

In whose best interests? A case study of a family affected by dementia

Rachael Webb, Karen Harrison Denning

Rachael Webb, Admiral Nurse, Small Heath, Birmingham; Karen Harrison Denning, Head of Research and Evaluation, Dementia UK, London

Rachael.webb@bsmhfhs.uk

People aged 60 years and over make up the most rapidly expanding segment of the international population. Their number is expected to treble from 605 million to 2 billion by 2050 (World Health Organization, 2012).

It is estimated that, worldwide, over 135 million people will have some form of dementia by 2050 (Alzheimer's Disease International, 2013), with increasing age being the strongest risk factor for developing the condition (O'Connor, 2010). An estimated 835 000 people are living with dementia in the UK, which is expected to rise to over two million by 2050 (Alzheimer's Society, 2014). In the UK, it has been estimated that as many as 25 million people (42% of the UK's population) will know a close friend or family member affected by dementia (Luengo-Fernandez et al, 2010).

Family carers

An estimated 670 000 family members and friends are the primary carers of someone with dementia (Newbrunner et al, 2013). Carer distress is all too common in people caring for someone with dementia, whether they are living with the person with dementia or trying to maintain

their independence when they are living alone (Harrison Denning and Hibberd, 2016).

Much is known about the needs of carers of people with dementia; research into the issues spans many decades (Newbrunner et al, 2013). We know that education for the carer on the illness, symptoms, communication, managing behavioural concerns, finances, legal issues and planning can all help to reduce some of the anxieties around caring (Yuhass et al, 2006; National Institute for Health and Care Excellence and Social Care Institute for Excellence, 2006; Brodaty and Donkin, 2009; Harrison Denning and Hibberd, 2016).

While carer research, arguably, has not moved the evidence base of knowledge significantly on from previous seminal work, there is now enquiry into how approaches in broader mental health and technology interventions may support this group of people. For example, Ho et al (2016) investigated if carers' biomarkers had any influence on building resilience and reducing psychological distress using a mindfulness-based stress reduction (MBSR) training course of eight weeks' duration. The study sample was small—20 carers underwent the course and the results were inconclusive—but Ho et al assert that MBSR may provide a basis for developing a personalised approach to supporting carers.

The use of assistive technology to support family carers is also a growing research field. Rialle et al (2008) surveyed 270 family carers regarding 14 innovative technologies to aid care and alleviate the burden; the research was carried out because of the severe physical and psychological stress induced by dementia care and the slow uptake in use of these technologies. Results indicated two almost equal and opposing views between those who found them useful and those with very adverse views of their utility.

The elements of the caring role that generate the most distress and the greatest sense of burden are around making the day-to-day decisions that caring for a person with dementia involves (Harrison Denning et al, 2012). It is essential to offer support and guidance on the many day-to-day decisions and issues that arise, as these can involve ethical dilemmas for families (Carers Trust, 2012).

ABSTRACT

Many people with dementia are cared for by family members. Family carers often feel bound to support the person with dementia at the expense of their own needs, which can be neglected. They often experience distress when making decisions, especially over ethical dilemmas when their own interests and those of the person being cared for conflict. This paper presents a case study approach to consider best interests decision making for families affected by dementia. In the case study, a carer is supporting his father to remain living at home although he feels this unsafe and the demands of this cause tension with his family and affect his performance at work.

KEY WORDS

- ♦ dementia ♦ family carers ♦ Admiral nursing
- ♦ best interest decisions ♦ balancing needs

Case study part 1. The dilemma

Phillip has cared for his father, George, for approximately five years. George was diagnosed with Alzheimer's disease nine years ago and has lived alone since the death of his wife Emily 10 years ago.

George's needs have increased over time and he now receives a social care package of three visits a day to assist with his personal care and meal preparation. However, he often attempted to wash and dress himself for the carers coming and often attempted to prepare his own meals as he felt this was helping them.

