Ethical issues encountered in healthcare decision making involving people living with dementia and other progressive cognitive impairments

Problemas éticos encontrados en la asistencia sanitaria y toma de decisiones que involucran a personas que viven con demencia y otros impedimentos cognitivos progresivos

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Abstract

This paper discusses issues around decision making in dementia (and other progressive cognitive impairments). I shall, present five such issues, namely those around place of residence, forced care, covert medication (in connection with which I shall also mention truth telling), sexuality, food and drink, which includes some consideration of withholding and withdrawing treatment generally. Turning to think about how decision-making is dealt with in clinical practice, I shall subsequently discuss some conceptual topics: capacity (or competence), best interests, and supported decision-making. I shall finish with some comments about the importance of personhood in relation to the ethical issues that surround decision making in dementia.

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Introduction

It is perhaps best to say what this paper is not: it is not a review of all the ethical issues that occur in relation to decision making in connection with people living with dementia and other progressive cognitive impairments. I should also highlight that, from now on, I shall only talk of people living with dementia, even though there is a range of other progressive conditions that can lead to cognitive impairments. This is mainly for the sake of brevity, but also because I am more familiar with the issues in connection with dementia, albeit they are essentially the same. It is certainly not, however, because decision making in other conditions should be ignored.

I have picked five issues. They are not picked completely at random. They are topical or they are issues where I am more familiar with the literature. I then move on to discuss, albeit briefly, background conceptual topics which are relevant to all sorts of decision-making discussions and dilemmas. Finally, I shall conclude with some general reflections around the topic of personhood in dementia. To start, I wish to highlight the range of ethical issues relevant to living with dementia.

1. Ethical issues in dementia

Some years ago, I was involved in research looking at ethical issues for caregivers of people living with dementia. I wish to draw out three points from that research. First, the researcher did not ask specifically about «ethical» issues, but rather about problems and difficulties. Nevertheless, more or less everything that was mentioned turned out to have an ethical component. Second, the variety of issues mentioned (see Table 1) was broad, going well beyond the sort of problems that would traditionally be discussed in an ethics textbook. Third, almost all the issues were to do with decision-making. This should not, after all, be a complete surprise given that a key feature of dementia is that the person gradually loses the ability to decide for him or herself.

More recently, Strech *et al.* (3) undertook a systematic qualitative review of the English and German literature to identify the full spectrum of ethical issues in dementia. They identified 56 ethical issues specific to dementia, which they grouped into seven major categories:

- Diagnosis and medical indication.
- Assessing patient decision-making competence.

Table 1. Ethical issues for carers of people living with dementia [derived from] (1) and (2).

Assessment	**Behaviour that is challenging**	**Communication**
Community resources	Confidentiality	Consent
Constraint	Driving	Dual loyalties
End-of-life	Euthanasia	Finance
Genetic testing	Giving up care	Guilt
Infantilization	Lack of support	Letting them down
Long-term care	Medication	Misunderstanding
Need for information	Personal care	Professionalism
Public embarrassment	Relations with doctors	Respite care
Self-care	Sleep deprivation	Taking over tasks
Taking risks	Talking about the person	Telephone calls
Telling the diagnosis	Treating the person as a person	Treatment decisions
Truth-telling	Vulnerability	Wandering

Source: Own elaboration.

- Information and disclosure.
- Decision-making and consent.
- Social and context-dependent aspects.
- Care process and process evaluation.
- Special situations, which included: ability to drive, sexual relationships, indication for genetic testing, usage of GPS (Global Positioning System) and other monitoring techniques, prescription of antibiotics, prescription of antipsychotic drugs, covert medication, restraints, tube feeding and end-of-life or palliative care.

What should be apparent is that two of the major categories are overtly to do with decision making, and almost all of the special situations involve decision making too. Hence, the topic before us is a broad and very real one in dementia care. I shall now discuss only five of these issues, but in a manner that I hope sheds some light on other issues as well. To anticipate, one thing that I shall bring out in the discussions that follow is the central importance of the notion of personhood as an underlying theme, to which I shall return in my conclusion.

2. Five issues

a) Place of residence

To illustrate each of these issues I shall start with a fictional vignette. These are scanty in terms of detail; they are only intended to orientate us to the particular problem.

