reasoning. However, the justification for consequentialist reasoning is based on the value produced by the decision rather than any moral duty we have to individuals. This basic division is highlighted in Box 1.

From a deontological point of view, telling the truth is linked with autonomy as well as trust (O’Neill 2002). Being lied to thwarts our

**Case study 1. Margaret**

Having always derived a great deal of pleasure and pride from preparing her own meals, Margaret has moved to a residential care home after the progression of her dementia. Since moving, she has been involved in incidents of unsafe behaviour involving management of hot substances in the residents’ kitchen and has left the gas switched on.

A safe solution would be to restrict this activity altogether. However, doing so would curtail Margaret’s freedom and a source of creative expression and pleasure for her.

**Case study 2. Sarah**

When Sarah, a woman with dementia on a hospital ward, asks when her husband is coming to visit her, staff usually try to distract her but if that fails they tell her the truth, that he died a year ago. This causes her to become distressed for some time, but she cannot retain the information and asks again.

One day, the nurse decides to lie and tells Sarah her husband is coming to visit on the next day. Sarah is happy with this, but soon forgets and asks the question again.

The tension in this dilemma is between respecting Sarah’s right to the truth and promoting a positive outcome. However, it is made more complicated by Sarah lacking the capacity to retain or understand the information. As a result of her forgetfulness, truth-telling in this example may be considered a futile act.
ability to make choices, an important if not essential aspect of being a person. However, in Sarah’s case, it appears not to be possible to respect her autonomy as a person in the standard way because of her forgetfulness (Schermer 2007). A possible strategy is for personhood to be reconceptualised to take account of Sarah’s level of cognitive ability.

One example of how this can be done is found in Hughes (2011) who argued that, regardless of cognitive abilities, personhood is maintained by existing as a human being situated in a context. This means seeing factors, such as family and culture, as an essential part of understanding the person as part of a broader social narrative.

Arguably, this could result in accepting Sarah’s belief that her husband is still alive because doing so respects her present belief and her personhood in the context of her life as a whole. Such a view would allow the prohibition on lying to be disregarded and a positive outcome to be promoted. Tuckett (2012) argues that, when strategies such as attempting to distract an individual have failed, a therapeutic lie can be a compassionate response.

TIME OUT 3
Therapeutic lying
Having read the discussion above, do you agree with the argument that telling a lie is ethical in this case study example? How would you justify your decision one way or the other? How does the need to adhere to the NMC (2018) Code affect your response here?

Drug administration
The act of administering medication can also raise ethical issues relating to truth-telling. A review of the literature by Haw and Stubbs (2010) found that 43% to 71% of nursing homes in the UK disguised medication in food or drink. Furthermore, Turner et al (2017) found that, among registered nurses on a general ward, lying was considered an acceptable way to facilitate medication administration for patients with dementia.

Box 1. Two main theories in ethics that are often in tension

| Deontology | Some actions are morally required, others are forbidden. Actions cannot be justified merely by their outcomes |
| Consequentialism | Actions or rules can be justified solely by the value of their outcomes |

Nurses aim to promote health, but are also duty bound to gain consent and be truthful. This is another area in which there is a tension between veracity and beneficence (Mitchell 2014).

Paragraph 2.5 of the NMC (2018) Code states that registered nurses must ‘respect, support and document a person’s right to accept or refuse care and treatment’, but they also have a legal, ethical and professional duty to act in someone’s best interests when essential medical treatment is required (Haw and Stubbs 2010, National Institute for Health and Care Excellence 2014).

Acting in a patient’s best interests can also be authorised under the Mental Capacity Act 2005 in England and Wales, and is supported by paragraph 4.3 of the NMC (2018) Code, which states that registrants must follow the law relating to mental capacity of the country in which they are practising. However, an ethical judgement about whether the methods are justified by the intended outcome must still be made.

Ethical issues are also raised by the practice of using medication to reduce behaviour that challenges staff. A dilemma results as sedation involving antipsychotic medications can harm people with dementia and may result in their premature death (Banerjee 2009), yet despite policy recommendations in the National Dementia Strategy (Department of Health 2009), prescribing rates of antipsychotic drugs in dementia care homes have not been reduced (Szczepura et al 2016).

Doll therapy
Concerns about dignity and infantilisation can also be raised by the therapeutic use of dolls in dementia care. Case study 3 is based on work by Hubbard and Olsen (2016).

