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Why is dementia different? Medical students' views about deceiving people with dementia

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Introduction

Over the past decade, a number of key reports have highlighted deficiencies in the care of people with dementia (Care Quality Commission, 2012; Department of Health, 2009) with poor communication between healthcare professionals and people with dementia frequently identified as a source of concern (Alzheimer's Society, 2009; National Audit Office, 2007; Royal College of Psychiatrists, 2011). Communicating with people with dementia is ethically complex (Hughes & Baldwin, 2006; Nuffield Council, 2009; Young, Manthorp, Howells & Tullo, 2011). A particularly challenging issue for healthcare professionals is whether or not it is ever ethical to lie to or deceive a patient with dementia. There is a lack of consensus as to the definition of "lying" and "deception" (Ryan, de Moore & Patfield, 1995; Schermer, 2007; Sokol, 2006). Some authors contend that lying is morally distinct from deception (Benn, 2001; Jackson, 2001), whereas others argue that both acts in clinical practice are ethically akin, because they are both a deliberate abuse of power and an "affront" to patient dignity (Bakhurst, 1992). Whatever the terminology used, empirical studies demonstrate that decision-making about honest communication is a common issue faced by professionals caring for patients with dementia (Day, James, Meyer & Lee, 2011; Elvish, James & Milne, 2010; James, Wood-Mitchell, Waterworth, Mackenzie & Cunningham, 2006; Tuckett, 2012).

Ethical discourse specific to dementia care tends towards the conclusion that lying in clinical practice should be avoided except in rare and specific circumstances (Schermer, 2007), although authors continue to debate the relative importance of deontological constraints, intentions and predicted consequences for patients and society (Bakhurst, 1992; Benn, 2001; Jackson, 2001; Ryan et al., 1995). Interestingly, people with dementia

themselves agree that there are circumstances under which it might be acceptable for a healthcare professional to lie to them (Day et al., 2011). There is diversity of opinion as to the specific circumstances in which lying to or deceiving a person with dementia might be justified, whatever definitions are used to describe these acts. Given the challenging situations that arise when caring for patients with dementia and their families in clinical practice, it may therefore be difficult for staff to consistently apply communicative ideals such as absolute honesty.

In acknowledgement of such challenges, schema to aid the analysis of decision making about lying and deception in practice have been developed, for example Sokol's "deception flowchart" (Sokol, 2007). The flowchart contains a list of potential reasons for deception and a list of potential objections to deception (Table 1) which were derived from empirical data collection from patients, doctors and members of the public; the flowchart is proposed as an educational tool for healthcare professionals to analyse ethical decision-making. However Sokol's flowchart considers the issue of deception in clinical practice *in general*, rather than specifically in the context of dementia care, and was originally developed in relation to adult patients with capacity.

Given the complexities outlined above of communicating with people with dementia and their families, this study aimed to compare and contrast the potential reasons for and objections to deception *in general*, as outlined by Sokol, with the views of medical students about deceiving patients with dementia. As clinicians in the making, medical students are undergoing a process of learning and professional development. As such, undergraduate medical students constitute an important target for on-going educational interventions relating to dementia. An exploration of their views on communicating with patients with

dementia, including the use of lying and deception, will help to identify some of their key learning needs. Specific study objectives were:

- To determine the extent to which the reasons for and objections to deceiving patients with dementia cited by medical students match those described by Sokol
- Whether there were other proposed justifications or objections to deception specific to care of patients with dementia.
- To identify student learning needs with regard to communication skills and ethical reasoning relating to dementia care.

