

Dementia and ethics: the views of informal carers

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SUMMARY

There has been little work on the ethical issues facing non-professionals who care for relatives or others with dementia. A qualitative pilot study was conducted in ten such individuals, eight of them women, caring for persons drawn mainly from one general practice. The interviews indicated that many of the dilemmas faced by carers are ethical and that the issues differ from those faced by professionals. Ethical issues are sometimes the most troublesome matter for carers. Unlike issues for professionals, they arise from a personal context and are shaped by long-term relationships.

INTRODUCTION

Much has been written from the viewpoint of professionals on the ethical issues that arise in the care of people with dementia. The ethical issues that confront non-professional carers have attracted less attention, and systematic studies are lacking¹. Here we present the results of a pilot study.

METHODS

We identified the ten participants largely from the computerized records of one general practice in West Berkshire (SR and DR). Participants either had been or still were the principal carers of people over 65 years old with dementia. The general practitioner made the initial contact with the potential participant to describe the study. A person willing to participate returned a form to the researchers. This person was then contacted by phone and gave verbal consent to be interviewed.

At the interview (performed by JCH) written informed consent was obtained. Demographic details were confirmed and the interview started with the open question: 'Can you tell me about the main problems or difficulties which arose for you as a carer?'. The interview followed the narrative given by the participant. A list of difficulties and problems was constructed and the interviewer clarified how the carer dealt with them and whether alternative solutions had been considered. The use of ethical terms, principles, or

Box 1 Demographic details of carers (n=10)

Female	8
Spouses	7
Daughters (non-resident)	3
Mean age (years)	68.4 (range 44-83)
Person cared for now deceased	4
Social class (mode)	3 (range 1-4)
Mean years in education	12.8 (range 9-19)

expressions that indicated value judgments was carefully noted throughout the interview.

Notes were taken during the interviews, with some responses being recorded verbatim. One interview was tape-recorded. The typed records of the interviews and the transcript of the final taped interview were reviewed (by JCH and TH) and analysed. First, we constructed a list of areas giving rise to ethical issues for the carers. Second, we were interested in the moral concepts and constructs used by the carers. The reports of the interviews were searched for evaluative concepts in order to pick out themes that emerged from the carers' perspectives.

The study had ethical approval from the local research ethics committees in West Berkshire and Oxfordshire.

RESULTS

Box 1 presents the demographic details of the ten participants. In four cases the person interviewed was still caring for the relative with dementia; in two cases the relative was in a residential home; and in four cases the relative with dementia had died.

Box 2 lists the areas giving rise to ethical issues for the carers, grouped according to whether the issues related to

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things that should or should not have been done by themselves, by others (including professionals), or by both themselves and others. These distinctions are not, however, clear-cut.

Areas giving rise to ethical issues for the carers

Carers often had to decide between options none of which seemed good. For instance, participants were concerned that sometimes, for the sake of safety, they had to restrict the liberty of the person with dementia. Carers had to coerce the people they cared for in various ways—into accepting more help, into giving up control of their finances, into day care. The carers had duties not only towards the person with dementia, but also towards other elderly relatives, spouses and children. Deciding between competing demands was a dilemma for carers. For some, a major issue was balancing their own needs against the needs of the person they cared for; this, as in several areas, could lead to a sense of guilt.

Another issue was how to protect the person with dementia from being confronted by his or her lessening abilities. One participant described how capable her spouse had been at mending things around the house. As he became less able, she had to call in help, even though this might undermine his confidence and make him feel useless.

Areas affecting the actions and decisions of others, including professionals

Many carers perceive the issue of information in ethical terms. One felt she should have been warned of the demands of the caring role. It was as if she had not consented to this role because she had not been fully informed.

Several participants raised general points about relationships with doctors. Participants were content when the relationship was one of partnership: shared decisions, about the need for antibiotics or investigations, were appreciated. The way information is given—for instance, concerning diagnosis—can also, from carers' perspectives, be handled rightly or wrongly. Just being told the diagnosis without any further support felt devastating to one carer.

