Deception in residential aged care

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Outline of Workshop

- Background Issues
- Overarching Care Models
- Deception
- Integrating Deception into Care Models
Framework: What is health?

- WHO definition of health
  - “…a state of complete physical, social and mental well-being, not merely the absence of disease or infirmity”
- Longevity and quality of life - incompatible?
- Given limitations of age and ageing, esp in residential care setting, how can best quality of life be achieved?
Mental health in 65+

- 15-25% of older adults report psychiatric symptoms or disorders in the community vs 60-90% in residential aged care facilities (RACFs)
- Excluding dementia is ~20%
- RACF designed to cope with physical rather than mental health needs with sometimes under-trained staff and few mental health resources
Effects of Institutionalisation

- Some potential problems: lack of privacy, lack of self-efficacy, multiple losses, deindividuation, dependency, stress, new unfamiliar environment, family issues, negative stereotyping, loss of identity, lack of personal attention, increased and unfamiliar restrictions…
Behavioural and Psychological Symptoms of Dementia (BPSD)

- A heterogeneous range of psychological reactions, psychiatric symptoms and behaviours resulting from the presence of dementia
- 90%+ will experience such symptoms at some point (Mega et al, 1996)
PIECES framework to understand BPSD

- Physical problem or discomfort
- Intellectual/cognitive changes
- Emotional
- Capacities (incl. sensory impairments)
- Environment
- Social/cultural
Your Thoughts?
Where is fluffy?
Models of Care: 1

- Lawton (1999) - person-environment fit
  - Residential settings must
    - Maintain competence
    - Provide stimulation
    - Provide a sense of security and support
Models of Care : 2

- Cohen-Mansfield (2001) - unmet needs model
  - Challenging behaviours often reflect unmet needs
  - Without exploring potential unmet needs, difficult to resolve behaviours
Kitwood (1995) - Person-centred Care

Holistic models where the patient is placed at the centre of care

As opposed to the routines, rules or processes of the facility being placed first
Top 5 Strategy

- If a patient has a cognitive impairment, a staff member speaks with the primary carer to identify the 5 best strategies they think staff could use to support the patient by assisting in communicating patient needs and keeping them reassured and secure.
- Top 5 Strategies form is placed in the bed chart notes.
- To ensure personalized patient care and management, a discreet identifying label is placed on the top of the bed head so that all staff are aware of the Top 5 Strategies.
Example

- Does she have her cardigan with the fur collar- she loves it. If not, could you give her a heated blanket as she gets quite cold. She has a very very quiet voice - you may think she is just mouthing, but if you get down very close to her, you will hear her voice. When she fidgets and points to the door, she wants to go to the toilet. Please don’t have a male nurse bath or toilet her - she is a very modest lady.
Your Thoughts?
Defining Deception

What constitutes a lie?
Blum’s Categories of Deception (1994)

• Going Along: Not challenging ideas that are factually incorrect in everyday reality or hallucinations. May involve omitting the truth.

• Not Telling: Keeping impending events from a person with dementia. It is a preventive action on the part of the carer. An omission of the truth.

• Little White Lies: An untrue verbal statement.

• Tricks: An action on the part of the carer that relies on a lack of reasoning ability on the part of the person with dementia.
IS it truthful to:

• Give people medications covertly?
• Disguise the environment – e.g. painting locked doors of a dementia units, concealing bars?
• Pretend life-like dolls and animals are real (as in doll therapy)?
• Not tell someone with severe dementia their prognosis?
Another Example (Schermer, 2007)

- Simulated Presence is a device developed for Alzheimer’s patients, intended to manage behavior problems like agitation and withdrawal that are believed to indicate personal discomfort, and hence a lack of well-being. SimPres® is an audiotape that includes a caller’s side of a telephone conversation. The tape is made by a family member of the patient trained in special communication techniques and with a list of previously selected cherished memories of the patient to talk about. The audiotape can be played through a recording device that looks like a telephone, or using a headset and auto reverse tape player enclosed in a hip pack. Patients respond to the tape as if they were having a real telephone conversation. They smile and talk back and thus appear to believe that they are actually on the phone with their family member. Because people with Alzheimer’s disease have recent memory defects, audio taped messages can be played repeatedly and yet be perceived as fresh conversation each time. An evaluation study showed that SimPres® improved agitated or withdrawn behaviors and appeared to make patients feel good and enjoy…
Your Thoughts?
Prevalence:
Who is using deception and how often?
Interdisciplinary Questionnaire Study

