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Do People with Dementia find lies and deception in dementia care acceptable?

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Deception in Dementia care

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Do People with Dementia find lies and deception in dementia care acceptable?

**Objectives:** Research suggests that the use of lies and deception are prevalent in dementia care settings. This issue has been explored from the viewpoint of carers and professionals, and the acceptability and ethicality of deception in dementia care remains an area of heated debate. This article explored the issue of lies and deception in dementia care from the unique perspective of the people being lied to: People with Dementia.

**Method:** This study used a qualitative methodology, specifically, Grounded Theory. The study used a two-phased design. Phase one involved a series of one-to-one interviews with People with Dementia. During phase two, the participants were re-interviewed in order to develop the emerging theory. **Results:** Lies were considered to be acceptable if told in People with Dementia’s best interest. This best interest decision was complex, and influenced by factors such as the person with dementia’s awareness of the lie, and the carer’s motivation for lying. A model depicting these factors is discussed. **Conclusion:** This study enables the perspective of People with Dementia to be considered, therefore providing a more complete understanding of the use of deceptive practices in dementia care settings. This study suggests that the use of lies and deception in dementia care warrants further investigation.

Keywords: deception; Alzheimer; qualitative, grounded theory
Do People with Dementia find lies and deception in dementia care acceptable?

Introduction

A lady with dementia asks you where her father is. She has already asked you this question twelve times today. You know that her father died ten years ago, but the lady does not remember this and becomes distressed when reminded. What would you say to her next time she asks?

The above scenario reflects a dilemma which faces many people on a regular basis. Some people might choose to tell her the truth, whereas others may choose to lie to avoid causing her distress. Which response is ‘correct’, or the most ethical? This is the topic of investigation for the current project.

The morality of lying and deception more generally has been an ongoing debate for philosophers for many years (e.g. Kant). This debate is linked to the equally heated deliberations about the definition of a lie, and whether or not it should be differentiated from deception. This question persists in medical ethics literature (e.g. Benn, 2001), and more recently has been played out in the domain of dementia care (Elvish, James and Milne, 2010). Research suggests that the use of lies and deceptive practices are prevalent in dementia care settings (e.g. James, Wood-Mitchell, Waterworth, Mackenzie & Cunningham, 2006), and poses an ethical dilemma, affecting both carers and People with Dementia. Unlike the current study, much of the previous work has focused on the behaviours and perspectives of carers and professionals regarding this issue (Blum, 1994; Elvish et al, 2010; Cunningham, unpublished). In contrast, few studies have examined the views of People with Dementia; this is in spite of a growing body of literature advocating the inclusion of their perspectives in research (e.g. Wilkinson, 2002).
Indeed, until recently a medical model dominated the conceptualisation of dementia (Wilkinson, 2002), and the associated focus on a ‘disease of the mind’ has resulted in stigma and power inequalities (Harding & Palfrey, 1997). This has been reflected in dementia research, whereby People with Dementias’ experiences were, until recently, excluded (Cotrell & Schultz, 1993). Reasons for this included: the belief that cognitive and communication impairments make inclusion problematic (Goldsmith, 1996); a focus on caregiver burden (Kitwood, 1993); and a paucity of research methods facilitating inclusion (Wilkinson, 2002). Mindful of these issues and difficulties, the study has adopted a qualitative approach which is sensitive, flexible and robust enough to meet the needs of both People with Dementia and researchers.

In summary, the present study has explored the opinions of People with Dementia towards the use of lies and deception in dementia care, providing the unique perspective of ‘those being lied to’.

Methods

A qualitative methodology was selected, allowing detailed descriptions and meaning to emerge (Willig, 2001). A constructionist epistemology was espoused, which views meaning as constructed through the interactions of human consciousness and the outside world (Crotty, 1998). This approach was considered appropriate as it disputes the existence of an expert position for understanding (Anderson & Goolishian, 1992), shifting power away from the researcher, and truly encouraging the voices of participants.
Constructionist Grounded Theory methodology was selected (GT; Charmaz, 2006), enabling systematic theory development for a topic where no theory currently exists, whilst remaining congruent with the chosen epistemology.