Methods

Recruitment process and participants

Questionnaires distributed to a total of 531 medical students in years 1, 3 and 5 at a UK medical school as part of a larger study evaluating attitudes towards communicating with people with dementia, found lying to people with dementia to be a divisive issue (unpublished data).ⁱ Students who completed the questionnaires were invited to indicate if they would be willing to take part in focus groups or interviews about communicating with people with dementia. Those who responded to the invitation (n = 85 (16%)) were contacted and provided with further details about the study. The proportion of students responding from each year group did not vary significantly (year 1 = 15%; year 3 = 20%, year 5 = 14%). All students were contacted to offer them the opportunity to take part, but either

ⁱ In response to the following statement - *It is acceptable to lie to a person with dementia if you think the truth might be upsetting to hear* - 1.3% of participants strongly agreed, 17.6% agreed, 45% neither agreed nor disagreed, 29.7% disagreed, 6.4% strongly disagreed.

did not reply to the invitation, could not attend sessions due to other commitments, or planned to attend a session but did not turn up.

In the next phase of the larger study 21 students were available to attend 1 of 6 focus-group sessions evaluating medical students' attitudes towards communicating with people with dementia in general (in the clinical and non-clinical context). Again, this process highlighted lying to or deceiving people with dementia as an ethically complex communicative concern for students. To further explore the topic of lying and deception in dementia care, an additional 10 students subsequently took part in in-depth face-to-face or telephone interviews. Students participating in focus-groups or interviews were offered a £10 book voucher to compensate them for their time, but were unaware of this incentive prior to responding to the invitation to participate.

Data collection and analysis

An inductive approach to data collection and analysis was adopted as part of a larger study of medical students' interaction with people with dementia. This paper presents data specific to lying and deception. The six focus groups were semi-structured, based on the format of questionnaires used previously (Tullo & Young, 2014; and unpublished data submitted with the manuscript as supplementary figure 1), using questionnaire statements as prompts for discussion (Figure 1). Students were encouraged to discuss in more detail the topics that they found the most interesting or challenging. Focus groups were audio-recorded, transcribed and anonymised. Content was initially categorised and divided using the questionnaire statements as major themes headings, with related subthemes emerging.

Data relating to lying or deceiving people with dementia was then extracted and further reviewed.

Sub-themes arising from the focus groups were used to construct an interview schedule to subsequently explore the topic of lying and deception with medical students in more detail using interviews as a method (see Figure 2). Early interviews were independently reviewed and coded by members of the research team (ET, RL, LA, LR), using an initial coding process (Saldaña, 2009) to identify emergent themes. Using the principles of constant comparison (Boeije, 2002) analysis of early interviews informed iterative changes to the interview schedule to pursue unresolved questions, until no new themes were emerging. All 6 focus groups and 10 interviews (7 face-to-face and 3 telephone) were then coded for potential reasons for and potential objections to lying to or deceiving patients with dementia. No obvious differences were identified between interviews conducted over the telephone (where interviewees may be more relaxed) and those conducted face-to-face (with the absence of visual cues) (Novick, 2008). Students were not offered a list of Sokol's criteria prior to data collection; rather, reasons for and objections to lying or deceiving people with dementia highlighted spontaneously by students were compared to Sokol's deception flowchart. This comparative analytic process was conducted by members of the research team (ET, RL, LA, LR) and disagreement about coding attribution resolved by team discussion.

Ethics

Students who agreed to be contacted with further information about focus groups and interviews were provided with an information sheet about the format and topic of discussion. Written consent was then obtained from those students who elected to

participate. Recordings were kept in a secure location and anonymised during transcription. The project met the University Preliminary ethical assessment guidelines for the School of Education, and approval was confirmed by the Medical School Board of Studies.

Results

Shared findings and common concerns

Students described a range of clinical situations they had witnessed where a healthcare professional had been prompted to consider whether deceiving a patient with dementia would be ethically acceptable or not (Table 2). The most commonly cited scenario was appropriately responding to a patient with dementia who was asking about the wellbeing of a spouse that they did not remember had died.

Arguments for and against deception that arose as a result of the situations described by students generally aligned with those of Sokol's flowchart – indeed, all of the potential justifications of and potential objections to deception listed in Tables 1 and 2 were represented by our data.ⁱⁱ As per Sokol's study participants, medical students recognised that opposing arguments about the acceptability or otherwise of deception required a process of “weighing-up” or balancing in order to try to come to a decision.