Recently, Phillip has begun to express concerns to the community mental health team (CMHT) about whether his father was safe living alone. The CMHT reviewed George's mental state and found his mental state and level of functioning had deteriorated since the last assessment, due to his Alzheimer's disease.

An occupational therapist assessed his care package and activities of daily living skills and the psychiatrist undertook a capacity assessment, which found George to lack capacity in relation to decision making. However, overall it was felt there were no risks that precluded him from continuing to live alone in his own home.

Phillip continued to contact the CMHT expressing his concerns, stating that he felt his father was not coping. The team felt that Phillip was experiencing considerable carer related stress so referred him to the Admiral nurse service.

Phillip is an only child and has a demanding job. Some days, he visits his father before and after work; his line manager has expressed some concern that his level of functioning within his job has recently been affected. He has a wife and two teenage children.

During assessment by the Admiral nurse, Phillip said his main concern was that his father was telephoning him frequently at all times of the day and night with small worries or problems, such as losing the remote control for the TV and asking what the time was and when he was coming to see him. Phillip felt the CMHT were not listening to his concerns regarding his father living at home alone.

When Phillip's mother Emily was dying, she made Phillip promise her that he would look after his father and not send him into a care home; they were both worried about his memory at that time.

Although Emily and George had not formalised their 'pact' to each other in a lasting power of attorney, Emily felt it would be in George's best interests to live in his own home. Phillip had made a promise to her that he would look after his father.

Ethical issues around care

An ethical dilemma is a problem without a satisfactory resolution in that neither choice will be a 'right' or 'wrong' decision (Fant, 2012).

Ethical dilemmas often occur when caring for a person with dementia; some can be overcome by a family carer and/or a professional carer without much thought or distress. However, sometimes such ethical dilemmas can cause significant distress, causing family carers to neglect their own needs when faced with the overriding desire or compulsion to meet the needs of the person with dementia for whom they care. This may result in a family carer struggling to balance their own needs, those of other family members and the needs of the person with dementia they care for. This can often have a reverberating impact on a carer's psychological as well as physical health or, perhaps worse, begin to negatively affect relationships between family members.

This paper presents a case study approach to consider best interests decision making for families affected by dementia.

Family decision making

There is a wealth of literature on family involvement in decision making in healthcare.

Family carers of people with dementia often experience increasing demands around making decisions as the illness progresses. Hansen et al (2004) stated that patterns of decision making differ according to a carer's experiences, education, and social and cultural background. Not surprisingly, carers often find decision making difficult and studies have reported on practical issues, including difficulties in deciding what to do about day-to-day care and distress in making health-related decisions (Vig et al,

2007), and having insufficient information about possible alternatives and their effects (Mezey et al, 2000; Hirschman et al, 2006).

In the case study, Phillip was finding it increasingly difficult to make decisions in respect of his father's care. He was seeking help in the dilemma that was facing him; trying to support his father to remain living at home according to his mother's expressed wish while fearing that this was unsafe. Family carers can struggle to support autonomy for the person with dementia and enable their wishes to be met, especially when in direct conflict with their own.

Autonomy and dementia

Autonomy is an important concept in relation to the philosophy of the self and with regard to decision making. A dictionary definition of autonomy is the ability of the person to make his or her own decisions (Oxford University Press, 2011), which includes in a medical context. German philosopher Immanuel Kant argued that autonomy is demonstrated by one who is able to decide on a course of action (Kant, 2008).

However, as the disease progresses, people with dementia may not be able to decide on the best course of action and be autonomous. Respect for a person's personal autonomy is considered one of many fundamental ethical principles in dementia care, and supporting autonomy wherever possible is the central premise of the concept of consent when considering care required in the future (Beauchamp and Childress, 2013). The four principles of medical ethics, devised by Beauchamp and Childress, are considered the standard theoretical framework from which to consider ethical situations in healthcare:

- ♦ **Autonomy:** the right for an individual to make his or her own choice
- ♦ **Beneficence:** the principle of acting with the best interest of the other in mind
- ♦ **Non maleficence:** the principle that 'above all, do no harm', as stated in the Hippocratic oath
- ♦ **Justice:** a concept that emphasises fairness and equality among individuals.