The advantages of using dolls therapeutically have been demonstrated consistently in the literature (Mitchell et al 2016). In this example, the doll settles Maria and improves her mood. If a consequentialist approach to ethics is taken, giving her the doll is the right thing to do because it promotes a positive therapeutic outcome. However, if a deontological approach is taken, other factors must be considered. For example, actively encouraging Maria to believe the doll is her baby is an act of deception, regardless of its outcome. It may also be infantilising and undignified for her.

Avoiding infantilisation is an important component of person-centred care (Kitwood 1997), and some writers have raised concerns about infantilisation relating to the therapeutic...
Conflict between past and present preferences
As a result of the psychological changes brought by dementia, another area of ethical concern is the potential conflict between present preferences and past wishes. Case study 4 illustrates the point.

As Hope and McMillan (2011) point out, much depends on the initial reasons for vegetarianism. It may have been that, in the past, Doris did not like the taste of meat. In which case, it seems more reasonable to yield to her present stated preference than it would if she was previously a vegetarian out of religious conviction or a moral objection, such as animal suffering.

Ethical theory can help us to understand the dilemma further. Dworkin (1993) makes a distinction between critical interests, which represent critical judgements relating to our life as a whole that are described as more deeply held, and experiential interests, which are the more transient interests we have in enjoying experiences. Doris's present wish to eat meat is an experiential interest, whereas being vegetarian is a critical interest.

Dworkin (1993) argues that, if we wish for our lives as a whole to be coherent,

Case study 3. Maria
Recently admitted to hospital due to uncontrolled agitated behaviour at home, Maria has moderate-to-severe dementia. Initially, she exhibited challenging behaviours that staff found difficult to manage so they decided to give her a realistic baby doll to hold. The doll settles her and improves her mood, and the nurses believe that her improved behaviour is related to the doll and encourage her to continue caring for it as a baby – they even ask her questions about her ‘baby’.

During Maria's two weeks in hospital, she becomes infatuated with the doll, acting as if it were her own child and refusing to put it down unless someone agrees to watch it while she is away. Her daughter acknowledges her mother's improved mood, but believes that it is undignified for her to be seen acting under the delusion that the doll is her baby. She is also worried about the implications when her mother is discharged. She has asked for the doll not to be used.

Case study 4. Doris
Now a resident in a care home, Doris has been a vegetarian for all her life. The staff are aware of this and they have always ensured that she receives the vegetarian option from the menu at meal times. However, as a result of dementia, she has seemingly lost all knowledge that she observes a vegetarian diet.

For one meal, Doris chooses the meat option and, due to a staff oversight, she eats the meal. The following day Doris asks for the meat option again. She is told that she is vegetarian and therefore she cannot have it. She does not understand what the staff mean and becomes distressed. On the third day, she asks for the meat option again, so the staff decide to let her have it to prevent her from getting distressed.

Doris's family hear about this and are angry, saying: ‘Our mum has always been vegetarian. It is something she has always believed in and it is part of who she is.’ They speak to her, but she appears not to understand why she cannot eat what she wants. The following evening, she asks for the meat option again, saying: ‘It is tasty.’

The care providers are faced with a dilemma. On the one hand, it seems reasonable to respect Doris’s present choice. On the other hand, her family argue that she is unaware of what she is eating and it is necessary to respect her past wish to be vegetarian.
Applying an ethical framework

This article has outlined how ethical theory can help us understand and respond to some of the issues that arise in dementia care. This section considers how a decision-making framework might assist further with making ethical choices.

One example of an influential framework in healthcare ethics is the four principles approach by Beauchamp and Childress (2013). These are reproduced with Beauchamp and Childress’s (2013) explanations of each principle in Figure 1.

These four principles can be applied to ethically challenging situations to inform judgements and formulate rules.

Figure 1. The four principles framework

Respect for autonomy
(a norm of respecting and supporting autonomous decisions)

Non-maleficence
(a norm of avoiding the causation of harm)

Beneficence
(a group of norms pertaining to relieving, lessening, or preventing harm and providing benefits and balancing benefits against risks and costs)

Justice
(a group of norms pertaining to distributing benefits, risks and costs fairly)

(Seachamp and Childress 2013)

The following describes how Beauchamp and Childress’s (2013) framework can be applied to the case studies.

