A response framework with untruths as last resort

Sometimes the truth causes distress, but is it ever right to lie to a person with dementia? **Edward O'Connor**, **Ian James** and **Roberta Caiazza** describe a practical framework which allows "therapeutic lies" as a last resort

In its recent report on the pros and cons of using untruths in dementia care (MHF 2016), the Mental Health Foundation concludes that in some circumstances the absolute truth may cause distress and that in these cases targeted untruths are appropriate. We have developed a four-step framework for responding to the problematic questions, sometimes leading to behaviours that challenge, which can be posed by people with dementia. The final step of the framework, which we will describe here, employs targeted untruths or "therapeutic lies" as a last resort.

The sorts of statements or questions asked include: "Let me get out, I've got to pick up the kids from school!", "Can I go home to see my mother, she is really ill?", and "Where's my wife?" We have been studying the manner in which staff deal with such questions for the last 14 years (James *et al* 2003) and have found that they frequently use lies when confronted with questions where truthful answers may cause distress to the person with dementia.

Our framework is designed to assist with the decision on how to respond to the difficult questions that give rise to these dilemmas. It was developed utilising practice-based evidence gathered by clinicians observing frontline staff using lies in dementia care settings, coupled with a review of the academic literature to support these observations. The framework provides a structure in which lies are the last resort as well as evidence that, where lying is deemed necessary, it has been done in a person's best interests and was the least restrictive option.

It could be argued that if therapeutic lies were recognised as a legitimate intervention, they would help to meet targets set by Banerjee (2009) to reduce the prescription of anti-psychotics as a response to behaviours that challenge. National Institute for Health and Care Excellence (NICE 2006) guidelines recommend deploying psychosocial interventions prior to the prescription of anti-psychotic medications. Our framework is based on just such an approach, calling on a range of psychosocial interventions and only turning to the use of lies if all else fails.

Framework in practice

When a person with dementia who frequently engages in behaviours that challenge expresses a specific wish or request (eg to go somewhere, or see someone, or meet a deceased member of the family), the "needs hierarchy" can help to frame a response. This is a progressive set of four interventions that was developed in line with the view that behaviours that challenge result from unmet needs. The four steps are:

1. Meet the request
2. Substitute or validate the need
3. Redirect to a new need
4. Meet the underlying need via a therapeutic lie (ie enter the person's reality).

Using the needs hierarchy one first tries to discover what the person wants (eg, a drink, to go to the toilet), and then one simply attempts to fulfil this need. We may discover, however, that the person's request is actually a means of getting something else. For example, a woman sitting in her room constantly shouting for her deceased husband may really want the company of others. Assisting her to go into the communal room resolves the shouting.

In trying to determine a person's needs, it is important to look at the context: what the person is saying, what her emotions are, and any behaviours that she is exhibiting. If we cannot meet the person's request (ie give them what they want), we must negotiate and see what can be done that will be an acceptable substitute. If this doesn't work we may use distraction methods, and if all else fails we may need to employ a therapeutic lie.

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These four steps are illustrated in tables 1 and 2. Each of the tables shows a progressive sequence of steps, whereby lack of success at one step leads to the next and lying is the last resort.

We have illustrated the needs hierarchy in practice with the example of "Peter" in table 2. Peter lives in a care home and gets up at 6am shouting and kicking at the exit door in an attempt to leave the building. He says: "Let me out, I mustn't be late for work." Last week, he hit a carer in the face when she told him that he was retired and did not need to go to work anymore.

It would not always be necessary to go through the steps in order every time Peter got agitated. For example, a care assistant's experience of caring for Peter may tell them that distraction is usually the best technique - so this is what would be tried first. Only if this was unsuccessful might a therapeutic lie be needed, and then only utilising the published guidelines (James *et al* 2006, box 1).

Real-world examples

In a series of training sessions the needs hierarchy framework was presented to staff, who were asked to use it over a period of four weeks to determine the hierarchy's utility. The full results of the project have not yet been analysed, but the following two examples show how care assistants have taken advantage of the framework (names have been changed).➤

Table 1: How the needs hierarchy works

STEPS

1. Meet the request or desire directly	If staff member can give the person what he/she wants in an appropriate and safe manner, this should be done
2. Substitute the need or validate the person's thinking	If staff can't meet the need directly then it may be possible to use a substitute. Alternatively, the person can be helped to talk about the topic in order to feel understood and accepted
3. Redirect from current need to a new one	Staff member should attempt to shift the person's need via distraction. It is hoped that through careful questioning and communication, the person will develop a new interest or desire, and forget the previous "problematic" one
4. Entering his/her reality: meet the underlying need via a therapeutic lie	Meet the need via the use of an untruth. The contents of the deception should be wholly consistent with the person's biography. The MHF report (2016) supports the use of untruths in such situations