Design

The study initially utilised a discussion group consisting of People with Dementia to develop the initial interview schedule, and to refine a series of vignettes for use in phase one. The study consisted of two phases: phase one involved a series of one-to-one interviews; and phase two involved re-visiting phase one participants for a second round of one-to-one interviews in order to refine the developing theory.

Participants

Fourteen participants took part in the study. Participants for all phases were recruited via clinicians working into local Older Adults (OA) services. The inclusion criteria were that participants had a diagnosis of Alzheimer’s Disease (in accordance with ICD-10 criteria), had adjusted to this diagnosis, were able to provide informed consent and possessed adequate memory functioning to engage in the interview process. The clinical judgements of clinicians were utilised to initially establish suitability rather than formal memory screening tools. Further discussions between the principle researcher (AD) and potential participants corroborated this judgement. Participants experiencing low mood were excluded due to the potentially distressing topic of discussion (as self reported and screened using an upper cut off score of 10 on the Geriatric Depression Scale, GDS, Yesavage et al., 1983).

The discussion group consisted of four participants (one male and three female, aged 69 – 91 years) residing in the care home where the discussion group was
held. This was for ethical reasons (participants could be seen in a familiar environment; Clarke & Keady, 2002), and practical reasons (increasing access; Bloor, Frankland, Thomas & Robson, 2001). Furthermore, a pre-existing group was deemed appropriate as participation in the group required disclosure of a potentially stigmatising condition (Farquhar & Das, 1999).

Ten newly identified participants were then interviewed on a one-to-one basis (phase one). The names of participant’s have been changed in order to provide anonymity. Demographic details are provided in Table 1.

Table 1. Phase one participant’s demographics

Sampling
Initial sampling was based on ‘sensible logic’; potential participants were invited from a variety of backgrounds and settings in order to facilitate variance. Theoretical sampling was then employed whereby data collection was informed by the emerging theory and the need to develop categories and their relationships (Coyne, 1997). After interviewing 10 participants, theoretical categories were saturated and recruitment ceased. Saturation occurs when interviews no longer reveal new insights into the categories, and the relationships between categories are sufficiently conceptualised (Charmaz, 2006).

Procedure
All participants were approached by their clinicians with an information leaflet and a reply slip. On receiving a reply slip, the researcher telephoned participants to arrange a visit to their preferred venue. During this meeting the researcher explained the
study, allowed the participant to ask questions, gained informed consent and administered the GDS.

The phase one one-to-one interviews were audio recorded, lasting between 26 and 57 minutes (mean: 36 minutes) and carried out in a setting familiar to the participant. At the beginning of the interview, participants were shown a series of vignettes, designed to facilitate discussion. Vignettes were selected from related literature (James et al., 2006; Blum, 1994; Roberts, 1999), and demonstrated the range and complexity of lies utilised in dementia care:

(1) A gentleman with dementia asks for his ‘deceased’ dog, the carer tells him his dog is asleep in the laundry room or is out for a walk. When the gentleman is told his dog is dead he gets distressed.

(2) A carer does not correct a resident who asks to go home to see a deceased relative.

(3) A lady with dementia urgently needs chiropody, but refuses to see the chiropodist. A carer tells the lady that she had already agreed to see the chiropodist, when in fact she has not.

(4) A carer hides the car keys of a gentleman so he cannot drive.

(5) A carer tells a lady that her daughter is coming to visit when in fact she is not. This is done in order to get the lady out of bed.
(6) Mirrors are placed on exit doors as a distraction in order to stop people ‘wandering’.

During phase two, eight of the participants were revisited in order to check the emerging model and develop certain categories further. The two participants not interviewed had moved out of the area. The latter interviews lasted between 7 and 17 minutes (mean: 13 minutes). Finally, the discussion group were revisited to inform them of the results of the study.

