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

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The last two decades have focused attention on the use of lies in dementia care (Blum 1994, Hertogh et al. 2004, James et al. 2003; Cunningham 2005; Wood-Mitchell, 2006).

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

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

- Mainly investigated in the UK and Australia (James, 2006; Tuckett 2012)
- Cross-cultural studies (James 2006; Caiazza 2015, 2016).

<table>
<thead>
<tr>
<th>Profession</th>
<th>Admitted to Lying</th>
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<tbody>
<tr>
<td>James at al. 2006</td>
<td>Nurses</td>
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<td>Culley 2013</td>
<td>Psychiatrist</td>
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<td>James et al. 2015</td>
<td>Psychologist</td>
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<tr>
<td>Caiazza et al. 2015</td>
<td>Medical Doctors</td>
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92% 69% 90% 53%
**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
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
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
(Caiazza & James 2015)

Information given to the person consistent with their beliefs, but inconsistent with the current reality.
Re-defining the notion of therapeutic lies: Dementia Orientated Reality

- Formulation-led
- DOR
- Well-being
- Lies of wellbeing
- Non-Biographical
- Manipulation
- Ill-being
- Outright lie

Therapeutic Lies
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><strong>Meet the need</strong></th>
<th><strong>Response</strong></th>
<th><strong>Outcome</strong></th>
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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>
<th><strong>Response</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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<th><strong>Distract</strong></th>
<th><strong>Response</strong></th>
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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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<tr>
<th><strong>Dementia Orientated Reality</strong></th>
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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>
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Nervous System – dizziness, fatigue, drowsiness, vertigo

- Restlessness
- Dry Mouth
- Fractures
- Diabetes
- Wandering
- Weight Gain
- Incontinence
- Sexual Dysfunction
- Parkinsonism
- Constipation
- Depression
- Tardive Dyskenisia
- Liver Toxicity
- Cognitive Decline
- Stroke
- Cardiotoxicity
- Increased mortality

For every 1000 CB cases treated over 12 wk 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
SIDE EFFECTS

**Benzodiazepines**

- Impaired judgement
- Agitation/aggression
- Withdrawal symptoms
- Tolerance to the drug
- Forgetfulness
- Impaired balance
- Dizziness
- Dependence
- Vertigo
- Depression
- Confusion
- Falls

**Examples of medications are:**

- Diazepam Librium
- Oxazepam Chlordiazapoxide
- Nitrazepam Temazepam
- Alprazolam Lorazepam

Hangover effect
What next….

- Mental health Foundation founded via Joseph Rowntree
- Truth telling Enquiry
- PHD’s
- International studies
Thank you
References

• Caiazza & James (2015). Re-defining the notion of the therapeutic lie: Person-centered lying. FPOP bulletin.
• 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.