> Mr. Bentley was admitted to hospital with confusion caused by a urine infection. The urine infection was treated, but he remained confused. Neighbors and family report he has been «wandering» in the street late in the evenings for some while. Is it safe, therefore, for him to go home, where he lived with his wife for the 50 years of their marriage?

This raises the issue of residence capacity: whether people have the ability to make decisions about where they live. It is a very real issue every day in all major hospitals. Older people like Mr. Bentley might simply have an acute confusion, a delirium, which will settle given more time; but he might have dementia. Even if he does have dementia, it might still be possible for him to live at home with the right sort of support. Still, he is now at risk of being deemed to lack the capacity or competence to make this decision, in which case he might be moved against his will to live in a care home, with little chance of getting back to his own home with all of its memories.

There have been a number of court cases around this issue in the United Kingdom (UK). The House of Lords looked in 2014 at how the law which governs decision-making capacity in England and Wales –the *Mental Capacity Act 2005*– was working (4). Although they felt that the law had good intentions, they felt it was not being implemented well. One of their conclusions is likely to be relevant in other countries and jurisdictions: «the prevailing cultures of paternalism (in health) and risk-aversion (in social care) have prevented the Act from becoming widely known or embedded». In other words, because doctors tend to feel they must protect their patients, such as Mr. Bentley, and because social workers are inclined to avoid risks and legal action by relatives, the easiest option will be to put him in a care home (5). For Mr. Bentley, however, this might be felt as a great blow to his self-esteem: as if he and his feelings no longer matter. He is helpless in the face of the professional and societal pressure to keep him safe.

b) Forced care

> Mrs. Jones, with marked dementia, is doubly incontinent, but refuses to let anyone change her when she is soiled. It is upsetting for staff to know that she is heavily soiled, and residents and their families are starting to complain. This leads to Mrs. Jones being ostracized and, indeed,

> there has been increasing verbal aggression towards her, with people calling her names. Staff are split about what they should do.

This can be a very delicate decision for care staff and families. Mrs. Jones wishes to remain in control of her life, especially her personal life, but it seems that she now lacks insight into the nature of her problems and the effects they are having on others. For staff not to force the issue (presuming they have used all their skill to get her to wash herself or to be helped in a kindly manner) seems to be to risk her safety (i.e. the risk of infections or the risk of aggression from other residents) and undermine her dignity. To use force, however, might feel to the staff (and others) as if they are assaulting her. To strip her naked against her will seems like abuse and undermines her standing as a person. Staff will often require a good deal of support to encourage them to intervene in a safe and legal manner in order to protect Mrs. Jones (6).

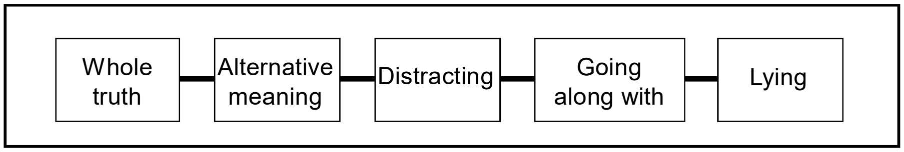
c) Covert medication and truth-telling

> Joseph Leblanc, the former managing director of a Canadian haulage company, does not believe there is anything wrong with him. As well as dementia, he has heart failure and if he does not take his medication, he becomes progressively short of breath, very distressed, and sometimes aggressive. Staff in his care home have discovered that if they put his medication in pudding, he eats it without complaint and remains stable. When stable he is content and seems to enjoy life. A new member of staff feels that the use of covert medication is deceitful and wrong.

There are two related issues here: that of concealing medication and the circumstances (if any) when this is justified; and the broader issue of truth telling. Many countries will now have guidance, especially for nurses, about the circumstances under which drugs can be concealed in food and drink –usually as a last resort and only if properly documented–. The issue, however, is certainly an ethical one (7).

Lying to people with dementia is also a significant problem. It takes many shapes and forms, from not telling the truth about the diagnosis to deception about the care that is to be provided for the person (e.g. going into a care home); from telling the person that a particular relative is still alive when they died some while ago to providing false environmental cues (e.g. a fake bus stop at which the person waits with the illusory promise that he or she is going somewhere). Sometimes the absolute truth can seem hurtful, but a blatant lie seems insulting to the person.

Figure 1. A continuum from whole truth to blatant lies (8).