In case study 1, Margaret has an autonomous wish to cook, a lifelong activity she has always enjoyed, but it is unsafe for her to do so. Respect for autonomy is necessary but, because her autonomy is diminished by her inability to understand the associated risks, it must be balanced with non-maleficence, or the need to avoid causing harm to Margaret and to those around her. Beneficence is considered in the wish to promote Margaret’s welfare, but must be balanced against the risk and resource implications of safe facilitation. Justice considers if it is fair for Margaret to cook based on the overall allocation of resources.

In case study 2, Sarah keeps asking when her deceased husband will visit her on a ward. The principle of beneficence is relevant here because there is an apparent benefit to Sarah’s welfare by telling a lie. This action can also be supported by the principle of nonmaleficence if telling the truth is thought to be a harmful act in this circumstance. On the other hand, it may be thought that telling lies contravenes the principle of respect for autonomy and is wrong according to deontological ethics, although this conclusion would be more contentious because Sarah is unable to understand the situation. As discussed above, there is an argument that if her perception of reality is considered in the context of her overall social narrative then to lie does not reduce her autonomy.

In case study 3, Maria’s mood improved after she was given a doll, so it appears that allowing her to keep the doll is the beneficent decision. However, Maria’s daughter claims that such an approach is undignified for her mother. This claim is effectively outside the scope of the four principles framework, which makes no direct reference to dignity. Nevertheless, dignity is an important nursing concept (Royal College of Nursing 2008).
The NMC (2018) Code states that nurses must uphold dignity, and the importance of the concept is also reflected in an international context (Tranvåg et al 2013). As such, the omission of dignity appears to be a weakness of Beauchamp and Childress’s (2013) approach as it would have to be tackled to address, for example, Maria’s daughter’s concerns. In case study 4, Doris, a lifelong vegetarian, has expressed a wish to eat meat. Application of the autonomy principle is complicated here by the question of whether her present choice counts as an autonomous one worthy of respect or if it should be overruled out of respect for her lifelong commitment to vegetarianism. It should also take into account the fact that respecting her experiential interests appears beneficent to her. Beauchamp and Childress’s (2013) framework helps to clarify thinking, but it cannot be relied on to give definitive answers. There is a need to balance these principles and put them in the context of dementia care, and application of the ethical theory of consequentialism can assist in this. This theory concerns actions that lead to best outcomes, such as overall welfare for everyone involved, while deontology considers principles as competing duties, such as a duty to respect autonomy or to do no harm.

**Moral character**

So far, this article has considered how choices can be improved by drawing on ethical theory and a framework such as the four principles approach. However, no ethical framework can be expected to provide a single answer to ethical dilemmas because ethical decisions are made in a social and human context (Barker 2011). To better adapt to this context, judgement and moral character are paramount when difficult decisions must be made.

**TIME OUT 7**

**Moral character**

What personal characteristics or qualities are important to healthcare professionals when they make difficult decisions?

The notion of good or moral character is an important aspect of professional life and is associated with the approach of virtue ethics. Such an approach requires asking what ought to be done in a situation and how an action can be performed in a way that reflects the good character of a healthcare provider. Virtue ethics, with its focus on character, arguably has a part to play in the moral decision-making of nurses and other health professionals. However, Holland (2010) argues that, although virtue ethics may provide a suitable approach for the personal moral life, it should not be extended to the professional sphere. Putman (2012), however, states that separating out the personal and professional life makes no sense in the context of virtue ethics.

The importance of developing moral character is acknowledged in the broader literature, including by the ethicists Beauchamp and Childress (2013), who see it as a way of promoting better decision-making for their four principles framework. Similarly, Banks and Gallagher (2009) argue that a virtue of professional wisdom involves exercising moral imagination to see a challenging situation in a different light and respond in a more empathic way.

Along with wisdom, another proposed virtue for a good nurse is courage (Armstrong 2006, Sellman 2011, Numminen et al 2017). Courage is required of nurses and others in situations where decisions are especially difficult or where they feel threatened. In such situations, taking an easier course of action may be tempting, but courage enables the person involved to make an ethical decision. For example, being courageous may involve arguing against a powerful colleague or relative for a course of action that you believe to be right. On the other hand, being open to the opinions of others and having the strength to change your own opinion also takes courage.

Another virtue associated with nursing is compassion (Armstrong 2006), which can be linked to empathy and receptivity. Receptivity involves being empathic to the thoughts and feelings of others but also ‘identifying with the other person, actually seeing things, however briefly, from their point of view’ (Slote 2015).