Echoing the challenging clinical situations cited by Sokol's study participants, students described examples involving patients with conditions other than dementia, most

ⁱⁱ The scope of this paper does not allow us to present specific examples of justification and objections to deceiving a person with dementia that match those of Sokol's flowchart. Rather, we have chosen to concentrate on examples where dementia care might present additional complexities.

frequently cancer, in order illustrate shared principles in terms of ethical reasoning about deception:

there are certain times when you may not tell the complete truth, you know, all at once.... you know... it's not just with dementia, but for cases of suspected malignancy, you know, where you don't want to distress the patient, like tell them that straight - where you just sort of skirt around the issue. Interview 2

In acknowledgement of shared principles, a minority of medical students (n=2) argued that ethical decision-making regarding patients with dementia was *no* different to decision-making for patients with any other condition:

I know nobody likes to be lied to so why should someone with dementia be any different, they're still a person and if they want to know the truth then they deserve to have the truth. Interview 1

However, the majority of students believed that dementia raised unique issues that warranted special consideration when reflecting on the acceptability of deception.

Dementia-specific considerations

Students discussed a number of factors that - when communicating with a patient with dementia - might make a difference to ethical reasoning. The three most commonly cited themes were capacity, perceived vulnerability, and family dynamics.

Capacity: understanding, retaining and emotional processing

Sokol's deception flowchart recognises the following potential justification for deception: "*Patient is not emotionally or cognitively equipped to decide or to cope with the truth*". Student participants in this study frequently voiced their concerns about the difficulty of determining whether or not an individual with dementia had the cognitive or emotional ability to cope with the truth. Moreover, the majority recognised that capacity in

dementia is dynamic and situation-specific, meaning that lack of capacity as a potential justification for deception is highly problematic in practice.

Students generally believed that in the early stages of dementia patients were likely to have the capacity to comprehend and process complex information. However, some students reasoned that at advanced stages of dementia these abilities might diminish – thus, candid disclosure of potentially distressing information would be, at best, futile and, at worst, damaging:

that does come down to the fact that it's distressing information that she won't be able to recall, and therefore in terms of her, it would distress her first time and then the information would be forgotten. Its not, it doesn't follow the normal grief process almost where we can impart bad news on a patient and work through it. So because of the memory loss it will distress her and to no avail I suppose.

Interview 6.

Students identified episodes where failure to retain information would mean disclosing distressing news repeatedly – the patient with dementia asking about the wellbeing of a dead spouse was frequently cited. Some of the students believed that cumulative distress caused by bad news could justify deceiving a patient with dementia:

So a lot of the time, I'd, I mean, depending on the patient, if I knew that whatever I said they'd have forgotten and they'd be asking again in an hour, I often would just have like, tell people like, "Oh, you know, they, I think they might be coming soon." Focus Group Participant 19

However, even where repetition and associated distress were anticipated, some students thought that deception (particularly lying) was still not ethically justifiable. One argument put forward was the importance of a patient with dementia's "right to know" bad news, even if this caused distress. Another argument was that causing distress in the short-term might later be justified in the long-term if repetition eventually led to a patient with dementia retaining information:

I'm not sure whether by repeating it and reinforcing the information means that they'll retain some of it and whether that in the long-term is actually quite, more beneficial. Interview 1.

Even when participants believed that deception might be ethically acceptable, they recognised the difficulty of making a judgement about the capacity of an individual with dementia. A number of participants expressed concern that using lack of capacity as an argument for deception in cases of severe dementia risked biased assumptions about all patients with dementia:

if we started saying "well it's fine with patients with severe dementia, if we do need to make something up to keep them happy, that's fine". Where do you draw the line? At what stage of dementia? Do we have a specific cut-off score? Do we do it as a clinical judgement, and then, why just dementia? And then when do we stop the sort of making up the falsehoods to reassure patients, which could be a very destructive and very dangerous thing. Interview 6

Some students felt strongly enough about this risk to state that deceiving patients with dementia, even where capacity was not present, could therefore never be justified.