(James, Wood-Mitchell, Waterworth, Mackenzie, & Cunningham, 2006)

Participants
• (N = 112) care staff, psychologists, doctors, occupational therapists, social workers and nurses

Results:
• Only 2 people (1.8%) never lied.
• 96% used lies in their work with people with dementia
• 81% felt comfortable telling their manager that they had lied
Results:

- 38% of psychiatrists ‘nearly always’ informed patients with mild dementia of their diagnosis
- Only 13% ‘nearly always’ informed patients with moderate dementia
- Only 6% ‘nearly always’ informed patients with severe dementia
83% of relatives of dementia sufferers DO NOT want the patient to be told the diagnosis

BUT

70% of the relatives would WANT the TRUTH if they had the disorder THEMSELVES!
Dementia Patient’s Perspectives
Marzanski, 2000

• 70% wanted to know what was wrong with them or wanted more information about their disorder
• 30% did NOT want to know
• Similarities with informed consent in neuropsychological evaluations
Reasons why staff use lies
(Elvish, James & Milne, 2010)

Number of responses

Purpose of lies

- Resident's distress
- Comply with treatment
- Get to do something
- Save time
- Carer's distress

Lies told by self
Colleague's lies
Current ethics and legislation are based on the premise of a common shared world, in which truth and reality, at least in principle have more or less the same meaning for everyone. That is also what we all think in daily life, but what is characteristic of the care provided for patients with advanced dementia is that care-giver and care-receiver no longer share the same reality. As a consequence, our common ethical standards no longer offer clear guidance and their applicability even becomes problematic in certain care situations.
Arguments FOR & AGAINST using deception
(James et al., 2006)

• 93% thought lying could be beneficial
  • eg reducing patients’ concern
  • Reduce desire to leave

• 88% acknowledged there could be problems
  • Increase distress
  • Foster distrust
Arguments in the Literature
Tuckett, 2004

For
• Autonomy
• Physical benefit
• Psychological Benefit
• Uncertainty principle

Against
• Autonomy
• Physical Benefit
• Psychological Benefit
• Intrinsic Good (of truth)
Develop Training and Guidelines  
(James et al, 2006)

- 85% welcome guidelines on lying
- Only 24% were aware of existing policies on lying
- 52% offered suggestions as to the content of guidelines on lying
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<tr>
<th>Suggested Guidelines</th>
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<td>Developed from participants qualitative comments (James et al, 2006)</td>
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<td>1. In the ‘best interest’ of the resident e.g. to ease distress.</td>
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<td>2. Use of lying requires care planning.</td>
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<td>3. A clear definition of what constitutes a ‘lie’ should be agreed within each setting.</td>
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<td>4. Consideration should be given to cognitive capacity, such as a residents’ ability to retain the truth.</td>
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<td>5. Communication with family and consent gained.</td>
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<td>6. Once a lie has been agreed it must be used consistently.</td>
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<td>7. All lies told should be documented.</td>
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<td>8. An individualised and flexible approach should be adopted towards each case – the relative costs and benefits.</td>
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<td>9. Staff should feel supported by manager and family.</td>
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<td>10. Circumstances in which a lie should <em>not</em> be told should be outlined and documented.</td>
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<td>11. The act of telling lies should not lead staff to disrespect the residents.</td>
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<td>12. Staff should receive training.</td>
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Your Thoughts?
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Models of Care: 2

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Models of Care: 3

- Kitwood (1995) - Person-centred Care
  - Holistic models where the patient is placed at the centre of care
  - As opposed to the routines, rules or processes of the facility being placed first
Example

- If she asks about her dog Winston, who had to be put down last year, she is probably thinking of him and missing him - they were friends for nearly 20 years. You might say “I know you loved Winston. Why don’t we go get a cup of tea and look at that photo album in your room together.” Usually after about 10 minutes she settles…
Conclusions 1

• Deception is widespread in dementia care
• Staff are often not advised about how to handle deception and the issue can inhibit good care.
Conclusions 2

• There a variety of reasons deception is used.
• There are pros and cons to both sides.
• It is an ethical and context dependent issue.
Conclusions 3

• The issue remains controversial; more guidelines and research are needed.
QUESTIONS?

- Thank you for your attention!