Ethical Considerations
The researcher initially met with participants to explain the study. Informed consent was taken at each point of contact, ensuring ongoing informed consent (Pratt & Wilkinson, 2001), and the researcher remained vigilant for any signs that the participants may wish to withdraw from the study. Participants were informed that withdrawing from the study would not affect any care they were receiving. Participants were sent a follow up letter after the interviews reminding them of available support. The project was independently peer-reviewed at Newcastle University and had a favourable ethical opinion from an NHS Ethical Committee.

Analytical procedures
The one-to-one interviews (phase one and two) were transcribed by the author (AD), and analysis undertaken using NVivo8 (QSR International, 2009). Data collection and analysis of the phase one one-to-one interviews occurred in an alternating sequence; analysis of the first interview informed the process for the next interview, resulting in a fluid and emergent data collection process. The range of topics narrowed as the
research progressed, allowing development of focused codes and the emerging theory (Charmaz, 2006). The Spencer et al., (2004) criteria for evaluating qualitative research were applied to this study to ensure methodological rigour. These included, for example, situating the sample and grounding the results in examples.

Results

The phase one and phase two one-to-one interviews provided an over-arching theme that the acceptability of lies and deception in dementia care varies according to whether or not the lie is in the person’s best interest. This ‘best interest’ decision was decided by three inter-locking categories: the person lied to (the person with dementia); the people lying (the carers); and the type of lie told. Figure 1 depicts a conceptual model which illustrates these categories and their inter-relationships.

Throughout the interviews, participants discussed their perspectives either by considering themselves as the subject (e.g. how do I feel about people lying to me because of my dementia, either now, or in the future?) or by considering other People with Dementia’s perspectives (how do I feel about people lying to other People with Dementia?). Generally, participants made use of both perspectives throughout their interviews. For reasons of clarity, the text will always refer to the people being lied to as ‘People with Dementia’.

Figure 1. Conceptual model depicting People with Dementias’ perspectives towards lies in dementia care
The acceptability of lies

The acceptability of lies emerged early in the analysis as a central concept. This central category describes a range of opinions towards the acceptability of lying to People with Dementia. These opinions sat along a continuum, ranging from unacceptable to acceptable. It became apparent throughout the analysis that overall, participants did not have a static view regarding the acceptability of lies. Rather, this varied in relation to other emerging categories. The acceptability of lies was therefore deemed central to the analysis due to its explanatory power and its ability to link other categories together.

The Person with Dementia

Awareness of lies

Participants discussed that People with Dementia’s awareness of lies would probably deteriorate as their illness progressed. Most participants reported that lies were unacceptable if People with Dementia had awareness of the lie i.e. if the lie was discovered (at the time or at a later stage), due to the negative impact this would have on people’s experience of dementia. However, when People with Dementia no longer have awareness of lies, most participants considered lying to be more acceptable.

‘...well that very much depends on how bad the dementia is. If it comes to an occasion where you’ve told a person that it’s not safe to do a thing and you find out she’s doing it, then I think that it would be satisfactory to use deception.’ Alf.

The experience of dementia

The main concepts constituting the experience of dementia as described by the
participants were: relationships; self-concept; personhood; and truth-related distress. All participants emphasised that, when awareness of lies existed, lying could produce a negative experience of dementia rendering their use unacceptable.

Participants reported that discovering lies would elicit negative emotions such as anger or distress, namely due to the impact on their relationships or self-concept. Participants suggested that discovering lies were being used could damage trust in their carers, putting themselves in a position of relative powerlessness.

‘...well if you said yes your daughter is coming, and she doesn’t, then she’ll never believe you again.’ Owen.

Participants consistently described lying as patronising or demeaning. They emphasised that lying could reduce their autonomy. As a consequence of being lied to, several participants said that peers might isolate themselves, leading to a reduction in their social support. Furthermore, it was thought that lies could impact negatively on people’s self-concepts, suggesting that others viewed them as being different: as a person with dementia rather than a ‘normal’ person.

‘...I’d think I must be stupid, there must be something wrong with us, I mustn’t be able to do things that I should be doing.’ Yasmine.

