

Should I lie?

Approaches to dementia care



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Research Team

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The full research report can be accessed at www.publichealth.ie

Introduction

A common symptom of cognitive decline and memory loss in dementia is when the person with dementia believes that a deceased spouse is alive or they ask to 'go home' when their spouse is dead or they now reside in a nursing home. Carers are then faced with a dilemma *i.e.* do they 'correct' the person with dementia, tell them the 'truth' or do they tell them a 'lie' (Casey, et al., 2016). If they correct the person this may cause aggravation or stress. However, if they lie they are faced with ethical and moral dilemmas about maintaining the personhood of the person with dementia and their own professional practice.

There is a growing focus on this area and especially the role of **therapeutic lying** (McElveen, 2015). When a person with dementia says something that is false, those who advocate therapeutic lying recommend that the carer 'goes along' with the person's disoriented state and 'lies' and thus avoids conflict and reduces the distress of the person with dementia (Shellenbarger, 2004). However, the debate of the best path of action is complex and depends on a range of factors.

This paper provides a summary of research led by Professor Dympna Casey, National University of Ireland, Galway. The research was commissioned by the Centre for Ageing Research and Development in Ireland (CARDI) which is now the Ageing Research and Development Division of the Institute of Public Health in Ireland (IPH). The purpose of the research was to address the question: *"What is the best approach to take when a person with dementia says something that is false?"* (Casey, et al., 2016).

Key findings

- The acceptability of therapeutic lying is a complex issue and its use depends on who is lying, the relationships involved, the motive behind the lie, the nature of the lie and the understanding and capacity of the person being lied to. The appropriateness of therapeutic lying can therefore only be determined on an individual basis (Sprinks, 2013).
- The fundamental principle of dementia care should be the right of the person with dementia to be treated as a human being, equal to all others. People with dementia indicated that the characteristic of a "good" or acceptable lie is the intention to benefit the person, for example, to minimise or not cause distress (Casey et al., 2016).
- It is a breach of professional codes of conduct to lie to a patient. This would preclude the use of the therapeutic lying approach (Casey et al., 2016). However, there is currently a discrepancy between professional codes of conduct and / or ethical guidelines and health professionals' approach to dementia care which needs to be addressed.
- The approach to use of therapeutic lying should be guided by principles including
 - knowing and understanding the person with dementia,
 - giving consideration to family preferences,
 - using an individualised strategy,
 - and preserving dignity and autonomy (Casey et al., 2016).

Casey, et al. (2016) indicate there are three main approaches in current dementia care practice when a person with dementia says something that is false. The first, known as **reality orientation**, seeks to provide supports such as orientation boards and sign-posting to help the person with dementia understand where s/he is (Woods, Aguirre, Spector, & Orrell, 2012).

The second approach is known as **validation therapy**. This approach seeks to promote empathy between the person with dementia and his/her carer. Contrary to reality orientation, validation therapy does not seek to orient the person with dementia to the present but encourages the carer to empathise with the person with dementia. Strategies include both the person with dementia and their carer retreating together into the past, and in doing so, experiencing the lived and more vivid experiences of the person with dementia (Feil, 1992).

The third approach is called **therapeutic lying** (fibbing or telling a white lie). Sometimes referred to as therapeutic fibbing (Green, 2015), therapeutic lying stipulates that rather than the carer reorienting a person with dementia, they 'go along' with the person's disoriented state and 'lie' and by so doing avoid conflict and reduce the distress of the person with dementia (Shellenbarger, 2004). Such lies are typically underpinned by empathy and compassion for the person with dementia and this distinguishes therapeutic intent from harmful intent (Green, 2015).

There is no clear consensus regarding the use of 'white lies' and this approach raises questions about honesty, trust and integrity in dementia care. The level of dementia is recognised as having great relevance on deciding whether therapeutic lying or the telling of 'white lies' is appropriate or not.

The acceptability of therapeutic lying is recognised to be a complex issue and its use depends on a number of factors, including:

- who is lying,
- the relationships involved,
- the motive behind the lie,
- the nature of the lie and the understanding and capacity of the person being lied to including their stage in the disease process (Casey, et al., 2016).

Dementia in Ireland, North and South

There are an estimated 60,000 people with dementia living on the island of Ireland. With improvements in life expectancy and resulting demographic ageing, this figure is set to increase significantly in the future. In Northern Ireland (NI), the Department of Health, Social Services and Public Safety (DHSSPS, 2011) forecast 60,000 people with dementia by 2051 and Cahill et al. (2012) predict 140,580 people with dementia living in the Republic of Ireland (ROI) in 2041 (Cahill, O'Shea, & Pierce, 2012).