Perceived vulnerability

Sokol's flowchart encapsulates considerations about the vulnerability of patients in a number of the potential justifications for deception. In general, students in our study believed that the clinical features of dementia as a disease state made patients with dementia more vulnerable to a range of harms (physical, mental and emotional) than other patients:

well I suppose you could harm them, their mental health in a way that if you told them that and they might consider, I suppose, doing something drastic like, I suppose suicide, you know, you might risk that, and then, or you might risk, kind of anxiety depression, and not just for a short-term period. Interview 3

The above extract – while describing relatively extreme actions – is based on uncertainty over vulnerability. Students disagreed as to whether this perceived vulnerability made deception more or less acceptable. Students who believed that patients with dementia were at risk of worsening confusion favoured making concerted efforts to tell them the truth:

I think the distinction is that people with dementia in general compared to other people, with problems with their cognitive function, are in a vulnerable position and they should make an extra attempt to tell the truth and be extra careful with them maybe. Interview 7

In contrast, some students believed that challenging the reality inhabited by a patient with dementia would be detrimental to their care:

I think sometimes you have to almost go along with their own thoughts and whatever sort of delusions or...or sort of whatever memory they are living out, you know you have to go along with it really if you are actually going to give them proper care. Interview 2

A minority of students thought that acknowledging the reality of a patient with dementia was important enough to justify lying to a disorientated individual.

Family dynamics

Recognition of the nuances of family dynamics influenced students' beliefs about the acceptability of deceiving someone with dementia. Students expressed a difficulty in trying to separate the interests of the patient with dementia from those of their family. Although the interests of the PWD were thought to be paramount, judgements about deception also warranted consideration of the impact on family and on caring relationships:

you know your second patient is the carer or family member so communication with them is just as important, and obviously you rely on them to help you communicate with the patient, they know the patient best, they have, you know, they know what the patient's wishes have been in the past or how they might act, or how they might want to be cared for. Interview 4

Some participants feared that candid disclosure of information by a healthcare professional to a patient with dementia risked damaging or destroying caring relationships, particularly if carers or family wanted to shield the person with dementia from the truth or had lied to them in the past:

your duty is to the patient rather than to the family, so you don't have an obligation actually to go along with a lie that they have decided to start, but then the added problem is that telling the patient the truth might, you know, as well as upsetting them in that sense, just by the fact that we have also ruined their trust of their family which may potentially lead to bigger distress. Interview 7

Although all of the participants thought that a professional should aim to reach a consensus with carers to be honest with a patient with dementia, they recognised that there may be situations where this would not be possible. A minority of the students felt that in the case of such an impasse, deceiving a patient with dementia would be justifiable to protect family dynamics:

if the family didn't want the relative with dementia to be told the truth then you wouldn't do it.
Interview 3

Discussion

Ethical concerns about deceiving patients in clinical practice as outlined by Sokol aligned with the views of the medical students about communicating specifically with people with dementia. All of the itemised justifications for and objections to deception derived from Sokol's study (Table 1) were independently cited by students in this study, adding validity to the model. However, the nature of dementia specific factors meant that judgements about the most ethical course of action were thought to be even more complex. Whilst a minority of students felt that the presence of dementia should not make any

difference to the ethical reasoning process, the majority believed that additional considerations were necessary. The existence of a body of literature specific to ethical issues in dementia care suggests that this is a widely held view (Hughes & Baldwin, 2006; Nuffield Council, 2009).

Students highlighted judgement about the capacity of a person with dementia to be particularly challenging. Many recognised that dementia has the potential to affect different facets of capacity such as understanding, retaining and processing information, and that the likely impact of deception depended on each of these facets. Students' recognition of the dynamic nature of capacity in dementia added to their concerns about making the right decision about honest communication, particularly in acute care situations. Students were unsure about the wisdom of endorsing the beliefs of a patient with dementia if those beliefs were in conflict with their own, and whether failing to challenge a patient's beliefs constituted deception. Such concerns echo ongoing controversy about therapeutic techniques such as reality orientation and validation therapy where respect for autonomy, and empathy, must be carefully balanced (Neal & Barton Wright, 2003).