Table 2: Trying to meet Peter's Needs

STEPS

Listen carefully to the request	Peter wants to leave the building, right now! (Do we know why he wants to leave?)
1. Meet the request or desire directly	Even though Peter's request to leave the building could possibly be met, we can't meet his desire to go to work.
Can the request be met at this step appropriately and safely?	*In this situation, we have chosen not to meet his request. On a previous occasion we tried to partially meet his request by assisting him to leave the building (we had hoped to take him for a walk). However, he became highly aggressive in his attempt to get to work, becoming a danger to himself and the public. So on this occasion we move to the next step in the hierarchy.*
2.Substitute the need or validate the person's thinking	We could ask him about his work, obtaining a better understanding of why he wants to go. If his request is associated with a need to be active, we could ask him to a do job for us on the ward (eg move boxes to another room). However, our knowledge of his memory difficulties and his past inform us that currently he is time-shifted. And at this moment he believes he needs to go to work, and if he doesn't get to work on time, he believes his pay will be docked. He thinks that, if this happens, he will be unable look after his family on the reduced wage.
Can we meet this need?	*In this instance, we think his need is to "look after and protect his family". Unfortunately, we have been unsuccessful in using either a validation technique or simulation method to meet or substitute his need. So we must move to the next step.*
3. Distract/redirect from current need to a new one	In order to distract we must initially connect with him. By getting his full attention, we can then try to refocus him on to a different need. We could ask him about a family member, or his favourite football team, guiding his attention away from work.
Can we distract?	*If the distraction is unsuccessful because he feels he is not being listened to, we will move to the next step.*
4. Entering his reality: meet the need via a therapeutic lie	If all the above fail, we are now justified in using a therapeutic lie. For example, inform him that it is Saturday, a day on which he did not work. Once we tell him it is the weekend, we can then suggest he has some toast and goes back to bed for some further rest.
Result of action	*Peter calms down, returns to bed*

➤ Example 1: "George"

George is an 89-year-old ex-engineer (see table 3), who was diagnosed with vascular dementia seven years ago. His wife Mary died six years ago, something he frequently forgets. The presenting need was that George wanted to go back home to see his wife every night. Initially, staff tried to re-orientate him by reminding him of his wife's death, but made him increasingly angry, upset and distressed.

Next staff tried to meet the need by substituting his desire to see his wife with another member of the family, so his son and daughter were invited to settle him in the evenings. But this did not appear to meet George's need either; in fact, it actually increased his distress. Given the negative outcome, staff attempted to shift his need by using distraction. They played music and talked about dance, which were two of his main interests in life. Unfortunately, after a short period of enjoyment George became socially isolated, depressed and withdrawn.

Finally, staff felt it was legitimate to "enter his sense of reality" and use a therapeutic lie. He was told that "Mary is staying over at her sister Edith's house". This event was a frequent occurrence throughout George's married life. It is important to recognise that this is a carefully constructed untruth, in which the place, person and topic are consistent with George's past experiences of his wife. In this sense, the lie is person–centred.

Table 3: Needs hierarchy framework for George

Meet the need Tell George the truth that his wife has passed away	**Response** He does not believe the care staff: "Don't lie to me, you are making this up!"	**Outcome** Angry, upset, crying and kicking doors and windows. Pacing around all night
Substitute the need Son and daughter come in every night to settle him	**Response** George wants to leave with his children and go back home	**Outcome** Again, he is angry and expresses feeling abandoned by his family. Becomes aggressive with the staff and family for attempting to leave
Distract Every evening care assistants try to distract George with music and dance	**Response** He enjoys this but still wants to go home to his wife	**Outcome** George becomes withdrawn and depressed, at times aggressive. Other residents become scared
Therapeutic lie Carers say that Mary (wife) is at the bingo with her sister Edith	**Response** "Oh she knows where I am and won't be annoyed or cross with me"	**Outcome** George is relieved and remains settled and calm. No display of the above emotions

Example 2: "Robert"

Robert is in 24 hour care due to his severe dementia and requires assistance for activities of daily living (ADLs) (see table 4). He is not orientated to the environment and is regularly confused, lacking insight into his dementia. This causes him to believe that he is in hospital being treated for poor mobility so he thinks he will be discharged soon.

