Therapeutic lying and approaches to dementia care in Ireland: North & South

Research Report

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Research Team

Prof. Dympna Casey, Dr Una Lynch (Sonrisa Solutions Limited, Banbridge, Co Down), Prof. Kathy Murphy, Dr. Adeline Cooney, Ms. Mary Gannon, Dr. Catherine Houghton, Dr. Andrew Hunter, Dr Fionnuala Jordan, Ms. Siobhán Smyth, Ms Aislinn Conway, Ms. Fidelma Kenny, Prof. Declan Devane and Dr. Pauline Meskell.

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Snowpetals

Gazing out at a garden
Assailed by a sudden hailstorm, you said
“Snowpetals” –
Grasping like a man overboard
For the raft of a word long sunk
In the shifting seas of memory –
“Is that the right word?” you asked
Like a child seeking affirmation.
I smiled, delighting in the endurance
of language, the resistance of the mind
to the closing waters of drowned neurons.
“No” I said “But it’s a better one.”
In the garden the sun-petalled daffodils
Defy the hailstones.

Carole Farnan (Carer)
Executive Summary

Background

There are currently more than 60,000 people with dementia living on the island of Ireland. Reflecting the demographic transition and improvements in life expectancy this figure is set to increase significantly in the years ahead. The Department of Health, Social Services and Public Safety (2011) forecast 60,000 people with dementia in Northern Ireland (NI) by 2051 and Cahill et al. (2012) predict 140,580 people with dementia living in the Republic of Ireland (ROI) in 2041. These demographic and epidemiological trends raise many questions and challenges for citizens and service providers across the island.

Aim

The focus of this study is to understand what the best approach for carers to take is for people with dementia when they ask questions or make statements that are false. The study employed a mixed methods design including; literature review, focus groups and an international Delphi survey of professional experts.

Literature review

The literature highlighted three main approaches in use when a person with dementia says something that is false. The first, known as reality orientation, seeks to provide supports such as orientation boards and sign-posting to help the person with dementia understand where s/he is. The second approach is known as validation therapy. This approach seeks to promote empathy between the person with dementia and his/her carer. Validation therapy encourages the carer to tap into the emotion of the person with dementia and empathise with her/him. The third approach is called therapeutic lying (fibbing or telling a white lie). There is no clear consensus regarding the use of this approach as it raises questions about honesty, trust and integrity. The level of dementia is recognised as having great relevance on deciding whether therapeutic lying is appropriate or not. The acceptability of therapeutic lying is recognised to be a complex issue and its use depends on a number of factors, including who is lying, the relationships involved, the motive behind the lie, the nature of the lie and the understanding and capacity of the person with dementia and their stage in the disease process. Of particular
significance is the apparent high prevalence of therapeutic lying despite the fact that a review of the codes of professional conducts state that the practitioner must tell the truth. In fact being untruthful is likely to put professional registration at risk. This apparent lack of coherence between practice and regulation needs to be addressed and merits further investigation.

Findings

Focus Group Interviews

In their interviews, 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. Interviewees indicated that a characteristic of a “good” or acceptable lie is the intention to benefit the person, for example, to or not to cause distress. Acceptable approaches were distracting or avoiding as opposed to outright lying or deceiving. Participants made clear that the action taken must be respectful and mindful of the person’s dignity and under no circumstances should the person’s autonomy and control be undermined by the action taken.

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 “unknowingness” of dementia, the constant changes in the person’s capacity, added to carers’ concerns about inadvertently making the situation worse by doing the wrong thing. However, similar to the findings in the literature it appeared that the benefits of reducing upset for the person with dementia in some circumstances may offset these concerns.

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 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. They identified an individualised approach, tailored to the person’s needs and
life history as being critical1. Such an approach they felt was not compatible within a system of hard and fast rules on “what to do”. In the context of the actions that formal carers should take, carers saw that therapeutic lying was appropriate when it benefited and respected the person’s dignity. They viewed themselves as the representatives of the person with dementia in the later stages because they knew them, knew their life history and knew what mattered to them. Consequently carers considered they had a role to play in preserving the rights of the person with dementia and they recommended the use of care plans, reflecting this knowledge, in formal care settings.

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1 The PWD’s life story is documented using photographs, stories or other memorabilia to help recall the important events, people and memoirs in the person’s life - the focus is on getting to know the person
Delphi survey of professional experts

The three round Delphi study found that there were strong similarities between the views of the professional carers and those of people with dementia and the unpaid carers. There was recognition that every person with dementia is an individual and therefore no one approach could suit everyone. The professional carers agreed that practitioners must know and understand the person with dementia to be able to respond appropriately. They agreed that therapeutic lying (white lies) were acceptable if done to protect the ‘personhood’ and autonomy of the person with dementia. They identified the need for development of guidelines for practice and the need for education and training for carers.

This research found that in determining the best approach for carers to take with people with dementia when they ask questions or make statements that are false that ‘one size does not fit all’. Consequently the governance structure within which practitioners are working must take cognisance of this and focus on capacity development for carers through training and education as opposed to creating a prescriptive model of care. Significantly, the codes of conduct for key health professionals e.g. nursing, medicine occupational therapists and physiotherapists stress that each individual practitioner must tell the truth. In fact being untruthful is likely to put professional registration at risk. Consequently, professional carers are left in a vulnerable and precarious position when faced with the dilemma as to how to respond when a person with dementia says something that is false.

Findings and implications for practice

No major conflicts or differences of opinion between study participants were identified. The consensus is that there is no single approach that will suit each person or be appropriate every time.

This study confirms that lying to the person with dementia with an intention to cause harm is never an acceptable strategy. The use of therapeutic lying was however considered to be an acceptable strategy by health professionals, informal/unpaid carers and people with dementia (PWD). The acceptability of therapeutic lying as an approach carries the caveat that it is being used to promote wellbeing and safeguard wellbeing of the person with dementia. The intention must be to minimise harm and distress for the person with dementia. The appropriateness of this approach can however only be determined on a case by case individual basis. The acceptance of therapeutic lying as a strategy is in keeping with other research (Culley et al. 2013; Tuckett 2012; James et al. 2006). The acceptance of therapeutic lying does however raise significant questions in relation to the codes of conduct, ethical and best practice guidelines governing the
practice of healthcare professionals; all of which specify the need for truth telling and stipulate that lying to patients is inappropriate.

Being empathetic and trying to understand the person with dementia’s entire frame of reference (validation therapy) was also deemed a valuable approach by health professionals. They were strongly of the opinion that validation therapy promoted interaction and had a positive impact on the behaviour of people with dementia despite the fact that the most recent Cochrane review concluded that the effectiveness of this approach remained inconclusive (Neal & Wright 2003). Most health professionals were also familiar with reality orientation (RO) therapy and were generally in agreement that RO is most effective when delivered at the individual level in a patient centred way and that not all patients with dementia will respond well to this therapy. These opinions correspond to the use of RO in a flexible patient centred manner (Woods et al. 2012).

Informal carers seemed less concerned about the label given to the approach used—therapeutic lying, validation therapy or reality orientation – rather they highlighted the fact that an individualised approach, tailored to the specific needs of the person with dementia cognisant of their life history was vital irrespective of the strategy used. They were wary therefore, given the unique needs of each person with dementia, of having specific rules and guidelines to follow. Similar to the health professionals they felt that irrespective of the strategies used, educating carers on their use should be a pre-requisite to implementation. Similarly, people with dementia were less concerned with the name given to the different strategies as long as the strategies used were respectful, mindful of the person’s dignity and autonomy and self-esteem. In this context acceptable approaches included therapeutic lying as well as the use of distraction and avoiding the false statement or question asked. Participants were clear that the dignity of the person with dementia must never be undermined and highlighted the importance of trust in relationships and the importance of carers taking time to get to know and understand the person.

In conclusion there were no major conflicts or differences of opinion among people with dementia, informal/unpaid carers and health professionals in terms of when it is acceptable to lie to a person with dementia. The consensus is that when caring for a person with dementia in the context of the best approach to take when they ask questions or make statements that are false, that there is no single approach that will suit each person or be appropriate every time. Rather than prescriptive guidelines, carers should 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. Consequently the governance structure within which practitioners are working must take cognisance of this and focus on capacity development for carers through training and education as opposed to creating a prescriptive model of care. It is also clear that a
discrepancy exists between respective health professional codes of conduct and ethical
guidelines and health professionals’ use of therapeutic lying, which is an alternative
approach to truth telling or correcting the person with dementia. This has serious
practical implications for health professionals. This paradox also increases the risk for
violation of the dignity of people with dementia and of professional carers and therefore
the formal regulatory frameworks merit urgent review and attention.

Principles of Care

The following principles of care have emerged from this study:

Prerequisites
In order to provide optimal care for people with dementia 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. This should enable the carer to know
the person they are caring for and plan care that builds on this knowledge.

Strategies
It is important that when caring for a person with dementia that carers should give
consideration to the family’s preferences. This means that the carer must work with the
family to identify what these preferences are.

Carers must use individualised strategies tailored to the needs of the person with
dementia. There can be no one approach that is appropriate for each person. Carers
should plan in advance what particular strategy/approach is most likely to be effective
when the person they are caring for with dementia ask questions or make statements that
are false.

Carers must use approaches that optimise the functioning of the person with dementia
whilst preserving their dignity and autonomy.

The following are a list of reflective questions which carers should consider before using
therapeutic lying (fibbing / telling a white lie) with a person with dementia:

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

Study Recommendations

• Each person with dementia is an individual. Therefore when s/he asks questions or make statements that are false the appropriate response from carers will be tailored to her/his personal needs.

• The response must improve the ability of the person with dementia to function, whilst preserving their dignity and autonomy.

• All carers must know and understand the person with dementia as an individual.

• All carers must be aware and understand the family’s wishes.

• All carers should receive education and training on the use of the accepted approach.

• This research should be used to address the lack of clarity or absence of formal guidelines for health professionals.

• An urgent review of health professional codes of conduct and ethical guidelines is required to include reference to and clarification of the use of therapeutic lying.

• Further research with larger populations to examine the effectiveness of approaches is required.

• Further research is needed to explore the development of a ‘spectrum’ of when it is acceptable for therapeutic lying to be employed.
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Introduction

Dementia affects 41,720 in the Republic of Ireland (ROI) and it is estimated that this will increase to 67,493 in 2021, representing a 63% increase, rising to 140,580 in 2041, corresponding to a 240% increase from 2006 to 2041 (Cahill et al. 2012). The most discernible growth in the number of people with dementia in the ROI will be in people aged 85 years and older. It is estimated that in Northern Ireland, 19,000 people have dementia, less than 1000 of whom are under 65 years of age. This figure is estimated to rise to 60,000 by 2051, representing a 215% increase (Department of Health, Social Services and Public Safety, 2011).

Progressive and debilitating in nature, the symptoms of dementia include continuing deterioration in cognition functioning leading to progressive memory loss, particularly recent memory, increasing levels of confusion and disorientation in time, place and person. Disease progression in dementia is generally described in three stages; early stage (1-2 years), middle stage (2-5 years) and late stage (5th year and after) (World Health Organization (WHO), 2012) or may also be described as; mild, moderate and severe stages (Hoe & Thompson, 2010).

As the disease progresses, behavioural and psychological symptoms become increasingly problematic, contributing to frequent hospitalisations and the decision to admit the person with dementia into a long term care facility (Finkel et al. 1996; Lawlor, 2000; Zuidema, 2007; Orgeta et al. 2011). Behavioural manifestations include wandering, agitation, aggression, insomnia, sexually inappropriate behaviour, hoarding and cursing. Psychological symptoms include depression, apathy, anxiety and psychosis (hallucinations and delusions) (NICE-SCIE, 2007; International Psychogeriatric Association (IPA), 2008).

Approaches to symptom control in dementia include pharmacological and non-pharmacological interventions. Non-pharmacological are more commonly referred to as psychological or psychosocial interventions. Psychosocial interventions for people with dementia are person centred in approach, defined as “human interactive behaviour between therapist and client” (Bates et al. 2004, p.654). In keeping with the concept of person-hood, common to all psychosocial approaches is the endeavour to understand the affected individual’s experience of dementia and, to employ strategies which optimise functioning and quality of life (Clare, 2003; Douglas et al. 2004).

A common symptom of cognitive decline and memory loss in dementia is when the person with dementia believes that a deceased spouse is alive or they ask to ‘go home’ when the reality is, their spouse is dead and they now reside in a long-stay care facility. Carers are then faced with a dilemma i.e., do they ‘correct’ the person with dementia, tell them the ‘truth’ or do they tell them a ‘lie’. In such situations Shellenbarger (2004)
recommends three different psychosocial approaches i.e., therapeutic lying, validation therapy and Aikido (a form of mindful communication). However it is not clear as to which of these is the optimal approach for people with dementia.
Aims & Objectives

The focus of this study is to understand what is the best approach for carers to take for people with dementia when they ask questions or make statements that are false. It consists of four objectives:

1. Determine the best approach for carers to take with people with dementia when they ask questions or make statements that are false.
2. Review the evidence on the preferences of people with dementia, particularly those who can make informed decisions at the earlier stages of their diagnosis.
3. Summarise the most recent research in the field of dementia care and the implications of the approaches taken e.g. therapeutic lying, reality therapy and other approaches.
4. Examine the practical implications for those health professionals who adopt alternatives to correcting a person with dementia, including a review of codes of conduct.

The promotion of dignity and the protection of rights for people with dementia was a key driver for the research team. Dignity is a notoriously difficult concept to define and this study is guided by Jacobson’s (2012) dignity encounters model. Jacobson (2012) separates dignity into human dignity that which we all have by nature of being human and social dignity, which is the result of our encounters with each other. Every social encounter is depicted as having one of two potential outcomes – promotion of dignity or a violation of dignity. The promotion of dignity is, she argues, dependent on trust and respectful communication. When two people meet if the more powerful person (carer) does not take account of the particular needs of the more vulnerable person (with dementia) there is a risk for violation of dignity.
Methodology

In keeping with the focus of this study a mixed method research design was employed. Mixed methods research involves the collection of both quantitative and qualitative data within the same study and combining the strengths of each approach to answer a research question (Creswell & Plano Clarke 2011). In the current study a mixed methods convergent parallel design was used whereby qualitative and quantitative data were collected at the same time, analysed independently, then conclusions were drawn through an integration of the results from the qualitative data and the quantitative data to answer the research question. The stages of the study are outlined in Figure 1.

Phase 1: Literature review

A comprehensive review of the literature on therapeutic lying, validation and reality therapy was undertaken, to determine which approach has a positive impact on the wellbeing and quality of life of people with dementia when they ask questions or make statements that are false. The importance of dignity in all encounters between people with dementia and carers was highlighted as essential and therefore a brief review of this concept was also undertaken. Finally a review of professional codes of conduct was completed.

The literature search was undertaken by a trained librarian who used the PICO principle to guide the search strategy\(^2\). A combination of free-text terms and appropriate controlled vocabulary from MeSH and Emtree were used to develop comprehensive search strategies for the databases selected\(^3\). This was an iterative process and terms were modified when required in response to the results.

\(^2\) This technique focuses on P Population/patient, I Intervention/indicator, C Comparator/control O Outcome

\(^3\) Emtree and MeSH are both comprehensive biomedical and life science thesauri.
The following key databases were searched to identify relevant studies: the Cochrane Library, PubMed, Embase, CINAHL, Scopus and Web of Science. Search strategies were structured and adapted to suit the functionality of each of the databases. The following information was documented for each database: the name of the database and the platform by which it is delivered, the years of coverage of the database, the date the search was conducted, the limits/filters used, the number of results and the search terms.

**Reality orientation**

Developed in the United States in the late 1960s, reality orientation (RO) was initially used to improve the quality of life of confused older persons. Its use was extended to persons with dementia in the early 1980s. RO, described as a cognitive-oriented intervention (American Psychiatric Association, 1997), aims to improve cognition. Sessions may be delivered one to one but are typically delivered at a group level, usually in a classroom setting and involve all staff caring for the person with dementia. Staff caring for the person with dementia and trained in the process of RO facilitate orientation to reality with the aid of a variety of props including orientation boards which detail the present date, time and location, discussion of recent events and sign-posting (Spector et al. 2000; Spector et al. 2010).

Early observational studies (Salter, 1975; Cornbleth & Cornbleth, 1978) reported that group
RO was associated with improvement in cognitive functioning and general behaviour. Likewise a Cochrane systematic review of RO for dementia in 2000 reported positive outcomes (Spector et al. 2000). Six randomised controlled trials (RCTs), with a total of 125 participants with a diagnosis of dementia based on DSM-IV or ICD-10 criteria were included in the review meta-analysis. A statistically non-significant change in cognition and behaviour was found but the trend was in favour of RO. The review concluded that there was some evidence that RO improved cognitive functioning and behaviour in older people with dementia but these positive effects may be short lived. Over time however RO became associated with a more inflexible challenging approach toward people with dementia and its use declined (Woods et al. 2012) It is now subsumed under the umbrella of cognitive stimulation therapy which seeks to employ the positive elements of RO in a more sensitive and person centred approach (Woods et al. 2012).

Validation Therapy

Validation therapy was conceived as a possible remedy to the seeming lack of efficacy of RO in nursing home residents with advanced dementia. Feil (1993) describes validation therapy as a therapy that facilitates communication between carers and people with dementia. Validation therapy is based on the acceptance of reality and the personal truth of a person’s experience and it puts emphasis on the emotional content of what the person with dementia is expressing (Feil, 1992). According to the Nuffield Council on bioethics, (2009) it may be appropriate to seek to respond to the emotions involved even if this involves some degree of latitude with the truth. This in itself could be considered truthful because it responds to the actual concerns of the person with dementia rather than what is being said (Nuffield Council on Bioethics, 2009). It is the more than what is said, it is about sincerity and being considered trustworthy (Hertogh et al. 2014).

Its creator, Naomi Feil (1993) outlines that validation therapy, contrary to RO, does not seek to orient the person with dementia to the present but encourages the carer to empathise with the person with dementia. Strategies include both the person with dementia and their carer retreating together into the past, and in doing so, experiencing the lived and more vivid experiences of the person with dementia. Feil (1993) contends that living in the past is not as demanding of the person with dementia as it concentrates on their preserved abilities, i.e., their ability to recall past memories. In contrast to living in an unfamiliar present, retreating to a familiar past is far more pleasing and less stressful for the person with dementia (Douglas et al. 2004). According to Kitwood (1997), validation therapy is recognised as offering a good level of empathy with the intention of understanding a person’s entire frame of reference. However, researchers argue that, like many psychosocial interventions advocated for use in dementia care, validation therapy does not have a definitive theoretical underpinning and the evidence to support its use stems largely from observational studies. These studies report that, validation therapy promotes better communication and interaction between the carer and person with dementia; it has a positive effect on behavioural symptoms and enhances the quality of life of both carer and person with dementia (Bleathman & Morton, 1988; Babins, 1998).
However, converse to findings arising from qualitative studies, evidence from the most recent Cochrane systematic review (Neal & Wright, 2003), evaluating the effectiveness of validation therapy for people with dementia concludes that there is inadequate evidence to support the use of validation therapy for people with dementia. Three RCTs met the inclusion criteria for this review but because of the diversity in duration of treatment, lack of comparability between control groups and outcome measurements, pooled analysis was not feasible. The review authors concluded that, as yet, there is insufficient evidence to support the use of validation therapy for people with dementia.

Aikido

This is another approach used with people with dementia to help resolve false beliefs. In this approach rather than seeking to lie or distract Aikido uses what the person with dementia is saying/doing as an opportunity/means of showing empathy. It is therefore more akin to validation therapy as the carer focuses on the underlying truth of the emotional content rather than just the word content of the communication process. However Aikido is poorly defined and no empirical evidence in the literature was identified to support its use with people with dementia.

Lies, and Therapeutic lying

An alternative approach to validation therapy is therapeutic lying. However, before discussing therapeutic lying it is important first to briefly examine the concept of ‘lying’ and how a lie is defined.

Lying is a deliberate form of deception and is described as having three key elements: it communicates information, the person communicating the information intends to deceive or mislead and the person receiving the information perceives the information to be true (Ludwig, 1965). In contrast a ‘white lie’ or a ‘fib’ is defined as a “a lie that is told in order to be polite or to stop someone from being upset by the truth” (Online Cambridge Dictionary, 2015). A white lie therefore is one not intended to harm the receiver. In reality it is often intended to benefit the receiver or make them feel good. However white lies are not without harm. They do actually deprive the receiver of information they might find beneficial, even if they do not like it and the person delivering the white lie may find lying an easier option in the future (Green 2015).

Therapeutic lying sometimes referred to as therapeutic fibbing (Green 2015), stipulates that rather than the carer reorienting a person with dementia, they ‘go along’ with the person’s disoriented state and ‘lie’ and by so doing avoid conflict and reduce the distress of the person with dementia (Shellenbarger 2004). Such lies are typically underpinned by empathy and compassion for the person with dementia and this distinguishes therapeutic intent from harmful intent (Green 2015, p13).

There are many ethical concerns associated with the practice of therapeutic lying which make it very challenging (Culley et al. 2013). The main ethical principles affected are
autonomy, beneficence and non-maleficence. Autonomy centres on the person’s right to self-determination and the carer’s role in promoting independence for the purpose of realising self-determination (Barber & Lyness, 2001). Beneficence is about making decisions that are in the best interest of the person with dementia and non-maleficence is about minimising harm to the person with dementia (Barber & Lyness, 2001). Therapeutic lying can threaten a person’s autonomy when it is used to deny the voice of the person with dementia in their care whilst only achieving short term goals such as reducing agitation (Brannelly and Whitewood (2014). However, therapeutic lying may be considered acceptable when non-maleficence and compassion are its motives (Sperber 2014; Stubbs, 2013; Tuckett, 2012). It is also important to consider the impact of therapeutic lying on the carer. Trust is a moral principle of care, and lying compromises the trusting relationship between the person with dementia and their carer (Feil & Altman, 2004; Schermer, 2007; Barnes & Brannelly, 2008). This behaviour/action may therefore have a negative impact on the carer who may feel uncomfortable with the deception and the associated impact on their integrity (Schermer, 2007). The literature also highlights that the stage of dementia is an important consideration when deciding to use therapeutic lying. Taylor (2007), writing from the perspective of the person with dementia, asserts that lying is not acceptable to people in the early stages of dementia as it heightens that disconnect that they experience from reality. However as dementia progresses and capacity diminishes, the less possible it becomes for the person with dementia to entertain beliefs, either false or true. Schermer (2007) purports that lying to someone requires a capacity to hold beliefs about what is true and what is not, thus making it conceptually impossible to lie to someone in an advanced state of dementia. If a person is not aware of being ‘lied’ to due to memory loss, the ‘deception’ may be viewed as less threatening and potentially beneficial (Kartalova-O’Doherty et al. 2014). Lying with an intention to cause harm is never acceptable.

The literature review found mixed perceptions on the use of therapeutic lying when caring for people with dementia. For some any type of lying is seen as deceptive, a form of abuse and using lies for the purpose of compliance is considered a form of treachery (Kitwood, 1997; Bush, 2003). James et al. (2006) explored the use of therapeutic lying using an exploratory survey of staff (n =112) working in residential homes, elderly mentally ill units and hospital wards from the United Kingdom (UK) and ROI. They found that the majority of health professionals (96.5%) reported that they lied to residents with dementia. Over half the staff (51.1%) used lying to promote compliance and to benefit staff and save time (30.2%). Likewise, Culley et al. (2013) found that of the 29 psychiatrists surveyed on the use of therapeutic lying, the majority (69%) reported they had lied to people with dementia when it was deemed to be in the best interests of the person. Elvish et al. (2010) also found that lying was more acceptable to health care professionals when the focus was to reduce harm to the person with dementia. Their study used a two phased design, the first of which involved developing and piloting the attitudes towards lying to people with dementia (ALPD) questionnaire; and the second aimed at validating the questionnaire at a workshop. In phase one, participants (n=151), including psychologists, nurses, care workers and social workers, were asked to complete the newly
developed questionnaire. Results showed that lying was considered more acceptable when it was in the person’s best interest or to prevent injury as opposed to being used for the purpose of compliance. Tuckett (2012) also found lying was used by nurses and allied health professionals (n=18) caring for people with dementia for the purpose of eliminating harm and to control behaviour. In this study, the consequences of lying were important as identified by the concept of ‘settling’ a resident by lying to them. Participants identified validating the person with dementia’s reality as benevolent lying as opposed to ‘out and out’ lying. It is interesting to note that despite the fact that professional guidelines and codes of conduct do not support lying to patients irrespective of cognitive status health professionals report that lying to people with dementia is an approach they use (Culley et al. 2013; Tuckett 2012, Nuffield Council on Bioethics, 2009; James et al. 2006)

Few studies have explored people with dementia’s perceptions of lying. Day et al. (2011) using a grounded theory approach explored lying from the perspective of the person with dementia. In this study, persons with dementia (n=14) felt that lying was acceptable if it was in the best interest of the person, but not if it caused distress or devalued the person. Green (2015) in her unpublished Masters thesis interviewed carers to explore the impact of therapeutic lying or therapeutic fibbing. All participants had experience of caring for the person with dementia from diagnosis to the advanced stage. The findings found that carers overwhelmingly supported the use of therapeutic lying. For them the benefits of reducing or preventing emotionally upsetting or agitated situations for the person with dementia outweighed any ethical or moral concerns. Most carers also focused on the value of therapeutic lying in improving and benefiting the person with dementia rather than the impact on themselves. However the relationship between the carer and the person with dementia, the importance of really understanding and knowing the person with dementia was identified as key to using therapeutic lying.

A recent literature review undertaken by Kartalova-O’Doherty et al. (2014) funded by the UK Mental Health Foundation, reveals similar factors that given the use of therapeutic lying to those mentioned above. They examined the argument around truth telling with people with severe dementia when they are confused and disorientated. This review included 13 peer reviewed articles, 4 Cochrane reviews and 5 books/book chapters as well as 20 ‘grey’ literature sources. The factors they identified governing the decision to tell the truth or not, include who is delivering the information; when is it delivered, in terms of dementia stage and timing; how or manner of the communication process; why or purpose of the lie; where this takes place e.g. home or residential care.

In summary, the acceptability of therapeutic lying is a complex issue and its use depends on a number of factors, including who is lying, the relationships involved, the motive behind the lie, the nature of the lie and the understanding and capacity of the person being lied to including their stage in the disease process. Ultimately, it seems that the appropriateness of therapeutic lying can only be determined on an individual basis (Sprinks (2013). However, it must be noted that few published studies have explored the use of therapeutic lying in caring for people with dementia (Culley et al. 2013, Day et al.
2011, Elvish et al. 2010, James et al. 2006, Tuckett 2012) and much of the discussion here regarding therapeutic lying comes from the ‘grey literature’ i.e. commentaries and letters to the editor (Zeltzer, 2003; Feil & Altman, 2004; Hardy, 2005; Schermer, 2007; Taylor, 2007; Sprinks, 2013; Stubbs, 2013; Brannelly & Whitewood, 2014; Sperber, 2014; Toivainen, 2014)

The next section presents some considerations around dignity as a concept and its context in relation to dementia care.

Dignity

Although widely accepted as a desirable outcome, dignity as a concept is also criticised as being subjective and difficult to operationalise (Nordenfelt and Spjuth, 2004). In the literature dignity is largely used as a stand-alone concept and is ill-defined or not defined at all (Macklin, 2003).

Nordenfelt and Edgar, (2005) identify four classifications of dignity. Dignity of merit is associated with a person’s position or role in society. This is culturally defined and may be associated with ‘old age’ and the inherent wisdom of elders (Tadd, 2004). Dignity of moral status is associated with an individual moral “autonomy or integrity…” Dignity of identity is associated with self-respect and reflects the individual’s sense of personhood. This type of dignity is dependent on relationships with others and a sense of inclusion in society. It can be violated by physical interference and emotional insults and may be affected by physical or cognitive decline. The final classification Menschenwürdem, is defined as the universal dignity. Menschenwürde has much in common with Kant’s notion of human dignity that requires human beings to be treated with respect as the ‘inalienable value of human beings’ and cannot be lost as long as the person exists.