Dementia confounds this perspective on autonomy because, as dementia progresses, the ability to consider future thoughts and actions becomes compromised, thus affecting decision-making abilities (Fratiglioni and Qiu, 2013); however, balancing this against the other principles enables a more considered view of an individual within the wider context of their social world.

Family carers often feel bound to support care for the person with dementia that is in conflict with their own needs (Wendler and Rid, 2011) and to honour their expressed wishes, such as not to place them in a care home. When reflecting on the ethical framework espoused by Beauchamp and Childress (2013), the perception of 'justice' can seem weighted in favour of the individual with dementia at times when, in reality, each person with dementia is embedded within relationships and social systems where each individual has needs that may at times be in conflict. Carers such as Phillip may find themselves increasingly in a position whereby providing such support can harm their own psychological or physical health and perhaps even damaging their relationships with those around them.

In whose best interests?

Mental capacity

In the UK, the Mental Capacity Act 2005 (MCA) (HM Government, 2005) protects and supports people who do not have the ability to make decisions. At its core is a set of principles that recognise the rights of people with impaired decision-making capacity caused by mental illness, learning disability, head injury, dementia or other conditions.

The act introduced a radical change to the legal concept of capacity from one that regarded decision-making capacity as all or nothing to one that recognises that capacity is decision specific, relating to the time when a decision or action needs to be taken.

The principles of the MCA encompass the right of a person (including someone with dementia) to exercise their autonomy as far as possible and requires others to support them to do so. The general legal and ethical rule is that people without capacity are treated in their 'best interests'. Part of what makes up their best interests are their own wishes and preferences as well as what is clinically viewed as the most appropriate action. Where individuals lack capacity, a fundamental consideration is their past wishes and preferences.

In George's case, he and his wife had discussed their wish to support each other at home and not to allow admission to a care home. Phillip had agreed to this too when his mother had asked him to 'take over' her promise to George, even though their 'pact' had been a verbal one and no lasting

power of attorney had been registered (Office of Public Guardianship, 2016).

Phillip was clearly struggling to balance his own needs with the needs of his family and the needs of his father. This was having an impact on both his physical and mental health. Phillip had to face the difficult decision of whether to place his father into full-time care as trying to maintain George to continue to live in his own home was failing.

As discussed, such decisions are not easy or straightforward, and for Phillip there were a number of conflicting factors; George's needs and demands were having a distressing effect on the wider family and placing Phillip in a difficult and dichotomous position over whose needs he should prioritise as there was conflict in meeting all.

A study by Lord et al (2015) found that relatives of people with dementia report proxy decision making to be difficult and distressing. Phillip felt distress and a huge sense of responsibility to make the right decision. But what was the right decision? The issues around decision making for people with dementia can become more complex because capacity is progressively lost as the illness advances. Phillip felt guilty over even giving thought to his own needs or those of his wife and children. It is in circumstances such as this that many family carers feel they have failed the person for whom they care and feel they should have been able to cope better (Bramble et al, 2009).

The Admiral nurse could see that the conflict of making decisions and the issue of in whose best interests was becoming very difficult and distressing for Phillip and that he would require specific guidance to ensure that he balanced his own needs and those of his family when considering those of his father.

Balancing the needs of the carer

The work of the Admiral nurse is centred on the whole family—the person with dementia and their family carers. A major component of support provided is in empowering decision making to enable the family to navigate the various transition points along the journey of dementia, such as seeking a

Case study part 2: exploring concerns

Over several sessions with Phillip, the Admiral nurse explored a number of concerns.

Phillip was under a lot of pressure at work, had always enjoyed his job but was now finding it hard at times. He had always take pride in his work but recently had started to make small mistakes.

His children and his wife had expressed that they felt he spent too much time with George and that he should 'put him in a home'. Although the family had said this as an off-the-cuff remark, it had made Phillip feel very guilty and unupprted by the rest of the family, which added to his feelings of a general lack of understanding and support by services.

