Can telling the absolute truth be unhelpful for people with dementia?

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UKDC
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Findings from the ‘Dementia Truth Inquiry’ panel

Work undertaken by
Mental Health Foundation commissioned by Joseph Rowntree Foundation
Panel members

Professor Graham Stokes (Co-Chair) Dr Daphne Wallace (Co-Chair)
Professor Murna Downs (Vice-Chair) Raydene Carver
Janice Clasper Ken Clasper
Jenny Edwards CBE Kate Emery
Philly Hare Professor Julian Hughes
Mark Ivory Dr Ian James
Dr Karan Jutlla Alise Kirtley
Simon Kitchen Keith Oliver
Catherine Ross Dr Kate Ross
Nada Savitch Rachel Thompson
Toby Williamson
Nature of the enquiry

Ran between 2014-2016
21 panel members; 18 expert witnesses

- Meetings
- Review of the literature
- Online survey open to general public
Why

“98% of professional carers admit to using untruths on a regular basis. Therefore this is a topic that can no longer be ignored. Carers are seeking guidance on what to do in challenging conditions. Simple, realistic and meaningful guidelines are essential.”

Panel member and Researcher on Communication in dementia
Key questions of the inquiry:

- What is the nature of reality for people who experience hallucinations or who are ‘time-shifted’?

- Is ‘non-truth telling’ justified in supporting people’s wellbeing?
Working definition

• “Lies” refers to blatant untruths initiated by a carer.

• “Untruths” refers to utterances which, in an attempt to match the person’s reality, convey less than the whole truth.
Deception (truth-lies) axis

- Whole-truth telling
- Looking for alternative meaning
- Distracting
- Going along with Misperception
- Lying

Carers Activity
Context

• Untruths viewed as forms of person-centred communication. Using this perspective, untruths can be seen as strategic therapeutic interventions.

• Their use is sometimes compared to use of psychotropic drugs (last resort).
6 underlying principles of all responses and interventions

- Realities/beliefs are meaningful.
- Know person to understand the meaning.
- When responding start *as close to whole-truth-telling as possible*.
- Environmental lies should be avoided.
- Consistent across family carers/staff.
- If ‘Not working’, should be documented
Moral and Practical Issues

• Emotive words - “truth” and “lies”
• Maintaining trusting relationships
• Supports wellbeing; not simply happiness
• Balancing the wellbeing of the person with dementia, their carer(s) and practitioners
• The pressures of ‘too little time’
• Fluctuating realities needs flexibility.
“I think my answer is the same as it always been. Whenever I’m running an education session and somebody asks me...’how do you deal with somebody who wants to go home and their home is no longer there?’ And my answer is always, ‘it’s complicated’.

It’s a very straightforward question, but it’s a very complicated answer”.

Expert Witness, Professional
Towards a consensus view

Untruths can of course be used deliberately for ill-gain,…

But this inquiry explored responses solely in relation to good intentions - of supporting wellbeing, avoiding unnecessary distress.
Consensus Statement:

Ultimately the panel agreed that there are times when untruths are justified in order to avoid unnecessary distress and to support the wellbeing of a person living with dementia.
Concern

This does not give a light for ‘lying as default practice’ (i.e. making it an “easy option”) in dementia care.
“It’s ‘horses for courses!’ Depending on the situation you are in.

Sometimes it’s best to go along with what the person is thinking. Not stay there, but at that moment to calm the situation down. So you’re not lying in the big word ‘lie’, you are not telling the truth, you are just floating sometimes in the middle, making the person feel more comfortable”

Expert witness, Family Carer
Dementia Orientated Reality: a tool for practice
The last two decades have focused attention on the use of lies in dementia care

- Ethical regulation of lies
  (GMC, 2013:21; NMC, 2008:2)

- Practical day-to-day effects of lying
Attitude toward ‘therapeutic lie’ (James 2003)

<table>
<thead>
<tr>
<th>Profession</th>
<th>Admitted to lying</th>
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<tr>
<td>Nurses</td>
<td>92%</td>
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<td>Psychiatrist</td>
<td>69%</td>
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<tr>
<td>Psychologist</td>
<td>90%</td>
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<td>Medical Doctors</td>
<td>53%</td>
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Mainly investigated in the UK and Australia (James, 2006; Tuckett 2012)

Cross-cultural studies (James 2006; Caiazzza 2015, 2016).
Therapeutic Lies
(Mackenzie et al. 2004; James et al. 2006)