Jacobson (2009) identifies two types of dignity, ‘human dignity’ which is similar to universal dignity and ‘social dignity’ which is created in the interpersonal interactions between individuals, groups and societies. Jacobson’s work is grounded in human rights and promotion of equality. Jacobson argues that every human interaction has the potential to be a ‘dignity encounter’. These encounters she argues can result in one of two outcomes: the promotion of dignity or the violation of dignity. Dignity violation is more likely to result from an encounter in which there is a power imbalance with one person placed in a position of vulnerability due for example to cognitive impairment as in the case of the person with dementia. The impact is further exacerbated when the other actor is not sympathetic due to prejudice, personality or ignorance. The setting in which encounters take place can also exacerbate the situation. So-called harsh environments that fail to take account of the diversity of users, serve to reinforce distance and power imbalances. Jacobson (2009) characterises these settings as hierarchal and inflexible characterised by stress and a sense of urgency but deficient in resources. The people working in such environments are less likely to be empathetic to others and are also more likely to perceive questioning or non-cooperation as an ‘attack on their dignity’. Being in a ‘position’ of vulnerability is at the core of dignity violation. This vulnerability may stem
from internal factors such as physical disability, and/or cognitive impairment and external factors such as lack of knowledge or skills.

The next section presents a review of national and international guidelines on dementia care and care of older people as well as relevant health professional codes of conduct.

National and international guidelines

A review of national and international guidelines on dementia care and care of older people and national and international codes of conduct, ethics and best practice guidelines for healthcare professionals was undertaken to examine the practical implications for those health professionals who adopt alternatives to correcting a person with dementia (Appendix 1).

This review found that in England, Scotland, Wales, Northern Ireland, America, Australia and the Republic of Ireland there are no official guidelines for health professionals on the best approach to take when working with persons with dementia who ask questions or make statements that are false. James et al. (2006) published guidelines as part of an academic study into lying in formal care settings. Professional codes for all the disciplines considered (nursing, medicine, occupational therapists and physiotherapists) stress that individual practitioners must tell the truth. Indeed these codes of conduct indicate that not being truthful is likely to put professional registration at risk. It is worth noting therefore that research on the use of informal efforts to support staff in therapeutic lying (Culley et al. 2013; Day et al. 2011) appear to be at odds with professional guidance to be truthful at all times.

Current guidance to nurses in the UK and Ireland is unambiguous regarding lying, stipulating that, all caring interactions should be underpinned by honesty (Nursing and Midwifery Council, 2008; Nursing and Midwifery Board of Ireland, 2013). Such guidance, when applied to working with persons with dementia is in keeping with the concept of personhood in dementia. This view holds that many of the difficulties associated with dementia are a construction of the social interaction rather than an inevitable consequence of dementia itself (Kitwood, 1997, Sabat, 2008). Also, from an Irish perspective, the Mental Health Foundation (2014) suggests that care provision which stems from untruth has the potential to result in abuse of persons with dementia.

Nonetheless, the approaches used in practice by health professionals when working with persons with dementia who ask questions or make statements that are false, as evidenced in this literature review, include therapeutic lying. Despite the fact that to do so could result in serious ramifications including a loss of licence to practice. It is clear that while the theoretical debate as to whether therapeutic lying is acceptable or not continues and the introduction of guidelines for therapeutic lying are frowned upon (Pemberton 2013),
health professionals as well as informal carers struggle at the coal face to cope with how best to respond to people with dementia who ask questions or make statements that are false.

**Summary**

This literature review firstly examined the published literature on the use of RO, validation therapy, aikido and therapeutic lying for use with people with dementia. The dearth of published research studies on any of these approaches, in particular the absence of randomised controlled trials, makes it difficult to ascertain the effectiveness and to advocate for any particular approach. Furthermore the context and setting in which interpersonal interactions occur govern the extent to which dignity is promoted or violated. The second phase of this review involved an examination of national and international guidelines on dementia care and care of older people and national and international codes of conduct, ethics and best practice guidelines for healthcare professionals. This revealed that there is little formal direction available to health professionals in how best to respond to persons with dementia who ask questions or make statements that are false apart from codes of practice which outlaw lying in any form and failure to comply with same has serious consequences. Yet once a number of caveats are in place carers and people with dementia appear to accept the merits of therapeutic lying. However, it is clear that further research is required that include the perceptions of people with dementia formal and informal carers as well as the views of other established experts in the field of dementia and care of older people. This will help inform the development of guidelines on the best approach to use when persons with dementia ask questions or make statements that are false.

**Ethical Considerations**

Ethical approval for the study was obtained from the National University of Ireland Research Ethics Committee and the Office for Research Ethics Committees Northern Ireland (ORECNI). Informed consent was obtained from each participant. Written information about the study was provided to all participants. In the context of older people with dementia information about the study was also provided to the relevant next of kin. The information provided informed potential participants and in the context of older people with dementia, their families, of the purpose, process, potential benefits and harms of the study, data collection procedures, time commitment, voluntary participation, the right to withdraw (without prejudice), as well as providing an assurance of confidentiality. In seeking consent, it was made clear that participation was voluntary and that participants had the right to withdraw at any point without prejudice or
consequence. Where a potential participant was willing to engage in the study and expressed an understanding of the purpose of the study and its voluntary nature, as well as expressing a choice to participate, the researcher finalised the consent process directly with the person. Consent by proxy was not used.

Consent was reviewed on an on-going basis throughout the study for all participants. When a participant became distressed during the study, the researcher stopped the interview, responded to the situation and only resumed the interview when the participant was happy to do so. In the context of interviewing people with dementia an ethical protocol was put in place. This protocol identified expected actions in a range of situations and was included in the ethical application process. The protocol was not utilised during the study.

Phase 2 (Part 1): Descriptive Qualitative Methodology

A qualitative descriptive approach, based on the work of Sandelowski (2000), was carried out to explore: the preferences of persons with dementia and their carers on the best approach to take for people with dementia when they ask questions or make statements that are false, in order to maximise the welfare and quality of life of the person with dementia. Qualitative description aims to describe participants’ perceptions, responses and concerns and to comprehensively summarise these (Sandelowski 2000). A qualitative descriptive approach is appropriate when seeking to understand complex ‘phenomena’ (as is the case in this study) and the use of this approach provides a description of and facilitates understanding of persons’ with dementia and informal/unpaid carer’s experiences and perceptions. The strength of qualitative descriptive designs in comparison to other qualitative approaches is that it “obtains straight and largely unadorned (i.e. minimally theorized) answers to questions of relevance to practitioners and policy makers” (Sandelowski 2000 p.337). Using this approach enabled the collection of detailed feedback from persons with dementia and informal/unpaid carers on their experiences. Qualitative descriptive design uses an “eclectic but reasonable and well-considered combination” of sampling, data collection and data analysis techniques (Sandelowski 2000). In this study focus group interviewing was used to collect data from participants.

Data collection methods

Focus groups are particularly useful when the aim is to learn about service user’s perceptions, feelings or thinking on an issue (Kreuger 1994; Beya & Nicoll 2000; Owens 2001; Halcomb et al. 2007). The aim is not to achieve consensus but rather to investigate experiences, needs and understanding (Crabtree and Miller 1992). A focus group normally comprises between 8 – 12 people (Stewart and Shamdasni 1992; Kreuger 1994) and the more homogenous the group the more likely it will result in candid discussions (Morgan
1992; Kruger 1994). An interview guide developed from the expertise of the researchers and an analysis of the literature was used to guide each set of interviews i.e. with people with dementia/memory problems and carers. In addition the CORTE interviewing framework (Murphy et al. 2014a) was used to guide the interview process with people with dementia. This guide consists of four main areas; gaining CONsent, maximising Responses, Telling the story, and Ending on a high (CORTE guide). This process maximises the meaningful involvement of persons with dementia, ensuring that their voices are heard and to the fore. Two members of the research team attended each focus group. One acted as facilitator (moderator). This person asked the questions on the interview guide, clarified issues with the group and explored the extent to which views expressed by a group member were shared by the entire group. The other (assistant moderator) listened to focus group participant perspectives, gathered demographic details from participants, took notes on group dynamics and ensured that the recording equipment was working. Each focus group took approximately 60 minutes including the opportunities taken for time breaks. The focus groups were convened at a time and place that was mutually convenient to participants and the researchers. Informed consent was gained from each of the participants prior to commencing the focus groups, see ethics section below for further details.

**Sampling Methods**

Capturing the voices of people with dementia and carers was of vital importance in the study given that they are the individuals at the coalface coping with dementia on a day to day basis. The capacity of people with dementia to articulate a viewpoint may be impacted by the stage of dementia, with those in the later stages having most problems. Therefore persons with mild to moderate dementia/memory problems were invited to participate in this study. The decision to include persons with memory problems was based on the fact that many people with the signs and symptoms of dementia may not have a formal dementia diagnosis. A purposive sampling strategy was employed and where possible due regard for age and gender was undertaken. Two focus groups with people with dementia were conducted in the Republic of Ireland and one focus group in Northern Ireland. In the Republic of Ireland potential participants were identified through the Carers Department HSE West, and DREAM. While participants in NI they were identified through Dementia Northern Ireland (NI).

In total 14 people with dementia/memory problems participated in the interviews, five from Northern Ireland and nine from ROI. Just over half (63%) were female (n=9) and 69% (n=9) were in the 70-80+ age bracket. The demographic details of the sample are presented in Table 1.

Three focus group interviews with carers of persons with dementia/memory problems were also undertaken. Again two focus groups were conducted in the Republic of Ireland and one in Northern Ireland. A purposive sampling strategy was again employed and where possible due regard for age, gender and length of time caregiving were considered. Potential participants were identified in the Republic through the Carers Department HSE
West, DREAM, and Western Alzheimer’s. While participants in NI were identified using the Carers’ panel at the Dementia Services Development Centre.

Table 1: Demographic profile of persons with dementia/memory problems (n=14)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>N(%)</th>
<th>Characteristic</th>
<th>N(%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>5(37%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>9(63%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Age group</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>40-49</td>
<td>2(15%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>50-59</td>
<td>0(0%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>60-69</td>
<td>2(15%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>70-79</td>
<td>6(46%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>80+</td>
<td>3(24%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Number of years with</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>memory loss</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than 1 year</td>
<td>1(9%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1-3 years</td>
<td>6(55%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4-6 years</td>
<td>4(36%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7+ years</td>
<td>0(0%)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Highest Level of Education Attained</th>
<th>N(%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>No formal education</td>
<td>0(0%)</td>
</tr>
<tr>
<td>Secondary Education</td>
<td>2(14%)</td>
</tr>
<tr>
<td>Third Level – Non Degree</td>
<td>2(14%)</td>
</tr>
<tr>
<td>Technical/Vocational Qualification</td>
<td>4(30%)</td>
</tr>
<tr>
<td>Third Level-Degree or above</td>
<td>3(21%)</td>
</tr>
<tr>
<td>Professional Qualification</td>
<td>2(14%)</td>
</tr>
<tr>
<td>Primary Education</td>
<td>1(7%)</td>
</tr>
</tbody>
</table>

In total 18 informal/unpaid carers participated in the interviews, five from NI and thirteen from ROI. Most were female (n=13, 72%) and in the over 50 age bracket and most (69%, n=11) were carers from 0-4 years. The demographic details of the sample are presented in Table 2.
Table 2: Demographic profile of informal/unpaid carers (n=18)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>N (%)</th>
<th>Characteristic</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age group</strong></td>
<td></td>
<td><strong>Years of caring for a person with dementia</strong></td>
<td></td>
</tr>
<tr>
<td>20-29</td>
<td>0(0%)</td>
<td>0-4</td>
<td>11(69%)</td>
</tr>
<tr>
<td>30-39</td>
<td>0(0%)</td>
<td>5-9</td>
<td>3(19%)</td>
</tr>
<tr>
<td>40-49</td>
<td>1(6%)</td>
<td>10-14</td>
<td>2(13%)</td>
</tr>
<tr>
<td>50-59</td>
<td>8(44%)</td>
<td>15-19</td>
<td>0(0%)</td>
</tr>
<tr>
<td>60-69</td>
<td>2(11%)</td>
<td>20-24</td>
<td>0(0%)</td>
</tr>
<tr>
<td>70+</td>
<td>7(39%)</td>
<td>25+</td>
<td>0(0%)</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>5(28%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>13(72%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Supports for caring for a person with dementia</strong></td>
<td></td>
<td><strong>Highest Level of Education Attained</strong></td>
<td></td>
</tr>
<tr>
<td>Respite</td>
<td>3(20%)</td>
<td>No formal education</td>
<td>0(0%)</td>
</tr>
<tr>
<td>Day Care</td>
<td>0(0%)</td>
<td>Secondary Education</td>
<td>7(39%)</td>
</tr>
<tr>
<td>Professional carers</td>
<td>2(13%)</td>
<td>Third Level – Non Degree</td>
<td>2(11%)</td>
</tr>
<tr>
<td>Family/other carers</td>
<td>7(47%)</td>
<td>Technical/Vocational Qualification</td>
<td>0(0%)</td>
</tr>
<tr>
<td>Other</td>
<td>3(20%)</td>
<td>Third Level- Degree or above</td>
<td>5(28%)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Professional Qualification</td>
<td>1(6%)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Primary Education</td>
<td>2(11%)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Post Leaving Cert</td>
<td>1(6%)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Other</td>
<td>0(0%)</td>
</tr>
</tbody>
</table>

Qualitative data analysis and rigour

Qualitative content analysis is the strategy of choice for analysis in qualitative descriptive studies (Sandelowski 2000). The specific type of content analysis chosen was conventional content analysis. This is used when: (1) the aim is to describe a phenomenon and (2) when there is limited research on the phenomenon. No preconceived categories are used, instead categories and their titles are allowed to “flow from the data” (Hsieh and Shannon, 2005). The process used is briefly described below (based on Hsieh and Shannon, 2005).

All interviews were transcribed verbatim. Analysis began by reading each transcript repeatedly to achieve immersion. Text that describes the phenomenon under study (open coding) was noted i.e. that described participants’ (people with dementia and carers) experiences and perceptions of approaches to managing when a person asked questions or make statements that were false. In-vivo codes (derived from participants’ words) were initially used to label these descriptions. Once all data has been coded, each code was examined and overlapping codes were collapsed, to form larger more inclusive categories. This process helped to make explicit the links between categories, enabling a hierarchical structure to emerge showing categories and their subcategories. The final categories were then organised into “meaningful clusters” (Hsieh and Shannon 2005 p.1279) that
“best fits the data” (Sandelowski 2000 p.339), for example, most prevalent to least prevalent themes. The computer software package NVivo 10 was used to assist the storage and management of the qualitative data and make the analysis process more transparent to scrutiny.
Findings from the qualitative data

This section presents the focus group interview findings and is divided into three sections: the first section presents the findings from the focus group interviews with persons with dementia, the second section presents the findings from the focus group interviews with carers and the third section compares the findings across both datasets and presents a model depicting both groups’ perspectives.

Focus Groups with Persons with Dementia

Data analysis found two categories: the “acceptability of lying continuum” and “respectful lying”. Each category is described below.

Acceptability of Lying Continuum

Participants had a range of opinions on the acceptability of lying. These ranged from “not acceptable under any circumstances” to “acceptable in certain circumstances”.

“I certainly wouldn’t think it’s acceptable to tell anyone lies, I don’t care what the situation is it’s not acceptable.” (FG3)

“No matter what you do he’s gone away or she’s gone (died), right, so if it’s going to help her or help me, do you know because what good is making her suffer because she’ll forget all about it again. And you have her up the wall for a while like you know, no I think you have to gauge it” (FG1)

This continuum - “the acceptability of lying” - was fluid with actions determined by the context. Minimising truth-related distress was identified as the sole context when lying may be acceptable.

“R1: I think a lie is not acceptable at any time.
Int: What do you say (Name)?
R2: I know that it’s not acceptable, I know it’s not acceptable but you’re only upsetting the person more with what you’re telling them.” (FG1)

The opinion of those who believed lying was not acceptable in any circumstances seemed to be grounded in their personal beliefs and values about the truth and being truthful, for
example, “… I don’t care what the situation is it’s not acceptable” (FG3). Others considered lying unacceptable if the result was loss of autonomy or control.

“I’d prefer to know the truth and not to be kind of brushing over things and, you know.

Int: And even if that truth might make you upset, you’d rather know it?

“I would, oh yes, because you kind of get through things, you know hopefully anyway you know but I would, definitely I would rather know, rather than to be thinking and waiting for somebody to come in or you know all the time but no definitely I would rather know.” (FG1)

Those who considered lying can be acceptable made clear that it was in certain circumstances and to prevent the person being distressed. To these participants the context and outcome mattered more than always telling the truth. However, they drew distinctions between outright lying (which was not acceptable) and not telling the whole truth, using language such as a “good lie” or a “small lie”. So the nature of the lie mattered as well as the context. Examples of approaches that were considered acceptable when not telling the whole truth were: distracting, moving the conversation on or avoidance.

“I think maybe even a wee bit, even move it around a bit you know I would feel that from, I just feel you can move it around a bit and maybe change the subject a bit.

Int: So kind of distract.
Try to, yeah try to distract.” (FG3)

“He’s not going to gain or anything.

Int: Yeah.
Or him anything like you know.
Int: By telling them the truth, yeah in that context.
They get upset and they’re unhappy, you’re better off with a smile and only small lies.
Int: A small lie, exactly.
A small lie.
Int: And that’s, I think that’s the important part (Name), it’s the type of lie.
You’ve got to gauge it.” (FG1)

A distinguishing characteristic of acceptable lying was the underlying intention of the lie. If the intention was “good”, for example to prevent distress, then it was more acceptable to lie. However, if the intention was to deceive the person, lying was not acceptable.

Int: You don’t think at any time it would be acceptable. Would it be to do again with the intention, if the intention was to fob you off or to do you harm, in that context lying may not be acceptable?
No.
No.
*I don’t believe in lying.*

*Int: Yeah, very good OK.*

Leave the person happy.

*Int: If it’s to make the person happy?*

Make her or him happy.

*Int: Happy, then it is acceptable?*

It’s worth anything.

*Int: It’s worth anything?*

I think.

*Int: I see you nodding and (Name) I see you nodding as well, is that right?*

I do, I think yeah.

*Int: If it makes, and how about you (Name), if you make the person who has the memory problem happy?*

Well I suppose if the memory is bad alright, yeah.

*Int: Yeah so it might be in that circumstances?*

It might be easier on the person. (FG1)

To give it as clear as it could be, that you’re not either fooling them or anything else.

*Int: So the intention is really important.*

It is, I think it is (FG1)

The fear of being “fooled” as suggested by the above comment was linked to the experience of dementia itself and the associated vulnerability of having a problem remembering. The stage of dementia or more importantly the person’s awareness was perceived to be another critical factor in determining what was acceptable.

“(Name) is different to what I am, and (Name) is different to what I am, we’re all different here. And personally at the stage that I’m at if I hear about the death of somebody or something like that there I would appreciate being told … because I’m at that stage.” (FG3)

Participants agreed that the stage of dementia mattered; if the person was at a “bad” stage then it was more acceptable to lie to minimise truth-related distress. Participants equated the stage of dementia with awareness, in that if the person was likely to become aware that they were being lied to it was never acceptable to lie. What mattered most at this stage was being “kept in the now”. However, if the person had diminished awareness and was likely to be distressed then it was more acceptable use a “white” lie.

*Keep reminding you.*

Oh yes.
Even though it might upset you to hear this news again and again. Yes because that’s reality, that’s the real thing, that’s not just covering up to keep me happy and content. Right.

You know you can’t always be wrapped up in bandages, you know. Yeah, so you think it would be worse for them not to keep reminding you. Yes I think so. And like I’m the mother, it’s my job to be there for my family, for my children and yeah it’s like your losing control as a mother. You’re losing control of your nest, do you know. (FG2)

Implicit across comments is the importance of doing what is right for the person in context of his/her beliefs, preferences and stage of dementia. This is explored further in the next category “respectful lying”.

Respectful Lying

Participants explained that their concern about being deceived was coloured by their experience of living with dementia. The experience of living with dementia made them feel vulnerable and at risk of losing control and autonomy.

“There’s nothing as bad as an individual living with confusion … to experience that and we’re in a unique situation here that we can tell people how it is because two years down the line, we could be sitting wanting to be told something and it’s not there, you know so it’s a very difficult situation … Confusion in anybody’s mind, in my mind anyway it’s so soul destroying, it’s unreal when I see a thing on the television that I know that I should know but it’s not there. I can’t lift the guitar in my hand that I used to love doing because the chords are not there anymore, I can’t remember them. I can’t spell, that sort of thing is soul destroying. And from the outside person would really need to understand the person with dementia considerably before they would make any moves. Everybody is an individual and that’s what it’s about.” (FG1)

“We have to remember about the person’s dignity, you know and you can’t take that away from them by deliberately telling them lies…” (FG3)

These participants’ comments make clear that respecting the person’s individuality and personhood should be the fundamental principle guiding decisions as to what action to take. The action taken (to distract, to lie or tell the truth) must also be informed through knowing the person and what matters to him/her. In addition, if the person is no longer able to determine what is right for him/herself, the action to take should be decided in consultation with the person’s family or significant others. Ideally the action to take
should be planned in advance.

“… it should be handled with kid gloves, you know, it certainly, it’s a difficult situation no matter what way you go to handle something like that there. But again it comes down to the individual. And to know certainly what the individual’s reaction is going to be before you go there … so it’s knowing him or knowing her, the relationship with the carers and the family and doing your homework before you go there, you know.” (FG3)

“Well what I would like to do would be to have the relative come meet with the staff and be part of that care plan, to try and avoid these problems.

Int: OK that’s a very good point.

Absolutely … so that everybody is involved.” (FG3 Note the person with dementia has a healthcare background)

Participants were clear that lying must never undermine the person’s dignity and if the decision is taken to distract or tell a “small lie” this must be done respectfully. In other words, the intention, spirit and manner in which the action is carried out matters.

“My sister rang this morning and said ‘will we be alright for lunch on Thursday’ and I said ‘yes’ and she said ‘what time do you want to go?’ She didn’t tell me ‘I’ll pick you up at such and such a time’, ‘what time would you like to go?’ I mean I appreciate that. Not somebody thinking for me or telling me.

Int: It’s giving you a choice and control.

It’s giving me a choice and its giving me a sense of … I like that.” (FG3)

“And you can do something else to side-line them, to distract them, to put them on to something that they like, it’s a matter of knowing the person. And of being really concerned about how they will react. And distracting them.

Int: So in some context the distraction may be you’re not addressing the question, you’re not saying that ‘Mary’ is dead but you’re actually addressing it by distracting them?
You’re distracting them, treating them as a person and being honest with them, still seen as an individual, to which they’re entitled.” (FG3)

Participants did flag the potential negative impact of lying on their relationship with and trust in carers. However, even more fundamental was the potential impact on their self-esteem, sense of control and autonomy, irrespective of the stage of dementia he/she was at.

“… (make) sure the individual is always at the centre of something and that they’re not saying ‘oh you’re three years into dementia or four years or five or six’ and this is where they should be … (it depends) on how each person is responding to it, accepting it and continue with their life or given up.” (FG3)

“No matter what the outcome would be, I would still like to be told … what upsets me a lot is that people doesn’t understand on the outside of this here, is still the same stigma behind dementia which you know is a big thing every day with me. There is a stigma out there. And it’s not very easy dealt with.” (FG3)

This comment emphasises the concern that lying might further reduce the individual’s autonomy and control with the potential for increasing the stigma of living with dementia.

Summary

To summarise, participants suggested that the fundamental principle which should guide decision-making on the action to take is maintaining the personhood of the individual. Their perception of the acceptability of lying ranged from “never acceptable” to being “acceptable under certain circumstances”. The former perspective was grounded in the belief that telling the truth is always the right thing to do, the latter that the situation colours what is right. The acceptability of lying was linked to the person’s altered awareness as distinct from stage of dementia as participants pointed out these are not necessarily the same. They indicated that characteristic of a “good” or acceptable lie is the intention to benefit the person, for example, to minimise or not cause distress. Acceptable approaches were distracting or avoiding as opposed to outright lying or deceiving (i.e. the latter was considered not in the interests of the person). Participants made clear that the action taken must be respectful and mindful of the person’s dignity, self-esteem and self-efficacy. Under no circumstances should the person’s autonomy and control be undermined by the action taken. At different points of awareness the risks vs. benefits of lying must be considered in taking the decision. Lying is acceptable when on balance the outcome benefits the person with dementia. That is, the “white” or “little” lie will minimise truth-related distress without negatively impacting on the individual’s personhood or experience of living with dementia.
Findings from Focus Groups with Carers

Data analysis revealed three categories “acceptability of lying continuum”, “approaches to managing mistakes” and “empathetic deception”. Each category is described below.

Acceptability of Lying Continuum

In tune with participants with dementia, carers viewed the acceptability of lying as a continuum ranging from “never acceptable” to “acceptable under certain circumstances”. Again individuals’ beliefs about “truth” and “being truthful” was a factor for those who thought lying was never acceptable. However, the acceptability of lying was more nuanced for carers than for people with dementia. Participants expressed concern that lying could cause mistrust, impacting negatively on their relationship with the person with dementia. Participants also worried that “going along with” or seeming to accept the person’s mistake could worsen their confusion. The “unknowingness” of dementia, the constant changes in the person’s capacity, added to their concern about inadvertently making it worse.

“You see my father is the most honest person I know … I was accordingly brought up to be honest as well. So it seems like short changing, do you understand … when you’re deliberately saying something which is rubbish.

Another Participant: He doesn’t know though.

I know that, but there are times when something comes through, you know when there is coherence and when my father says ‘don’t treat me like a child’, you know so there’s always that wire that you’re on …” (FG2 Carers)

“… (it’s like) she’s getting little snippets of past things where she thinks people are there that are dead and you know what I mean they’re not.

Int: So from your point of view (Name), you took the decision that you’re going to tell her the truth?

Yeah.

Int:…. telling her that your dad had died, each time she gets upset in relation to it.
She does yeah … you see because she kind of knows but is beginning now to get that she thinks he’s gone somewhere, you know what I mean, she’s beginning to think that he’s not dead. Even though like she went through the process of like, he’s dead eight years now so it’s not like recent …” (FG1 Carers)

“I do have qualms, its personality, what’s left of it, of the person, you take into consideration. So I have difficulty lying to my father because neither of us is a liar, you know and truth has always been very important to both of us. So I have difficulty with it, especially if it’s taking him further into where I feel is confusion. I feel, I know this may be totally wrong but it’s just my own feeling about it, I feel that maybe there has to be some flag post sticking up somewhere out of the fog, you know. So I’m unhappy to lead someone further into the fog all the time” (FG2 Carers)

Other participants viewed the decision to lie as relatively straightforward. To them it was acceptable to lie (distract or avoid) if it was of benefit to the person. Minimising truth-related distress was one reason for opting to lie or avoid the truth. However, the outcome of this decision could not always be anticipated and sometimes had emotional consequences for the carer.