Discovering lies might also impact on people’s personhood, i.e. the status granted to People with Dementia by others. This sub-category overlapped considerably with ‘relationship’, particularly in reference to feelings of powerlessness and reduced autonomy. However, this sub-category was unique in that it also described the
detrimental impact of lying on People with Dementia even in the absence of awareness of a lie.

Participants also outlined the potential distress caused by the truth, and the capacity of a lie to reduce this ‘truth-related distress’. Generally, truth-related distress was viewed as having an emotional impact. However, truth-related distress could also be physical, and participants reported that lying could prevent physical harm. Thus, lies became more acceptable when they were used to reduce truth-related distress.

Personal beliefs

Some participants expressed the belief that lies are always unacceptable. This was linked to their understanding of the nature of the truth; a belief that the truth would always emerge. The concept of People with Dementia lacking awareness of lies was therefore obsolete for these participants, as truth would emerge regardless. Participants who believed this could not, therefore, discount the negative impact on the experience of dementia associated with lying, influencing their belief that lies are always unacceptable.

‘...The truth, the truth, you cannot beat the truth, ‘cause it comes out somewhere, sometime.’ Theresa.

Participants who did not express strong opinions about the nature of the truth tended to consider the conditions under which lying might be acceptable, and seemed to engage more in balancing the positives and negatives of lying.
The Carers

Who is lying and why?

Participants explained that the nature of the person telling the lie (the carer) was a key factor in determining its impact. Important variables included: who the carer was and their motive for lying; how they told the lie; and the alternatives available to them.

Several participants said that they would be more upset if they found out a relative or close friend was lying to them because of their dementia. This was linked to the fact that the participant’s expectations of these relationships were higher, and so the breach of trust would be greater. Furthermore, as relationships with family members tend to be long and enduring, the act of lying would mark a greater change in the carers’ behaviour.

‘...your friends, you would expect them to tell you the truth wouldn’t you.’ Abigail.

However, if the carer’s motivation for lying was in order to reduce truth-related distress (regardless of whether they did or not), lies were considered more acceptable.

How is the lie told?

Several participants described that lies told in an individualised and respectful manner were more acceptable than habitual lying. This was linked to the concept of personhood: even in the absence of awareness of lies, carers can grant People with Dementia dignity and respect. It also reduced the chance of carers lying habitually, and accidentally lying to People with Dementia who could discover the lie.
‘... if you can tell the person would be better with a lie… carefully tell the person one, you know. But I sometimes think that if you were continuously doing it… that’s when it makes our job difficult.’ Ollie.

‘... but he says it in a nice way, you know, he doesn’t say ‘ah your daft’’ Abigail.

What alternatives are available?
Lies were also deemed more acceptable if no alternatives were available to the carer. These alternatives were strategies that allowed truth-related distress to be reduced, and a more positive experience of dementia promoted, without lying. Examples provided were distraction or discussing the past. A further alternative strategy involved truth-telling in a way that minimised truth-related distress. Overall there was a feeling that if the truth was explained in a kind way, it would not be as distressing for the People with Dementia.

The nature of the lie
Different types of lies
Participants described several different types of lies, namely, blatant lies and little white lies. Telling People with Dementia something contrary to the truth was generally coined a blatant lie, whereas little white lies were described as deceptive acts more subtle in nature (e.g. misleading). Blatant lies were considered less acceptable than little white lies for several reasons. Firstly, participants felt that they would produce a more negative experience of dementia for People with Dementia if discovered. Also, blatant lies were linked to falsehoods regarding more significant events than were little white lies e.g. lying about the death of a relative. Again, this
resulted in greater distress if the lie was discovered. Little white lies however, were
demed more common-place, therefore their discovery by People with Dementia
would not impact so negatively on people’s self-concept (i.e. ‘normal’ people are told
little white lies too).

‘...well I think there is a sort of continuum of degrees of deception. When you get to
the point where you’re explicit, you say something that is simply false, I think that
falls into a slightly different category’. Nathan.

However, several participants viewed all lies as unacceptable, even little white
lies. Participants who expressed this opinion tended to view the nature of truth as
always emerging, and seemed to hold rigid personal beliefs about truth-telling.