Whilst students recognised the importance of the autonomy of each individual with dementia, they expressed difficulties with determining an individual's "best interests" in isolation. Students recognised that each patient with dementia was situated in a wider community, with interdependent links to family and carers. Thus, decisions about deception could not occur without consideration of the impact on other parties. This type of reasoning in dementia care, recognising solidarity amongst families, is perhaps more akin to the frameworks of perspectivism and virtue ethics rather than traditional models of deontology, consequentialism and principlism (Hughes & Baldwin, 2006).

Implications for medical education

Students' concerns about the complexity of clinical judgement in dementia care highlighted a number of unmet learning needs. Students discussed dilemmas from a range of clinical spheres including general practice, acute medicine and psychiatry, demonstrating that communicating with PWD is not confined to specialist practice. As students progress through medical school, their clinical experience and the complexity of medical ethics teaching evolves. However, whilst students in year 1 had significantly less clinical experience than students in years 3 and 5, they cited examples of ethical dilemmas that they had witnessed prior to medical school, had read about in the media, or had arisen during medical ethics teaching. Even at this early stage, they were alert to the complexity of dementia care. Inevitably, students' learning needs in relation to communicating with PWD will change as they progress - further research with students at different stages of training, including recent graduates, would help to identify specific needs at each stage.

In a number of instances students witnessed behaviours of staff towards patients with dementia that they believed to be less than ideal, highlighting a recognised gap between educational messages received in the classroom and in clinical practice (Bennett, McCarthy, O'Flynn & Kelly, 2013; Hafferty & Franks, 1994). Students commented on the apparent mismatch between rule-based ethical ideals, as promoted in formal documents about professionalism, and the complexities that they had seen in practice. They expressed anxiety about their own ability to interpret professional guidelines and act in the best interests of individual patients at all times. It has been suggested that medical ethics teaching should be orientated towards the realities of clinical practice, with attention to the

practical difficulties of upholding ethical ideals in practice, in order to sufficiently prepare graduates (Vivekananda-Schmidt & Vernon, 2014). One of the means of doing so is encouraging students to recall and reflect upon dilemmas that they have directly witnessed. Our study suggests that dementia care encompasses a wealth of complex ethical issues that provide scope for such reflective activity, even at undergraduate level.

Care of PWD is relevant to medical students at all stages of training. As such, it has been suggested that dementia should be embedded as core topic within medical school curricula, associated with learning outcomes relevant to developing appropriate knowledge, skills and attitudes (Tullo & Gordon, 2013). The scope of this paper does not allow for an in-depth discussion of the nature of students' learning needs at different stages of training, or possible educational approaches to meeting them. However, a recurrent theme of uncertainty and anxiety about communicating with people with dementia in clinical practice suggests that there is scope to explore and improve medical education about dementia. Existing tools such as the Nuffield ethical framework (2009) and Sokol's flowchart (2007) may provide a helpful starting point.

Limitations

We acknowledge a number of limitations. The study took place at a single UK medical school – students at other UK medical schools and internationally may express different approaches to and concerns about communicating with people with dementia. It is possible that students volunteering to take part in focus groups and interviews were more interested in dementia or medical ethics than those who did not. Not all students expressing

an interest attended a session due to other commitments or for unexplained reasons. The anonymous nature of the questionnaire meant that individual responses to the question about lying could not be matched to the students that subsequently took part in focus-groups and interviews. However, as all students follow the same curriculum and clinical rotations, it is likely that the clinical scenarios cited by the participating students are relevant to the wider student population and that associated learning needs are shared. Whilst interviewing continued until no new themes were emerging, the complex nature of individual clinical scenarios means that we cannot claim to have reached saturation as such.