“I have no qualms about telling a massive whopper. If it keeps the mood sweet … I think it’s so important for them because they do know something isn’t right … And it’s such an awful disease, I think if their mood is sweet, it is important.” (FG2 Carers)

“I’d a recent one now where mother was asking for Dad … suddenly it occurred to her, ‘where is Dad?’, he’s not sitting in his usual chair. Now he’s dead three years. So I kind of thought well the last time I told her that he was dead we had to go through the whole grieving process and I got terribly upset as well. So I thought well OK this time now I’ll just kind of go with the flow and I’ll try and put her off a little bit and I just said ‘oh sure he must be out’. So that was grand, but ‘he would have told me if he was going out’, so we went right through the whole evening with me fobbing it off a little bit and we got as far as bed time where I had to be bringing him tea upstairs because he’s not coming down because he’s tired at this point. But I just didn’t want to put her through the whole grieving process again. … It’s nicer to kind of believe that he’s just maybe in the other room or something. Doesn’t crop up very often now but when it does and as she gets more agitated or anxious she’ll kind of pursue it. I’m surprised she didn’t say ‘well pick up the phone and see where he is at’ … And I was kind of sorry in a little bit because I was kind of light about it in the beginning and I thought this is going to be easy, now she’ll forget but she didn’t.” (FG3 Carers)
To a degree the discussion on “what is the best action to take” is hypothetical for people with dementia. In contrast, carers were speaking in context of having experienced situations where they were faced with the dilemma of “what to do” (as indicated in the excerpt above). Participants with dementia viewed minimising truth-related distress as the main reason for not telling the whole truth. However, for carers this was not the only reason. Carer participants reported using distraction and other strategies to reduce agitation as well as to truth-related distress. Failing to manage the person with dementia’s agitation or negative thoughts sometimes escalated into behaviours that challenge.

“(My husband)… he always loved golf and my granddaughter is a very good golfer. And if I want to get him (in a good mood), I’d say ‘(granddaughter’s name) is playing this weekend’… oh God, then he’s watching the television and if he sees any woman golfer, ‘that’s (Name)’, he’s delighted … So I have him in good form … And it’s very important as well, when they’re agitated to be able to press the right buttons. … You know say if (my husband) was very agitated now, like he thinks everybody is taking our money and everybody is trying to steal our house and everything else and then all of a sudden do you know I’ll say ‘do you know what, (Name) rang today’ and ‘(Name) is doing very well at such a thing and he’s doing this and that’. All of a sudden then he’s delighted and he’s forgotten all these dreadful things…” (FG1 Carers)

This participant went on to explain why she prioritised keeping her husband in “good form”, giving insight into carers’ reality of living with dementia. Distracting or not telling the whole truth helped prevent a situation escalating to crisis point.

“(My husband) is very gentle and he would never ever, because I had this awful incident last year and I had to get the doctor for him … but he said, by the time the doctor came he was … grand and he said ‘I would never hit a woman’ … you see that’s alright but when he’s going through this awful thing and the face changes completely and he’s a completely different person … that’s the frightening part of it you know. (FG1 Carers)

Some participants gave examples of circumstances where it was considered best “to go with” the person. “Going with” the person was a common strategy used by carers. This is discussed in the next category. Again the analogy of living with a “different person” and the “taking-over” of dementia are used.

“I would be afraid to say to either my aunt or uncle ‘oh that’s wrong what you’ve just said …’ because he, especially my uncle could get a bit nasty. Now it is not like him, it is not in his nature, never was, but obviously this has taken over. And I would be concerned that I’d have to tell him ‘no that’s wrong’. (FG2 Carers)
On the other hand there were situations where it was considered imperative to correct the person’s mistake. This was usually when the person’s physical safety was at risk. Participants did not like “having to contradict” the person but on balance believed it was the lesser of two evils.

“… my father is no longer mobile except with a Zimmer frame, I have to constantly contradict him when he says ‘yes I can do that’. I have to say ‘no you can’t’, because if he tries to he will fall over … I have to contradict when it comes to his mobility for the sake of his safety. You see none of it goes in because I’m saying the same thing every day. But I feel obliged to try, in the hope that some of it will stick.” (FG2 Carers)

In relation to the acceptability of formal carers lying, participants felt that in certain circumstances it is necessary. They believed that formal carers should act in a way that is appropriate to the person (assumes knowing the person) and in line with what the carer thinks is appropriate (because they know the person best). They believed they had a responsibility to represent the person with dementia’s needs, likes and dislikes. This participant refers to this as giving “the backdrop”.

“What I would do if a carer comes in the door? I’ll tell her where mother is at and I’ll tell her what’s her reality at the minute … and try and go along with that if you can. And I’ll give her little backdrops if it’s not working. And I’ll expect that they’ll respect that, I would be very disappointed if somebody came along cold or whatever and said something that would bring mother too much to her reality …” (FG3 Carers)

“My father has been in respite, you know and I accepted that the people who work in those places have to (tell a therapeutic lie) because they haven’t got the time apart from anything else to kind of get into discussions about what is the reality for this person. So I think it’s kind of acceptable in that environment because I don’t understand how it can work otherwise. But there is a disconnect then when the person comes home from respite.” (FG2 Carers)

“… nurses, they should have a meeting with the family before the patient (is admitted) but for them to sit down with a family member and ask their dislikes and you know what I mean. Like instead of, like if somebody comes on duty, you know they need to get to know personal things about the person, you know.” (FG1 Carers)

Participants gave examples of various approaches that they used to manage the situation when the person with dementia makes a mistake. This is explored further in the next category “approaches to managing mistakes”.

Approaches to Managing Mistakes

Carers used a range of strategies to manage the situation when the person made a
mistake or became confused. These did not normally involve an outright lie (considered not acceptable) but centred on reframing the situation, moving the conversation on or distracting. In some situations carers simply told the truth, for example, some opted to tell the truth when the person with dementia asked for somebody who has died. They emphasised that there is not one right thing to do. Their actions were determined by the context, their knowledge of the person and the person’s reaction.

“I remember when Dad would be asking, I would distract him, he’d say ‘where is mum’, I’d kind of switch it around quick and I’d say something completely (different), you know … They were always together and she loved talking about the fact that they were 61 years married and they were 7 years going out and how this other guy fancied her and daddy stole her, she loves talking about that so I try … and jump into that part of the conversation as soon as possible … So (when) she asks me the first time I answer all her five questions in one answer, you were there with him, he knew he was dying, he said good bye … But I answer them five questions and I end up with ‘God you were 61 years married, how did you suffer him that long’ and then she goes back into ‘oh and I remember (Name) and he fancied me and your father stole me off him.” (FG1 Carers)

“… now a sister of mine died and … he was asking about her one day, he said ‘oh where is she now’ … and I said ‘oh she’s dead now’ you know and he said ‘oh that’s right’ and he sort of, tears came down his face you know and then I thought ‘oh’, I changed the subject then to something else … and then he forgot all about it …” (FG3 Carers)

“With my mother, she regularly wanted to go home to her mother who was long gone. And if we were out … she would say ‘when are we going? I want you to take me home’ and I’d say ‘I just have to collect something’, just excuses that I had to go somewhere. And of course as soon as we hit our, the gate of her house she just gets out of the car and walked in happy as Larry, she knew, she recognised when she got there but there were times when I would have said to her that you know ‘that’s not right, that’s not correct’, but I think you have to gauge, depending on what they’re able for at the time.” (FG2 Carers)

The excerpts above suggests that the strategies employed by carers were learnt through trial and error and they varied the strategies they used, telling the truth sometimes worked, not telling the whole truth sometimes worked. Some participants had attended workshops (or similar) on managing people with dementia and had picked up some suggestions. However, carers’ decisions on what to do evolved over time and were shaped by: their knowledge of the person, his/her reaction, the specific context and the stage of dementia. Learning to “let mistakes go” was part of this learning process but also part of accepting that their loved one had dementia and what this means. Reaching acceptance was a painful and distressing journey for carers.
“I know at the beginning we were a bit corrective of mother but I have been to some of the seminars and things like that and I was talking to my wife who hadn’t been to those and she was more corrective and I was trying to pull her back. Letting it go really.

And when you would be corrective, what was the reaction of your mum.

Well obviously in the beginning she would be a bit confused herself, doubting and things like that so when I said that (the effect on her) then I said well … ‘You’re fobbing me off’ she would say and then she’d say well (Name) told me that, whatever you know, she became accepting that way, she was never angry as such but just that pause and (you) saw the face … You knew there was something going on there, something.

Yeah that it was causing some type of upset.

It was stressful so we had to try and stop that.” (FG2 Carers)

“My wife she’s just two years more or less into memory loss like you know and I have to say in the first couple of months I was like a brier, I could not accept that she’d forget this, that or the other, she’d forget, you’d tell her something in the morning and that evening you might remind her again about it ‘What are you talking about?’ and it took me a while, I have to be honest about it, it took me a while to more or less have the patience to more or less deal with it.” (FG3 Carers)

“(My father had been incontinent) … and I had to force him to have a shower … (I kept) trying to get him into the shower and I kept saying to him ‘Daddy I’m really struggling, I have to say this, you have to have a shower.’ … I changed his bed (and he came back)... sat on the bed that I had just changed and then that was all messed … in the end I had to literally stand outside his bedroom door and say ‘Dad you have to go right now (and shower)’… I was so upset and he sort of looked at me … he was not happy with me, I knew he was thinking ‘why are you speaking to me like this’... (He showered) … and I said ‘do you feel better’, ‘yeah it was great’ and he totally forgot about it. (but) I was really upset. My husband says to me ‘but (Name) you know your Daddy doesn’t remember…’ This is the thing you see and this is why it’s so cruel because you don’t know what will sink in. And I find with my father it’s generally the negative things that stick, you know. So my father will not remember all the good things but he will remember when I shouted at him, you know and stuff like that…” (FG2 Carers)
Participants’ comments also suggested that in addition to “shades of acceptable/unacceptable deception” there were also “shades of acceptable/unacceptable mistakes” on the part of the person with dementia. There were some mistakes that they always corrected, that they could not ignore. In other cases they did not challenge the mistake or deliberately went along with the mistake. The acceptability of “going along” with the person varied in context of the circumstances therefore.

“Where it’s just rubbish, like yes I’ve been to Egypt or I was around in 1900, then I’d just use diversionary stuff, change the subject. … I have an expression, I didn’t become an angel when I became a carer, I really didn’t. (I wish I could tell a whopper) but I can’t … Well there (is a) halfway point, (where I leave it and others when I don’t) … I can’t go along with, that you’re 18, (or that he doesn’t remember) my mother … (he doesn’t remember) being married to her at all you know I sometimes would get the photographs out and show him and stuff like that … And obviously in terms of his physical situation it’s important that he doesn’t think that, yes he went outside and took the bins out yesterday, or that he didn’t do this, that or the other on his own, or that he can go to get in the shower on his own because he can’t.” (FG2 Carers)

Inevitably the carer’s personality and experience also shaped how he/she responded and reacted. To some degree learning not to react meant having to suppress their natural response. Their relationship with the person (their mother, father, spouse) also shaped their expectations and response.

“It’s very difficult for me because … I naturally correct, I do it automatically and reflexively. So it took quite a while to get to the point where … (I could go) ‘oh really’ or ‘yes’… But it’s, as I say it’s taken a long time to get to that point because I know all the arguments about not contradicting, but from my point of view it’s kind of a debate about whether you should encourage someone in a flawed reality, where does that leave them, do you know. So it’s kind of a philosophical question I think”. (FG2 Carers)

“I work for the (name of organisation) as well and I was working with a person with Alzheimer’s and it’s like, it’s different when it’s a family member, because I know all the details of my mother, I’m inclined to correct her and things, which it’s a thing they say you shouldn’t do. Like when I’m with a client I wouldn’t correct them, I’d play along with the story … Like it does make the person more calmer and a lot easier to work with than if you’re telling them all the time ‘that’s not right, that’s not right’, you know what I mean. And I know that with my own mother I try not to do it but it’s different, it’s difficult.” (FG1 Carers)

Implicit in these excerpts is the balancing act “… the wire that you’re on!” (FG3 Carers) between not lying outright, not over correcting the person, while still correcting some
mistakes. This balancing act was required to meet the person’s care needs—“keep them safe”, “keep them happy” - while simultaneously protecting their personhood. This is explored further in the category “empathetic deception”.

**Empathetic Deception**

Carers resorted to “not telling the whole truth” to prevent distress or minimise aggressive behaviour. Their actions were altruistic with the sole aim of reducing the person’s distress.

“...we can’t tell her anything because it plays on her mind, and you can see its affecting her, even though she’ll forget why”. (FG1 Carers)

The “lies” (deception, distraction, white lies) they told were shaped by their knowledge of the person and designed to reassure them. Carer participants evaluated their actions in context of what is in the person’s best interests and acceptable. Implicit in participants’ comments was a focus on maintaining the person with dementia’s dignity and personhood. Participants’ made clear that the nature (content) of the lie mattered but so did the way in which it was told (delivery).

“(I have to be creative but) because it’s my mother and I’m not caring for a stranger, I know what she thinks … So if she goes well ‘where is (Daughter’s name)’ and I can know what she will accept about where (she) is? … She will only accept that my brother is working, he is not allowed to be enjoying himself.

**So you tell a white like.**

Yes I do. (FG1 Carers)

“I was actually thinking, it isn’t even so much what they say (formal carers), it’s the way it’s being said.

**Yeah.**

Sometimes I think if the staff can, you know there are certain things that they collude with, just because it’s easier, but it’s said in a way, a kind of tone that might still get a reaction off them.

**Ok so how it’s done.**

I think what you said, if you’re telling a white lie on the basis of it’s going to reduce stress and keep the person happy, I think go for it because you don’t want the
person to stress.” (FG2 Carers)

The strategy of “going with” the person, i.e. not challenging them (except if it put the person at risk) was used with empathy and not to deliberately deceive. In their experience confronting the person with the truth was not always in their best interest. Participants viewed “lying” as kinder because it allayed the person with dementia’s stress or anxiety and reassured them that everything was alright.

“… all his family are living in different parts of the world and he forgets that they’re not just down the road. So I just don’t contradict anymore. I just say ‘she’s coming to see you in a few weeks’ or you know, because they do come to see him quite often. But he doesn’t have any idea of the length of time so if I just say to him a few weeks, a few months, a day or whatever, it doesn’t matter because it reassures him that they are coming. And yeah he’ll forget the next day but when they do come he’s delighted.” (FG2 Carers)

“… if I got annoyed with him, he would have got annoyed back. So when that happened once doing an IKEA, putting things together, I decided, no, we walk away or we deflect. And that has worked I have to say, because he is quite happy.” (FG2 Carers)

The person with dementia’s awareness also shaped the carer’s approach. Carers’ approach changed as the person’s memory loss worsened.

“… you’re in chat and you’re just chatting away and you suddenly say something or other and then she might ask a question and you don’t know whether to tell her or not to tell her. And at a certain stage, she was at the stage of you might say something and then she knows your hesitating and she’ll say ‘oh but is she dead’, so she was still in the awareness of, at a stage where she could not totally remember she’s dead, had a sense of she was so it wouldn’t have helped at that stage to be giving her a story. But further down the line then we wouldn’t mention people’s names or if we’d mention them we’d mention them as if the person was still alive, you wouldn’t pertain to them being dead then.” (FG3 Carers)

“My mother asks about the rest of the family and I’d a brother died 10 years ago and her own sister died as well. She does ask, you know ‘what about so and so’. And at the start I was reluctant to break it to her oh they’re dead but there’s no difficulty now, she just accepts, there might be a moment ‘oh dear, I must have forgotten that’.” (FG2 Carers)
The personhood and individuality of the person with dementia was stressed. To their mind what mattered to the person with dementia must be reflected in the approach taken. Given that participants believed the approach used must be individualised it is not surprising that some questioned the value of having a set of hard and fast rules. Rather they thought you have used “common sense” (FG1 Carers)

“... every individual, they’re all unique so every circumstance is different, every person is different.” (FG3 Carers)

“I don’t understand how there could be hard and fast guidelines because it’s going to be different depending on what type of dementia you have … and the relationship with the person.” (FG2)

“... I don’t think there’s any wrong way or right way to deal with it, everyone has to deal with it the best they can.” (FG1 Carers)

Summary

To summarise, carer participants indicated there were benefits and concerns about lying to people with dementia. Minimising truth-related distress or agitation was the main reasons for lying. Carer participants expressed concern however, that lying could increase the person with dementia’s confusion or negatively impact on their relationship with the person. Several alternative strategies to managing the person’s anxiety, stress or agitation were identified. These ranged from: telling the truth, moving on the conversation, reframing the situation, distraction and “going with” the person. Carer participants did however confront or correct the person if they believed it was in their best interests. “Empathetic deception” captures their approach to “lying” or telling the truth: it was done in the person’s best interest, in context of knowing what matters to the person and in a way that maintained the person’s dignity. The person’s capacity (loosely aligned to stage of dementia) was also considered and reflected in using different types of strategies e.g. it was more likely that carers would tell the truth in earlier stages and lie by omission or avoidance in the later stages. At the heart of carers’ actions was the intention to benefit the person. They viewed an individualised approach, tailored to the person’s needs and life history as critical, they questioned the benefit of hard and fast rules on “what to do” therefore. In context of the actions that formal carers should take, carers saw that therapeutic lying was appropriate when it benefited and respected the person’s dignity. They viewed themselves as the representatives of the person with dementia’s personhood in the later stages because they knew them, knew their life history and knew what mattered to them. Consequently they considered they had a role to play in preserving the person. They advised that in formal care settings a care plan should be agreed that reflected this knowledge.
There was no agreement on “truth-telling” or “lying”. However, some consistency was found on what is important, for example, the intention, nature and approach to the “lie”. This is reflected in the similarity across datasets with some shared or comparable categories. People with dementia and carers agreed that lying is not acceptable in certain circumstances, for example, when the person is aware and striving to retain control and autonomy. To lie would undermine their efforts. Both groups acknowledged that therapeutic lying was appropriate if it clearly benefited the person i.e. diminished or allayed distress or agitation. However, the nature of the lie as well as the intention matters. A small lie (for example, reframing, distracting or moving the conversation on) was acceptable, whereas a blatant lie with the intention to fool or manipulate the person was not acceptable. The person’s beliefs and values must be central to the decision on what action to take. The person’s awareness of his/her deficits must also be considered (loosely linked to stage of dementia). Carer participants indicated that knowing the person and what was appropriate to and for them was critical. Both groups flagged the importance of maintaining the person’s dignity and respecting his/her personhood. The risk-benefit of therapeutic lying should be assessed in context of the individual needs therefore. Furthermore the actions of formal carers should be negotiated and agreed with carers and/or the person with dementia where possible. Figure 2 below depicts the relationship between categories in context of the “lying not acceptable” to “lying acceptable” continuum (X-axis) and the stage of awareness “altered awareness” to “limited awareness” continuum (Y-axis)
Figure 2: Model of persons with dementia and carers perspectives on lying when the person with dementia makes a statement that is false

Lying is not acceptable rather the objective is to “keep in the now”. The goal is to support the person to retain control and autonomy.

Lying not acceptable under any circumstances

Weigh up the impact of the “lie” on the person and on his/her relationship with the carer in context of the “benefit” of the lie, for example, diminished distress. Lying should support personhood (see across)

Altered awareness

(Earlier stages of dementia)

Personhood

Limited awareness

(Later stages of dementia)

Lying typically not appropriate but may in certain circumstances benefit the person but the decision must be taken in context of the benefit vs. potential for diminished autonomy

Lying acceptable under certain circumstance

Lying may be acceptable when the person has limited awareness provided the lie (reframing, moving on, distracting or avoiding) is respectful, will benefit the person (good intention) and is compatible with the person’s beliefs (i.e. the carer must know the person and what matters to him or her). In the case of formal carers the decision on the action to take should be taken in collaboration with family/significant others and assumes the person’s dignity, autonomy and control is respected.
Phase 2 (Part 2): Delphi survey of key dementia experts

A Delphi survey was used in this study with dementia care experts to explore the most beneficial approach to take with people with dementia when they ask questions or make statements that are false.

Delphi survey methodology is appropriate to achieve consensus on a topic lacking substantial prior exploration (as is the case in this study) (Delbecq et al. 1975; Linstone & Turoff, 1975; Hasson et al. 2000; Hanafin, 2005; Kenney et al. 2006). The Delphi technique is a multistage process involving a series of questionnaire rounds, interspersed by controlled feedback based on the results of previous rounds that seek to gain the most reliable consensus of opinion of a group of experts (Linstone & Turoff, 1975; Gordon & Pease, 2005; Vernon, 2009). It involves progressive rounds of survey construction, analysis and iterative revision until predefined criteria for consensus are reached. Participants receive feedback on responses to previous rounds and can use this feedback to inform their decisions about future survey responses and the process continues until there is emergence of consensus (Gordon & Pease 2006; Vernon 2009). Delphi studies commonly comprise three rounds before consensus is achieved (Hasson et al. 2000; Hanafin & Brooks 2005). Information on the topic under investigation may be derived from alternative sources obtained prior to the first round of the Delphi and this can inform initial survey content and structural features (Landeta 2006).

The panel for a Delphi is composed of individuals/experts who have applicable speciality or relevant expertise in the area under investigation (Linstone & Turoff 1975), reflect the constituency of identified stakeholders, and represent those who are generating the evidence or those who will be applying it in practice (Beech, 2001; Keeney et al. 2001; Hanafin 2005). There is no agreement in the literature regarding the size of the panel, nor any recommendations concerning sampling technique (Williams & Webb 1994; Crisp et al. 1997; Hasson et al. 2000). Linstone & Turoff (1975) suggest that anywhere between 10 to 50 participants should be sufficient in a panel in order to achieve objectives but they also acknowledge that group size is heavily dependent on the number of ‘experts’ available in the field under study. A review of 13 published Delphi studies found that panel size varied from 10 to 3000 (Reid 1998; Campell & Cantrill 2001). Keeney et al. (2006) suggest that the number of experts on a panel is related to common sense and practical logistics rather than hard and fast criteria.

A three round electronic Delphi survey was used in this study with dementia care experts to identify the most beneficial approach to take with people with dementia when they ask questions or make statements that are false. This survey was run through a bespoke online website ‘COMET’ that was designed specifically for the conduct of Delphi surveys. In the first round a structured form was presented, rather than using an open-ended process of participants identifying potential strategies. In subsequent rounds, the participants
received feedback on group ratings of the previous round in a revised questionnaire, and were asked to re-rate the items. Participants were offered the opportunity to add any items that they considered important but which had not been included in the first round instrument.

Study Sample

Purposive and snowball sampling was used to recruit panellists based on the criteria of the panellist having appropriate knowledge concerning approaches to take with people with dementia when they ask questions or make statements that are false. The aim was to recruit panellists from a wide range of areas involved in the planning and delivery of dementia care. Participants were identified through the Galway Dementia Network, Alzheimer Europe, INTERDEM, Alzheimer’s Society Ireland, Alzheimer’s Society Northern Ireland, and Dementia Services Development Centre Northern Ireland. Each eligible participant was sent details of the study aims and objectives and an email invitation to participate.

Table 3: Demographic profile of Delphi panel (n=54)

<table>
<thead>
<tr>
<th>Variable</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Geographical spread</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ireland</td>
<td>31</td>
<td>57.4</td>
</tr>
<tr>
<td>United Kingdom</td>
<td>20</td>
<td>37.0</td>
</tr>
<tr>
<td>Australia</td>
<td>3</td>
<td>5.6</td>
</tr>
<tr>
<td>Age group</td>
<td></td>
<td></td>
</tr>
<tr>
<td>24-34</td>
<td>3</td>
<td>5.5</td>
</tr>
<tr>
<td>35-44</td>
<td>18</td>
<td>33.3</td>
</tr>
<tr>
<td>45-54</td>
<td>22</td>
<td>40.7</td>
</tr>
<tr>
<td>55-64</td>
<td>9</td>
<td>16.8</td>
</tr>
<tr>
<td>65+</td>
<td>3</td>
<td>3.7</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>10</td>
<td>18.5</td>
</tr>
<tr>
<td>Female</td>
<td>44</td>
<td>81.5</td>
</tr>
<tr>
<td>Place of work</td>
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<td></td>
</tr>
<tr>
<td>Acute hospital</td>
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<td>18.5</td>
</tr>
<tr>
<td>Community care</td>
<td>17</td>
<td>31.5</td>
</tr>
<tr>
<td>Educational Institution</td>
<td>10</td>
<td>18.5</td>
</tr>
<tr>
<td>Other</td>
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<td>31.5</td>
</tr>
<tr>
<td>Current work setting</td>
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<tr>
<td>Mental Health</td>
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<td>7.5</td>
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<tr>
<td>Education</td>
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<td>20.4</td>
</tr>
<tr>
<td>Acute Care</td>
<td>7</td>
<td>13.0</td>
</tr>
<tr>
<td>Long stay/residential Care</td>
<td>10</td>
<td>18.5</td>
</tr>
<tr>
<td>Nursing</td>
<td>9</td>
<td>16.7</td>
</tr>
<tr>
<td>Medicine</td>
<td>4</td>
<td>7.4</td>
</tr>
<tr>
<td>Public Health</td>
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<td>3.7</td>
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<tr>
<td>Occupation</td>
<td>Count</td>
<td>Percentage</td>
</tr>
<tr>
<td>-------------------------------------------</td>
<td>-------</td>
<td>------------</td>
</tr>
<tr>
<td>Administration</td>
<td>2</td>
<td>3.7</td>
</tr>
<tr>
<td>Sociology</td>
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</tr>
<tr>
<td>Psychology</td>
<td>1</td>
<td>1.9</td>
</tr>
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<td>5.4</td>
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<td>Current occupation</td>
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<td></td>
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<td>Lecturer</td>
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<td>11.1</td>
</tr>
<tr>
<td>ANP/CNS</td>
<td>4</td>
<td>7.4</td>
</tr>
<tr>
<td>Director Older Persons Services</td>
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<td>12.9</td>
</tr>
<tr>
<td>Consultant</td>
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<td>7.4</td>
</tr>
<tr>
<td>Training &amp; Development Manager</td>
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<td>5.5</td>
</tr>
<tr>
<td>Social Worker</td>
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<td>7.4</td>
</tr>
<tr>
<td>O/T</td>
<td>2</td>
<td>3.7</td>
</tr>
<tr>
<td>Psychologist</td>
<td>2</td>
<td>3.7</td>
</tr>
<tr>
<td>GP</td>
<td>2</td>
<td>3.7</td>
</tr>
<tr>
<td>Support worker</td>
<td>2</td>
<td>3.7</td>
</tr>
<tr>
<td>Other</td>
<td>18</td>
<td>33.5</td>
</tr>
<tr>
<td>Length of time working in role</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1-5 years</td>
<td>28</td>
<td>51.9</td>
</tr>
<tr>
<td>6-10 years</td>
<td>7</td>
<td>13.0</td>
</tr>
<tr>
<td>10 years +</td>
<td>19</td>
<td>35.1</td>
</tr>
<tr>
<td>Educational Qualifications</td>
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<tr>
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<td>87.0</td>
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<tr>
<td>Postgraduate Diploma</td>
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<td>44.4</td>
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<tr>
<td>Masters</td>
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<td>59.2</td>
</tr>
<tr>
<td>PhD</td>
<td>15</td>
<td>27.8</td>
</tr>
<tr>
<td>Higher Diploma</td>
<td>12</td>
<td>22.2</td>
</tr>
<tr>
<td>Other</td>
<td>18</td>
<td>33.5</td>
</tr>
<tr>
<td>Time working in dementia</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1-5 years</td>
<td>6</td>
<td>11.1</td>
</tr>
<tr>
<td>6-10 years</td>
<td>15</td>
<td>27.8</td>
</tr>
<tr>
<td>11-15 years</td>
<td>13</td>
<td>24.1</td>
</tr>
<tr>
<td>16-20 years</td>
<td>12</td>
<td>22.2</td>
</tr>
<tr>
<td>20 years +</td>
<td>8</td>
<td>14.8</td>
</tr>
<tr>
<td>Rate dementia care expertise</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 = low level, 10 = highest level</td>
<td></td>
<td></td>
</tr>
<tr>
<td>0-4</td>
<td>0</td>
<td>0.0</td>
</tr>
<tr>
<td>5-6</td>
<td>12</td>
<td>22.2</td>
</tr>
<tr>
<td>7-8</td>
<td>34</td>
<td>63.0</td>
</tr>
<tr>
<td>9-10</td>
<td>8</td>
<td>14.8</td>
</tr>
</tbody>
</table>

The Delphi process requires a continued commitment from participants being questioned about the same topic in successive rounds using a slightly modified questionnaire each time. It is important that panellists commit to the process and that their interest and involvement is maintained until the process is complete (Hanafin, 2005; Kennedy, 2004; Hasson et al. 2000; McKenna, 1994; Williams and Webb, 1994). Panellists received information on the Delphi technique outlining the process when they were invited to
participate on the panel, in an effort to inform them of the commitment that was required before they accepted the invitation to participate (Appendix 2). Panellists were requested to complete all three rounds of the questionnaire but were informed of their freedom to withdraw at any time. Any person meeting the eligibility criteria and willing to participate was asked to complete and return a reply slip confirming contact details and a signed consent form.