James et al. (2006) developed a set of 12 ethical guidelines governing the use of therapeutic lies in formal care settings. The guidelines focused on the lack of transparency regarding the use of lies in dementia care. The 12 points were:

1. Lies should only be told if they are in the best interests of the resident e.g. to ease distress.
2. Specific areas, such as covert medication and dealing with aggressive behaviour require individualised policies that are documented in the care plan.
3. A clear definition of what constitutes a lie should be agreed within each setting.
4. Mental capacity assessments should be performed on each patient prior to use of therapeutic lies.
5. Communication with family should be required and family consent gained if a lie is to be told to the patient.
6. Once a lie has been agreed it must be used consistently across people and settings.
7. All lies told should be documented to ensure lies are being told in patients' best interests.
8. An individualised approach should be adopted towards each case – the relative costs and benefits established relating to the lie.
9. Staff should feel supported by their manager and the patient's family. They should not feel at risk of being accused of misconduct by telling lies if they have been agreed using these guidelines.
10. Circumstances in which lies should not be told need to be outlined and documented.
11. The act of telling lies should not lead to staff disrespecting the patient. The lies should be seen as a strategy to enhance the patient's wellbeing rather than an infringement of their basic rights.
12. Staff should receive training and supervision on the potential problems of lying, and taught alternative strategies to use when lies are not appropriate (James et al., 2006).

Some psychiatrists have found the guidelines bureaucratic but a good starting point for ensuring a consistent and considered approach to the use of therapeutic lies within a nursing home setting. The guidelines also provide a framework to ensure that lies and deception do not spiral out of control and become an abusive means of social control rather than a therapeutic intervention to alleviate distress (McElveen, 2015). However, the introduction of guidelines for 'therapeutic lying' has been criticised by the Alzheimer's Society as encouraging people to live in a 'false reality' (Pemberton, 2013 cited in Kartalova-O'Doherty 2014). Debates remain regarding the appropriateness of providing formal guidelines for 'lying' in dementia care (Kartalova-O'Doherty 2014; Casey 2016).

Views of people with dementia

Casey et al. (2016) conducted focus groups, 14 people with dementia and their carers (five from NI and nine from ROI). Participants had a range of opinions on the acceptability of lying. These ranged from “not acceptable under any circumstances” to “acceptable in certain circumstances”. This continuum - “the acceptability of lying” - was fluid with actions determined by the context. Minimising truth-related distress was identified as the sole context when lying may be acceptable.

Participants agreed that the stage of dementia mattered. If the person was at a “bad” stage then it was more acceptable to lie to minimise truth-related distress. Participants equated the stage of dementia with awareness i.e. if the person was likely to become aware that they were being lied to it was never acceptable to lie. However, if the person had diminished awareness and was likely to be distressed then it was more acceptable use a “white” lie.

The fundamental principle identified as guiding actions by carers was the right of the person with dementia to be treated as a human being, equal to all others. People with dementia indicated that the characteristic of a “good” or acceptable lie is the intention to benefit the person, for example, to minimise or not cause distress. Acceptable approaches were distracting or avoiding as opposed to outright lying or deceiving. Participants in the focus groups made clear that the action taken must be respectful and mindful of the person’s dignity and under no circumstances should the person’s autonomy and control be undermined by the action taken.

Views of carers

In the focus groups, carers also viewed the acceptability of lying as a continuum ranging from “never acceptable” to “acceptable under certain circumstances”. Carers expressed concern that lying could cause mistrust, impacting negatively on their relationship with the person with dementia and they worried that “going along with” or seeming to accept the person’s mistake could make confusion worse. The “unknowingness” of dementia, the constant changes in the person’s capacity, added to carers’ concerns about inadvertently making the situation worse by doing the wrong thing. However, similar to the findings in the literature it appeared that the benefits of reducing upset for the person with dementia in some cases offset these concerns.

The carers talked about a range of different strategies that they used to manage the person’s anxiety, stress or agitation. These ranged from: telling the truth, moving on the conversation, reframing the situation, distraction and “going with” the person. Carers said that at times, in the interest of the person with dementia, they confronted or corrected statements. The carers’ approach to lying is described by Casey et al. (2016) as “*empathetic deception*”. It was done in the person’s best interest, in a context of knowing what matters to the person and in a way that maintained the person’s dignity. Carers were influenced by the capacity of the person with dementia and were more likely to tell the truth in the

earlier stages and lie by omission or avoidance in the later stages of the disease. At the heart of carers' actions was the intention to benefit the person with dementia. They identified an individualised approach, tailored to the person's needs and life history as being critical.