The different perspectives of some carers and professionals are illustrated by experience with cognitive assessment. One participant said her husband cried when he did badly on formal testing. Another said she and her husband had been upset. She suggested, instead of questions about who the Prime Minister was, to engage the person in a conversation about politics would be less patronizing and would show more respect.

Box 2 Ethical issues for carers

Areas primarily affecting actions and decisions of carers

- Compulsion and coercion
- Dealing with difficult behaviour
- Dual loyalties
- Feelings of guilt
- Giving up care
- Handling constant telephone calls from the person with dementia
- Letting down the person with dementia
- Self-care
- Sleep deprivation
- Taking over tasks
- Taking risks
- Wandering

Areas primarily affecting actions and decisions of others, including professionals

- Assessment
- Community resources (e.g. for respite care)
- Confidentiality
- End-of-life decisions
- Lack of support
- Need for information
- Professionalism
- Relations with family doctor
- Telling diagnosis

Areas affecting actions and decisions of both carers and others, including professionals

- Avoiding infantilization
- Communication
- Consent
- Driving
- Misunderstanding
- Providing personal care
- Public embarrassment
- Recognizing vulnerability
- Safe use of medication
- Talking about people with dementia in front of them
- Treating the person as a person (recognition and validation)
- Truth-telling
- Use of respite care

Ethical issues for the carers and others

Talking in front of the person with dementia, as if he or she did not understand, is a practice some participants deplored. Their view was that people with dementia should not be excluded from case conferences, they should not be patronized, they should be kept independent, they should receive good medical and social care, and at the appropriate point they should be allowed to die.

Participants also had concerns about their neighbours. Some carers felt the need to protect their neighbours (and at times their families or the wider public) from upsetting

or dangerous behaviours such as shouting, driving, or unsightly eating. At other times, however, neighbours were perceived as potentially or actually critical. This should remind us that carers' perceptions are not uniform, as shown by differing attitudes towards hygiene. There were instances of participants complaining about the poor personal care given by professionals; but one carer described how at times she left her relative with dementia in a dirty state in order to avoid the upset caused by trying to clean him.

Moral concepts and ethical constructs

We shall group examples from our data around six notions that appeared important—duty and responsibility; guilt; consequences; substituted judgments and wishes; best interests; and reciprocity.

Duty and responsibility

Several carers spoke of their duties, towards the person they care for, towards their families, towards themselves, and towards the broader society (as shown by the duty felt by one carer to inform the Driver and Vehicle Licensing Agency [DVLA] of her husband's lack of safety whilst driving). One carer pointed to the notion of 'conscience' as underpinning his duty to care. Another spoke of the duty to keep the person with dementia independent and regarded this as something that *ought* to be done. The duty to care was sometimes felt as a burden (e.g. by a daughter with her own job and family); but one husband said, 'It was a duty, but it was something I didn't mind doing'. In many cases the sense of duty towards the person with dementia displayed an imperative quality: it was not something the carer could shirk.

Guilt

Aligned with the sense of duty and responsibility were feelings of guilt. These were quite common. One wife felt guilty about what she had said to her husband when he was being violent towards her. Another felt guilty at having to get help, and there was guilt at having to give up caring, even when the carer was clearly unable to cope. A wife felt guilty about leaving her husband at home in order to pursue her own interests. A daughter felt guilty at not having enough time to look after her mother to the standard she would have wished and guilty at having to look after her own family.

An example of a carer who showed both a sense of duty and feelings of guilt was the wife who wanted to keep her husband at home but could only manage this if she kept him sedated—otherwise he was prone to violence. The need to sedate him left her feeling guilty.