Round One questionnaire development and pilot testing

The objectives of the first round were to:

- Obtain the panellists perceptions on statements relating to the best approach to take when persons with dementia make statements that are false.

- Allow panellists the opportunity to provide reasons for ratings

- Obtain an indication of how panellists rated their own level of expertise in relation to evaluating the role.

- Obtain demographic details on the panellists.

The items in Round One were derived from two sources: a review of the literature and concepts previously identified in care practices and rehabilitative approaches.

The questionnaire for Round One was based on the themes that evolved from the identified sources in previous phases of the study. The survey instrument was divided into six sections as grouping items in a meaningful manner facilitates ease of completion (Cox 1996). Each section reflected a theme and each theme contained a number of statements that emerged from the literature and previously identified care practices.

A pilot of the Round One questionnaire was considered by an expert panel of five individuals with extensive experience in dementia care and research. Panel members were asked to rate whether the draft survey items were valid, understandable and practical. Based on their feedback items were revised. Experts were also asked to indicate any additional items that had not been included in the questionnaire, which they considered important to incorporate.

The revised instrument was then pilot tested with the purpose of testing the questionnaires for any ambiguity in statements, overall clarity and clarity in relation to the instructions with five participants who met the inclusion criteria but were not part of the main study. If more than two participants indicated a problem with an item, it was reviewed. Participants were also asked to add any items which they considered important but had not been included. All participants completed the questionnaire and evaluation
sheets. The wording of two questions was changed as a result of this pilot and one additional item was included. In addition, the online questionnaire was tested by four participants not included in the main study (n=4) for technological difficulties with the system.

A demographic information sheet was also developed to allow the collection of information on the geographical location, age, current professional role, previous clinical and educational experience, and professional and academic qualifications of participants.

Reliability of the instrument

Following the pilot study, homogeneity of items in the questionnaire was measured using Cronbach’s alpha coefficient. Results for each section ranged from .73 to .84 and the overall instrument had a co-efficient of .79. Full results are reported in Appendix 3.

Delphi process

In both Round one and two panellists were asked to rate their agreement with each statement using a 9-point Likert-type scale rating their agreement with the statement: 1-3= Not Important (Strong Disagreement), 4-6= Important but not critical (Neither Agree nor Disagree) and 7-9= Critical (Strong Agreement). In Round One panellists were invited to suggest any additional items that they considered important but which had not been included. For an item to be included it had to be recommended by more than two panellists. Panellists identifying the items had to initially rate the item themselves in Round One on a 1-9 Likert scale. Additional ‘new’ items identified by panellists in Round One were rated in Round Two by all panellists. All the items presented in Round One were re-presented in Round Two to assess stability of responses across rounds (Boote et al. 2006) and to allow participants the opportunity to reconsider their position in light of feedback from the group rating. The overall group’s mean rating and standard deviation is presented for each item within the results section. Items in Round Three were rated for importance as to whether each should be included in the best approach for carers to take for people with dementia when they ask questions or make statements that are false.

Consensus

Within this study consensus was determined in two ways. Firstly, consensus on each statement was determined where the overall mean or median score for inclusion was greater than the mean or median score for all respondents for all items in the section combined. Such a strategy has been used successfully in the past by members of the team (Murphy et al. 2014b; Devane et al. 2007). In addition, a consensus matrix developed by deLoe (1995) was used to calculate the level of consensus on each statement. The level of consensus for each statement was checked following calculation of the percentage of ratings that were in each category of a four point rating scale (Strongly agree to strongly disagree). Four levels of consensus were defined: high, moderate, low and none; these are outlined with their cut-off points in Table 4. The cut-off percentages used to define
consensus are considered to be fairly conservative and varying levels of these would strongly influence the results (deLoe, 1995). Therefore, the actual number of ratings is presented in the results section.

Table 4: Definitions of levels of consensus (deLoe, 1995)

<table>
<thead>
<tr>
<th>Consensus</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>High</td>
<td>70% of ratings in one agreement category or 80% in two contiguous categories*</td>
</tr>
<tr>
<td>Moderate</td>
<td>60% of ratings in one agreement category or 70% in two contiguous categories*</td>
</tr>
<tr>
<td>Low</td>
<td>50% of ratings in one agreement category or 60% in two contiguous categories*</td>
</tr>
<tr>
<td>None</td>
<td>Less than 50% of ratings in one agreement category or less than 60% in two contiguous categories*</td>
</tr>
</tbody>
</table>

Response rate

Participants who agreed to participate accessed the survey online by clicking a link provided in an invitation email. The first round questionnaire was sent on 26th June 2015 to 65 panellists who had indicated willingness to participate and 54 people registered to complete the survey. Following one reminder, fully completed questionnaires were received from 47 panellists (RR 87%).

The final panel who registered to complete the Delphi survey was composed of participants from Ireland (57.4%, n=31), United Kingdom (37%, n=20) and Australia (5.6%, n=3). The majority of panellists (74%, n=40) were in the 35-54 age group and predominantly female (81.5%, n=44). There were similar proportions of participants who worked in acute hospital, community care and educational institution and similar proportions of participants across occupations. Just over half the panel had between 1-5 years experience in their current role and over 35% (n=19) of panellists were longer than ten years in their current role. Over 87% (n=47) of panellists held a degree qualification, with other qualifications including Postgraduate diplomas, Masters and PhD’s. The wealth of experience of the panel was evident in the number of years working in dementia, with over 88% (n=48) with 6-20+ years of experience in dementia care.

Panellists were asked to rate their perceived level of expertise in dementia care on a 1-10 scale, with 1 being a low level of expertise and 10 the highest level. All participants rated themselves greater than five, with over 77% (n=42) rating themselves as 7 or above. Full demographic details are presented in Table 3.
Round Two

The purpose of Round Two was to provide panellists with a) the opportunity to reflect on their original answers in the context of b) feedback on the overall group rating of items. In Round Two, panellists were able to view the group mean rating for each statement and the percentage rating of each scale item (1-9). Panellists were asked to consider the group rating when re-rating each statement. Panellists were also given a summary of qualitative responses received from panellists who provided rationale for their choices in Round One. Round Two was sent to the 47 panellists who had completed Round One and a total of 43 replies were received giving a response rate of 91.4%.

Round Three

The purpose of Round Three was to a) provide panellists with feedback on levels of agreement in Rounds one and two; b) introduce action statements derived from statements in Rounds one and two, c) provide panellists with the opportunity to reflect on the action statements d) provide panellists with the opportunity to rate their perceived importance of each action statement and e) utilise ratings on action statements to identify strategies that would inform a best practice approach when people with dementia make statements that are false. In order to develop action statements for the Round Three questionnaire, statements from Rounds one and two were reworded based on the levels of consensus and qualitative feedback received. Round Three was sent to the 43 panellists who had completed Round Two and replies were received from 40 panellists (93%).

Results Round One

Section A: Care Environment Influences

Section A related to the care environment influences that impact on the person with dementia regarding the best approaches to care when they make statements that are false. Panellists were asked to rate their level of agreement with 14 statements that were concerned with particular items that impacted on the care experienced by the person with dementia.

The highest rating was given to item A13. Treating a person with dementia in a person centred manner aids their social interaction and connectedness, with a mean of 9.1(SD .75). Items that also scored high included item A1. The person with dementia should be
central to planning their own care with a mean of 8.4 (SD 1.2), and item A2. The main aim of psychosocial care for the person with dementia is to understand the person's individual experience of dementia and employ strategies which optimise functioning scoring a mean of 8.5 (SD .95).

Statement panellists most disagreed with was item A7: In my opinion, support from external agencies such as GP, Social worker, Carers agencies etc. has little impact on the person with dementia with a mean of 3.0 (SD 3) and item A12: Support from external agencies such as GP, Social worker, Carers agencies etc. has little impact on the family of the person with dementia with a mean of 3.0 (SD 3). This would suggest that panellists felt that the support provided by external agencies had a positive impact both on the individual with dementia and the family.

Panellists were undecided about some issues such as who should be responsible for deciding the best approach to take when people with dementia make statements that are false as evidenced in item A10: The family of the person with dementia should be the ones who ultimately decide the most appropriate approach to take when the person with dementia make statements that are false scoring a mean of 5.6 (SD 2.6). Similarly, opinion in relation to item A9 was divided: The formal carer (i.e. health professional) should be the person who ultimately decides the most appropriate approach to take when the person with dementia make statements that are false with a mean of 4.4 (SD 2.4).
### Table 5: Mean and Standard Deviation ratings of Section A, Round One

<table>
<thead>
<tr>
<th>Section A: Care Environment Influences (9 = strongly agree, 6= agree, 3= disagree, 1=strongly disagree)</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>A1. The person with dementia should be central to planning their own care</td>
<td>8.4</td>
<td>1.2</td>
</tr>
<tr>
<td>A2. The main aim of psychosocial care for the person with dementia is to understand the persons individual experience of dementia and employ strategies which optimise functioning</td>
<td>8.5</td>
<td>.95</td>
</tr>
<tr>
<td>A3. The type of dementia has a significant influence on appropriate strategies that can be used by carers</td>
<td>7.3</td>
<td>1.8</td>
</tr>
<tr>
<td>A4. The stage of dementia has a significant influence on appropriate strategies that can be used by carers</td>
<td>8.0</td>
<td>1.6</td>
</tr>
<tr>
<td>A5. Discussion between family members is necessary to agree approaches to care for the person with dementia</td>
<td>8.3</td>
<td>.97</td>
</tr>
<tr>
<td>A6. Discussion between family members is necessary to agree strategies that will be used when the person with dementia make statement that are false</td>
<td>7.9</td>
<td>2.3</td>
</tr>
<tr>
<td>A7. In my opinion, support from external agencies such as GP, Social worker, Carers agencies etc. has little impact on the person with dementia</td>
<td>3.0</td>
<td>3.0</td>
</tr>
<tr>
<td>A8. Disharmony among the family can negatively affect strategies that will be used when the person with dementia make statement that are false</td>
<td>7.5</td>
<td>2.1</td>
</tr>
<tr>
<td>A9. The formal carer (i.e. health professional) should be the person who ultimately decides the most appropriate approach to take when the person with dementia make statement that are false</td>
<td>4.4</td>
<td>2.4</td>
</tr>
<tr>
<td>A10. The family of the person with dementia should be the ones who ultimately decide the most appropriate approach to take when the person with dementia make statement that are false</td>
<td>5.6</td>
<td>2.6</td>
</tr>
<tr>
<td>A11. Counselling support is necessary for families to facilitate them to make appropriate decisions regarding care of the person with dementia</td>
<td>7.4</td>
<td>1.9</td>
</tr>
<tr>
<td>A12. Support from external agencies such as GP, Social worker, Carers agencies etc. has little impact on the family of the person with dementia.</td>
<td>3.0</td>
<td>2.9</td>
</tr>
</tbody>
</table>

---

4 The highlighted number in each table indicates that the overall mean score for a single item is greater than the mean score for all the items combined.
Analysis of the consensus levels found the following:

**Statements with high consensus**

There was a high consensus on nine statements in Section A. Panellists indicated that:

1. *Treating a person with dementia in a person centred manner aids their social interaction and connectedness (98%, A13)*

2. *The main aim of psychosocial care for the person with dementia is to understand the person’s individual experience of dementia and employ strategies which optimise functioning (96%, A2)*

3. *Discussion between family members is necessary to agree approaches to care for the person with dementia (96%, A5)*

4. *The stage of dementia has a significant influence on the appropriate strategies that can be used by carers (94%, A4)*

5. *The person with dementia should be central to planning their own care (91%, A1)*

6. *Discussion between family members is necessary to agree strategies that will be used when the person with dementia makes statements that are false (81%, A6)*

High consensus against the statement

7. *Support from external agencies such as GP; social worker; carers agencies etc. has little impact on the family of the person with dementia (85% against, A12)*

8. *In my opinion; support from external agencies such as GP; Social worker; carers agencies etc. has little impact on the family of the person with dementia (83% against, A7)*
9. The formal carer (i.e. health professional) should be the person who ultimately decides the most appropriate approach to take when the person with dementia make statements that are false (81%, against)

Statements with moderate consensus

Moderate consensus was reached on three statements in Section A. Panellists indicated that:

1. Disharmony among the family can negatively affect strategies that will be used when the person with dementia makes statements that are false (75%, A8).

2. The ability to proactively plan ahead for what to do when a person with dementia makes statements that are false is often impacted by the trajectory of the person’s dementia (74%, A14).

3. The type of dementia has a significant influence on appropriate strategies that can be used by carers (72%, A3).

Moderate consensus against the statement

4. The family of the person with dementia should ultimately decide the most appropriate approach to take when the person with dementia makes statements that are false (60% against, A10)

Statements with low consensus

Low consensus was evident in one statement. Panellists indicated that:

1. Counselling support is necessary for families to facilitate them to make appropriate decisions regarding care of the person with dementia (64%, A11).
Figure 3 Round One Section A: Care Environment Influences

- The person with dementia should be central to planning their own care
- The main aim of psychosocial care for the person with dementia is to understand the person's individual experience of dementia and employ strategies which optimise functioning
- The type of dementia has a significant influence on appropriate strategies that can be used by caregivers
- The stage of dementia has a significant influence on the appropriate strategies that can be used by caregivers
- Discussion between family members is necessary to agree approaches to care for the person with dementia
- Discussion between family members is necessary to agree strategies that will be used when the person with dementia makes statements that are false
- In my opinion, support from external agencies such as GP; Social worker; carers agencies etc. has little impact on the family of the person with dementia
- Disharmony among the family can negatively affect strategies that will be used when the person with dementia makes statements that are false
- The formal caregiver (i.e., health professional) should be the person who ultimately decides the most appropriate approach to take when the person with dementia make statement that are false
- The family of the person with dementia should ultimately decide the most appropriate approach to take when the person with dementia makes statements that are false
- Counselling support is necessary for families to facilitate them to make appropriate decisions regarding care of the person with dementia
- Support from external agencies such as GP; social worker; carers agencies etc. has little impact on the family of the person with dementia
- Treating a person with dementia in a person-centred manner aids their social interaction and connectedness
- The ability to proactively plan ahead for what to do when a person with dementia makes statements that are false is often impacted by the trajectory of the person's dementia

■ Strongly Disagree ■ Disagree ■ Neither Agree nor Disagree ■ Agree ■ Strongly Agree
The mean score for all items in Section A was 6.5 and applying the principle that items on which consensus is agreed will be items where the overall mean score for a single item is greater than the mean score for all the items combined, meant that items scoring over 6.5 were indicative of consensus.

Nine items in Section A had a mean rating over 6.5 indicating that panellists were largely in agreement on these items, and these are highlighted in Table 5. These items correspond with the nine items of consensus as indicated by the definitions of levels of consensus (deLoe, 1995).

Additional items

Following Round One an additional item proposed by two panellists was added to Section A as follows: The adoption of relationship centred approaches/interventions is critical in providing meaningful care for people with dementia and their families. Panellists who identified the item rated it as a 9 on the Likert scale.

Supporting rationale and commentary made by panellists in Section A Round One.

Panellists had the opportunity to include rationales for their item ratings in Round One. Many panellists took the opportunity to include commentary on particular items within the sections in addition to the issue overall. Qualitative comments were anonymised, summarised and given to panellists with the Round two questionnaire feedback. Comments in relation to Section A are presented in Appendix 4.

Summary of section A: Care environment influences

Section A related to the care environment influences that impact on the person with dementia. Panellists were strongly in favour of the person with dementia being central to care planning, with a person centered approach preferred. Panellists strongly supported the concept that the main aim of care was around knowing the person, delivering person centred care and employing strategies that optimise functioning. The stage of dementia had a significant impact on the strategies that were suitable at that point in time. It was considered important to include family members in planning care approaches and external agencies had a significant role to play in terms of patient and family support. Panellists were less convinced that the type of dementia impacted on potential effective strategies, and that the decisions about strategies were the responsibility of the family.

Section B Therapeutic Lying

This section was concerned with how panellists viewed therapeutic lying in the care of the person with dementia. Panellists were asked to rate their level of agreement with 21 statements related to the use of therapeutic lying on the care experienced by the person with dementia.

The highest rating was given to item B9. *Therapeutic lying is sometimes acceptable* with a
mean of 7.6 (SD 2) and B10: Therapeutic lying designed to ease the distress of the person with dementia is acceptable, with a mean of 7.6 (SD 2.2). Items that also scored reasonably high included item B11. It is acceptable for the carer to use therapeutic lying if they have a good knowledge of the person and are aware of what approach works best with them, with a mean of 7.3 (SD 2.5) and item B8. It is acceptable to lie in a crisis situation when there is a risk that a person might harm themselves with a mean of 7.2 (SD 2.2).

The statement panellists disagreed with most was item B7. Therapeutic lying is deceptive and should never be used, with a mean of 3.6 (SD 3). This would suggest that panellists felt that the support provided by external agencies had a positive impact both on the individual with dementia and the family. Statement B3: It is appropriate to use therapeutic lying when a person has a Clinical Dementia Rating (CDR) indicating mild impairment only scored a mean of 3.8 (SD 3) also indicating high levels of disagreement.

Panellists were undecided about some issues such as who should be responsible for deciding the best approach to take when people with dementia make statements that are false as evidenced in item B18. The acceptability of therapeutic lying depends on the type of dementia the person is suffering from which scored a mean of 4.5 (SD 3.2) and statement B19. Therapeutic lying is acceptable if it helps the carer give treatment (e.g. medication; nutrition) to the person with dementia with a mean of 5.5 (SD 2.9).
Table 6: Mean and Standard Deviation ratings of Section B, Round One

<table>
<thead>
<tr>
<th>Section B: Therapeutic Lying (9 = strongly agree, 6 = agree, 3 = disagree, 1 = strongly disagree)</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>B1. I am familiar with the use of therapeutic lying in the care of persons with dementia</td>
<td>7.1</td>
<td>2.3</td>
</tr>
<tr>
<td>B2. Therapeutic lying involves the carer ‘going along’ with what the person with dementia is saying rather than trying to re-orientate</td>
<td>7.0</td>
<td>2.4</td>
</tr>
<tr>
<td>B3. It is appropriate to use therapeutic lying when a person has a Clinical Dementia Rating (CDR) indicating mild impairment only</td>
<td>3.8</td>
<td>3.0</td>
</tr>
<tr>
<td>B4. It is appropriate to use therapeutic lying when a person has a Clinical Dementia Rating (CDR) indicating moderate impairment</td>
<td>4.6</td>
<td>3.0</td>
</tr>
<tr>
<td>B5. It is appropriate to use therapeutic lying when a person has a Clinical Dementia Rating (CDR) indicating moderate to severe impairment</td>
<td>6.3</td>
<td>2.7</td>
</tr>
<tr>
<td>B6. Therapeutic lying is a specific communication strategy used in the best interest of the person with dementia</td>
<td>7.0</td>
<td>2.5</td>
</tr>
<tr>
<td>B7. Therapeutic lying is deceptive and should never be used</td>
<td>3.6</td>
<td>3.0</td>
</tr>
<tr>
<td>B8. It is acceptable to lie in a crisis situation when there is a risk that a person might harm themselves</td>
<td>7.2</td>
<td>2.2</td>
</tr>
<tr>
<td>B9. Therapeutic lying is sometimes acceptable</td>
<td>7.6</td>
<td>2.0</td>
</tr>
<tr>
<td>B10. Therapeutic lying designed to ease the distress of the person with dementia is acceptable</td>
<td>7.6</td>
<td>2.2</td>
</tr>
<tr>
<td>B11. It is acceptable for the carer to use therapeutic lying if they have a good knowledge of the person and are aware of what approach works best with them</td>
<td>7.3</td>
<td>2.5</td>
</tr>
<tr>
<td>B12. The use of therapeutic lying is justified if it reduces challenging behaviour in the person with dementia</td>
<td>6.5</td>
<td>2.8</td>
</tr>
<tr>
<td>B13. It is acceptable to use therapeutic lying if you know from past experience that the person with dementia gets upset when told the truth</td>
<td>7.1</td>
<td>2.5</td>
</tr>
<tr>
<td>B14. Carers should always tell the truth to a person with dementia</td>
<td>4.3</td>
<td>2.9</td>
</tr>
<tr>
<td>B15. Therapeutic lying is acceptable if it reduces aggressive behaviour in the person with dementia</td>
<td>7.1</td>
<td>2.7</td>
</tr>
<tr>
<td>B16. The acceptability of therapeutic lying depends on the stage of dementia of the person</td>
<td>6.3</td>
<td>3.0</td>
</tr>
<tr>
<td>B17. Therapeutic lying could be considered as a person centred strategy</td>
<td>6.8</td>
<td>2.6</td>
</tr>
<tr>
<td>B18. The acceptability of therapeutic lying depends on the type of dementia the person is suffering from</td>
<td>4.5</td>
<td>3.2</td>
</tr>
<tr>
<td>B19. Therapeutic lying is acceptable if it helps the carer give treatment (e.g. medication; nutrition) to the person with dementia</td>
<td>5.5</td>
<td>2.9</td>
</tr>
<tr>
<td>B20. Carers would need formal training to be able to carry out therapeutic lying appropriately</td>
<td>6.9</td>
<td>2.9</td>
</tr>
<tr>
<td>B21. Carers should discuss the acceptability of therapeutic lying with the person with dementia while the person is in the early stages of dementia and has adequate memory</td>
<td>6.2</td>
<td>2.6</td>
</tr>
</tbody>
</table>
Analysis of the consensus levels found the following:

**Statements with high consensus**

There were no statements evidencing a high consensus in Section B.

**Statements with moderate consensus**

Moderate consensus was reached on ten statements in Section B. Panellists indicated that:

1. *Therapeutic lying is deceptive and should never be used* (B, 79%)

2. *Therapeutic lying designed to ease the distress of the person with dementia is acceptable* (B10, 75%)

3. *It is acceptable to lie in a crisis situation when there is a risk that a person might harm themselves* (B8, 75%)

4. *Therapeutic lying is sometimes acceptable* (B9, 73%)

5. *It is acceptable for the carer to use therapeutic lying if they have a good knowledge of the person and are aware of what approach works best with them* (B11, 71%)

6. *Therapeutic lying involves the carer ‘going along’ with what the person with dementia is saying rather than trying to re-orientate them* (B2, 71%).

**Statements with moderate consensus against the statement**

7. *It is appropriate to use therapeutic lying when a person has a Clinical Dementia Rating (CDR) indicating moderate impairment only* (B3, 73%)

8. *Therapeutic lying is deceptive and should never be used* (B, 79%)

9. *Carers should always tell the truth to a person with dementia* (B14, 78%)

10. *Therapeutic lying is acceptable if it reduces aggressive behaviour in the person with dementia* (B15, 71%)
Statements with low consensus

Low consensus was evident in seven statements. Panellists indicated agreement that:

1. *I am familiar with the use of therapeutic lying in the care of persons with dementia* (67%, B1).
2. *Therapeutic lying is a specific communication strategy used in the best interest of the person with dementia* (B6, 63%)
3. *The use of therapeutic lying is justified if it reduces challenging behaviour in the person with dementia* (B12, 63%)
4. *It is acceptable to use therapeutic lying if you know from past experience that the person with dementia gets upset when told the truth* (B13, 67%)
5. *Therapeutic lying is acceptable if it reduces aggressive behaviour in the person with dementia* (B15, 69%)
6. *Therapeutic lying could be considered as a person centred strategy* (B17, 62%)
7. *Carers would need formal training to be able to carry out therapeutic lying appropriately* (B20, 62%)

There were two statements with low consensus against the statement. Panellists indicated disagreement that:

1. *The acceptability of therapeutic lying depends on the type of dementia the person is suffering from* (B16, 69%)
2. *Therapeutic lying is acceptable if it helps the carer give treatment (e.g. medication; nutrition) to the person with dementia* (B19, 60%)

Panellists were polarised on two statements in section B which were:

1. *It is appropriate to use therapeutic lying when a person has a Clinical Dementia Rating (CDR) indicating moderate to severe impairment* (B5, Against 46%, For 54%)
2. *Carers should discuss the acceptability of therapeutic lying with the person with dementia while the person is in the early stages of dementia and has adequate memory* (B21, Against 56%, For 44%).

Statements with low consensus against the statement would suggest that the panel were split between whether the use of therapeutic lying with people with moderate to severe dementia was appropriate or not. There were also split between the choice of discussing the future use of therapeutic lying with the person with dementia while they still had
cognitive capacity was appropriate. Figure 4 shows the Round One percentage rating of statements by panellists.

The mean score for all items in Section B was 7.0 and, applying the principle that items on which consensus is agreed will be items where the overall mean score for a single item is greater than the mean score for all the items combined, meant that items scoring over 7.0 were indicative of consensus.

Nine items in Section B had a mean rating over 7.0 indicating that panellists were largely in agreement on these items, and these are highlighted in Table 6. These items correspond with the nine items of consensus as indicated by the Definitions of levels of consensus (deLoe, 1995).
Supporting rationale and commentary made by panellists in Round One.

Panellists had the opportunity to include rationale for their item rating in Round One. Many panellists took the opportunity to include commentary on particular items within the sections in addition to the issue overall. Qualitative comments were anonymised and summarised and given to panellists with the Round Two questionnaire feedback. Comments in relation to Section B are presented in Appendix 5.

Summary of section B: Therapeutic lying

Section B related to the use of therapeutic lying as a strategy for use in caring for people with dementia when they make statements that are false. Panellists were generally in agreement that therapeutic lying was acceptable as a strategy depending on the stage of dementia of the person and a variety of other factors including knowledge of the person and previous experience of reactions. There was some divergence of opinion on whether the level of dementia impacted on the use of the strategy and a lack of consensus around forward planning with the person to make decisions about what would be done in later stages if the person’s memory declined further.

Section C: Validation Therapy

This section was concerned with how panellists viewed validation therapy in the care of the person with dementia. Panellists rated their level of agreement with statements focused around the use of validation therapy as part of the care experienced by the person with dementia.

The highest rating was given to item C2: Validation therapy puts emphasis on the emotional content of what the person with dementia is expressing and item C10. In my experience, validation therapy promotes better communication between the carer and the person with dementia with both statements getting a mean rating of 7.8 (SD 1.7).

Items that also scored reasonably high included item C9. Using validation therapy can help the carer better understand the person with dementia’s entire frame of reference, with a mean rating of 7.5 (SD 1.8), and item C11. In my experience; validation therapy promotes better interaction between the carer and the person with dementia with a mean rating of 7.6 (SD 1.5).