Deceptive practices
Deceptive practices were also discussed, such as avoiding the truth, softening the
truth, or environmental deception (e.g. hiding people’s car keys). Participants
implicitly positioned these practices somewhere between the two polar opposites of
truth-telling and lying.

Reframing deceptive practices
The way in which participants understood deceptive practices influenced their
acceptability. For example if someone viewed these acts as variants of truth-telling,
rather than deception per se, the acts became more acceptable. Thus a number of
people who were not in favour of lying, were happier with deceptive practices, often
viewing them as viable alternatives to lying. Thus, acceptability of lies varied even
for those participants with rigid belief systems surrounding lying.

‘Well that’s good idea, a carer hid the car keys, then she doesn’t need any sort of conversation. Unless he says ‘where’s me car? I’m looking for me car’, ‘oh I haven’t seen it’ and then you would have told a lie.’ Owen.

The category ‘reframing deceptive practices’ had notable overlap with the category ‘how to tell the truth’, however, the emphasis when reframing deceptive practices was on the deceptive element (e.g. avoiding the truth), whereas the emphasis on how to tell the truth was based more on interpersonal processes (e.g. speak softly, hold their hand).

Summary of results

The acceptability of lies and deception in dementia care varied for participants according to whether or not the lie is in the person’s best interest. This ‘best interest’ decision was decided by three inter-locking categories: the person lied to (the person with dementia); the person lying (the carers); and the type of lie told. Thus, People with Dementia felt that the use of lies and deception could be acceptable if used in People with Dementia’s best interest.

Discussion

The current study indicated that some People with Dementia feel that lies can be acceptable when told in the person’s best interest. So when is a lie a ‘best interest lie’, and when is it not?
Namely, a lie was considered not to be in a person’s best interests if it produces distress, distrust or devalues the person. Understanding of this is offered by Cooley’s looking glass self (1902). The self develops through our perceptions of our interactions with others. Kitwood’s (1997) definition of personhood is congruent with this concept, whereby human value is bestowed on another in the context of a relationship. Thus, a discovered lie would impact negatively on People with Dementia’s relationships, and how they viewed themselves in the context of their social interactions.

This explains why several participants considered it less acceptable for someone close to lie to them rather than an acquaintance. It is those whom People with Dementia see every day and value who will have the greatest impact on their ‘looking-glass self’. This mirrors DePaulo and Kashy’s (1998) finding that lying can jeopardise the authenticity valued in close relationships. Furthermore, DePaulo and Kashy found that people lied less to those they felt closer to. Discovering close friends/family were lying would highlight a more notable change in carer behaviour, which would carry pejorative meaning to People with Dementia about the progression of their illness and their self-concept.

Further understanding of the potential negative impact of a discovered lie is offered by Clare (2003), who found that People with Dementia often use emotion-based coping strategies to deal with the onset of dementia (e.g. denial of their illness and normalisation of symptoms). However, discovering lying is likely to inhibit these coping strategies as reminding People with Dementia of their progressing illness. Therefore, lying not only produces distress, but also interferes with the emotion-based coping styles that many people may be utilising to adjust to their illness more generally.
However, lies are considered more likely to be in People with Dementia’s best interest if they have no awareness of lies, i.e. in the later stages of illness progression. Lying, therefore, became more acceptable if, on balance, it promoted the most beneficial outcome. That is, it reduced truth-related distress without producing the negative impact on people’s experience of dementia. Although most participants thought that lying was more acceptable when an awareness of lies had ceased, they were still wary of the negative impact of lying on people’s personhood. Advocating that staff lie in an individualised and kind way was likely a means of maintaining personhood whilst reducing truth-related distress.

A minority of participants described lying as always unacceptable. This was underpinned by a belief about the nature of truth: ‘the truth will always out’. These participants espoused a deontological, or ‘rule-based’, ethical approach (Kant): lying is always wrong. However, a consequentialist approach was also implied, as a lie, in their opinion, would always be discovered and therefore always produce an unfavourable outcome.