Conclusion

This study provides insight into some of the ethical dilemmas faced by medical students interacting with patients with dementia and their families during their undergraduate training. Using a pre-existing model of potential justifications for and objections to deceiving patients in general, we have demonstrated that the disease-specific nature of dementia may make ethical judgements about honest communication even more challenging. Whilst Sokol's model appears to apply to this distinct population of patients, we have further explored some of the most pertinent reasons for and objections against deception in the context of dementia. Medical students are aware of the complexities inherent to good communication in dementia care and are concerned about consistently applying ethical ideals in clinical practice. Growing numbers of patients with dementia accessing health services means that this is an increasingly pertinent topic, requiring further exploration of medical students' learning needs, and extension and improvement of medical education about dementia.

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Table 1

Potential reasons for deception

- To prevent great physical or psychological harm to patient (including death)
- To preserve or enhance hope
- Temporary deception to prevent potential great distress (for example, postponing disclosure)
- Compassionate deception (for example, to reduce great stress or anxiety)
- Patient is reliably believed or known not to want information
- Patient is not emotionally or cognitively equipped to decide or to cope with the truth
- Deception will enhance autonomy in the long run (for example, by preventing life threatening heart attack)

Potential objections to deception

- Violation of prima facie norm of honesty and codes of ethics
- If discovered, possible loss of trust by patient (greater in lying than non-lying deception?) and possible loss of public trust in medical profession (greater in lying than non-lying deception?)
- Possible emotional distress if lie/deception is discovered
- Failure to respect or enhance patient's immediate autonomy
- Violation of patient's right to know or right not to be lied to/deceived
- Difficulty of balancing potential harms and benefits of lying/deception
- Biased perspective/self deception may affect evaluation of lying/deception

- Greater tendency to lie/deceive in the future, including possible need to “shore up” present lie/ deception with further lies/deception

Table 2

- Responding to a patient with dementia who was asking about the wellbeing of a spouse that they did not remember had died.
- Communicating with a patient with dementia who was agitated, distressed or disorientated
- Safeguarding a patient with dementia if they were a risk to themselves or to others
- Disclosing the possibility of dementia as a diagnosis before clinical assessment was complete
- Responding to family members asking for the truth to be withheld from a relative with dementia

Table legends

Table 1. Potential justifications for deception and potential objections to deception in clinical practice as per Sokol (2007).

Table 2. Examples of clinical situations when a healthcare professional might consider whether deceiving a patient with dementia would be ethically acceptable or not.

Figure 1

Outline of focus group topic guide

1. Look at the questionnaires (ADQ/DCQ) you have already completed. Do you have any comments about any of the statements?

Statements with most variation (ADQ) (to pursue if not forthcoming):

2. Please consider these 2 scenarios, and discuss the related questions.

What are your thoughts on the actions taken so far?

What actions should hospital staff take now?

2.2 Imagine you are working as a doctor, and have a patient, Mr A, who has been exhibiting confused behaviour. Clinical assessment indicates that Mr A is in the early stages of Alzheimer's Disease.

What considerations would guide how you would inform the patient of this diagnosis?

What would you plan to do and to actually say when you inform them?

How might your delivery of this diagnosis differ from that of any other serious, non-dementia, condition (such as, for example, heart disease)?

3. Please discuss the following questions

3.1 How much control over their own lives can people with dementia be expected to have?

3.2 What do you think the effects of dementia might be on the way people with the condition communicate with others?

[continues]

Figure 2

Outline of interview topic guide

1. Orientation

Example: Is this an issue that you have thought about before? In what context?

2. Terminology

FG question used the term "lying", however participants introduced different terms such as (give list to participant). Example: What would be an appropriate umbrella term for these concepts?

3. Potential justifications for lying / Potential objections to lying

Present list (to what extent do you agree?). Example: To prevent great physical or psychological harm to patient

4. Rules (professional conduct)

5. Is dementia different?

6. Becoming a doctor

Some FG participants suggested that they would feel more comfortable not being completely honest with a family member who has dementia than a patient. Example: Are you told never to lie? By who? Does advice or teaching conflict?

7. Conclusion

Anything else we should know? Questions or concerns?