Statement panellists most disagreed with item C3. Validation therapy is effective when a person has a Clinical Dementia Rating (CDR) indicating mild impairment only with a mean rating of 5.2 (SD 3.1) and C13. In my experience; validation therapy is seldom used in the care of persons with dementia, with a mean of 5.3 (SD 2.9).
Table 7: Mean and Standard Deviation ratings of Section C, Round One

<table>
<thead>
<tr>
<th>Section C: Validation Therapy</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>(9 = strongly agree, 6= agree, 3= disagree, 1=strongly disagree)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>C1. I am familiar with the use of validation therapy in the care of persons with dementia</td>
<td>7.1</td>
<td>2.5</td>
</tr>
<tr>
<td>C2. Validation therapy puts emphasis on the emotional content of what the person with dementia is expressing</td>
<td>7.8</td>
<td>1.7</td>
</tr>
<tr>
<td>C3. Validation therapy is effective when a person has a Clinical Dementia Rating (CDR) indicating mild impairment only</td>
<td>5.2</td>
<td>3.1</td>
</tr>
<tr>
<td>C5. Validation therapy is effective when a person has a Clinical Dementia Rating (CDR) indicating moderate impairment</td>
<td>6.3</td>
<td>2.7</td>
</tr>
<tr>
<td>C6. Validation therapy is effective when a person has a Clinical Dementia Rating (CDR) indicating moderate to severe impairment</td>
<td>6.5</td>
<td>2.7</td>
</tr>
<tr>
<td>C7. Validation therapy involves the person with dementia and their carer retreating together into the past and by doing so; exploring the lived experiences of the person with dementia</td>
<td>6.1</td>
<td>2.8</td>
</tr>
<tr>
<td>C8. Living in the past is less demanding for the person with dementia than living in an unfamiliar present</td>
<td>6.8</td>
<td>2.2</td>
</tr>
<tr>
<td>C9. Using validation therapy can help the carer better understand the person with dementia’s entire frame of reference</td>
<td>7.5</td>
<td>1.8</td>
</tr>
<tr>
<td>C10. In my experience, validation therapy promotes better communication between the carer and the person with dementia</td>
<td>7.8</td>
<td>1.7</td>
</tr>
<tr>
<td>C11. In my experience; validation therapy promotes better interaction between the carer and the person with dementia</td>
<td>7.6</td>
<td>1.5</td>
</tr>
<tr>
<td>C12. In my experience; validation therapy has a positive effect of behavioural symptoms of the person with dementia</td>
<td>7.5</td>
<td>1.8</td>
</tr>
<tr>
<td>C13. In my experience; validation therapy is seldom used in the care of persons with dementia</td>
<td>5.3</td>
<td>2.9</td>
</tr>
<tr>
<td>C14. Carers would need formal training to be able to carry out validation therapy</td>
<td>7.5</td>
<td>2.3</td>
</tr>
</tbody>
</table>

Analysis of the consensus levels reveals the following:

**Statements with high consensus**

There was one statement evidencing a high consensus in Section C.

*Validation therapy puts emphasis on the emotional content of what the person with dementia is expressing* (C2, 80%)

**Statements with moderate consensus**

Moderate consensus was reached on six statements in Section C. Panellists indicated that:

1. *Using validation therapy can help the carer better understand the person with dementia’s entire frame of reference* (C8, 76%)
2. *In my experience; validation therapy promotes better interaction between the carer and the person with dementia* (C10, 75%)

3. *In my experience; validation therapy has a positive effect on behavioural symptoms of the person with dementia* (C11, 75%)

4. *Carers would need formal training to be able to carry out validation therapy* (C13, 75%)

5. *I am familiar with the use of validation therapy in the care of persons with dementia* (C1, 73%)

6. *In my experience; validation therapy promotes better communication between the carer and the person with dementia* (C9, 71%)

**Statements with low consensus**

There was one statement with low consensus for the statement in Section C.

1. *Living in the past is less demanding for the person with dementia than living in an unfamiliar present* (C7, 63%)

There were two statements with low consensus against the statement in Section C. Panellists indicated disagreement with:

1. *In my experience; validation therapy is seldom used in the care of persons with dementia*
   - (C12, 69%)

2. *Validation therapy is effective when a person has a Clinical Dementia Rating (CDR) indicating mild impairment only* (C3, 67%)

**Polarised statements**

Panellists were polarised on three statements in Section C which were:

1. *Validation therapy involves the person with dementia and their carer retreating together into the past and by doing so; exploring the lived experiences of the person with dementia* (C6, 51% against, 49% for)

2. *Validation therapy is effective when a person has a Clinical Dementia Rating (CDR) indicating moderate impairment* (C4, 49% against, 51% for)

3. *Validation therapy is effective when a person has a Clinical Dementia Rating (CDR) indicating moderate to severe impairment* (C5, 43% against, 57% for)
Statements with low and no consensus were concerned with what validation therapy involved and the appropriateness of validation therapy at certain stages of dementia. The panel were split almost evenly between the two opposing considerations. Figure 5 shows the Round One percentage rating of statements by panellists for Section C.

The mean score for all items in Section C was 7.5 and, applying the principle that items on which consensus is agreed will be items where the overall mean score for a single item is greater than the mean score for all the items combined, meant that items scoring over 7.5 were indicative of consensus.

Nine items in Section C had a mean rating over 7.5 indicating that panellists were largely in agreement on these items, which are highlighted in Table 7. These items correspond with the nine items of consensus as indicated by the Definitions of levels of consensus (deLoe, 1995).

Supporting rationale and commentary made by panellists in Round One.

Panellists had the opportunity to include rationale for their item rating in Round One. Many panellists took the opportunity to include commentary on particular items within the sections in addition to the issue overall. Qualitative comments were anonymised and summarised and given to panellists with the Round Two questionnaire feedback. There was very little commentary on the section on validation therapy. Some panellists commented that it was not a technique with which they were familiar and a few suggested that validation therapy is seldom used in the care of persons with dementia.

Panellists suggested that the use of validation therapy depended on the individual assessment and that it was the person with dementias care needs that should drive the choice of use of this strategy rather than a Clinical Dementia Rating (CDR).

Summary of Section C: Validation Therapy

Panellists were strongly of the opinion that validation therapy promoted communication and interaction with the person with dementia and positively impacted behaviour. Panellist choices suggested that they considered validation therapy a more suitable strategy with mild impairment rather than moderate or severe.
Figure 5: Round One, Section C: Validation Therapy

- I am familiar with the use of validation therapy in the care of persons with dementia
- Validation therapy puts emphasis on the emotional content of what the person with dementia is expressing
- Validation therapy is effective when a person has a Clinical Dementia Rating (CDR) indicating mild impairment only
- Validation therapy is effective when a person has a Clinical Dementia Rating (CDR) indicating moderate impairment
- Validation therapy is effective when a person has a Clinical Dementia Rating (CDR) indicating moderate to severe impairment
- Validation therapy involves the person with dementia and their caregiver retreating together into the past and by doing so; exploring the lived experiences of the person with dementia
- Living in the past is less demanding for the person with dementia than living in an unfamiliar present
- Using validation therapy can help the caregiver better understand the person with dementia’s entire frame of reference
- In my experience; validation therapy promotes better communication between the caregiver and the person with dementia
- In my experience; validation therapy promotes better interaction between the caregiver and the person with dementia
- In my experience; validation therapy has a positive effect of behavioural symptoms of the person with dementia
- In my experience; validation therapy is seldom used in the care of persons with dementia
- Caregivers would need formal training to be able to carry out validation therapy

■ Strongly Disagree ■ Disagree ■ Neither Agree nor Disagree ■ Agree ■ Strongly Agree
Results from Section D: Reality Orientation (RO) Therapy

This section is concerned with how panellists perceived reality orientation therapy in the care of the person with dementia.

Section D related to the perceptions around reality orientation therapy and its effectiveness in relation to the care of the person with dementia. Panellists were asked to rate their level of agreement with 17 statements that were concerned with particular items that impacted on the care experienced by the person with dementia.

The highest rating was given to items D2. Reality orientation (RO) is about continually presenting confused persons with information about time; place and person to help keep them in the "now" with a mean of 7.8 (SD1.5) and item D15. Cognitive stimulation therapy such as the use of word games; puzzles; group discussion and activities such as cooking and gardening is an effective therapy for persons with mild to moderate dementia, with a mean rating of 7.8 (SD1.8)

Items that also scored high included item D16: Cognitive stimulation therapy is more effective than RO therapy for persons with mild to moderate dementia, with a mean rating of 7.7 (SD2.1) and item D6. When RO is used with people with severe dementia it can result in increased levels of agitation, with a mean rating of 7.5(SD2.2).

Statement panellists most disagreed with was item D5. RO is effective when a person has a Clinical Dementia Rating (CDR) indicating moderate to severe impairment, with a mean rating of 4.4 (SD3.3), and item D7. RO therapy never results in lowering of mood when used with people with severe dementia with a mean rating of 5.3(SD3.3). This would suggest that panellists disagreed on the effectiveness of RO therapy in severe impairment. They were also in disagreement regarding whether RO resulted in lowering the person’s mood.

Panellists were undecided about some issues such as whether RO had a long lasting therapeutic effect in item D12. Positive effects of RO therapy are long-lasting for the person with dementia, with a mean of 5.9 (SD3.3).
Table 8: Mean and Standard Deviation ratings of Section D, Round One

<table>
<thead>
<tr>
<th>Section D: Reality Orientation (RO) Therapy</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>(9 = strongly agree, 6 = agree, 3 = disagree, 1 = strongly disagree)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>D1. I am familiar with the use of reality orientation (RO) therapy in the</td>
<td>7.1</td>
<td>2.5</td>
</tr>
<tr>
<td>care of persons with dementia</td>
<td></td>
<td></td>
</tr>
<tr>
<td>D2. Reality orientation (RO) is about continually presenting confused</td>
<td>7.8</td>
<td>1.5</td>
</tr>
<tr>
<td>persons with information about time; place and person to help keep them in</td>
<td></td>
<td></td>
</tr>
<tr>
<td>the &quot;now&quot;</td>
<td></td>
<td></td>
</tr>
<tr>
<td>D3. RO therapy is effective when a person has a Clinical Dementia Rating</td>
<td>6.8</td>
<td>2.8</td>
</tr>
<tr>
<td>(CDR) indicating mild impairment only</td>
<td></td>
<td></td>
</tr>
<tr>
<td>D4. RO is effective when a person has a Clinical Dementia Rating (CDR)</td>
<td>5.7</td>
<td>2.8</td>
</tr>
<tr>
<td>indicating moderate impairment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>D5. RO is effective when a person has a Clinical Dementia Rating (CDR)</td>
<td>4.4</td>
<td>3.3</td>
</tr>
<tr>
<td>indicating moderate to severe impairment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>D6. When RO is used with people with severe dementia it can result in</td>
<td>7.5</td>
<td>2.2</td>
</tr>
<tr>
<td>increased levels of agitation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>D7. RO therapy never results in lowering of mood when used with people</td>
<td>5.3</td>
<td>3.3</td>
</tr>
<tr>
<td>with severe dementia</td>
<td></td>
<td></td>
</tr>
<tr>
<td>D8. RO is most effective when delivered in a group setting</td>
<td>5.5</td>
<td>3.5</td>
</tr>
<tr>
<td>D9. RO is most effective when delivered at the level of the individual</td>
<td>7.4</td>
<td>2.2</td>
</tr>
<tr>
<td>D10. Discussion of recent events is an appropriate strategy for RO therapy</td>
<td>7.4</td>
<td>2.3</td>
</tr>
<tr>
<td>D11. Carers using RO therapy are more prone to frustration and stress</td>
<td>7.1</td>
<td>2.9</td>
</tr>
<tr>
<td>D12. Positive effects of RO therapy are long-lasting for the person with</td>
<td>5.9</td>
<td>3.3</td>
</tr>
<tr>
<td>dementia</td>
<td></td>
<td></td>
</tr>
<tr>
<td>D13. I am familiar with the use of cognitive stimulation therapy in the</td>
<td>7.4</td>
<td>2.3</td>
</tr>
<tr>
<td>care of persons with dementia</td>
<td></td>
<td></td>
</tr>
<tr>
<td>D14. Cognitive stimulation therapy such as the use of word games;</td>
<td>6.5</td>
<td>2.6</td>
</tr>
<tr>
<td>puzzles; group discussion; and activities such as cooking and gardening is</td>
<td></td>
<td></td>
</tr>
<tr>
<td>an effective therapy for all persons with dementia</td>
<td></td>
<td></td>
</tr>
<tr>
<td>D15. Cognitive stimulation therapy such as the use of word games;</td>
<td>7.8</td>
<td>1.8</td>
</tr>
<tr>
<td>puzzles; group discussion and activities such as cooking and</td>
<td></td>
<td></td>
</tr>
<tr>
<td>gardening is an effective therapy for persons with mild to moderate dementia</td>
<td></td>
<td></td>
</tr>
<tr>
<td>D16. Cognitive stimulation therapy is more effective than RO therapy for</td>
<td>7.2</td>
<td>2.1</td>
</tr>
<tr>
<td>persons with mild to moderate dementia</td>
<td></td>
<td></td>
</tr>
<tr>
<td>D17. Carers would need formal training to be able to carry out RO therapy</td>
<td>7.1</td>
<td>2.8</td>
</tr>
</tbody>
</table>

Analysis of the consensus levels found the following:

Statements with high consensus

There were two statements evidencing a high consensus in Section D.
1. **Reality orientation (RO) is about continually presenting confused persons with information about time; place and person to help keep them in the "now"** (D2, 84%)

2. **Cognitive stimulation therapy such as the use of word games; puzzles; group discussion and activities such as cooking and gardening is an effective therapy for persons with mild to moderate dementia** (D15, 90%)

**Statements with moderate consensus**

Moderate consensus was reached on six statements in Section D. Panellists indicated that:

1. **I am familiar with the use of RO therapy in the care of persons with dementia** (D1, 72%)

2. **When RO is used with people with severe dementia it can result in increased levels of agitation** (D6, 76%)

3. **RO is most effective when delivered at the level of the individual** (D9, 72%)

4. **I am familiar with the use of cognitive stimulation therapy in the care of persons with dementia** (D13, 78%)

5. **Cognitive stimulation therapy is more effective than RO therapy for persons with mild to moderate dementia** (D16, 74%)

6. **Carers would need formal training to be able to carry out RO therapy** (D17, 71%)

There was one statement with moderate consensus against the statement

RO is effective when a person has a Clinical Dementia Rating (CDR) indicating moderate to severe impairment (D5, 78%) indicating that panellist did not think RO a suitable therapy for moderate to severe dementia.

**Statements with low consensus**

There were two statements with low consensus for the statement in Section D.

1. **Discussion of recent events is an appropriate strategy for RO therapy** (D10, 62%)

2. **Carers using RO therapy are more prone to frustration and stress** (D11, 60%)

There were four statements with low consensus against the statement in Section D. Panellists indicated disagreement with:
1. **RO is effective when a person has a Clinical Dementia Rating (CDR) indicating moderate impairment** (D4, 64%).

2. **Positive effects of RO therapy are long-lasting for the person with dementia** (D12, 62%).

3. **RO therapy never results in lowering of mood when used with people with severe dementia** (D7, 64%)

4. **RO is most effective when delivered in a group setting** (D8, 62%).

**Polarised statements**

Panellists were polarised on two statements in Section D which were:

1. **RO is effective when a person has a Clinical Dementia Rating (CDR) indicating mild impairment only** (D3, 42% against, 58% for)

2. **Cognitive stimulation therapy such as the use of word games; puzzles; group discussion; and activities such as cooking and gardening is an effective therapy for all persons with dementia** (D14, 42% against, 58% for)

Statements with low and no consensus were concerned with strategies that may be used in RO therapy and the appropriateness of RO therapy at certain stages of dementia. The panel were split almost evenly between the two opposing considerations. Figure 6 shows the Round One percentage rating of statements by panellists for Section D.

The mean score for all items in Section D was 7.0 and, applying the principle that items on which consensus is agreed will be items where the overall mean score for a single item is greater than the mean score for all the items combined, meant that items scoring over 7.0 were indicative of consensus.

Ten items in Section D had a mean rating over 7.0 indicating that panellists were largely in agreement on these items, and these are highlighted in Table 8. These items correspond with the ten items of consensus as indicated by the Definitions of levels of consensus (deLoe, 1995).
Supporting rationale and commentary made by panellists in Round One.

Panellists had the opportunity to include rationale for their item rating in Round One. Many panellists took the opportunity to include commentary on particular items within the sections in addition to the issue overall. Qualitative comments were anonymised and summarised and given to panellists with the Round Two questionnaire feedback. A summary of comments on Section D is presented in Appendix 6.

Summary of Section D

Section D related to the perceptions around reality orientation therapy and its effectiveness in relation to the care of the person with dementia. Panellists were strongly of the opinion that cognitive strategies were extremely useful with people in early stages of dementia. They supported the notion that the strategy had the potential to increase agitation levels in moderate or severe dementia. Differences of views were apparent in relation to the different strategies that were effective when using RO therapy.

Section E: Information & Guidelines

This section related to panellists perceptions of information and guidelines available to carers regarding the best approach to take when people with dementia make statements that are false.

The section contained nine statements around information and guidelines

The highest rating was given to item E9. Knowing the person/life stories aids the delivery of therapeutic strategies, with a mean of 8.9 (SD1.2).

Items that also scored high included item E5 Guidance should be available from relevant professional governing bodies and/or local and National Health Service providers regarding ethical issues for carers in the use of "untruths" in the course of care delivery, with a mean of 8.2(SD1.5) and item E6. Guidance should be available from relevant professional governing bodies regarding accountability issues for carers in the use of "untruths" in the course of care delivery, with a mean of 8.2(SD 1.5).

Statement panellists most disagreed with was item E7. Guidance would not be of benefit in the care of persons with dementia who make statements that are false because care should be tailored to the individual and be person centred, with a mean of 3.4(SD 3.2) and item E1. The approach to take with persons with dementia who make statements that are false requires no further clarification, with a mean of 3.9(SD2.9).

Panellists were undecided about some issues such as whether the governing body to whom they were accountable / employer / local and/or national healthcare provider actually provided adequate guidance for practice in relation to the care of persons with dementia who make statements that are false, with a mean of 4.7(SD 3.2).
Table 9: Mean and Standard Deviation ratings of Section E, Round One

<table>
<thead>
<tr>
<th>Section E: Information &amp; guidelines</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>(9 = strongly agree, 6 = agree, 3 = disagree, 1 = strongly disagree)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>E1. The approach to take with persons with dementia who make statements that are false requires no further clarification</td>
<td>3.9</td>
<td>2.9</td>
</tr>
<tr>
<td>E2. The governing body to whom I am accountable / my employer / my local and/or national healthcare provider provides adequate guidance for my practice in relation to the care of persons with dementia who make statements that are false</td>
<td>4.7</td>
<td>3.2</td>
</tr>
<tr>
<td>E3. Education should be provided for carers in relation to strategies such as RO and validation therapy</td>
<td>8.2</td>
<td>1.1</td>
</tr>
<tr>
<td>E4. Explicit direction should be provided for carers regarding the best approach to take with persons with dementia who make statements that are false</td>
<td>7.7</td>
<td>2.0</td>
</tr>
<tr>
<td>E5. Guidance should be available from relevant professional governing bodies and/or local and national health service providers regarding ethical issues for carers in the use of &quot;untruths&quot; in the course of care delivery</td>
<td>8.2</td>
<td>1.5</td>
</tr>
<tr>
<td>E6. Guidance should be available from relevant professional governing bodies regarding accountability issues for carers in the use of &quot;untruths&quot; in the course of care delivery</td>
<td>8.2</td>
<td>1.5</td>
</tr>
<tr>
<td>E7. Guidance would not be of benefit in the care of persons with dementia who make statements that are false because care should be tailored to the individual and be person centred</td>
<td>3.4</td>
<td>3.2</td>
</tr>
<tr>
<td>E8. Explicit guidance would have a positive impact on my practice in relation to the care of persons with dementia to make statements that are false</td>
<td>5.0</td>
<td>2.3</td>
</tr>
<tr>
<td>E9. Knowing the person/life stories aids the delivery of therapeutic strategies</td>
<td>8.9</td>
<td>1.2</td>
</tr>
</tbody>
</table>

Analysis of the consensus levels found the following:

Statements with high consensus

There were six statements evidencing a high consensus in favour of the statement in Section E

1. *Education should be provided for carers in relation to strategies such as RO and validation therapy* (E3, 94%)

2. *Explicit direction should be provided for carers regarding the best approach to take with persons with dementia who make statements that are false* (E4, 82%)

3. *Guidance should be available from relevant professional governing bodies and/or local and National Health Service providers regarding ethical issues for carers in the use of "untruths" in the course of care delivery* (E5, 94%)
4. Guidance should be available from relevant professional governing bodies regarding accountability issues for carers in the use of "untruths" in the course of care delivery (E6, 90%).

5. Guidance should be available from relevant professional governing bodies regarding ethical issues for carers in the use of "untruths" in the course of care delivery ((E6, 90%).

6. Knowing the person / life stories aids the delivery of therapeutic strategies (E9, 96%)

There was one statement evidencing a high consensus against the statement in Section E

1. The approach to take with persons with dementia who make statements that are false requires no further clarification (E1, 82%)

Statements with moderate consensus

Moderate consensus was reached on two statements in Section D against the statement. Panellists indicated that:

1. The governing body to whom I am accountable / my employer / my local and/or national healthcare provider provides adequate guidance for my practice in relation to the care of persons with dementia who make statements that are false (E2, 71%)

2. Guidance would not be of benefit in the care of persons with dementia who make statements that are false because care should be tailored to the individual and be person centred (E7, 78%)

Statements with low consensus

There were no statements with low consensus for the statement in Section E.

Panellists were polarised on one statement in Section E which was:

1. Explicit guidance would have a positive impact on my practice in relation to the care of persons with dementia to make statements that are false (E8, 43% against, 57% for)

Figure 7 shows the Round One percentage rating of statements by panellists for Section E.

The mean score for all items in Section E was 7.5 and, applying the principle that items on which consensus is agreed will be items where the overall mean score for a single item is greater than the mean score for all the items combined, meant that items scoring over 7.5
were indicative of consensus.

Five items in Section E had a mean rating over 7.5 indicating that panellists were largely in agreement on these items, and these are highlighted in Table 9.
Figure 7: Round One, Section E: Information and Guidelines

- The approach to take with persons with dementia who make statements that are false requires no further clarification
- The governing body to whom I am accountable / my employer / my local and/or national healthcare provider provides adequate guidance for my practice in relation to the care of persons with dementia who make statements that are false
- Education should be provided for caregivers in relation to strategies such as RO and validation therapy
- Explicit direction should be provided for caregivers regarding the best approach to take with persons with dementia who make statements that are false
- Guidance should be available from relevant professional governing bodies and/or local and national health service providers regarding ethical issues for caregivers in the use of "untruths" in the course of care delivery
- Guidance should be available from relevant professional governing bodies regarding accountability issues for caregivers in the use of "untruths" in the course of care delivery
- Guidance would not be of benefit in the care of persons with dementia who make statements that are false because care should be tailored to the individual and be person-centred
- Explicit guidance would have a positive impact on my practice in relation to the care of persons with dementia to make statements that are false
- Knowing the person / life stories aids the delivery of therapeutic strategies

- Strongly Disagree
- Disagree
- Neither Agree nor Disagree
- Agree
- Strongly Agree
Supporting rationale and commentary made by panellists in Round One.

Panellists had the opportunity to include rationale for their item rating in Round One. Many panellists took the opportunity to include commentary on particular items within the sections in addition to the issue overall. Qualitative comments were anonymised and summarised and given to panellists with the Round Two questionnaire feedback. Comments in relation to Section E are presented in Appendix 7.

Summary of Section E: Information and Guidance.

This section related to panellists perceptions of information and guidelines available to carers regarding the best approach to take when people with dementia make statements that are false. Panellists were strongly supportive of the need for education and guidelines both for formal and informal carers in the care of patients with dementia regarding the best strategies to use when people with dementia make statements that are false.

Results Round Two

The Round Two questionnaire contained the same statements as Round One. Panellists were given feedback of group mean of each Round One statement together with their personal rating. This allowed panellists to see the group rating for each item, enabling them to make a judgement on their own rating within the group rating range. Panellists were asked to re-rate each statement having considered the group rating. Panellists were also forwarded a summary of qualitative comments made in Round One as rationale for their choices.

Rating scales and response options were as used in Round One.

The Round Two questionnaire was sent to the 47 panellists who replied to Round One, and replies were received from 43, yielding a 91.4% response rate.

The consensus level was calculated using methods described for Round One. Results of the analysis for Round Two were then compared to the ratings for Round One to determine whether there had been a change in consensus between rounds.

Section A, Round Two

In reviewing all of the statements in Section A it was evident that very few panellists had changed their opinion as no statement had changed in level of consensus based on mean average score after re-rating. Details of the changes for Section A are displayed in Table 10.

There remained strong agreement, which was increased by 16%, that disharmony among the family can negatively affect strategies that will be used when the person with dementia make statements that are false (A8). There was very little change in any of the
ratings to statements in Round Two evidenced by the minimal percentage rating of statements with no statement changing consensus level. Appendix 8 contains

Table 10: Mean ratings of Section A: Round One & Round Two

<table>
<thead>
<tr>
<th>Section A: Care Environment Influences (9 = strongly agree, 6= agree, 3= disagree, 1=strongly disagree)</th>
<th>R1 Mean</th>
<th>R2 Mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>A1. The person with dementia should be central to planning their own care</td>
<td>8.4</td>
<td>8.5</td>
</tr>
<tr>
<td>A2. The main aim of psychosocial care for the person with dementia is to understand the persons individual experience of dementia and employ strategies which optimise functioning</td>
<td>8.5</td>
<td>8.8</td>
</tr>
<tr>
<td>A3. The type of dementia has a significant influence on appropriate strategies that can be used by carers</td>
<td>7.3</td>
<td>7.8</td>
</tr>
<tr>
<td>A4. The stage of dementia has a significant influence on appropriate strategies that can be used by carers</td>
<td>8.0</td>
<td>8.4</td>
</tr>
<tr>
<td>A5. Discussion between family members is necessary to agree approaches to care for the person with dementia</td>
<td>8.3</td>
<td>8.5</td>
</tr>
<tr>
<td>A6. Discussion between family members is necessary to agree strategies that will be used when the person with dementia make statements that are false</td>
<td>7.9</td>
<td>8.1</td>
</tr>
<tr>
<td>A7. In my opinion, support from external agencies such as GP, Social worker, Carers agencies etc. has little impact on the person with dementia</td>
<td>3.0</td>
<td>2.2</td>
</tr>
<tr>
<td>A8. Disharmony among the family can negatively affect strategies that will be used when the person with dementia make statements that are false</td>
<td>7.5</td>
<td>8.0</td>
</tr>
<tr>
<td>A9. The formal carer (i.e. health professional) should be the person who ultimately decides the most appropriate approach to take when the person with dementia make statements that are false</td>
<td>4.4</td>
<td>3.8</td>
</tr>
<tr>
<td>A10. The family of the person with dementia should be the ones who ultimately decide the most appropriate approach to take when the person with dementia make statements that are false</td>
<td>5.6</td>
<td>5.2</td>
</tr>
<tr>
<td>A11. Counselling support is necessary for families to facilitate them to make appropriate decisions regarding care of the person with dementia</td>
<td>7.4</td>
<td>6.9</td>
</tr>
<tr>
<td>A12. The adoption of relationship centred approaches/interventions is critical in providing meaningful care for people with dementia and their families</td>
<td>7.4</td>
<td>7.7</td>
</tr>
<tr>
<td>A13. Support from external agencies such as GP, Social worker, Carers agencies etc. has little impact on the family of the person with dementia.</td>
<td>3.0</td>
<td>2.3</td>
</tr>
<tr>
<td>A14. Treating a person with dementia in a person centred manner aids their social interaction and connectedness.</td>
<td>9.1</td>
<td>8.9</td>
</tr>
<tr>
<td>A15. The ability to proactively plan ahead for what to do when a person with dementia makes statements that are false is often impacted by the trajectory of the person’s dementia.</td>
<td>7.6</td>
<td>7.5</td>
</tr>
</tbody>
</table>

Section B, Round Two

In reviewing all of the statements in Section B it was evident that very few panellists had changed their opinion. One statement changed consensus level:B1. I am familiar with the use of therapeutic lying in the care of persons as the mean fell from 7.1 to 6.8 bringing it just below the mean consensus rating. Analysis of percentage consensus highlighted an increased level of consensus in relation to 6 statements.