Consequences

One carer used consequentialist arguments (i.e. the consequences justified the action) to justify deceiving the person with dementia into believing she was being taken for a ride in the country when in fact she was being taken into respite care. Another participant described forcing her father to accept medication so that he would be allowed home from hospital. Pressure was also placed on a man with dementia to hand over control of his finances to his family. People were coerced into accepting certain forms of care. One man with dementia was locked in his bedroom at night because he was otherwise incontinent elsewhere in the house. Other carers judged confinement unacceptable. However, in all these cases the carers felt that the consequences of using pressure, force, coercion or restraint justified such measures. These were practical ways of solving problems and were, hence, perceived as right and justifiable.

Substituted judgments and wishes

In several instances, when faced by difficult decisions, carers made reference to what the person with dementia had said or done in the past. These are substituted judgments. For example, a wife did not wish her husband to be investigated for a medical complaint because he had always avoided medical investigations and treatments. Again, even though it meant more work for her, a daughter did not use her mother's money to pay for extra help, because this was not what her mother would have wanted. Another daughter spoke of the need to represent her father's views.

Indeed, the notion of the person's wishes and wants, and the way in which these might come into conflict with the wishes and wants of others, was the most frequently encountered theme in our interviews. Carers wished to be able to cope; doctors wanted to investigate; the wishes of care assistants had to be complied with; a carer's husband did not wish his mother-in-law to live with them; grandchildren did not want the grandmother with dementia to be at their parties; the mother's wish to remain in her own home was paramount. The participants in this study often had to represent the wishes of the people they cared for with dementia, but sometimes they had to balance those wishes against the wishes of others.

Substituted judgments were sometimes problematic. There was a very distressing incident for one daughter when her mother started choking in a nursing home and she left the decision about what to do up to a nurse. Previously she had tried to restrict treatment, in accordance with her estimation of what her mother would have wanted. On this occasion, however, her mother was clearly very distressed. The nurse aspirated her mother and the daughter acknowledged that, despite

previous thoughts on the matter, sometimes decisions have to be made quickly in particular situations.

Best interests

When professionals talk of 'best interests' they tend to be referring to the *patient's* best interests. In two of our interviews the best interests of the person with dementia were indeed the concern of the carers. However, two of our participants spoke of their *own* best interests, as opposed to the best interests of the person with dementia; and two more made the point that their best interests and the best interests of the person for whom they cared were entwined. 'My best interests', said one wife, 'are his best interests' and vice versa. People are embedded in their relationships, as well as in their histories and broader social contexts². This is an example of how ethical notions can be understood differently from different perspectives.

Reciprocity

The difference in perspective reflects the different standing of carers and professionals *vis-à-vis* the person with dementia. Thus, one carer said to her husband, 'You've looked after us all our days; perhaps it's time for us to look after you now'. This notion of reciprocity, which has been highlighted elsewhere³, was also demonstrated by the family, who were well aware that their parents had said they would not wish to be a burden and should be put in a home when the time came. The father became a widower, developed dementia, and placed an increasing burden on his family, but he was also clearly fearful of being moved into a home. The family wished to look after him as he had looked after them. They decided to move him into a home only if he became unsafe or if he could no longer recognize his own home. In taking this stance, on the basis of reciprocity, they were ignoring his previously expressed wishes. Professionals might find it harder to ignore clearly expressed prior wishes. They might, on the grounds of best interests, reach the same decision as the family, but the ethical connotations of reciprocity are not the same.

DISCUSSION

Before discussing the results we must acknowledge the limitations of the study.

The sample was small and the sampling and qualitative methodology were poor. So, for example, we made no contact with carers from social class 5; nor did we interview sons who were carers, although there is evidence that sons face particular problems of an ethical nature⁴.

Our main observation, is that professionals and non-professional carers have different ethical perspectives.

The ethical issues not only *seem* different but *are* different.