Robert kept asking care staff (several times a day) when he would be discharged. Initially they tried to orientate him to his situation (telling him he was now living in care, etc), but he became angry. As he did not have insight into his circumstances, he did not believe what the carers were saying to him and distrusted them, which led him to refuse any further form of intervention or input to meet his other needs. Now the care assistants were telling the truth, but Robert insisted they were lying to him.

Changing tack, staff attempted to substitute Robert's need with the help of his wife. She decided to visit more

Table 4: Needs hierarchy framework for Robert

Meet the need Tell Robert the truth, that he is retired and in 24 hour care. That he is unable to walk and he will never regain this ability again	**Response** He does not believe the care staff and can't understand why they are "lying" to him. He becomes angry with the carers and fixed in his thought process	**Outcome** Negative impact on therapeutic relationship. Robert is angry with staff and now distrusts them, calling them liars. He now refuses to engage with staff, refusing personal care intervention. Causes distress to his wife as he remains fixed in the thought process, dampening his mood
Substitute the need Care staff request that Robert's wife engages with him	**Response** Again, Robert becomes angry and begins to argue with his wife. Not able to engage in a meaningful activity or conversation with her due to fixed thought process (belief that he is in hospital & will be discharged once able to walk)	**Outcome** Again, refuses any further care interventions due to low and angry mood. Detrimental to relationship with wife. Feels that he is being disrespected
Distract Talk to Robert about his interests and hobbies (royal family, football or other sports)	**Response** "Why are you avoiding the question?" Irritable and annoyed at carers for ignoring him and not taking him seriously	**Outcome** Robert demands to see the hospital manager and that the carers should leave. He becomes upset at their presence, refusing care interventions. Begins to shout loudly for the manager
Therapeutic lie Carers tell Robert that they are unaware of his discharge date but will arrange a meeting to get this organised	**Response** Robert thanks the carers for their help	**Outcome** He feels listened to and in control. He is accepting of all other care interventions offered, maintains his dignity, and is able to engage with carers in meaningful activity. Mood is not compromised and relationships (therapeutic and personal) are maintained

regularly to see if this might settle him, reassuring him in case he felt abandoned. However, he became angrier, now becoming distrustful towards his wife as well as staff. The next ploy tried by staff was to utilise his interests (football, sports, royal family) subtly to distract him whenever he started to query his discharge. But this technique proved unsuccessful too and Robert felt ignored, not taken seriously or listened to.

In view of these negative outcomes, with the support of Robert's family staff decided to enter Robert's world and use a therapeutic lie. When he asked about discharge, they told him they were unaware of his discharge date but that he needed to stay while his poor mobility was being treated. Following such statements Robert felt listened to and his mood improved markedly. Other outcomes were better relationships with staff and family, and greater amenability to intervention from staff to meet his ADL needs.

Conclusion

We have outlined the importance of a structured, evidenced and person-centred approach when interacting with people with dementia in circumstances where the truth may not be in their best interests. Clinicians are aware that lies are not the least restrictive approach, but are less restrictive than other options.

As a matter of fact evidence has shown (James *et al* 2006; Culley *et al* 2013) that untruths are frequently used in response to behaviours that challenge. Our framework ensures untruths are only told in the interest of the person concerned, giving a valid alternative to antipsychotic medication, benzodiazepine and physical restraint which can all be detrimental.

Capacity assessments and care planning with regular reviews are an important part of the picture. If a therapeutic lie is agreed on, staff have to ensure that the family concur and that a best interests assessment has been completed under the Mental Capacity Act. Whenever another intervention from an earlier step in the needs hierarchy can be implemented, for example distraction, then the care plan allowing the therapeutic lie should be stopped and a new care plan written.

In this context, communication strategies based on untruths such as therapeutic lies should be considered as a method of de-escalation of behaviours that challenge. In consequence, other aspects of care can be less restrictive than they otherwise would be. Staff can move between the different types of intervention based on the person's needs and identify which method is appropriate at a particular time - distraction, substituting the need, re-orienting and meaningful engagement, or therapeutic lying.

It should also be recognised that the framework can provide evidence of when lies are not effective as a response to behaviour that challenges. This would allow for the use of medications to be more thoroughly evidenced when taking into consideration the Banerjee (2009) and NICE (2006) recommendations.

Research is being carried out to generate more evidence to support the interactions we advocate and develop structured guidelines that ensure people's best interests are preserved within an ethical framework.

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