Phillip was experiencing a lot of the common signs of carer stress—low mood, tiredness, anxiety and a lack of concentration. He was expressing feelings of guilt in that he was not a good enough son to his father, husband to his wife or father to his children.

Case study part 3: resolution

Initially, Phillip struggled to understand how the various stressors in all areas of his life were affecting his emotions, decision making and thought processes as well as his wider family members.

He agreed that to continue with the current situation would be difficult. George was receiving the maximum level of community care at home but this still had not reduced the number of telephone calls or his increasing reliance and demands on Phillip.

The Admiral nurse supported and enabled Phillip to see that he had been hoping other people would make the decision for his father to be placed in residential care.

He felt an overwhelming sense of pressure to make the right decision since the death of his mother and being the sole next of kin for his father. He felt a huge sense of

guilt at even thinking about putting George into a home given his promise to his mother.

The Admiral nurse explored Phillip's understanding of why his parents had made their pact. It transpired that several years ago they had watched a TV documentary about underperforming care homes and perceived all homes to be of a similar, poor quality.

The Admiral nurse supported Phillip to consider his father's overall values and beliefs and what else might be important to him.

George was a very family-orientated person and would always put his family first. In reflection with Phillip about his situation and what George's thoughts would have been if he had the capacity to express them, Phillip acknowledged that his father would have told Phillip to put himself and his family first.

Similarly, the Admiral nurse helped Phillip to explore the meaning behind George's frequent calls. He felt that George may not have remembered having calling previously and he might be lonely and seeking company.

Phillip was able to consider all aspects of the current situation. This included considering George's values and beliefs, and how his own needs and those of his family were to be balanced with those of his father; this enabled him to come to a decision to place George in residential care.

He understood that there are times when one must make decisions that are balanced and, wherever possible, consider the 'best interests' of all affected.

This did not eliminate Phillip's sense of guilt on making the decision but it no longer felt powerfully overwhelming.

diagnosis, access to support services, admission to a care home and end of life care options. Often, as in Phillip's case, it is important to support the carer to ensure their own needs and wishes are balanced with those of the person they care for.

Older people often trust loved ones to make decisions on their behalf (High, 1994) and want those decisions to be in keeping with their wishes and preferences (Roberto, 1999; Whitlatch et al, 2009). However, they also wish to keep the burden of such decisions upon their family to a minimum (Rosenfeld et al, 2000). Supporting families in successful decision making, such as on a move into residential care, is multifaceted and may involve giving careful consideration to the balance between the perspectives and wishes of the person with dementia and those of the carer.

A core competency domain for Admiral nursing is in supporting carers to balance the needs of the person with dementia with their own needs, ensuring that equity remains in the caring partnership wherever possible (Bunn et al, 2015). In practice, it can be challenging to support this balance of interests and needs when caring for a person with dementia. Admiral nurses strive to make the wishes and preferences of the person with dementia influence the care delivered. When these become at odds with what is in the best interests of the carer, this demands skilful attendance of the nurse involved.

Conclusion

Family carers need much more support in tackling the ethical problems they face. As this case shows, Admiral nurses play a vital role in supporting family carers to do this. As the Admiral nurse developed a good therapeutic relationship and took time to understand Phillip's needs and wishes fully, she explored the presenting problem and conflicting factors, and was able to support Phillip in his decision to place George in a care home, not with an overwhelming sense of guilt

but in facing the decision through a best interests approach.

As this case shows, Admiral nurses are able to support family carers through the difficult process of trying to balance their own needs against those of the person with dementia. This case was very complex and the Admiral nurse was able to support Phillip to recognise and, most importantly, place making an difficult ethical decision into the wider family context.

In a nurse-patient relationship, the nurse is often believed to hold the power but, as Kubsch (1996) argued, this power can be used to positively influence others because of the very knowledge and skills the nurse possesses. As Manojlovich (2010) stated, intuitive professionals closest to carers and people with dementia can enable and empower care for the ultimate good of all concerned.