The nature of the lie further impacted on People with Dementia’s experience of dementia. In line with the existing literature on lies and deception (e.g. Blum, 1994), participants differentiated between deception and lies. Their definition of ‘blatant lies’ was similar to ‘outright lies’ defined by Vrij (2000; information provided is contradictory to the truth), and participants considered deception as more acceptable than ‘blatant lies’. Participants thought that ‘little white lies’ and deception would be less upsetting for People with Dementia if discovered, partly because they considered these to be more common place than ‘blatant lies’. This would not, therefore, mark such a change in carer-behaviour, resulting in a less negative situational appraisal, and a reduced impact on the person’s ‘looking-glass self’.
Interestingly, participants who believed that lying was always wrong, did not consider ‘avoiding’ or softening’ the truth to be deception. This allowed them to justify the reduction of truth-related distress, whilst maintaining their ethical stance that lies are always unacceptable. This corroborates Cunningham’s (unpublished) finding that euphemistic expressions can reduce lie-associated cognitive dissonance.

Thus, the factors of the person with dementia, the carers and the nature of the lie, combine in a complex equation to determine whether or not a lie is in the person’s best interests, and therefore whether or not it is acceptable.

A final implication of the current study is that the acceptability of lies varies between participants. The variation in personal beliefs suggests that a unified approach towards truth-telling in everyday dementia care would not be helpful, as this could reduce People with Dementia’s personhood and individuality. Carers should therefore enter into discussions with people, identifying their views towards lying before advanced disease progression. This would allow personhood and identity to be maintained in the context of social interactions even during advanced disease stages. De Boer et al., (2007) advocated the use of advanced directives with People with Dementia, and these may be a fruitful way of identifying people’s preferences towards truth-telling, informing their future care.

James et al., (2006) produced a draft guideline regarding truth-telling in dementia care, based on the suggestions of professional carers. Not surprisingly, these guidelines focused more on lies and deception from the view point of professional carers, for example, offering practical advice regarding record keeping and policies. These guidelines could be combined with the implications of the current study, resulting in a more balanced approach towards truth-telling in dementia care.

There were a number of limitations to this study. Firstly, although the
inclusion criteria included participants informed of their diagnosis, awareness of diagnosis fluctuated for some participants and was, at times, limited. This may have reduced the self-referential impact of this research. Secondly, it could be argued that asking People with Dementia about truth-telling could cause distress. However, it is anticipated that gaining the perspective of People with Dementia empowered them. Indeed, participants reported that they enjoyed the chance to share their thoughts and experiences on such an emotive subject area. Thirdly, as the inclusion criteria required the ability of People with Dementia to participate in an interview and the ability to provide ongoing informed consent, people in the later stages of dementia were excluded from this study. Although this was an inevitable consequence of an interview-based method, it is paradoxical in a study advocating inclusion and personhood for all People with Dementia. Finally, the current study explored theoretical perspectives only, and did not examine people’s actual reactions to lies. Other methods such as observation would facilitate the inclusion of participants with later stage dementia, and would allow observation of participants’ reactions when they are actually being lied to. This is potentially a fruitful area of future research.

Conclusion

This study explored the perspectives of People with Dementia towards truth-telling in everyday dementia care. The findings offered a unique focus on the impact of a lie on people’s personhood and their ‘looking glass self’ should a lie be discovered. In these circumstances lies were considered not to be in the person’s best interest, and their usage condemned. However, the findings also indicated that People with Dementia may consider lying to be acceptable if told in their best interest. Although this best
interest decision was complex and varied between participants, it suggests that the acceptability and ethicality of lies in dementia care settings warrants further investigation.
References


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Table 1. Phase one participant’s demographics

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Figure 1. Conceptual model depicting People with Dementias’ perspectives towards lies in dementia care

The Person with Dementia
- Awareness of lies
- Experience of dementia
- Personal beliefs

The Carers
- Who is lying and why?
- How is the lie told?
- What alternative are available?

The Nature of the lie
- Different types of lies
- Deceptive practices
- Reframing deceptive practices

The acceptability of lies