Overall support for therapeutic lying as an appropriate strategy in certain circumstances had increased.
Table 11: Mean ratings of Section B, Round One & Round Two

<table>
<thead>
<tr>
<th>Section B: Therapeutic Lying (9 = strongly agree, 6 = agree, 3 = disagree, 1 = strongly disagree)</th>
<th>R1 Mean</th>
<th>R2 Mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>B1. I am familiar with the use of therapeutic lying in the care of persons with dementia</td>
<td>7.1</td>
<td>6.8</td>
</tr>
<tr>
<td>B2. Therapeutic lying involves the carer ‘going along’ with what the person with dementia is saying rather than trying to re-orientate</td>
<td>7.0</td>
<td>7.1</td>
</tr>
<tr>
<td>B3. It is appropriate to use therapeutic lying when a person has a Clinical Dementia Rating (CDR) indicating mild impairment only</td>
<td>3.8</td>
<td>3.4</td>
</tr>
<tr>
<td>B4. It is appropriate to use therapeutic lying when a person has a Clinical Dementia Rating (CDR) indicating moderate impairment</td>
<td>4.6</td>
<td>4.2</td>
</tr>
<tr>
<td>B5. It is appropriate to use therapeutic lying when a person has a Clinical Dementia Rating (CDR) indicating moderate to severe impairment</td>
<td>6.3</td>
<td>6.2</td>
</tr>
<tr>
<td>B6. Therapeutic lying is a specific communication strategy used in the best interest of the person with dementia</td>
<td>7.0</td>
<td>7.1</td>
</tr>
<tr>
<td>B7. Therapeutic lying is deceptive and should never be used</td>
<td>3.6</td>
<td>3.1</td>
</tr>
<tr>
<td>B8. It is acceptable to lie in a crisis situation when there is a risk that a person might harm themselves</td>
<td>7.2</td>
<td>7.7</td>
</tr>
<tr>
<td>B9. Therapeutic lying is sometimes acceptable</td>
<td>7.6</td>
<td>7.8</td>
</tr>
<tr>
<td>B10. Therapeutic lying designed to ease the distress of the person with dementia is acceptable</td>
<td>7.6</td>
<td>7.9</td>
</tr>
<tr>
<td>B11. It is acceptable for the carer to use therapeutic lying if they have a good knowledge of the person and are aware of what approach works best with them</td>
<td>7.3</td>
<td>7.4</td>
</tr>
<tr>
<td>B12. The use of therapeutic lying is justified if it reduces challenging behaviour in the person with dementia</td>
<td>6.5</td>
<td>6.7</td>
</tr>
<tr>
<td>B13. It is acceptable to use therapeutic lying if you know from past experience that the person with dementia gets upset when told the truth</td>
<td>7.1</td>
<td>7.3</td>
</tr>
<tr>
<td>B14. Carers should always tell the truth to a person with dementia</td>
<td>4.3</td>
<td>3.4</td>
</tr>
<tr>
<td>B15. Therapeutic lying is acceptable if it reduces aggressive behaviour in the person with dementia</td>
<td>7.1</td>
<td>7.2</td>
</tr>
<tr>
<td>B16. The acceptability of therapeutic lying depends on the stage of dementia of the person</td>
<td>6.3</td>
<td>6.5</td>
</tr>
<tr>
<td>B17. Therapeutic lying could be considered as a person centred strategy</td>
<td>6.8</td>
<td>6.4</td>
</tr>
<tr>
<td>B18. The acceptability of therapeutic lying depends on the type of dementia the person is suffering from</td>
<td>4.5</td>
<td>3.7</td>
</tr>
<tr>
<td>B19. Therapeutic lying is acceptable if it helps the carer give treatment (e.g. medication; nutrition) to the person with dementia</td>
<td>5.5</td>
<td>5.6</td>
</tr>
<tr>
<td>B20. Carers would need formal training to be able to carry out therapeutic lying appropriately</td>
<td>6.9</td>
<td>7.1</td>
</tr>
<tr>
<td>B21. Carers should discuss the acceptability of therapeutic lying with the person with dementia while the person is in the early stages of dementia and has adequate memory</td>
<td>6.2</td>
<td>6.0</td>
</tr>
</tbody>
</table>

Statement B11: It is acceptable for the carer to use therapeutic lying if they have a good knowledge of the person and are aware of what approach works best with them showed an increase of 15% in the number of panellists who agreed with it. Statement B2: Therapeutic lying involves the carer ‘going along’ with what the person with dementia is saying rather than trying to re-orientate them, showed an increase in 13% of panellists.
who agreed with the statement. Statement B6: Therapeutic lying is a specific
communication strategy used in the best interest of the person with dementia showed an
increase of 8% in the number of panellists that agreed with the statement. Statement B8, It
is acceptable to lie in a crisis situation when there is a risk that a person might harm
themselves, showed an increase of 9% in the number of panellists who agreed with the
statement. Statement B9, Therapeutic lying is sometimes acceptable showed an increase
of 8% in the number of panellists who agreed with it. Statement B10, Therapeutic lying
designed to ease the distress of the person with dementia is acceptable, showed an
increase of 9% in the number of panellists agreeing with the statement.

Appendix 9 (Figure 9) displays the percentage agreement of panellists with statement in
section B Round Two

Section C, Round Two

In reviewing all of the statements in Section C it was evident that very few panellists had
changed their opinion. One statement changed mean rating level C2. Validation therapy
puts emphasis on the emotional content of what the person with dementia is expressing
as the mean increased from 7.8 to 8.3. Analysis of percentage consensus highlighted an
increased level of consensus in relation to 6 statements.

Table 12: Mean ratings of Section C, Round One & Round Two

<table>
<thead>
<tr>
<th>Section C: Validation Therapy</th>
<th>R1 Mean</th>
<th>R2 Mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>(9 = strongly agree, 6 = agree, 3 = disagree, 1 = strongly disagree)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>C1. I am familiar with the use of validation therapy in the care of persons with dementia</td>
<td>7.1</td>
<td>7.3</td>
</tr>
<tr>
<td>C2. Validation therapy puts emphasis on the emotional content of what the person with dementia is expressing</td>
<td>7.8</td>
<td>8.3</td>
</tr>
<tr>
<td>C3. Validation therapy is effective when a person has a Clinical Dementia Rating (CDR) indicating mild impairment only</td>
<td>5.2</td>
<td>5.4</td>
</tr>
<tr>
<td>C4. Validation therapy is effective when a person has a Clinical Dementia Rating (CDR) indicating moderate impairment</td>
<td>6.3</td>
<td>6.8</td>
</tr>
<tr>
<td>C5. Validation therapy is effective when a person has a Clinical Dementia Rating (CDR) indicating moderate to severe impairment</td>
<td>6.5</td>
<td>6.7</td>
</tr>
<tr>
<td>C6. Validation therapy involves the person with dementia and their carer retreating together into the past and by doing so; exploring the lived experiences of the person with dementia</td>
<td>6.1</td>
<td>6.6</td>
</tr>
<tr>
<td>C7. Living in the past is less demanding for the person with dementia than living in an unfamiliar present</td>
<td>6.8</td>
<td>7.5</td>
</tr>
<tr>
<td>C8. Using validation therapy can help the carer better understand the person with dementia’s entire frame of reference</td>
<td>7.5</td>
<td>7.8</td>
</tr>
<tr>
<td>C9. In my experience, validation therapy promotes better communication between the carer and the person with dementia</td>
<td>7.8</td>
<td>7.9</td>
</tr>
<tr>
<td>C10. In my experience; validation therapy promotes better interaction between the carer and the person with dementia</td>
<td>7.6</td>
<td>8.1</td>
</tr>
<tr>
<td>C11. In my experience; validation therapy has a positive effect of behavioural symptoms of the person with dementia</td>
<td>7.5</td>
<td>7.8</td>
</tr>
<tr>
<td>C12. In my experience; validation therapy is seldom used in the care of persons with dementia</td>
<td>5.3</td>
<td>5.3</td>
</tr>
<tr>
<td>C13. Carers would need formal training to be able to carry out validation therapy</td>
<td>7.5</td>
<td>8.0</td>
</tr>
</tbody>
</table>
Change in percentage agreement

Analysis of percentage agreement levels identified changes in percentage ratings of 7% or over on 6 statements. Statement C2, *Validation therapy puts emphasis on the emotional content of what the person with dementia is expressing* showed an increase of 13% in the number of panellists who agreed with it. Statement C8, *Using validation therapy can help the carer better understand the person with dementia’s entire frame of reference,* showed an increase in 15% of panellists who agreed with the statement. Statement C10, *In my experience; validation therapy promotes better interaction between the carer and the person with dementia* showed an increase of 11% in the number of panellists that agreed with the statement. Statement C9, *In my experience, validation therapy promotes better communication between the carer and the person with dementia,* showed an increase of 9% in the number of panellists who agreed with the statement. Statement C11, *In my experience; validation therapy has a positive effect of behavioural symptoms of the person with dementia* showed an increase of 7% in the number of panellists who agreed with it. Statement C13, *Carers would need formal training to be able to carry out validation therapy* showed an increase of 11% in the number of panellists agreeing with the statement.

Overall support for validation therapy as an effective strategy increased between rounds.

**Section D Round Two**

In reviewing all of the statements in Section D it was evident that very few panellists had changed their opinion. There were slight changes in mean average rating but most in the direction of agreement. The level of disagreement with statement increased in relation to two statements: D8. *RO therapy never results in lowering of mood when used with people with severe dementia* the mean rating fell from 5.3 to 3.8 and statement D9. *RO is most effective when delivered in a group setting* where the rating fell from 5.5 to 4, indicating that panellists were less convinced that reality orientation therapy can result in lowering of mood and that it is not appropriate in a group setting.
Table 13: Mean ratings of Section D, Round One & Round Two

<table>
<thead>
<tr>
<th>Section D: Reality Orientation (RO) Therapy</th>
<th>R1 Mean</th>
<th>R2 Mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>(9 = strongly agree, 6 = agree, 3 = disagree, 1 = strongly disagree)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>D1. I am familiar with the use of reality orientation (RO) therapy in the care of persons with dementia</td>
<td>7.1</td>
<td>7.6</td>
</tr>
<tr>
<td>D2. Reality orientation (RO) is about continually presenting confused persons with information about time; place and person to help keep them in the “now”</td>
<td>7.8</td>
<td>8.1</td>
</tr>
<tr>
<td>D3. RO therapy is effective when a person has a Clinical Dementia Rating (CDR) indicating mild impairment only</td>
<td>6.8</td>
<td>7.0</td>
</tr>
<tr>
<td>D4. RO is effective when a person has a Clinical Dementia Rating (CDR) indicating moderate impairment</td>
<td>5.7</td>
<td>5.5</td>
</tr>
<tr>
<td>D5. RO is effective when a person has a Clinical Dementia Rating (CDR) indicating moderate to severe impairment</td>
<td>4.4</td>
<td>3.8</td>
</tr>
<tr>
<td>D6. When RO is used with people with severe dementia it can result in increased levels of agitation</td>
<td>7.5</td>
<td>7.9</td>
</tr>
<tr>
<td>D7. Reminiscence therapy is extremely effective as a RO strategy</td>
<td>New</td>
<td>6.4</td>
</tr>
<tr>
<td>D8. RO therapy never results in lowering of mood when used with people with severe dementia</td>
<td>5.3</td>
<td>3.8</td>
</tr>
<tr>
<td>D9. RO is most effective when delivered in a group setting</td>
<td>5.5</td>
<td>4.0</td>
</tr>
<tr>
<td>D10. RO is most effective when delivered at the level of the individual</td>
<td>7.4</td>
<td>7.4</td>
</tr>
<tr>
<td>D11. Discussion of recent events is an appropriate strategy for RO therapy</td>
<td>7.1</td>
<td>7.1</td>
</tr>
<tr>
<td>D12. Carers using RO therapy are more prone to frustration and stress</td>
<td>7.1</td>
<td>6.3</td>
</tr>
<tr>
<td>D13. Positive effects of RO therapy are long-lasting for the person with dementia</td>
<td>5.9</td>
<td>4.9</td>
</tr>
<tr>
<td>D14. I am familiar with the use of cognitive stimulation therapy in the care of persons with dementia</td>
<td>7.4</td>
<td>7.6</td>
</tr>
<tr>
<td>D15. Cognitive stimulation therapy such as the use of word games; puzzles; group discussion; and activities such as cooking and gardening is an effective therapy for all persons with dementia</td>
<td>6.5</td>
<td>6.8</td>
</tr>
<tr>
<td>D16. Cognitive stimulation therapy such as the use of word games; puzzles; group discussion and activities such as cooking and gardening is an effective therapy for persons with mild to moderate dementia</td>
<td>7.8</td>
<td>8.0</td>
</tr>
<tr>
<td>D17. Cognitive stimulation therapy is more effective than RO therapy for persons with mild to moderate dementia</td>
<td>7.7</td>
<td>7.6</td>
</tr>
<tr>
<td>D18. Carers would need formal training to be able to carry out RO therapy</td>
<td>7.1</td>
<td>7.7</td>
</tr>
</tbody>
</table>

Change in percentage agreement

Analysis of percentage agreement levels identified changes in percentage ratings of 7% or over on 7 statements. Statement D1, I am familiar with the use of reality orientation (RO) therapy in the care of persons with dementia showed an increase of 10% in the number of
panellists who agreed with it. Statement D2, *Reality orientation (RO) is about continually presenting confused persons with information about time; place and person to help keep them in the "now"*, showed an increase in 12% of panellists who agreed with the statement. Statement D3, *RO therapy is effective when a person has a Clinical Dementia Rating (CDR) indicating mild impairment only showed an increase of 13% in the number of panellists that agreed with the statement*. Statement D6, *When RO is used with people with severe dementia it can result in increased levels of agitation*, showed an increase of 15% in the number of panellists who agreed with the statement. Statement D7, *Reminiscence therapy is extremely effective as a RO strategy showed an increase of 21% in the number of panellists who agreed with it*. Statement D11, *Discussion of recent events is an appropriate strategy for RO therapy showed an increase of 11% in the number of panellists agreeing with the statement*.

One statement D9, *RO is most effective when delivered in a group setting showed a decrease of 16% in the number of panellists agreeing with it*. Overall support for reality orientation therapy as an effective strategy increased between rounds.

Appendix 11 (Figure 11) displays the percentage agreement of panellists with statement in section D Round Two.

**Section E Round Two**

In reviewing all of the statements in Section E it was evident that very few panellists had changed their opinion. There were slight changes in mean average rating but most in the direction of agreement. Support for the benefit of guidance in statement E8, *Explicit guidance would have a positive impact on my practice in relation to the care of persons with dementia to make statements that are false*, showed an increase in mean rating from 5.0 to 7.6. Panellists were more convinced by the need for guidance regardless of a person centred care approach evidenced by the decrease in mean rating from 3.4 to 2.2 for statement E7. *Guidance would not be of benefit in the care of persons with dementia who make statements that are false because care should be tailored to the individual and be person centred*.
Table 14: Mean ratings of Section E, Round One & Round Two

<table>
<thead>
<tr>
<th>Section E: Information &amp; guidelines</th>
<th>R1 Mean</th>
<th>R2 Mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>(9 = strongly agree, 6 = agree, 3 = disagree, 1 = strongly disagree)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>E1. The approach to take with persons with dementia who make statements that are false requires no further clarification</td>
<td>3.9</td>
<td>2.8</td>
</tr>
<tr>
<td>E2. The governing body to whom I am accountable / my employer / my local and/or national healthcare provider provides adequate guidance for my practice in relation to the care of persons with dementia who make statements that are false</td>
<td>4.7</td>
<td>3.6</td>
</tr>
<tr>
<td>E3. Education should be provided for carers in relation to strategies such as RO and validation therapy</td>
<td>8.2</td>
<td>8.5</td>
</tr>
<tr>
<td>E4. Explicit direction should be provided for carers regarding the best approach to take with persons with dementia who make statements that are false</td>
<td>7.7</td>
<td>8.2</td>
</tr>
<tr>
<td>E5. Guidance should be available from relevant professional governing bodies and/or local and national health service providers regarding ethical issues for carers in the use of “untruths” in the course of care delivery</td>
<td>8.2</td>
<td>8.4</td>
</tr>
<tr>
<td>E6. Guidance should be available from relevant professional governing bodies regarding accountability issues for carers in the use of “untruths” in the course of care delivery</td>
<td>8.2</td>
<td>8.5</td>
</tr>
<tr>
<td>E7. Guidance would not be of benefit in the care of persons with dementia who make statements that are false because care should be tailored to the individual and be person centred</td>
<td>3.4</td>
<td>2.2</td>
</tr>
<tr>
<td>E8. Explicit guidance would have a positive impact on my practice in relation to the care of persons with dementia to make statements that are false</td>
<td>5.0</td>
<td>7.6</td>
</tr>
<tr>
<td>E9. Knowing the person/life stories aids the delivery of therapeutic strategies</td>
<td></td>
<td></td>
</tr>
<tr>
<td>E10. Greater provision is required for carer education around understanding of dementia</td>
<td>New</td>
<td>8.6</td>
</tr>
<tr>
<td>E11. Guidance for carers is required on ethics in decision-making for people who do not have capacity</td>
<td>New</td>
<td>8.5</td>
</tr>
</tbody>
</table>

Change in percentage agreement

Analysis of percentage agreement levels identified changes in percentage ratings of 7% or over on one statement E7. Guidance would not be of benefit in the care of persons with dementia who make statements that are false because care should be tailored to the individual and be person centred with a decrease of 10% in the number agreeing with the statement thereby indicating strongly that guidance should be provided regardless of a person centred care approach. The remainder of statements showed negligible change in agreement levels.

Appendix 12 (Figure 12) displays the percentage agreement of panellists with statement in section E Round Two

Based on the consensus levels identified across Round One and 2, statements were rephrased into action statements for Round Three and panellists requested to rate the importance of each statement.
Results from Section A: Care Environment Influences

Section A related to the care environment influences that impact on the person with dementia regarding the best approaches to care when they make statements that are false. Statements were adapted from the Round One and Two statements to be action statements and panellists were asked to rate the level of importance of 15 statements that were concerned with particular items that impacted on the care experienced by the person with dementia.

The mean score for all items in Section A was 7.3 and, applying the principle that items on which consensus is agreed will be items where the overall mean score for a single item is greater than the mean score for all the items combined, meant that items scoring over 7.3 were indicative of consensus.

Ten items in Section A had a mean rating over 7.3 indicating that panellists were largely in agreement on these items, and these are highlighted in Table 15. Eight statements had a mean rating of 8 or greater, indicating strong agreement or consensus. The highest rating was given to item A14. *The person with dementia will be treated in a person centred manner at all times* with a mean of 9.1 (SD .75). These items correspond with the ten items of consensus as indicated by the Definitions of levels of consensus (deLoe, 1995).

Items that also scored high include item A2. *Carers should be cognisant of the person’s individual experience of dementia and employ strategies which optimise functioning* scoring a mean of 8.9 (SD 0.3).

The statement panellists most disagreed with was A13. *Support from external agencies such as GP; Social worker; Carers agencies etc. has little impact on the family of the person with dementia* with a mean of 2.7 (SD 2.9) and item A7. *Referral will be made to external such as GP; Social worker; Carers agencies etc. to facilitate the provision of appropriate support* with a mean of 3.2 (SD 3.3). This would suggest that panellists felt that referral to external agencies was outside their remit but they supported the positive impact of that external support.

Panellists were undecided about some issues such as liaison with the person with dementia and their family in deciding appropriate strategies as evidenced in item A9. *The formal carer should liaise with the person with dementia and the family to decide the most appropriate approach to take when the person with dementia make statements that are false* with a mean rating of 5.1(SD2.4). In addition panellists were undecided on statement A10. *The family of the person with dementia should liaise with the person with dementia and formal carers to decide the most appropriate approach to take when the person with dementia make statements that are false*, with a mean rating of 5.8(SD2.1)
Table 15: Mean and Standard Deviation ratings of Section A, Round Three

<table>
<thead>
<tr>
<th>Section A: Care Environment Influences (9 = strongly agree, 6 = agree, 3 = disagree, 1 = strongly disagree)</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>A1. The person with dementia will be involved in planning their own care</td>
<td>8.8</td>
<td>0.4</td>
</tr>
<tr>
<td>A2. Carers should be cognisant of the persons individual experience of dementia and employ strategies which optimise functioning</td>
<td>8.9</td>
<td>0.3</td>
</tr>
<tr>
<td>A3. The strategies that can be used by carers will be influenced by the type of dementia.</td>
<td>8.0</td>
<td>1.7</td>
</tr>
<tr>
<td>A4. The stage of dementia will be considered when determining appropriate strategies that can be used by carers</td>
<td>8.5</td>
<td>1.5</td>
</tr>
<tr>
<td>A5. Family members will be advised and facilitated to agree approaches to care for the person with dementia</td>
<td>8.7</td>
<td>0.7</td>
</tr>
<tr>
<td>A6. Family members will agree on strategies that will be used when the person with dementia make statements that are false</td>
<td>7.5</td>
<td>0.9</td>
</tr>
<tr>
<td>A7. Referral will be made to external such as GP; Social worker; Carers agencies etc. to facilitate the provision of appropriate support</td>
<td>3.2</td>
<td>3.3</td>
</tr>
<tr>
<td>A8. Healthcare staff will endeavour to reduce disharmony among the family regarding decisions about strategies that will be used when the person with dementia make statement that are false</td>
<td>8.6</td>
<td>0.7</td>
</tr>
<tr>
<td>A9. The formal carer should liaise with the person with dementia and the family to decide the most appropriate approach to take when the person with dementia make statement that are false</td>
<td>5.1</td>
<td>2.4</td>
</tr>
<tr>
<td>A10. The family of the person with dementia should liaise with the person with dementia and formal carers to decide the most appropriate approach to take when the person with dementia make statement that are false</td>
<td>5.8</td>
<td>2.1</td>
</tr>
<tr>
<td>A11. Counselling support should be provided for families to facilitate them to make appropriate decisions regarding care of the person with dementia</td>
<td>7.0</td>
<td>1.6</td>
</tr>
<tr>
<td>A12. Relationship centered approaches/interventions will be used at all times with a person with dementia</td>
<td>8.6</td>
<td>1.3</td>
</tr>
<tr>
<td>A13. Support from external agencies such as GP; Social worker; Carers agencies etc. has little impact on the family of the person with dementia</td>
<td>2.7</td>
<td>2.9</td>
</tr>
<tr>
<td>A14. The person with dementia will be treated in a person centred manner at all times.</td>
<td>9.0</td>
<td>0.2</td>
</tr>
<tr>
<td>A15. Families will be advised and encouraged to proactively plan ahead for what to do when a person with dementia makes statements that are false as early as possible in the disease trajectory.</td>
<td>7.9</td>
<td>1.2</td>
</tr>
</tbody>
</table>

Analysis of the consensus levels found the following:

Statements with high consensus

There was a high consensus on the importance given to twelve statements in Section A. Panellists indicated the importance of:

A1. *The person with dementia will be involved in planning their own care (100%)*
A2. Carers should be cognisant of the person’s individual experience of dementia and employ strategies which optimise functioning (100%)

A3. The strategies that can be used by carers will be influenced by the type of dementia (89%)

A4. The stage of dementia will be considered when determining appropriate strategies that can be used by carers (95%)

A5. Family members will be advised and facilitated to agree approaches to care for the person with dementia (98%)

A6. Family members will agree on strategies that will be used when the person with dementia make statements that are false (93%)

A8. Healthcare staff will endeavour to reduce disharmony among the family regarding decisions about strategies that will be used when the person with dementia makes statements that are false (98%)

A9. The formal carer should liaise with the person with dementia and the family to decide the most appropriate approach to take when the person with dementia make statements that are false (94%)

A10. The family of the person with dementia should liaise with the person with dementia and formal carers to decide the most appropriate approach to take when the person with dementia makes statements that are false (90%)

A12. Relationship centered approaches/interventions will be used at all times with a person with dementia (89%)

A14. The person with dementia will be treated in a person centred manner at all times (100%).

A15. Families will be advised and encouraged to proactively plan ahead for what to do when a person with dementia makes statements that are false as early as possible in the disease trajectory. (89%)

There was a high consensus against the importance given to three statements in Section A.

A7. Referral will be made to external agencies such as GP; Social worker; Carers agencies etc. to facilitate the provision of appropriate support (75%)

A9. The formal carer should liaise with the person with dementia and the family to decide the most appropriate approach to take when the person with dementia make statements that are false (75%)

A13. Support from external agencies such as GP; Social worker; Carers agencies etc. has little impact on the family of the person with dementia (84%).
There were no statements with moderate or low consensus, but there were two statements on which panellists were polarised

A10. *The family of the person with dementia should liaise with the person with dementia and formal carers to decide the most appropriate approach to take when the person with dementia makes statements that are false* (59% against, 41% for)

A11. *Counselling support should be provided for families to facilitate them to make appropriate decisions regarding care of the person with dementia* (50% against, 50% for)

**Summary of Section A, Round Three: Care environment influences**

Section A related to the care environment influences that impact on the person with dementia regarding the best approaches to care when they make statements that are false. Panellists were strongly in favour of the person with dementia being central to care planning, with a person centred approach essential. The stage and type of dementia should be considered when planning strategies of care. Panellists strongly supported the employment of strategies to optimise function. Healthcare staff had a role to play in liaising with family members in planning ongoing care strategies however referral to outside agencies was considered outside the remit.
Figure 13: Round Three, Section A: Care Environment Influences

<table>
<thead>
<tr>
<th>Statement</th>
<th>0%</th>
<th>10%</th>
<th>20%</th>
<th>30%</th>
<th>40%</th>
<th>50%</th>
<th>60%</th>
<th>70%</th>
<th>80%</th>
<th>90%</th>
<th>100%</th>
</tr>
</thead>
<tbody>
<tr>
<td>The person with dementia will be involved in planning their own care</td>
<td></td>
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<tr>
<td>Carers should be cognisant of the persons individual experience of dementia and employ strategies which optimise functioning</td>
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<tr>
<td>The strategies that can be used by carers will be influenced by the type of dementia.</td>
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<tr>
<td>The stage of dementia will be considered when determining appropriate strategies that can be used by carers</td>
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<tr>
<td>Family members will be advised and facilitated to agree approaches to care for the person with dementia</td>
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<tr>
<td>Family members will agree on strategies that will be used when the person with dementia make statements that are false</td>
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<tr>
<td>Referral will be made to external such as GP; Social worker; Carers agencies etc. to facilitate the provision of appropriate support</td>
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<tr>
<td>Healthcare staff will endeavour to reduce disharmony among the family regarding decisions about strategies that will be used when the person with dementia make statement that are false</td>
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<tr>
<td>The formal caregiver should liaise with the person with dementia and the family to decide the most appropriate approach to take when the person with dementia make statement that are false</td>
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</tr>
<tr>
<td>The family of the person with dementia should liaise with the person with dementia and formal caregivers to decide the most appropriate approach to take when the person with dementia make statement that are false</td>
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<tr>
<td>Counselling support should be provided for families to facilitate them to make appropriate decisions regarding care of the person with dementia</td>
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</tr>
<tr>
<td>Relationship centered approaches/interventions will be used at all times with a person with dementia</td>
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</tr>
<tr>
<td>Support from external agencies such as GP; Social worker; Carers agencies etc. has little impact on the family of the person with dementia</td>
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</tr>
<tr>
<td>The person with dementia will be treated in a person centred manner at all times.</td>
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<tr>
<td>Families will be advised and encouraged to proactively plan ahead for what to do when a person with dementia makes statements that are false as early as possible in the disease trajectory.</td>
<td></td>
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</tr>
</tbody>
</table>
Section B Therapeutic Lying

This section was concerned with how panellists viewed therapeutic lying in the care of the person with dementia. Panellists were asked to rate their level of agreement with 21 statements that were concerned with particular items that related to the use of therapeutic lying on the care experienced by the person with dementia.