Developing the ideas of Slote (2013, 2015), Mitchell (2016) proposes receptivity as a central virtue to guide nurses and others who are caring for people with dementia.

As has been seen in the case studies above, there are times when an impasse is reached and a seemingly intractable dilemma appears. Ascertaining the preferences of someone who cannot communicate verbally may require a more intuitive style of working (Hughes 2013). Although it is possible to weigh up all the options in a purely rationalistic and detached way, a receptive approach involves, not only rational thinking, but also sympathy for the feelings and preferences of the people concerned.
The attention that receptivity brings to the emotional aspect of decision-making is also aligned to the ‘new culture’ of person-centred dementia care, as originally outlined by Kitwood (1997). Bringing these elements together can give a fuller ethical picture and encourage decision-making that is more sensitive to the context of dementia care.

Conclusion

This article considers several case study examples of challenging ethical situations that might be encountered in the practice of dementia care. It shows how ethical concepts are relevant in these situations and how they can affect our response. It also explores the tension between deontological and consequentialist ethical thinking in the context of dementia care, and how an ethical framework can be used in practice to aid decision-making. Finally, it argues that decision-making can be enhanced, not only by good reasoning skills, but also by the development of virtues, such as professional wisdom, courage and receptivity.

References

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Ethical practice in dementia care

TEST YOUR KNOWLEDGE BY COMPLETING THIS MULTIPLE-CHOICE QUIZ

1. Which of the following best describes nursing ethics?
   a) The study of law as applied to nursing practice
   b) Providing good quality nursing care
   c) How nurses ought to respond to difficult moral situations
   d) Understanding the professional aspects of nursing

2. Which one of the following is a common ethical issue in dementia care?
   a) Drug-calculation errors
   b) Truth-telling
   c) Risk assessment
   d) Providing a therapeutic environment

3. Kitwood (1997) pioneered which theory commonly associated with dementia care?
   a) Menschenwürde
   b) Situated embodied agency view of the person
   c) Person-centred care
   d) Consequentialism

4. Deontology is a term that means:
   a) Morality based in duties to others not consequences
   b) An ethical dilemma
   c) The ends justify the means
   d) A religious code of ethics

5. Consequentialism is a term that means:
   a) A principled approach
   b) Actions should promote positive outcomes
   c) To assume the best-case scenario
   d) All of the above

6. There is a distinction made between two types of interests that people might have relating to their autonomy. One of these is experiential. What is the other?
   a) Vital
   b) General
   c) Dignity
   d) Critical

7. Which of the following concepts forms a possible objection to doll therapy?
   a) Consequentialism
   b) Infantilisation
   c) Personhood
   d) Justice

8. Virtue ethics is based primarily on:
   a) The study of character in moral decision-making
   b) A rights-based approach
   c) A religious code of ethics
   d) A Kantian view of ethics

9. A common ethical problem arising from writing advance statements is:
   a) Loss of dignity
   b) A possible tension between past and present values
   c) It consumes vital resources
   d) It can be used to actively assist dying

10. Which of the following is part of the ethical framework of Beauchamp and Childress (2013)?
    a) Autonomy
    b) Beneficence
    c) Justice
    d) All of the above

How to complete this assessment
This multiple-choice quiz will help you test your knowledge. It comprises ten multiple choice questions broadly linked to the previous article. There is one correct answer to each question. You can read the article before answering the questions or attempt the questions first, then read the article and see if you would answer them differently. When you have completed the quiz, cut out this page and add it to your professional portfolio. You can record the amount of time it has taken you to complete it.

You may want to write a reflective account. Go to rcni.com/reflective-account

Visit rcni.com/cpd/test-your-knowledge

This multiple-choice quiz was compiled by Vincent Mitchell

The answers to this quiz are:

This activity has taken me ___ minutes/hours to complete. Now that I have read this article and completed this assessment, I think my knowledge is:

Excellent □ □ □ □ □ □ □ □ □ □ □ Good □ □ □ □ □ □ □ □ □ □ □ Satisfactory □ □ □ □ □ □ □ □ □ □ □ Unsatisfactory □ □ □ □ □ □ □ □ □ □ □ Poor □ □ □ □ □ □ □ □ □ □ □

As a result of this I intend to:

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