Source: Own elaboration.

In a report on this issue, the Mental Health Foundation (8) came up with a continuum, as shown in Figure 1. The suggestion is that you should always start as close to truth telling as possible. If you have to deviate from this, you should do so only on good grounds and you should move down the continuum in steps, unless there are good reasons not to. For example, if it is already known there will be a catastrophic reaction, say, to «looking for an alternative meaning» (i.e., trying to understand the emotions that are being expressed), then it might be better to use «distracting» immediately. Even so, best practice is that staff should keep care plans for decisions which involve any form of deception.

d) Sexuality

> Mrs. Gauthier was new to the care home for people with advanced dementia, but within days she had struck up a friendship with Mr. Wong. Both were married and their spouses visited daily. Their spouses were

> disconcerted to discover that the relationship seemed to be deepening. Devout Catholics, both had always been faithful to their respective spouses. After three months, members of the staff had to let the families know that Mr. Wong had been found naked with Mrs. Gauthier in her bed. Mrs. Wong is upset but accepts that her husband needs companionship. Mr. Gauthier is furious and states that Mr. Wong is a predator and a dirty old man who should be booted out of the care home.

Sexuality in older people is prone to elicit ageist attitudes which are compounded by stigma when it comes to people living with dementia. In cases like those of Mrs. Gauthier and Mr. Wong, the initial reaction can often be a legal one, and it can also be a sexist one. The man is often seen as the perpetrator and, given that a question arises about the woman's ability to give fully informed consent, it is often then alleged that such cases amount to rape. Hence the police are informed, and matters become very upsetting for everyone.

It may, after all, be that a rape has indeed occurred. On the other hand, it may be that Mr. Wong genuinely believes that Mrs. Gauthier is his wife, and perhaps she initiated the sexual activity. They might both believe that they are a young unwedded couple and be quite shocked at the fuss being made. An issue in itself is how capacity to consent is assessed in such situations, especially if the residents in the home have communication difficulties. Issues around sexuality also include gay and lesbian relationships and the attitudes of staff and other residents to homosexuality or transgender issues and so on.

If, on the one hand, such dilemmas are viewed through a legal lens, they can also be seen, on the other hand, as having to do with intimacy and the human need for comfort and close reassuring relationships (9). The reality, however, is that our responses to human sexuality and intimacy, which will include attitudes to masturbation, pornography, fetishes and so on, are varied. We know that sexuality and the need for intimacy are intrinsic to our nature as human beings, but in vulnerable groups, there will inevitably be some caution in allowing certain sorts of activity. The ethical dilemma, as is the case so often, is in deciding in particular cases where lines should be drawn so as to allow full expression of sexuality and intimacy without allowing abuse to occur.

e) Food and drink (withholding and withdrawing)

> Miss Cote is in the severe stages of dementia. Her swallowing is becoming increasingly compromised. She chokes and has already had several chest infections. She lives at home and has caregivers coming in to feed her, but this is taking longer and longer. It is suggested by her general practitioner (GP) to the family that she should be given a percutaneous endoscopic gastrostomy (PEG) tube to put the food and drink directly into her stomach. This will require a hospital admission. Her family would rather, whatever the risks, that she should continue to be fed by hand. Her carers, however, are alarmed by her choking.

Cases like Miss Cote's are not unusual. Again, the ethical issue is real. It is the issue of withholding or withdrawing investigations or treatment. Similar issues arise in various circumstances in dementia, not just in connection with swallowing, but also regarding the use of antibiotics or around judgements concerning cardiopulmonary resuscitation (10).

There is, however, a well-established doctrine, that of ordinary and extraordinary means, which can be helpful in facing these dilemmas. The doctrine can be stated as follows: we are not morally obliged to carry out an investigation or treatment if it can be regarded as extraordinary; it is extraordinary if it is unlikely to work and if it is burdensome to the patient.

In the case of Miss Cotes, we can say that the PEG tube is unlikely to achieve its aims (11), and it is burdensome in that it involves an anaesthetic and a variety of risks (e.g. of infection and bleeding). Thus, it can be regarded as extraordinary treatment and there should be no moral obligation to pursue the use of PEG feeding in this case. Similar reasoning can be used for cardiopulmonary resuscitation. The use of antibiotics in severe dementia is more complex because it is more debatable whether or not antibiotics are efficacious. For, even if they do not effect a cure, they can be used in a palliative manner (12). If their use, however, were to require admission to hospital to place an intravenous line, it could also be regarded as too burdensome for a particular patient.