The mean score for all items in Section B was 6.3 and, applying the principle that items on which consensus is agreed will be items where the overall mean score for a single item is greater than the mean score for all the items combined, meant that items scoring over 6.3 were indicative of consensus.

Fourteen items in Section B had a mean rating over 6.3 indicating that panellists were largely in agreement on these items, and these are highlighted in Table 16. Eleven statements had a mean rating of 7 or greater, indicating strong agreement or consensus. The highest rating was given to item B8. Therapeutic lying can be used in a crisis situation when there is a risk that a person might harm themselves with a mean of 8.1(SD 1.6) and item B10. Therapeutic lying can be used to ease the distress of the person with dementia with a mean rating of 8.1(SD 2.1).

Items that also scored reasonably high included item B9. Therapeutic lying can be used as an acceptable care strategy where appropriate, with a mean of 7.9 (SD2.2) and B11. A carer should have a good knowledge of the person and are aware of what approach works best with them before they use therapeutic lying as a strategy, mean 7.9 (SD1.8).

The statement panellists most disagreed with was B18. Therapeutic lying should be used with specific types of dementia only as advised by a healthcare professional, with a mean of 3.0(SD3.1), and B7. Therapeutic lying should not be regarded as being deceptive, with a mean of 3.3(SD3.1). This would suggest that panellists still considered therapeutic lying as being deceptive, and did not feel it was the remit of the health professional to advise on its use.

Panellists were undecided about some issues such as B21. Carers should discuss the acceptability of therapeutic lying with the person with dementia while the person is in the early stages of dementia and has adequate memory, with a mean of 5.9(SD2.8).
<table>
<thead>
<tr>
<th>Section B: Therapeutic Lying (9 = strongly agree, 6= agree, 3= disagree, 1=strongly disagree)</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>B1. Carers should be familiar with the use of therapeutic lying in the care of persons with dementia</td>
<td>7.5</td>
<td>2.0</td>
</tr>
<tr>
<td>B2. Therapeutic lying should involve the carer going along with what the person with dementia is saying as well as trying to re-orientate them if appropriate.</td>
<td>7.4</td>
<td>1.7</td>
</tr>
<tr>
<td>B3. Therapeutic lying should not be used when a person is in the early stages of dementia or has a Clinical Dementia Rating (CDR) indicating mild impairment only</td>
<td>3.5</td>
<td>3.2</td>
</tr>
<tr>
<td>B4. Therapeutic lying can be used when a person is in the middle stages of dementia or has a Clinical Dementia Rating (CDR) indicating moderate impairment</td>
<td>3.6</td>
<td>3.0</td>
</tr>
<tr>
<td>B5. Therapeutic lying can be used when a person is in the late stages of dementia or has a Clinical Dementia Rating (CDR) indicating severe impairment</td>
<td>6.4</td>
<td>2.6</td>
</tr>
<tr>
<td>B6. Therapeutic lying is a specific communication strategy that can be used when it is in the best interest of the person with dementia</td>
<td>7.4</td>
<td>2.5</td>
</tr>
<tr>
<td>B7. Therapeutic lying should not be regarded as being deceptive</td>
<td>3.3</td>
<td>3.1</td>
</tr>
<tr>
<td>B8. Therapeutic lying can be used in a crisis situation when there is a risk that a person might harm themselves</td>
<td>8.1</td>
<td>1.6</td>
</tr>
<tr>
<td>B9. Therapeutic lying can be used as an acceptable care strategy where appropriate</td>
<td>7.9</td>
<td>2.2</td>
</tr>
<tr>
<td>B10. Therapeutic lying can be used to ease the distress of the person with dementia</td>
<td>8.1</td>
<td>2.1</td>
</tr>
<tr>
<td>B11. A carer should have a good knowledge of the person and are aware of what approach works best with them before they use therapeutic lying as a strategy.</td>
<td>7.9</td>
<td>1.8</td>
</tr>
<tr>
<td>B12. Therapeutic lying can be used to help reduce challenging behaviour in a person with dementia</td>
<td>7.1</td>
<td>2.3</td>
</tr>
<tr>
<td>B13. Therapeutic lying can be used if a carer knows from past experience that the person with dementia gets upset when told the truth</td>
<td>7.8</td>
<td>2.3</td>
</tr>
<tr>
<td>B14. Carers should use therapeutic lying as a strategy only when appropriate and not as a routine measure</td>
<td>3.9</td>
<td>3.3</td>
</tr>
<tr>
<td>B15. Therapeutic lying can be used if it reduces aggressive behaviour in the person with dementia</td>
<td>7.9</td>
<td>2.2</td>
</tr>
<tr>
<td>B16. The acceptability of therapeutic lying depends on the stage of dementia of the person</td>
<td>6.6</td>
<td>2.6</td>
</tr>
<tr>
<td>B17. Therapeutic lying should be considered as a person centred strategy</td>
<td>6.6</td>
<td>2.5</td>
</tr>
<tr>
<td>B18. Therapeutic lying should be used with specific types of dementia only as advised by a healthcare professional</td>
<td>3.0</td>
<td>3.1</td>
</tr>
<tr>
<td>B19. Therapeutic lying can be used if it helps the carer give treatment (e.g. medication; nutrition) to the person with dementia</td>
<td>6.1</td>
<td>2.9</td>
</tr>
<tr>
<td>B20. Carers should be given formal training in therapeutic lying as a care strategy before they use it</td>
<td>7.2</td>
<td>2.9</td>
</tr>
<tr>
<td>B21. Carers should discuss the acceptability of therapeutic lying with the person with dementia while the person is in the early stages of dementia and has adequate memory</td>
<td>5.9</td>
<td>2.8</td>
</tr>
</tbody>
</table>
Analysis of the consensus levels found the following

**Statements with high consensus**

There was a high consensus for the importance given to eleven statements in Section A. Panellists indicated the importance of:

B1. *Carers should be familiar with the use of therapeutic lying in the care of persons with dementia* (82%)

B2. *Therapeutic lying should involve the carer going along with what the person with dementia is saying as well as trying to re-orientate them if appropriate* (86%)

B6. *Therapeutic lying is a specific communication strategy that can be used when it is in the best interest of the person with dementia* (77%)

B8. *Therapeutic lying can be used in a crisis situation when there is a risk that a person might harm themselves* (91%)

B9. *Therapeutic lying can be used as an acceptable care strategy where appropriate* (84%)

B10. *Therapeutic lying can be used to ease the distress of the person with dementia* (89%)

B11. *A carer should have a good knowledge of the person and are aware of what approach works best with them before they use therapeutic lying as a strategy* (89%)

B12. *Therapeutic lying can be used to help reduce challenging behaviour in a person with dementia* (80%)

B13. *Therapeutic lying can be used if a carer knows from past experience that the person with dementia gets upset when told the truth* (82%)

B15. *Therapeutic lying can be used if it reduces aggressive behaviour in the person with dementia* (89%)

B20. *Carers should be given formal training in therapeutic lying as a care strategy before they use it* (70%)

There was a high consensus against the importance given to five statements in Section B.

B3. *Therapeutic lying should not be used when a person is in the early stages of dementia or has a Clinical Dementia Rating (CDR) indicating mild impairment only* (77%)

B4. *Therapeutic lying can be used when a person is in the middle stages of dementia or has a Clinical Dementia Rating (CDR) indicating moderate impairment* (84%)

B7. *Therapeutic lying should not be regarded as being deceptive* (77%)
B14. Carers should use therapeutic lying as a strategy only when appropriate and not as a routine measure (763%)

B18. Therapeutic lying should be used with specific types of dementia only as advised by a healthcare professional (82%)

Statements with low consensus

There were three statements with low consensus,

B16. The acceptability of therapeutic lying depends on the stage of dementia of the person (64%)

B17. Therapeutic lying should be considered as a person centred strategy (68%)

B5. Therapeutic lying can be used when a person is in the late stages of dementia or has a Clinical Dementia Rating (CDR) indicating severe impairment (64%)

Panellists were polarised on the following statements:

B19. Therapeutic lying can be used if it helps the carer give treatment (e.g. medication; nutrition) to the person with dementia (43% against, 57% for)

B21. Carers should discuss the acceptability of therapeutic lying with the person with dementia while the person is in the early stages of dementia and has adequate memory (44% against, 56% for)

Summary of section B, Round Three: Care environment influences

Section B related to the use of therapeutic lying as a strategy for use in caring for people with dementia. Panellists were generally in strong agreement that therapeutic lying was acceptable as a strategy particularly if it eased the distress of the person with dementia. It was also useful in reducing challenging behaviours in the person with dementia. It was important that the person using therapeutic lying knew the person with dementia and had experience of dealing with them. There was some divergence of opinion on whether the level of dementia impacted on the use of the strategy and a lack of consensus on the use of therapeutic lying to manage treatments.
Figure 14: Round Three, Section B: Therapeutic Lying

- Carers should be familiar with the use of therapeutic lying in the care of persons with dementia
- Therapeutic lying should involve the caregiver going along with what the person with dementia is saying as well as trying to re-orientate them if appropriate.
- Therapeutic lying should not be used when a person is in the early stages of dementia or has a Clinical Dementia Rating (CDR) indicating mild impairment only.
- Therapeutic lying can be used when a person is in the middle stages of dementia or has a Clinical Dementia Rating (CDR) indicating moderate impairment.
- Therapeutic lying can be used when a person is in the late stages of dementia or has a Clinical Dementia Rating (CDR) indicating severe impairment.
- Therapeutic lying is a specific communication strategy that can be used when it is in the best interest of the person with dementia.
- Therapeutic lying should not be regarded as being deceptive.
- Therapeutic lying can be used in a crisis situation when there is a risk that a person might harm themselves.
- Therapeutic lying can be used as an acceptable care strategy where appropriate.
- Therapeutic lying can be used to ease the distress of the person with dementia.
- A caregiver should have a good knowledge of the person and are aware of what approach works best with them before they use therapeutic lying as a strategy.
- Therapeutic lying can be used to help reduce challenging behaviour in a person with dementia.
- Therapeutic lying can be used if a carer knows from past experience that the person with dementia gets upset when told the truth.
- Caregivers should use therapeutic lying as a strategy only when appropriate and not as a routine measure.
- Therapeutic lying can be used if it reduces aggressive behaviour in the person with dementia.
- The acceptability of therapeutic lying depends on the stage of dementia of the person.
- Therapeutic lying should be considered as a person-centred strategy.
- Therapeutic lying should be used with specific types of dementia only as advised by a healthcare professional.
- Therapeutic lying can be used if it helps the caregiver give treatment (e.g., medication; nutrition) to the person with dementia.
- Caregivers should be given formal training in therapeutic lying as a care strategy before they use it.
- Caregivers should discuss the acceptability of therapeutic lying with the person with dementia while the person is in the early stages of dementia and has adequate memory.
Section C: Validation Therapy

This section was concerned with how panellists viewed validation therapy in the care of the person with dementia. Panellists rated the level of importance of action statements related to the use of validation therapy on the care experienced by the person with dementia.

The mean score for all items in Section C was 7.1 and, applying the principle that items on which consensus is agreed will be items where the overall mean score for a single item is greater than the mean score for all the items combined, meant that items scoring over 7.1 were indicative of consensus.

Eight items in Section C had a mean rating over 7.1 indicating that panellists were largely in agreement on these items, and these are highlighted in Table17. The highest rating was given to item C2. Validation therapy should put emphasis on the emotional content of what the person with dementia is expressing with a mean of 8.5(SD0.9) and item C10. Used effectively validation therapy can promote better interaction between the carer and the person with dementia with a mean of 8.2(SD 1.4) and item B10. Therapeutic lying can be used to ease the distress of the person with dementia with a mean rating of 8.1(SD 2.1).

Items that also scored reasonably high included item C1. Carers should be familiar with the use of validation therapy in the care of persons with dementia, with a mean of 8.0 (SD1.8) and C9. Used effectively validation therapy should promote better communication between the carer and the person with dementia, mean 8.0 (SD1.4).

Statement panellists most disagreed with was item C3. Validation therapy can be used when a person has a Clinical Dementia Rating (CDR) indicating mild impairment only, with a mean of 5.0 (SD2.7). This would suggest that some panellists considered validation therapy unsuitable in mild impairment.
Table 17: Mean and Standard Deviation ratings of Section C, Round Three

<table>
<thead>
<tr>
<th>Section C: Validation Therapy</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>(9 = strongly agree, 6= agree, 3= disagree, 1=strongly disagree)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>C1. Carers should be familiar with the use of validation therapy in the care of persons with dementia</td>
<td>8.0</td>
<td>1.8</td>
</tr>
<tr>
<td>C2. Validation therapy should put emphasis on the emotional content of what the person with dementia is expressing</td>
<td>8.5</td>
<td>0.9</td>
</tr>
<tr>
<td>C3. Validation therapy can be used when a person has a Clinical Dementia Rating (CDR) indicating mild impairment only</td>
<td>5.0</td>
<td>2.7</td>
</tr>
<tr>
<td>C4. Validation therapy can be used when a person has a Clinical Dementia Rating (CDR) indicating moderate impairment</td>
<td>6.3</td>
<td>2.5</td>
</tr>
<tr>
<td>C5. Validation therapy can be used when a person has a Clinical Dementia Rating (CDR) indicating severe impairment only</td>
<td>6.0</td>
<td>2.5</td>
</tr>
<tr>
<td>C6. Validation therapy should involve the person with dementia and their carer retreating together into the past and thereby enabling the carer experience the lived experiences of the person with dementia</td>
<td>6.7</td>
<td>2.5</td>
</tr>
<tr>
<td>C7. Carers should be aware that living in the past can be less demanding for the person with dementia than living in an unfamiliar present</td>
<td>7.7</td>
<td>1.6</td>
</tr>
<tr>
<td>C8. Validation therapy can be used to help the carer better understand the person with dementia’s entire frame of reference</td>
<td>7.6</td>
<td>1.3</td>
</tr>
<tr>
<td>C9. Used effectively validation therapy should promote better communication between the carer and the person with dementia</td>
<td>8.0</td>
<td>1.4</td>
</tr>
<tr>
<td>C10. Used effectively validation therapy can promote better interaction between the carer and the person with dementia</td>
<td>8.2</td>
<td>1.4</td>
</tr>
<tr>
<td>C11. Used effectively validation therapy can have a positive effect on behavioural symptoms of the person with dementia</td>
<td>7.6</td>
<td>1.5</td>
</tr>
<tr>
<td>C12. Validation therapy should be used more commonly in the care of persons with dementia</td>
<td>5.5</td>
<td>2.7</td>
</tr>
<tr>
<td>C13. Carers should receive formal training to be able to carry out validation therapy</td>
<td>7.8</td>
<td>1.7</td>
</tr>
</tbody>
</table>

Analysis of the consensus levels found the following:

**Statements with high consensus**

There were eight statements evidencing a high consensus in Section C.

C1. **Carers should be familiar with the use of validation therapy in the care of persons with dementia (93%)**

C2. **Validation therapy should put emphasis on the emotional content of what the person with dementia is expressing (95%)**

C7. **Carers should be aware that living in the past can be less demanding for the person with dementia than living in an unfamiliar present (91%)**

C8. **Validation therapy can be used to help the carer better understand the person with**
dementia’s entire frame of reference (93%)

C9. Used effectively validation therapy should promote better communication between the carer and the person with dementia (88%)

C10. Used effectively validation therapy can promote better interaction between the carer and the person with dementia (91%)

C11. Used effectively validation therapy can have a positive effect on behavioural symptoms of the person with dementia (88%)

C13. Carers should receive formal training to be able to carry out validation therapy (86%).

There was a high consensus against the importance of two statements in Section C.

C3. Validation therapy can be used when a person has a Clinical Dementia Rating (CDR) indicating mild impairment only (79% against)

C12. Validation therapy should be used more commonly in the care of persons with dementia (74% against)

There were no statements with moderate consensus but there were two statements with low consensus, one for and one against the statement C6 and C5 respectively.

C6. Validation therapy should involve the person with dementia and their carer retreating together into the past and thereby enabling the carer experience the lived experiences of the person with dementia (67% for)

C5. Validation therapy can be used when a person has a Clinical Dementia Rating (CDR) indicating severe impairment only (63% against)

Panellists were polarised on the following statement:

C4. Validation therapy can be used when a person has a Clinical Dementia Rating (CDR) indicating moderate impairment (56% against, 44% for).

Summary of section C, Round Three: Validation Therapy

Section C related to the use of validation therapy as a strategy for use in caring for people with dementia. Panellists were strongly of the opinion that validation therapy promoted communication and interaction with the person with dementia and positively impacted behaviour. Panellist choices suggested that they considered validation therapy a more suitable strategy with mild cognitive impairment rather than moderate or severe.
Figure 15: Round Three, Section C: Validation Therapy

- Carers should be familiar with the use of validation therapy in the care of persons with dementia
- Validation therapy should put emphasis on the emotional content of what the person with dementia is expressing
- Validation therapy can be used when a person has a Clinical Dementia Rating (CDR) indicating mild impairment only
- Validation therapy can be used when a person has a Clinical Dementia Rating (CDR) indicating moderate impairment
- Validation therapy can be used when a person has a Clinical Dementia Rating (CDR) indicating severe impairment only
- Validation therapy should involve the person with dementia and their caregiver retreating together into the past and thereby enabling the carer experience the lived experiences of the person with dementia
- Carers should be aware that living in the past can be less demanding for the person with dementia than living in an unfamiliar present
- Validation therapy can be used to help the caregiver better understand the person with dementia’s entire frame of reference
- Used effectively validation therapy should promote better communication between the caregiver and the person with dementia
- Used effectively validation therapy can promote better interaction between the caregiver and the person with dementia
- Used effectively validation therapy can have a positive effect on behavioral symptoms of the person with dementia
- Validation therapy should be used more commonly in the care of persons with dementia
- Caregivers should receive formal training to be able to carry out validation therapy
Results from Section D: Reality Orientation (RO) Therapy

This section is concerned with how panellists perceived reality orientation therapy in the care of the person with dementia.

Panellists were asked to rate the level of importance of 18 action statements that were concerned with particular items that impacted on the care experienced by the person with dementia.

The mean score for all items in Section D was 7.2 and applying the principle that items on which consensus is agreed will be items where the overall mean score for a single item is greater than the mean score for all the items combined, meant that items scoring over 7.2 were indicative of consensus.

Eleven items in Section D had a mean rating over 7.1 indicating that panellists were largely in agreement on the importance of these items and these are highlighted in Table 18. The highest rating was given to item D1. Carers should be familiar with the use of Reality Orientation Therapy in the care of persons with dementia, with a mean of 8.4(SD1.5) and item D6. Carers should be mindful that RO therapy can result in increased levels of agitation when used with people with severe dementia with a mean rating of 8.1(SD 1.5).

Items that also scored reasonably high included item D14. Carers should be familiar with the use of cognitive stimulation therapy in the care of persons with dementia with a mean of 8.2 (SD1.0) and D6. Carers should be mindful that RO therapy can result in increased levels of agitation when used with people with severe dementia, mean 8.1 (SD1.5).

Statement panellists most disagreed with was item D5. RO should be used when a person has a clinical Dementia Rating (CDR) indicating severe impairment, mean 3.1(SD2.9). This would suggest that some panellists considered RO therapy unsuitable in severe cognitive impairment.
<table>
<thead>
<tr>
<th>Section D: Reality Orientation (RO)</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>(9 = strongly agree, 6 = agree, 3 = disagree, 1 = strongly disagree)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>D1. Carers should be familiar with the use of Reality Orientation Therapy in the care of persons with dementia</td>
<td>8.4</td>
<td>1.5</td>
</tr>
<tr>
<td>D2. Reality orientation (RO) should focus on presenting confused persons with information about time; place and person to help keep them in the now</td>
<td>7.9</td>
<td>1.2</td>
</tr>
<tr>
<td>D3. RO should be used when a person has a clinical Dementia Rating (CDR) indicating mild impairment only</td>
<td>6.8</td>
<td>3.0</td>
</tr>
<tr>
<td>D4. RO should be used when a person has a clinical Dementia Rating (CDR) indicating moderate impairment only</td>
<td>5.3</td>
<td>2.3</td>
</tr>
<tr>
<td>D5. RO should be used when a person has a clinical Dementia Rating (CDR) indicating severe impairment</td>
<td>3.1</td>
<td>2.9</td>
</tr>
<tr>
<td>D6. Carers should be mindful that RO therapy can result in increased levels of agitation when used with people with severe dementia</td>
<td>8.1</td>
<td>1.5</td>
</tr>
<tr>
<td>D7. Reminiscence therapy should be incorporated into care as an RO strategy</td>
<td>6.5</td>
<td>2.5</td>
</tr>
<tr>
<td>D8. Effective RO therapy should not result in lowering of mood when used with people with severe dementia</td>
<td>3.9</td>
<td>3.2</td>
</tr>
<tr>
<td>D9. Where possible RO should be delivered in a group setting</td>
<td>3.8</td>
<td>3.1</td>
</tr>
<tr>
<td>D10. Where possible RO should be delivered at the level of an individual</td>
<td>7.5</td>
<td>1.6</td>
</tr>
<tr>
<td>D11. Discussion of recent events can be used as an appropriate strategy for reality orientation</td>
<td>7.3</td>
<td>1.7</td>
</tr>
<tr>
<td>D12 Carers need to be aware that using RO therapy can make them more prone to frustration and stress</td>
<td>7.1</td>
<td>2.5</td>
</tr>
<tr>
<td>D13. Positive effects of RO therapy should be evident and long-lasting for the person with dementia</td>
<td>4.3</td>
<td>3.3</td>
</tr>
<tr>
<td>D14. Carers should be familiar with the use of cognitive stimulation therapy in the care of persons with dementia</td>
<td>8.2</td>
<td>1.0</td>
</tr>
<tr>
<td>D15. Cognitive stimulation therapy such as the use of word games; puzzles; group discussion and activities such as cooking and gardening should be used as a therapy for all persons with dementia</td>
<td>7.1</td>
<td>1.7</td>
</tr>
<tr>
<td>D16. Cognitive stimulation therapy such as the use of word games; puzzles; group discussion and activities such as cooking and gardening should be used as a therapy for persons with mild to moderate dementia only</td>
<td>7.6</td>
<td>1.6</td>
</tr>
<tr>
<td>D17. Cognitive stimulation therapy should be used in preference to RO therapy for persons with mild to moderate dementia</td>
<td>7.7</td>
<td>1.7</td>
</tr>
<tr>
<td>D18. Carers should be given formal training to be able to carry out RO therapy</td>
<td>7.8</td>
<td>2.4</td>
</tr>
</tbody>
</table>
Analysis of the consensus levels found the following:

**Statements with high consensus**

There were ten statements evidencing a high consensus in favour of importance in Section D.

D1. *Carers should be familiar with the use of Reality Orientation Therapy in the care of persons with dementia* (95%)

D2. *Reality orientation (RO) should focus on presenting confused persons with information about time; place and person to help keep them in the ‘now’* (93%)

D6. *Carers should be mindful that RO therapy can result in increased levels of agitation when used with people with severe dementia* (95%)

D10. *Where possible RO should be delivered at the level of an individual* (83%)

D11. *Discussion of recent events can be used as an appropriate strategy for reality orientation* (80%)

D14. *Carers should be familiar with the use of cognitive stimulation therapy in the care of persons with dementia* (100%)

D15. *Cognitive stimulation therapy such as the use of word games; puzzles; group discussion and activities such as cooking and gardening should be used as a therapy for all persons with dementia* (85%)

D16. *Cognitive stimulation therapy such as the use of word games; puzzles; group discussion and activities such as cooking and gardening should be used as a therapy for persons with mild to moderate dementia only* (93%)

D17. *Cognitive stimulation therapy should be used in preference to RO therapy for persons with mild to moderate dementia* (90%)

D18. *Carers should be given formal training to be able to carry out RO therapy* (88%)

There was a high consensus ‘against’ the importance of five statements in Section D.

D4. *RO should be used when a person has a clinical Dementia Rating (CDR) indicating moderate impairment only* (83% against)

D5. *RO should be used when a person has a clinical Dementia Rating (CDR) indicating severe impairment* (88% against)

D8. *Effective RO therapy should not result in lowering of mood when used with people with severe dementia* (78% against)
D9. Where possible RO should be delivered in a group setting (78% against)

D13. Positive effects of RO therapy should be evident and long-lasting for the person with dementia (78% against)

There were no statements with moderate consensus, but there were two statements with low consensus.

**Statements with low consensus**

D3. RO should be used when a person has a clinical Dementia Rating (CDR) indicating mild impairment only (66%)

D12 Carers need to be aware that using RO therapy can make them more prone to frustration and stress (63%)

Panellists were polarised on the following statement:

D7. Reminiscence therapy should be incorporated into care as an RO strategy (51% against, 49% for) suggesting that the panel was split between the effectiveness of reminiscence therapy.

**Summary of Section D, Round Three: Reality Orientation Therapy**

Section D related to the use of Reality Orientation (RO) therapy as a strategy for use in caring for people with dementia. Panellists were strongly of the opinion that RO therapy promoted communication and interaction with the person with dementia and positively impacted behaviour. Panellists however were strongly supportive of carers being made aware on the challenges that using RO therapy can entail.

**Section E: Information & Guidelines**

This section related to panellists perceptions of information and guidelines available to carers regarding the best approach to take when people with dementia make statements that are false.

The section contained eleven statements around information and guidelines. Panellists were asked to rate the importance of the eleven action statements that were concerned with particular items that impacted on the care experienced by the person with dementia.

Applying the principle that items on which consensus is agreed will be items where the overall mean score for inclusion is greater than the mean score for all the items combined identified a mean score for all items in Section D as 7.1. Therefore items scoring over 7.1
were indicative of consensus.

Eight items in Section E had a mean rating over 7.1 indicating that panellists were largely in agreement on the importance of these items, and these are highlighted in Table 19. The highest rating was given to item E9. *Carers should know the life story of the person with dementia to empower them to deliver therapeutic strategies* with a mean of 8.8 (SD 1.1) and item E10. *Greater provision is required for carer education around understanding of dementia* with a mean rating of 8.7 (SD 1.3).

Items that also scored reasonably high included item E6. *Guidance should be available from relevant professional governing bodies regarding accountability issues for carers in the use of "untruths" in the course of care delivery,* with a mean of 8.6 (SD 1.1) and E11. *Guidance for carers is required on ethics in decision-making for people who do not have capacity,* mean 8.5 (SD 1.4).
Figure 16: Round Three, Section D: Reality Orientation (RO)

- Caregivers should be given formal training to be able to carry out RO therapy
- Cognitive stimulation therapy should be used in preference to RO therapy for persons with mild to moderate dementia
- Cognitive stimulation therapy such as the use of word games; puzzles; group discussion and activities such as cooking and gardening should be used as a therapy for persons with mild to moderate dementia only
- Cognitive stimulation therapy such as the use of word games; puzzles; group discussion and activities such as cooking and gardening should be used as a therapy for all persons with dementia
- Carers should be familiar with the use of cognitive stimulation therapy in the care of persons with dementia
- Positive effects of RO therapy should be evident and long-lasting for the person with dementia
- Caregivers need to be aware that using RO therapy can make them more prone to frustration and stress
- Discussion of recent events can be used as an appropriate strategy for reality orientation
- Where possible RO should be delivered at the level of an individual
- Where possible RO should be delivered in a group setting
- Effective RO therapy should not result in lowering of mood when used with people with severe dementia
- Reminiscence therapy should be incorporated into care as an RO strategy
- Carers should be mindful that RO therapy can result in increased levels of agitation when used with people with severe dementia
- RO should be used when a person has a clinical Dementia Rating (CDR) indicating severe impairment
- RO should be used when a person has a clinical Dementia Rating (CDR) indicating moderate impairment only
- RO should be used when a person has a clinical Dementia Rating (CDR) indicating mild impairment only
- Reality orientation (RO) should focus on presenting confused persons with information about time; place and person to help keep them in the A6 now

- Carers should be familiar with the use of Reality Orientation Therapy in the care of persons with dementia

[Bar chart showing responses to each statement]
Statement panellists most disagreed with was item E7. By using an individual and person centred approach carers should be free to choose an appropriate strategy regarding the care of persons with dementia who make statements that are false, mean 2.91 (SD 3.1).