Informal carers in the focus groups were less concerned about the label given to the approach used – therapeutic lying, validation therapy or reality orientation –they highlighted that an **individualised approach**, tailored to the specific needs of the person with dementia cognisant of their life history was essential irrespective of the strategy used.

Views of Health Professionals

Casey et al. (2016) used a Delphi¹ survey² with dementia care experts to explore the most beneficial approach to take with people with dementia when they ask questions or make statements that are false. There were 54 participating experts in total (31 from ROI, 20 from the UK and 3 from Australia).

There were strong similarities between the views of the expert panel and those of people with dementia and their carers. There was recognition that every person with dementia is an individual and therefore no one approach could suit everyone. The expert panel agreed that practitioners must know and understand the person with dementia to be able to respond appropriately. The majority agreed that therapeutic lying was acceptable if done to protect the 'personhood' and autonomy of the person with dementia. The experts identified the need for guidelines for practice and for education and training for carers.

Being empathetic and trying to understand the person with dementia's entire frame of reference (validation therapy) was also deemed valuable in dementia care settings. They were strongly of the opinion that validation therapy promoted interaction and had a positive impact on the behaviour of people with dementia. However, a Cochrane review concluded that the effectiveness of this approach remained inconclusive (Neal & Wright, 2003). Most of the experts were familiar with reality orientation therapy and were generally in agreement that it is most effective when delivered at the individual level in a patient centred way and that not all patients with dementia will respond well to this therapy (Woods et al. 2012).

Professional codes of conduct and ethical guidelines

Casey et al. (2016) found a difference between respective health professional codes of conduct and ethical guidelines and health professionals' use of lying. It is a breach of professional codes of conduct to lie to a patient, which precludes the use of the

¹ <http://www.rand.org/topics/delphi-method.html>

² The Delphi technique is a multistage process involving a series of questionnaire rounds, interspersed by controlled feedback based on the results of previous rounds that seek to gain the most reliable consensus of opinion of a group of experts (Casey et al 2016).

therapeutic lying as an approach. For example, the ROI *Code of Professional Conduct and Ethics for Registered Nurses and Registered Midwives* declares that honesty, integrity and trustworthiness should underpin dealings with patients and “You should give honest, truthful, balanced information and advice to patients” (Nursing and Midwifery Board of Ireland, 2014). Similarly, the UK *Standards of conduct, performance and ethics for nurses and midwives* declare that professionals must act with honesty and integrity toward patients (Nursing and Midwifery Council, 2008).

Implications for policy and practice

Casey et al. (2016) confirmed that lying to a person with dementia with an intention to cause harm is of course never an acceptable strategy. The use of therapeutic lying was however considered to be an acceptable strategy by health professionals, informal/unpaid carers and people with dementia. The acceptability of therapeutic lying as an approach carries the caveat that it is being used to promote wellbeing and safeguard wellbeing of the person with dementia. The intention must be to minimise harm and distress. The appropriateness of this approach can only be determined on an individual basis.

Questions remain in relation to the codes of conduct, ethical and best practice guidelines governing the practice of healthcare professionals. These specify the need for truth telling and stipulate that lying to patients is inappropriate. As a result, revised guidelines are required which allow for the use of therapeutic lying by professional carers in acceptable circumstances.

Casey et al. (2016) developed a set of principles of care which should guide the approach taken to caring for people with dementia. The principles are relevant at all stages of the disease and promote the ideas of individualised approaches and individual dignity.

Principles of care

In order to provide optimal care for people with dementia it is essential that carers **know and understand the person with dementia**. A detailed life history of the person with dementia should be taken and updated regularly. This should enable the carer to know the person they are caring for and plan care that builds on this knowledge.

It is important when caring for a person with dementia that carers should give consideration to the family's preferences. The carer must **work with the family** to identify what these preferences are.

Carers must use **individualised strategies tailored to the needs of the person with dementia**. Carers should plan in advance what particular strategy/approach is most likely to be effective when the person they are caring for with dementia asks questions or makes statements that are false.

Carers must use approaches that optimise the functioning of the person with dementia whilst preserving their dignity and autonomy.

In addition to these principles of care, Casey et al. (2016) provide a list of reflective questions for carers, both formal and informal, to consider before using therapeutic lying with a person with dementia:

- Does this approach avoid harm to the person with dementia?
- Will this benefit the person with dementia?
- Is this approach in line with the wishes of the family?
- Does this approach maintain the personhood and dignity of the person with dementia?
- How will the use of this approach affect me as a person or carer?

Conclusion

The use of therapeutic lying in dementia care is a contentious and complex issue intertwined with considerations regarding the stage of the disease, individual and family preferences. This research concluded that therapeutic lying can be an appropriate response as long as it is used with the best interests of the person with dementia in mind.

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