In this case, the Admiral nurse, while appreciating the best course of action and outcome for all involved, guided, enabled and empowered Phillip to make a decision that was appropriate for the whole family unit.

BJCN

Accepted for publication: 23 May 2016

Declaration of interest: Authors have no conflict of interest to report.

- Alzheimer's Disease International (2013) *Dementia Statistics*. ADI, London. www.alz.co.uk/research/statistics (accessed 23 May 2016)
- Alzheimer's Society (2014) *Dementia UK. Second Edition*. Alzheimer's Society, London
- Beauchamp TL, Childress JF (2013) *Principles of Biomedical Ethics*. Oxford University Press, Oxford
- Bramble M, Moyle W, McAllister M (2009) Seeking connection: family care experiences following long-term dementia care placement. *J Clin Nurs* 18(22): 3118–25
- Brodaty H, Donkin M (2009) Family caregivers of people with dementia. *Dialogues Clin Neurosci* 11(2): 217–28
- Bunn F, Goodman C, Pinkney E, Drennan VM (2015) Specialist nursing and community support for the carers of people with dementia living at home: an evidence synthesis. *Health Soc Care Community* 24(1): 48–67
- Carers Trust (2012) *What is a Carer?* <https://www.carers.org/what-carer> (accessed 23 May 2016)
- Fant C (2012) *Major Ethical Dilemmas in Nursing*. www.nursetogether.com/

KEY POINTS

- ◆ Family carers need much more support in tackling the ethical problems day-to-day decision making presents in caring for a person with dementia
- ◆ Nurses are well placed to recognise and support approaches that balance best interest decision making in a family context where one persons needs cannot always outweigh those of another
- ◆ Admiral nurses are in a key position to provide relationship centred care for families affected by dementia and support best interests decision making in complex scenarios

ethical-dilemmas-in-nursing (accessed 23 May 2016)

Fratiglioni L, Qiu C (2013) Chapter 31: Epidemiology of dementia. In: Denning T, Thomas A, eds, *Oxford Textbook of Old Age Psychiatry*, 2nd edn. Oxford University Press, Oxford

Hansen L, Archbold PG, Stewart BJ (2004) Role strain and ease in decision-making to withdraw or withhold life support for elderly relatives. *J Nurs Scholarsh* 36(3): 233–8

Harrison Denning K, Greenish W, Jones L, Mandal U, Sampson EL (2012) Barriers to providing end-of-life care for people with dementia: a whole-system qualitative study. *BMJ Support Palliat Care* 2(2): 103–7

Harrison Denning K, Hibberd P (2016) Exploring the community nurse role in family-centred care for patients with dementia. *Br J Community Nurs* 21(6): doi: 10.1136/eoljnl-2015-000018

High DM (1994) Surrogate decision making. Who will make decisions for me when I can't? *Clin Geriatr Med* 10(3): 445–62

Hirschman KB, Kapo JM, Karlawish JH (2006) Why doesn't a family member of a person with advanced dementia use a substituted judgment when making a decision for that person? *Am J Geriatr Psychiatry* 14(8): 659–67

HM Government (2005) *Mental Capacity Act 2005*. <http://www.legislation.gov.uk/ukpga/2005/9/contents> (accessed 23 May 2016)

Kubsch SM (1996) Conflict, enactment, empowerment: conditions of independent therapeutic nursing intervention. *J Adv Nurs* 23(1):192–200.