To show how ethical issues seem different we use the example of truth-telling. Our data confirm that the telling of the diagnosis is an important issue for carers; but whilst there is growing pressure for doctors to be honest with people about their diagnosis⁵, one of our participants thought her husband should not have been told. Even when professionals do not tell a person with dementia the whole truth, they try to avoid telling lies. A carer in our study, however, on good consequentialist grounds, had no qualms about telling her mother that she was going for a ride in the country when in fact she was going to respite care. A wife spoke bluntly to her husband about his problems and then felt bad because she had upset him. Honesty does not always seem to carers to be the best policy, although the issue might also be *how* the truth is told. On the other hand, one carer had no hesitation in informing the DVLA about her husband's driving because of the risks; and when carers are seeking help, they wish themselves to be dealt with honestly.

There were also contrasting views on issues such as coercion, the need for medical treatment, best interests and the wishes of the person with dementia. Carers themselves hold different views, but so do professionals. It is the context that has to be appreciated, particularly the context of long-term relationships, in order to understand how carers judge these various issues.

The second way in which ethical perspectives differ is that carers raise some issues that simply do not appear as ethical issues for professionals. Feelings of guilt, for instance, are pervasive for carers and cannot be rationalized easily (as they can be, perhaps, by professionals). This presumably reflects the deep connections between the carer and the person with dementia. The different perspective from this engaged context is something the professional cannot share, even if he or she can be empathic. Another example is the notion of reciprocity, which featured strongly in this study, but is quite unlike a professional's duty of care. Moreover, there are some problems, such as whether or not to get someone in to do routine house maintenance, which are not obviously ethical from the perspective of the professional, but which carry moral significance for the carer. Similarly, if the best interests of the person with dementia are entwined with the carer's best interests, a judgment about what is right in response to a particular problem cannot be made objectively without reference to the carer's viewpoint.

The second key observation to emerge from this study is that ethical issues are important for carers. Several examples appear in Box 2. One was the participant who was concerned about sedating her husband at night when he

was agitated. This was partly a concern about pharmacology (would there be untoward side effects?), but it was also a question about the rightness of using sedation *at all* to keep him at home. Simply answering her pharmacological question would not have settled her ethical concern. Attending to the psychosocial needs for carers might entail an awareness of the ethical issues from their perspectives. To be unaware of the carers' ethical views might well lead to inappropriate or even bad clinical decisions. In this particular case the whole ethical question surrounding whether she could meet her husband's needs was an important issue for the carer.

Another major issue for carers in this study was that the person with dementia should be treated as a person. Many carers referred to needs and wants, perhaps as a way of recognizing the personhood of the one they cared for. A link was often made between the notion of communication and that of the person. Carers are aware that the style and content of communication can either enhance or detract from the personhood of someone with dementia. Recognizing someone and using his or her name is a way of affirming the uniqueness of the person. So, for example, one carer said of his wife: 'I certainly think recognition was one of the biggest things... To be called by her name meant a lot to her'.

In addition, communication allows the possibility of validation: it acknowledges the reality of a person's emotions and feelings⁶. One daughter described her parent as needing to take time in conversations. To interrupt would have been to undermine selfhood, which depends to some extent on communication⁷. Communications have to be empathic in order to avoid upset and the sort of infantilization which, according to one of our participants, elicited the response 'I'm not a little boy!'.

The concluding key point to be drawn from this study is that professionals need to be alert to and sensitive to ethical issues for family carers. There is the potential problem that the 'ethical' vocabulary used by professionals and family carers might be different, leading to misunderstanding. For

the carer a question about medication might require an ethical discussion, not reassurance about the half-life of the drug; feelings of guilt might not be easily rationalized and the need to go on caring might reflect an ethical intuition, involving reciprocity, not just a failure to appreciate the strain of caring. In summary, a substantial part of carer burden is, perhaps, 'ethical' burden⁸. Overt acknowledgment of the ethical nature of the difficulties facing carers, a willingness to discuss matters of value as well as matters of fact⁹, some grasp of alternative ethical viewpoints to allow informed discussion—all these might make a positive contribution to the support given to carers.

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