3. Conceptual topics

I shall now consider three conceptual topics raised by the cases discussed above.

The first topic is to do with the standing of capacity assessments as objective tests. We routinely talk of testing a person's capacity (called competence in some jurisdictions). One mistake that doctors are prone to make is to view capacity as depending on the outcome of any decision being made. Thus, if a person makes a choice that seems safe, he or she is said to have capacity (if other criteria are satisfied). If, like Mr. Bentley in the case described above, I want to go home even though there are dangers attached to this option, it might well be found that I lack the requisite capacity to make this decision. This tendency, to favour an outcomes approach rather than a functional one (i.e., one that looks at the cognitive functioning involved in the decision making irrespective of any outcomes chosen), itself reflects the tendency to do the best for patients, where this tends to mean keeping them safe (13). In itself, this is an evaluative decision: it involves a value judgement, in this case one that is erroneous. Even if the error of making an assessment based on outcome rather than functional abilities is avoided, however, judgments about capacity seem likely always to contain a normative element (14). For a person to have capacity, how much information should they be required to hold in mind, for how long and what might constitute weighing up that information sufficiently? It is a pretence that these criteria are entirely objective.

The second topic is that of best interests. The point here is that, if we are to make judgements about what is best for a person, we need to take as broad a view as possible. In England and Wales, the *Mental Capacity Act 2005* (section 4) sets out a checklist for best interests, which seems very sensible:

- General:
  - *Avoid discrimination.*
  - *Consider all relevant circumstances.*
- Particular steps:
  - *Assess whether the person might regain capacity in near future;*
  - *Encourage participation.*
  - *Avoid being motivated in any way by a desire to bring about the person's death.*
- Consider as far as practicable:
  - *The person's wishes, feelings, beliefs and values.*
  - *Take into account views of those caring for the person.*

This broad view directly reflects the broad view necessary to characterize personhood itself.

The last topic is that of supported decision-making, which arises from the United Nations' *Convention on the Rights of Persons with Disabilities* (UNCRPD)(15). The notion of *supported* decision-making is intended to make the point that it is still the person's decision, even if he or she is very disabled (including with dementia). A *substituted* decision is essentially a decision made by someone else for the person; and even a *shared* decision sounds as if someone other than the person plays too big a role. The issue has been put well by Scholten and Gather (16):

'Notwithstanding its promise, SDM [Supported Decision-Making] has its limits. Undeniably, there are situations where despite the decision-support offered, a patient remains unable to make an informed treatment decision. The comatose patient provides a pertinent example, but similar considerations hold for a range of persons with other conditions, such as late stage dementia or psychosis.

Accordingly, SDM does not make competence assessment and substitute decision-making superfluous. That said, reasonable accommodation requires health professionals to exhaust the available resources of SDM before they take recourse to substitute decision-making.

The argument is that the person should be put first, which is after all the clarion call of person-centred care in dementia (17).

Conclusion

Each of the topics briefly mentioned above involve us thinking about persons and what we are as persons. Put more simply, they raise issues about personhood. Attention to personhood involves values and making evaluative judgements (18). Broad judgements are required in deciding what is best for the person, because what it is to be a person must be broadly conceived. Supported decision making is important precisely because it emphasizes the standing of persons even when they live with profound disabilities. In turn, the five issues we discussed above also require us to think deeply about the person who should stand centre stage when these difficult decisions have to be made.

According to my lights, the suitable way to characterize the personhood of people with dementia is to regard them as situated embodied agents (19, 20). They are situated in a variety of fields, involving their own narratives and those of others, as well as in cultural, societal, legal, normative fields and so on. Indeed, the ways in which persons are situated cannot be circumscribed. Meanwhile, persons are embodied: their bodily natures and the way they express themselves bodily cannot be ignored. Finally, they are agents, and they continue to have agentive inclinations even when they are living with severe dementias. Decision making in dementia is an ethical issue precisely because the temptation is to take the easy route and to undercut the standing of the person with dementia. This is a temptation that must be resisted if we are to behave as flourishing moral human beings.

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