Lies as a last resort:
- Truth
- Meet the need
- Simulate/substitute the need
- Distract
- Therapeutic lie

Ethical Guidelines for care settings.
First attempt to bring a pragmatic and ethical framework to bear on the topic
Carper 1978 – ‘Problem with nursing as a practice discipline’

- Nursing involves processes of dynamic interactions
- Nurses know more than they can communicate
Features

• Dealing with emotions
• Forming relationships
• Orientation to the present
• Time-shifted & memory
• Distraction
• Personal space/intimate space
• Reassurance
• Approaches to ADL
• Memory problems
• Misidentification
• Entering the world of the person with dementia
• Family interactions
• Going along with the person/therapeutic lies
Ideas

• Responding not reacting

• Verbal judo & use of functional language

• Empathic RAM
Why “Lying” is beneficial:

• Reduce concern when asking about deceased loved ones
• Reduces distress and aggression
• Improve compliance with care needs
• Reduce desire to leave
• Improve medication compliance
• Truths are often viewed as lies because of people with dementias’ memory problems
For every 1000 CB cases treated over 12 wks. period 91-200 patients will improve. But there’ll be an additional: 10 deaths, 18 vascular events (50% severe) & 60-94 patients with gait disturbance (Banerjee 2009)

Figure: Anti-psychotic side-effects
Problems with “Lies”

• Increase confusion due to lack of consistency
• Increase residents distress
• Cause friction between parties
• Cause distrust if recognised as a lie
• Problematic for carers and families
Dementia Orientated Reality - DOR
(Caiazzza & James 2015)

Information given to the person consistent with their beliefs, but inconsistent with the current reality.
Therapeutic Lies

Well-being

Ill-Being

Formulation-led

Lies of Wellbeing

Outright Lie

DOR

Manipulation

Non-Biographical
Newcastle team- current research in practice

- Guidelines for the use of DORc
- DORc Toolkit
Daisy Jones

Behaviour:
Wanting to go home at 3.30pm to pick up children from school
# DOR in practice: ‘Daisy’

<table>
<thead>
<tr>
<th>Meet the need</th>
<th>Response</th>
<th>Outcome</th>
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<tbody>
<tr>
<td>Substitute the need</td>
<td>Response</td>
<td>Outcome</td>
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<tr>
<td>Distract</td>
<td>Response</td>
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## DOR in practice: ‘Daisy’

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<tr>
<td>Explanation given that children are now grown up, have children of their own and are at work.</td>
<td>Daisy replies “you are lying my children are at school, why are you making things up?” . Shouting for police and screaming to be let out.</td>
<td>Daisy then becomes increasingly anxious and agitated, crying and shouting at staff. When continued to be used as a response and intervention results in Daisy kicking and hitting doors and windows.</td>
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<tr>
<th><strong>Substitute the need</strong></th>
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<td>Family have agreed when Daisy is wanting to pick up the children staff to support Daisy to ring the family via telephone.</td>
<td>When this interventions is used Daisy replies that she does not want to speak to family on the telephone she needs to pick her children up from school. Daisy also states ‘do you think I am Stupid?’</td>
<td>Increased anger pushing staff out of the way, throwing cups at windows. If continuing with this response then becomes physically aggressive towards staff and screams in a distressed manner wanting the police. Other residents in area become upset and start shouting at Daisy to shut up.</td>
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<td>From life story information Daisy has always been a family orientated person and enjoys talking about family life Also enjoys listening to Frank Sinatra type music Staff around 3.10pm ask Daisy to help them put her clean clothes away.</td>
<td>Can be distracted initially using life story work and music however at 3.30pm still returns to asking to be out to pick children up from school.</td>
<td>Wanting out of the home to pick up children. If not able to get out behaviours as above for ‘meet the need’ and ‘substitute’ the need. Considered moving clock however wears a watch and can still use appropriately.</td>
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<td>From life story aware that sister Olive used to share Picking the children up from school. When asking to be out to collect children from school tell Daisy that it is her sister’s turn to pick the children up from school today.</td>
<td>Daisy replies I forgot why did you not remind me I have been sitting here and could have been doing something else.</td>
<td>Remains settled and calm. Staff able to use the photo albums to engage in activity as well as the music that Daisy enjoys listening too. No aggression or agitation.</td>
</tr>
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Thank you
References

- Caiazza, James, Rippon, Grossi & Cantone. (2016). Should we tell lies to people with dementia in their best interest? The views of Italian and English medical doctors. FPOP bulletin.