

Should I lie?

Approaches to dementia care



Lay Summary





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Research Team

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

Introduction

This document presents the findings from a research project conducted on approaches to dementia care. It specifically addresses the issue of whether or not it is acceptable to lie to someone with dementia when providing care.

Key messages

- 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.
- It is never acceptable to lie to someone with dementia if the carer is not acting in their best interests.
- It may be acceptable to lie as long as the interests of the person with dementia are taken account of.

Why was this research done?

It is estimated that there are more than 60,000 people living on the island of Ireland with dementia. This is set to rise because people are living much longer. This research project was carried out to help improve our knowledge of dementia and make sure that people with the condition and their carers are supported in the best way possible.

What was the question?

“What is the best approach to take when a person with dementia says something that is false?” For example, if a person with dementia asks about a deceased relative or friend as if they were still alive.

Not knowing what to do or how to answer such a question is a source of worry and stress for carers and can violate the dignity of the person with dementia.

How was it done?

Carers and people with dementia took part in focus groups. In addition the research team searched published literature to identify relevant research that had been done previously. The information was then used to develop an online survey questionnaire which was completed by 47 experts like doctors, nurses, occupational therapists, physiotherapists, researchers and social workers.

What did the literature say?

Therapeutic lying is when a carer of a person with dementia responds to a false statement with the telling of a lie to minimise distress.

There is no clear consensus regarding the use of lying 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 i.e. does it make the person with dementia confused and anxious or does it have a comforting or a calming effect?

What did people with dementia say?

In the focus groups (14 people with dementia and 18 unpaid carers), people with dementia said that the fundamental principle guiding actions by carers should be the right of the person with dementia to be treated as a human being, equal to all others.

The perception of the acceptability of lying ranged from "never acceptable" to being "acceptable under certain circumstances". They indicated that characteristic of an acceptable lie is the intention to benefit the person. One example is to not cause distress. Acceptable approaches were distracting or avoiding as opposed to outright lying or deceiving.

What did the unpaid carers say?

Carers also viewed the acceptability of lying as a continuum ranging from “never acceptable” to “acceptable under certain circumstances”. In their interviews 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 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 best described as “**empathetic deception**”. In other words 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 in their decision 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.

What did the professional carers say?

There were strong similarities between the views of the professional carers and those of people with dementia and the unpaid carers. The professional carers agreed that therapeutic lying was acceptable if done to protect the ‘**personhood**’ of the person with dementia.

Significantly, however, the research found that codes of conduct for health professionals stress that each individual practitioner must tell the truth. In fact being untruthful is likely to put professional registration at risk. As a consequence professionals are left in a vulnerable and precarious position when faced with the dilemma of how to respond when a person with dementia says something that is false. They identified the need for formal guidelines for practice and the need for education and training for carers.

Implications for practice

The general consensus of participants was that when caring for a person with dementia there is **no single approach that will suit each person or be appropriate every time** when they ask questions or make statements that are false. Each situation requires carers to undertake an **individualised assessment** that enables a judgement to be made as to the best approach to take in any given context.

A key requirement for making these judgements is that carers must know the person with dementia including their preferences and know what their families think. In the context of nursing home care the detailed life history of the person with dementia is considered crucial to this process.

Principles of Care

The following four principles of care have emerged from this study:

1. 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.
2. It is important when caring for a person with dementia that carers should give consideration to the family's preferences.
3. Carers must use individualised strategies tailored to the needs of the person with dementia. Carers should plan in advance what particular strategy is most likely to be effective when the person they are caring for with dementia ask questions or make statements that are false.
4. Carers must use approaches that optimise the functioning of the person with dementia whilst preserving their dignity and autonomy.

In addition to the principles of care, the researchers created a list of reflective questions for carers, both formal and informal, to consider before using therapeutic lying with a person with dementia. These five questions are:

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

Conclusion

It is never acceptable to lie to someone with dementia if the carer is not acting in their best interests. However, if the intention is to benefit the person and not cause them distress, it may be acceptable to lie as long as the interests of the person with dementia are taken account of.

For further information on dementia care,
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