Ho L, Bloom PA, Vega JG, Yemul S et al (2016) Biomarkers of resilience in stress reduction for caregivers of Alzheimer's patients. *Neuromolecular Med* 17 Mar [Epub ahead of print]

Kant I (2008) *Immanuel Kant: Critique of Judgement*. Edited by Walker N, translated by Meredith JC. Oxford University Press, Oxford

Kubsch SM (1996) Conflict, enactment, empowerment: conditions of independent

therapeutic nursing intervention. *J Adv Nurs* 23(1): 192–200

Lord K, Livingston G, Cooper C (2015) A systematic review of barriers and facilitators to and interventions for proxy decision-making by family carers of people with dementia. *Int Psychogeriatr* 27(8): 1301–12

Luengo-Fernandez R, Leal J, Gray A (2010) *Dementia 2010*. Alzheimer's Research Trust, London

Manojlovich M (2010) Predictors of professional nursing practice behaviors in hospital settings. *J Nurs Adm* 40(10 Suppl):S45–51. doi: 10.1097/NNA.0b013e3181f37e7d

Mezey M, Teresi J, Ramsey G, Mitty E, Bobrowitz T (2000) Decision-making capacity to execute a health care proxy: development and testing of guidelines. *J Am Geriatr Soc* 48(2): 179–87

Newbrunner L, Chamberlain R, Borthwick R, Baxter M, Glendinning C (2013) *A Road Less Rocky: Supporting Carers of People with Dementia*. Carers Trust, London

National Institute for Health and Care Excellence and Social Care Institute for Excellence (2006) *Dementia. A NICE–SCIE Guideline on Supporting People with Dementia and their Carers in Health and Social Care. National Clinical Practice Guideline Number 42*. British Psychological Society, Royal College of Psychiatrists and Gaskell, London. <http://www.scie.org.uk/publications/misc/dementia/dementia-fullguideline.pdf> (accessed 23 May 2016)

Oxford University Press (2011) *Oxford English Dictionary*. Oxford University Press, Oxford

O'Connor D (2010) Prevalence and incidence of dementia. In: Ames D, Burns A, O'Brien J, eds, *Dementia*. Hodder Arnold, London

Office of Public Guardianship (2016) *What We Do*. <https://www.gov.uk/government/organisations/office-of-the-public-guardian> (accessed 23 May 2016)

Rialle V, Ollivet C, Guigui C, Hervé C (2008) What do family caregivers of Alzheimer's disease patients desire in smart home technologies? Contrasted results of a wide survey. *Methods Inf Med* 47(1): 63–9

Roberto KA (1999) Making critical health care decisions for older adults: Consensus among family members. *Fam Relat* 48(2): 167–75

Rosenfeld KE, Wenger NS, Kagawa-Singer M (2000) End-of-life decision making: a qualitative study of elderly individuals. *J Gen Intern Med* 15(9): 620–5

Vig EK, Starks H, Taylor JS, Hopley EK, Fryer-Edwards K (2007) Surviving surrogate decision-making: what helps and hampers the experience of making medical decisions for others. *J Gen Intern Med* 22(9): 1274–9

Wendler D, Rid A (2011) Systematic review: the effect on surrogates of making treatment decisions for others. *Ann Intern Med* 154(5): 336–46

Whitatch CJ, Piiparinen R, Feinberg LF (2009) How well do family caregivers know their relatives' care values and preferences? *Dement* 8(2): 223–43

World Health Organization (2012) *World Health Statistics 2012. Indicator Compendium*. http://www.who.int/gho/publications/world_health_statistics/WHIS2012_IndicatorCompendium.pdf (accessed 23 May 2016)

Yuhas N, McGowan B, Fontaine T, Czech J, Gambrell-Jones J (2006) Psychosocial interventions for disruptive symptoms of dementia. *J Psychosoc Nurs Ment Health Serv* 44(11): 34–42

Would you like to write for the British Journal of Community Nursing?

We provide support and advice for first-time writers and want to hear from you. Get in touch and we will send you a copy of our author guidelines.

Phone: 020 7501 6705 | Email: bjcn@markallengroup.com
Or write to: BJCN, St Jude's Church, Dulwich Road, London SE24 0PB

Copyright of British Journal of Community Nursing is the property of Mark Allen Publishing Ltd and its content may not be copied or emailed to multiple sites or posted to a listserv without the copyright holder's express written permission. However, users may print, download, or email articles for individual use.