Table 19: Mean and Standard Deviation ratings of Section E, Round Three

<table>
<thead>
<tr>
<th>Section E: Information and Guidelines (9 = strongly agree, 6 = agree, 3 = disagree, 1 = strongly disagree)</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>E1. Clarifications should be provided on the approach to take with persons with dementia who make statements that are false</td>
<td>3.6</td>
<td>3.1</td>
</tr>
<tr>
<td>E2. The governing body to whom I am accountable/my employer/my local and/or national healthcare provider should provide guidelines for my practice in relation to the care of persons with dementia who make statements that are false</td>
<td>4.4</td>
<td>3.5</td>
</tr>
<tr>
<td>E3. Education should be provided for carers in relation to strategies such as RO and validation therapy</td>
<td>8.7</td>
<td>0.9</td>
</tr>
<tr>
<td>E4. Explicit guidelines should be provided for carers regarding the best approach to take with persons with dementia who make statements that are false</td>
<td>8.2</td>
<td>1.3</td>
</tr>
<tr>
<td>E5. Guidance should be available from relevant professional governing bodies and/or local and national health service providers regarding ethical issues for carers in the use of &quot;untruths&quot; in the course of care delivery</td>
<td>8.5</td>
<td>1.2</td>
</tr>
<tr>
<td>E6. Guidance should be available from relevant professional governing bodies regarding accountability issues for carers in the use of &quot;untruths&quot; in the course of care delivery</td>
<td>8.6</td>
<td>1.1</td>
</tr>
<tr>
<td>E7. By using an individual and person centered approach carers should be free to choose an appropriate strategy regarding the care of persons with dementia who make statements that are false</td>
<td>2.9</td>
<td>3.1</td>
</tr>
<tr>
<td>E8. Clinical practice will be positively impacted by the availability of explicit guidelines in relation to the care of persons with dementia who make statements that are false</td>
<td>8.1</td>
<td>1.5</td>
</tr>
<tr>
<td>E9. Carers should know the life story of the person with dementia to empower them to deliver therapeutic strategies</td>
<td>8.8</td>
<td>1.1</td>
</tr>
<tr>
<td>E10. Greater provision is required for carer education around understanding of dementia</td>
<td>8.7</td>
<td>1.3</td>
</tr>
<tr>
<td>E11. Guidance for carers is required on ethics in decision-making for people who do not have capacity</td>
<td>8.5</td>
<td>1.4</td>
</tr>
</tbody>
</table>

Analysis of the consensus levels found the following:

Statements with high consensus

There were eight statements evidencing a high consensus in favour of importance in Section E.

E3. **Education should be provided for carers in relation to strategies such as RO and validation therapy** (98%)

E4. **Explicit guidelines should be provided for carers regarding the best approach to take**
with persons with dementia who make statements that are false (95%)

E5. Guidance should be available from relevant professional governing bodies and/or local and national health service providers regarding ethical issues for carers in the use of "untruths" in the course of care delivery (95%)

E6. Guidance should be available from relevant professional governing bodies regarding accountability issues for carers in the use of "untruths" in the course of care delivery (95%)

E8. Clinical practice will be positively impacted by the availability of explicit guidelines in relation to the care of persons with dementia who make statements that are false (90%)

E9. Carers should know the life story of the person with dementia to empower them to deliver therapeutic strategies (98%)

E10. Greater provision is required for carer education around understanding of dementia (98%)

E11. Guidance for carers is required on ethics in decision-making for people who do not have capacity (95%)

There was a high consensus ‘against’ the importance of two statements in Section E.

E1. Clarifications should be provided on the approach to take with persons with dementia who make statements that are false (75%)

E7. By using an individual and person centered approach carers should be free to choose an appropriate strategy regarding the care of persons with dementia who make statements that are false (80%)

There were no statements with moderate consensus, but there was one statement with low consensus against the importance.

Statement of low consensus

E2. The governing body to whom I am accountable/my employer/my local and/or national healthcare provider should provide guidelines for my practice in relation to the care of persons with dementia who make statements that are false (60%).

Panellists were not polarised on any statement and the strength of percentage ratings indicated that panellists were of strong opinions in this section.

Summary of Section E, Round Three: Guidance and information

Section E related to the guidance and information that is important in relation to dementia care and effective strategies that can be used when people with dementia make
statements that are false. Panellists strongly supported the need for education, explicit guidelines and information both for formal and informal carers.
Figure 17: Round Three, Section E: Information and Guidelines

- Clarifications should be provided on the approach to take with persons with dementia who make statements that are false
- The governing body to whom I am accountable/my employer/my local and/or national healthcare provider should provide guidelines for my practice in relation to the care of persons with dementia who make statements that are false
- Education should be provided for caregivers in relation to strategies such as RO and validation therapy
- Explicit guidelines should be provided for caregivers regarding the best approach to take with persons with dementia who make statements that are false
- Guidance should be available from relevant professional governing bodies and/or local and national health service providers regarding ethical issues for caregivers in the use of "untruths" in the course of care delivery
- Guidance should be available from relevant professional governing bodies regarding accountability issues for caregivers in the use of "untruths" in the course of care delivery
- By using an individual and person-centered approach carers should be free to choose an appropriate strategy regarding the care of persons with dementia who make statements that are false
- Clinical practice will be positively impacted by the availability of explicit guidelines in relation to the care of persons with dementia who make statements that are false
- Carers should know the life story of the person with dementia to empower them to deliver therapeutic strategies
- Greater provision is required for carer education around understanding of dementia
- Guidance for carers is required on ethics in decision making for people who do not have capacity

Legend:
- Strongly Disagree
- Disagree
- Neither Agree nor Disagree
- Agree
- Strongly Agree
Summary of Delphi

Within this 3 round Delphi study panellists were asked to consider items that impacted on the person with dementia regarding the best approaches to care when they make statements that are false. The first round presented panellists with five sections and statements within each section related to particular issues. Panellists rated their level of agreement with statements on a 1-9 rating.

Results indicated that panellist were strongly in favour of the person with dementia being central to care planning. Panellists strongly supported the concept that the main aim of care was around knowing the person, delivering person centered care and employing strategies that optimise functioning. The stage of dementia had a significant impact on strategies that were suitable. It was considered important to include family members in planning care approaches and external agencies had a significant role to play in terms of patient and family support. Panellists were less convinced that the type of dementia impacted on potential effective strategies, and that the decisions about strategies were the responsibility of the family. There was a lack of consensus around forward planning with the person to make decisions about what would be done in later stages if the person’s memory declined further.

Panellists were generally in agreement that the use of therapeutic lying was sometimes acceptable if it was in the person’s best interest. Its use as a strategy depended on the stage of dementia of the person and a variety of other factors including knowledge of the person and previous experience of reactions. Panellists were strongly of the opinion that validation therapy promoted communication and interaction with the person with dementia and positively impacted behaviour. Panellist considered validation therapy a more suitable strategy with mild impairment rather than moderate or severe.

Panellists were strongly of the opinion that the cognitive strategies used in Reality Orientation (RO) therapy were extremely useful with people in early stages of dementia. They supported the notion that the strategy had the potential to increase agitation levels in moderate or severe dementia.

Panellists were strongly supportive of the need for education both for formal and informal carers in the care of patients with dementia regarding the best strategies to use when people with dementia make statements that are false. Panellists strongly supported the need for guidance from relevant professional governing bodies and/or local and National Health Service providers regarding ethical issues for carers in the course of care delivery.

The purpose of Round Two was to allow the panellist to re-rate the items from Round One in cognisance of the group rating and feedback to ensure stability of responses and check
for change in consensus levels. Within all sections there was very little change in either the rating of items or the percentage agreement on statements. Overall support for therapeutic lying as an appropriate strategy in certain circumstances had increased. Consensus levels did not change from Round One and support for the different strategies increased as did the requirement for increased guidance and education. Based on the consensus levels identified across rounds 1 and 2 statements were rephrased into action statements for Round Three.

In Round Three panellists were presented with a series of action statements and asked to rate the importance of each in relation to the best approaches to care when persons with dementia make statements that are false. Panellists were strongly in favour of the person with dementia being central to care planning, with a person centered approach essential. They considered it important to consider the stage and type of dementia when planning strategies of care, and felt that strategies used should optimise functioning. Panellists strongly supported the employment of strategies to optimise function. They supported the concept of healthcare staff having a role to play in liaising with family members in planning ongoing care strategies however referral to outside agencies was considered outside their remit.

Panellists were generally in strong agreement that therapeutic lying was acceptable as a strategy particularly if it eased the distress of the person with dementia. It was also useful in reducing challenging behaviours in the person with dementia. It was important that the person using therapeutic lying knew the person with dementia and had experience of dealing with them. There was some divergence of opinion on whether the level of dementia impacted on the use of the respective strategy and a lack of consensus on the use of therapeutic lying to manage treatments (such as giving medication). Panellists were also strongly of the opinion that validation therapy promoted communication and interaction with the person with dementia and positively impacted behaviour. Panellist choices suggested that they considered validation therapy a more suitable strategy with mild cognitive impairment rather than moderate or severe. Panellists were strongly of the opinion that RO therapy promoted communication and interaction with the person with dementia and positively impacted behaviour. Panellist however were strongly supportive of carers being made aware on the challenges that using RO therapy can entail. Panellists also strongly supported the need for education, explicit guidelines and information both for formal and informal carers.
Integration and interpretation of the results of the qualitative and quantitative data

This section focuses on comparing the findings of the qualitative and quantitative data sets. Quantitative and qualitative data were collected and analysed separately and then the findings were reviewed to identify similarities and differences. No major differences in stakeholder views or differences of opinion across the qualitative and quantitative data sets were identified. The key results across data sets are highlighted and a matrix of results was created to facilitate comparison (Table 20). In phase one four qualitative categories were identified. These are presented in column 1. In phase two five areas of interest were explored within the Delphi work. Items with high consensus are presented in column 2. Column 3 highlights some similarities and column 4 comments on the data set comparisons.

Table 20: Table integrating Qualitative and Quantitative Findings

<table>
<thead>
<tr>
<th>Qualitative Categories</th>
<th>Quantitative Results, comparison based on high consensus</th>
<th>Similarities</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acceptability of lying continuum.</td>
<td>Therapeutic lying is sometimes acceptable (B9, 73%)</td>
<td>Both data sets showed that therapeutic lying is sometimes acceptable if the intention is to minimise distress and optimise functioning.</td>
<td>Across data sets it was evident that therapeutic lying was acceptable under certain circumstances. Taking into account stage of dementia, autonomy and that the intention is to optimise functioning and minimise distress.</td>
</tr>
<tr>
<td>Lying considered acceptable under certain circumstances, impact, intention and benefit. Support of personhood.</td>
<td>It is acceptable to lie in a crisis situation when there is a risk that a person might harm themselves (B8, 75%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Therapeutic lying designed to ease the distress of the person with dementia is acceptable (B10, 75%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Respectful lying.</td>
<td>Treating a person with dementia in a person centred manner aids their social interaction and connectedness (98%, A13)</td>
<td>The importance of person centred care was emphasised.</td>
<td></td>
</tr>
<tr>
<td>------------------</td>
<td>-------------------------------------------------------------------------------------------------------------</td>
<td>-------------------------------------------------</td>
<td></td>
</tr>
<tr>
<td>Issues related to retaining control and autonomy, supporting personhood</td>
<td>The formal carer (i.e. health professional) should be the person who ultimately decides the most appropriate approach to take when the person with dementia makes statements that are false (81% against A9)</td>
<td>There was agreement that the health professional should not be the only decision maker in relation to strategies.</td>
<td></td>
</tr>
<tr>
<td>Approaches to managing mistakes</td>
<td>Using validation therapy can help the carer better understand the person with dementia’s entire frame of reference (C8, 76%)</td>
<td>Both data sets reveal the importance of employing strategies that optimise functioning. They also confirm that the stage of dementia has a significant impact on the selection of appropriate strategies.</td>
<td></td>
</tr>
<tr>
<td>The purpose of strategies should be to promote communication, promote understanding and preserve personhood.</td>
<td>Validation therapy puts emphasis on the emotional content of what the person with dementia is expressing (C2, 80%)</td>
<td>There was consensus that the effectiveness of some of the strategies depends on the stage of dementia.</td>
<td></td>
</tr>
<tr>
<td>Cognitive stimulation therapy such as the use of word games; puzzles; group discussion and activities such as cooking and gardening is an effective therapy for persons with mild to moderate dementia (D15, 90%)</td>
<td>Therapeutic lying is deceptive and should never be used (54% disagree B7)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Empathetic deception</td>
<td>Knowing the person/life stories aids the delivery of therapeutic strategies (E9, 96%)</td>
<td>There was consensus across data sets that knowing the person was essential to ensuring that the</td>
<td>Central to selecting an appropriate strategy is the requirement to know and understand the person with dementia, and</td>
</tr>
<tr>
<td>Use of strategies must be shaped by knowing and understanding the person, and deployed by skilled and knowledgeable carers.</td>
<td>psychosocial care for the person with dementia is to understand the person’s individual experience of dementia and employ strategies which optimise functioning (96%, A2)</td>
<td>strategies used were appropriate.</td>
<td>providing education for carers in the use of strategies.</td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>Education should be provided for carers in relation to strategies such as RO and validation therapy (E3, 94%)</td>
<td>Explicit direction should be provided for carers regarding the best approach to take with persons with dementia who make statements that are false (E4, 82%)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Comparison of data sets highlights consensus around a number of issues including:

- The acceptability of therapeutic lying if done to maintain personhood and uphold the autonomy of the person with dementia.
- There is no one strategy that is appropriate for all people with dementia.
- Knowing and understanding the person with dementia is central to the appropriate selection of strategies.
- The need for education and training on strategies and development of guidelines to support carers.

It is not surprising that these were the areas of consensus as maintaining personhood, upholding autonomy and knowing ‘the person’ are key principles of care for people with dementia. Understanding that there cannot be one strategy that can be used across the spectrum of dementia acknowledges that individual differences and preferences of people with dementia matter and must be taken into account in care decisions. Consensus around the need for education and training is not surprising either, the important point will be the way this is prioritised in health settings. All participants including people with dementia believed that respectful lying was acceptable within the circumstances outlined above.
Discussion and Conclusions

This study used a mixed methods approach to explore with people with dementia, informal/unpaid carers and health professionals the best approach to take when people with dementia ask questions or make statements that are false. In particular the use of three approaches - therapeutic lying, reality orientation and validation therapy was explored. The research found no major conflicts or differences of opinion between people with dementia, health professionals and formal/unpaid carers were identified. The consensus is that ‘one size does not fit all’ and there is no single approach that will suit each person with dementia or be appropriate every time.

Lying to the person with dementia with an intention to cause harm was of course considered an unacceptable strategy at all times. However, under certain circumstances therapeutic lying, when the intention is to minimise harm and distress for the person with dementia may be an acceptable strategy. Other researchers have also reported this finding (Culley et al. 2013; Tuckett 2012; James et al. 2006). In this study the circumstances included: a more advanced stage of dementia; that the motivation behind the ‘lie’ is to do good and reduce harm; that the intention of the carer was to optimise autonomy, quality of life and reduce distress; that the person telling the therapeutic lie knows the person with dementia and was cognisant of family preferences. Similarly, literature focused on health care professionals perspectives found that therapeutic lying was considered acceptable when non-maleficence and compassion were the intentions (Kartalova-O’Doherty et al. 2014; Sperber 2014; Stubbs, 2013; Tuckett, 2012; Elvish et al. 2010). Codes of conduct, ethical and best practice guidelines for healthcare professionals however stress the need for truth telling and stipulate that lying to patients is inappropriate. There is an apparent discrepancy therefore between the findings of this study, other research literature and professional codes of practice and ethics which clearly outline that lying in any form is inappropriate and unacceptable.

Our study found that people with dementia and informal/unpaid carers believed that therapeutic lying was acceptable under the same circumstances as those described by health care professionals. Again these findings are supported by other literature that explored the perspective of people with dementia (Green et al. 2015; Day et al. 2011; Taylor 2007). Informal/unpaid carers were influenced 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. They viewed themselves as the representatives of the person with dementia in the later stages because they knew them, knew their life history and knew what mattered to them. At the heart of informal/unpaid carers actions was the intention to benefit the person with dementia and they reported that therapeutic lying was appropriate when it benefited and respected the person’s dignity. A few informal/unpaid carers in the current study reported that they sometimes
felt uncomfortable ‘lying’ to the person with dementia as it might increase the person with dementia’s confusion or negatively impact on their relationship. However, similar to the findings in (Green 2015), it appeared that the benefits of reducing upset for the person with dementia offset these concerns. The use of therapeutic lying therefore in instances when people with dementia who ask questions or make statements that are false is, similar to the literature, deemed to be an acceptable strategy both by health professionals, informal/unpaid carers and people with dementia. The appropriateness of this approach can however only be determined on a case by case individual basis.

Being empathetic and trying to understand the person with dementia’s entire frame of reference (validation therapy) was also deemed a valuable approach by health professionals. They were strongly of the opinion that validation therapy promoted interaction and had a positive impact on the behaviour of people with dementia despite the fact that the most recent Cochrane review concluded that the effectiveness of this approach remained inconclusive (Neal & Wright 2003). Most health professionals were also familiar with RO therapy and were generally in agreement that RO is most effective when delivered at the individual level in a patient centred way and that not all patients with dementia will respond well to this therapy. These opinions correspond to the use of RO in a flexible patient centred manner (Woods et al. 2012).

Informal carers seemed less concerned about the label given to the approach used – therapeutic lying, validation therapy or reality orientation – rather they highlighted the fact that an individualised approach, tailored to the specific needs of the person with dementia cognisant of their life history was key irrespective of the strategy used. Therefore, they were wary given the unique needs of each person with dementia, of having specific rules and guidelines to follow in relation to which strategy to choose. Similar to the health professionals they felt that irrespective of the strategies used educating carers on their use should be a pre-requisite to implementation. Similarly to the informal/unpaid carers people with dementia were less concerned with the name given to the different strategies as long as the strategies used were respectful, mindful of the person’s dignity and autonomy and self-esteem. In this context, acceptable approaches included therapeutic lying as well as the use of distraction and avoiding the false statement or question asked. Participants were clear that the dignity of the person with dementia must never be undermined and highlighted the importance of trust in relationships and the importance of carers taking time to get to know and understand the person. Such encounters have the potential to promote dignity (Jacobson 2012). The environment where two people meet is also important. If the person with dementia does not feel safe and secure then the potential for violation of dignity is increased. Finally, the policy and social context, within which encounters take place, has a major influence on whether encounters will promote or violate dignity. It is imperative therefore that the context of care provision for people with dementia is unhurried, non-hierarchical and flexible, so that dignity can be promoted and nurtured (Jacobson 2012).

In conclusion there were no major conflicts or differences of opinion among people with dementia, informal/unpaid carers and health professionals in the context of the best
approach to take when people with dementia ask questions or make statements that are false. The consensus is that there is no single approach that will suit each person or be appropriate every time. Rather than prescriptive guidelines, carers should 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. Consequently, the governance structure within which practitioners are working must take cognisance of this and focus on capacity development for carers through training and education as opposed to creating a prescriptive model of care. It is also clear that a discrepancy exists between respective health professional codes of conduct and ethical guidelines and health professionals' use of therapeutic lying, which is an alternative approach to truth telling or correcting the person with dementia. This has serious practical implications for health professionals. This paradox also increases the risk for violation of the dignity of people with dementia and of professional carers and therefore the regulatory frameworks merit urgent review and attention.
Recommendations

The following recommendations have emerged from this study:

- Individualised strategies tailored to the needs of the person with dementia are required when caring for people with dementia when they ask questions or make statements that are false.

- The approaches used must optimise the functioning of the person with dementia whilst preserving their dignity and autonomy.

- Carers must know and understand the person with dementia and consideration should be given to the family’s preferences when caring for a person with dementia.

- Education must be provided to all carers on the use of these strategies.

- This research should be used to address the lack of clarity or absence of formal guidelines for health professionals.

- Formal guidelines for health professionals in relation to selection of strategies should be developed.

- An urgent review of health professional codes of conduct and ethical guidelines is required to include reference to and clarification of the use of therapeutic lying.

- Further research studies with larger sample sizes are needed to further examine the effectiveness of strategies.

- Further research is needed to explore the development of a ‘spectrum’ of when it is acceptable for therapeutic lying to be employed.
Principles of Care

Prerequisites

In order to provide optimal care for people with dementia it is essential that carers know and understand the person with dementia. A detailed life history should be taken and updated regularly. This should enable the carer to know the person they are caring for and plan care that builds on this knowledge.

Strategies

It is important when caring for a person with dementia that carers should give consideration to the family’s preferences. This means that the carer must work with the family to identify what these preferences are.

Carers must use individualised strategies tailored to the needs of the person with dementia, they should therefore know in advance what the appropriate strategy is likely to be when people with dementia ask questions or make statements that are false. There can be no one approach that is appropriate for each person.

Carers must use approaches that optimise the functioning of the person with dementia whilst preserving their dignity and autonomy.

The following are a list of reflective questions which carers should consider before using therapeutic lying (fibbing / telling a white lie) with a person with dementia.

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

The qualitative findings are based on a small purposive sample of informal/unpaid carers and people with dementia. Furthermore their understanding of validation therapy and reality orientation was difficult to capture and it was clear that the concept of therapeutic lying and ‘fibbing’ was an easier concept to understand, hence most of the focus group discussions tended to revolve around this rather than the other strategies. The sample size of 40 for the Delphi fell short of our original target of 100 participants. Nevertheless the response for each round of the Delphi was in keeping with that of other studies and the demographic characteristics highlight the variety of stakeholder groups represented and their high level of expertise. Despite these limitations important recommendations and guidelines have emerged as regards the best approach to use with people with dementia when they ask questions or make statements that are false.
Final method to ensure rigour

To further enhance the credibility of the study people with dementia and carers from Dementia Northern Ireland, an advocacy group comprised of people with dementia that work on behalf of people with dementia and DREAM (Dementia Research Education Advocacy in Motion) in the Republic of Ireland, were invited to comment on the executive summary of the report. The feedback from both groups endorsed the findings of this report - in particular the person centred approach, need for training and the importance of protecting dignity for people with dementia. Dementia Northern Ireland recommended that careful consideration should be given to the use of the term ‘false’ to describe statements made by the person with dementia: “Realistically they [people with dementia] are telling the truth, it just happened at a different time in their life.” (Dementia NI). This observation raises important questions for future research and challenges researchers, policy makers and carers to question ‘our’ understanding of the use of the term ‘false’.
References


[Accessed 06 July 2015]


Dogged

I am your Cerberus

Multi-headed, serpent-tailed and lion-clawed
I guard the gates to the Underworld;
You strayed in there already
And sat in the Chair of Forgetfulness,
Lured by a cunning Hades.

I am your bulldog:
I bark and bite at bureaucrats
On your behalf

I am your Labrador,
Leading you through the maze
Of hospitals and clinics.

I am your collie:
Collector of wayward words and information,
Corralling them into a safe pen.

I am your retriever:
Rescuer of lost glasses, mislaid keys,
Papers, pens and memories.

Carol Farnan (Carer)
Appendices
## Appendix 1

### Health Professional Codes of Conduct & Ethics and Relevant Literature/Policy Documents

<table>
<thead>
<tr>
<th>IRELAND</th>
<th>UK</th>
<th>INTERNATIONAL</th>
</tr>
</thead>
</table>
| Occupational Therapy | The Association of Occupational Therapists of Ireland (AOTI)  
CORU Regulating health and social care professionals  
[http://www.cot.co.uk/standards-ethics/standards-ethics](http://www.cot.co.uk/standards-ethics/standards-ethics) | The American Occupational Therapy Association Codes of Ethics  
| --- | --- | --- | --- |
| Medicine | Medical Council (2009) Guide to professional conduct and ethics for registered medical practitioners  
[www.medicalcouncil.ie](http://www.medicalcouncil.ie) | General Medical Council (GMC) (2013) Good Medical Practice  
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| Department of Health Social Security    |
| *Residential Care Homes Minimum        |
| Standards.*   DHSSPS Belfast.           |

| Department of Health, Social Services   |
| and Public Safety (2011) Improving     |
| dementia services in Northern Ireland:  |
| a regional strategy. (From our perspective this strategy identifies areas where improvements need to be made in the way services for people with dementia and their carers are delivered including; raising awareness and addressing stigma and improving staff awareness and skills. |

| Commissioner for Older People Northern |
| Ireland (2011) Hope, Confidence and    |
| Certainty: corporate plans 2013-2015. [link](http://www.copni.org/tag/Hope-Confidence-Certainty/) |
| NICE Quality Standards – including dementia (2010) [link](https://www.nice.org.uk/guidance/qs1) |
| Regulation and Quality Improvement Authority |
Participant Information Sheet- Delphi

Title of the study: Approaches to dementia care in Ireland, North and South

Version 1: 17/12/2014 Delphi Panel

Invitation

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. This participant information sheet will tell you about the purpose, risks and benefits of this study. If you agree to take part, we will ask you to sign a consent form. If there is anything you are not clear about, we will be happy to explain it to you. Please take as much time as you need to read it. You should only consent to participate in this research study when you feel that you understand what is being asked of you, and you have had enough time to think about your decision. Thank you for reading this.

Who is doing the research?

The research is being conducted by a team of researchers from the College of Medicine, Nursing & Health Sciences at the National University of Ireland, Galway. Most of the team are all qualified general nurses who now work as lecturers in the School of Nursing & Midwifery at the National University of Ireland, Galway. Our jobs involve educating student nurses and qualified nurses. Our research interest is in the area of dementia and older people and we have been involved in several major national studies on dementia over the past few years.

Purpose of the study

The aim of this study is to understand your experience of what you do in situations when memory loss is evident and the best approach for carers to take for people with dementia when they ask questions or make statements that are false. I am inviting you to participate
as a member of an expert panel that is being compiled in order to determine the best approach for carers to take for people with dementia when they ask questions or make statements that are false. The panel will consist of personnel who are involved in the delivery of care to people with dementia. Your expertise and insights would make a valuable contribution in investigating this complex issue.

Do I have to take part?

It is up to you to decide whether or not to take part. If you decide to take part you will be given this information sheet to keep, asked to sign a consent form and post it back to me in the stamped addressed envelope provided. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect your rights in any way.

How do I take part?

If you choose to take part, you will be asked to be a member of a Delphi study. A Delphi study consists of questioning a panel of experts on specific questions or issues. The Delphi method is a multistage process involving a panel of experts to whom questionnaires and feedback are given in order to obtain group consensus on a particular topic. A summary of responses to the previous round questionnaire will be fed back to the panel and panellists will be able to review their opinions in light of views generated in previous rounds.

This Delphi study will be comprised of three rounds of a questionnaire emailed individually to each identified expert in the field of dementia care provision. Participants will be known to the researcher only, for purposes of feedback from previous questionnaire rounds but their opinions and judgements will remain anonymous and confidentiality is guaranteed. Any potentially identifying features will be omitted from the final report and only the researcher will have access to the data and no participant will be recognizable in any report derived from the study.

How long will my part in the study last?

As a panellist, you will be requested to complete all rounds of the process; however should you agree to participate you will be free to withdraw at any time.
What do I have to do?

You will be asked to complete an initial questionnaire in Round One of the study which will be emailed to you. You will be requested to return the questionnaire within a week of receiving it, and you will receive the next questionnaire in the sequence approximately three weeks later, together with feedback from the consensus of opinion regarding the first questionnaire. This questionnaire should again be returned within a week of receiving it and it will be followed by a third questionnaire again with feedback from the proceeding round. This feedback will allow you to consider your responses in light of group opinion. You may retract previous opinions, alter them or leave them unaltered in light of received feedback.

What are the benefits of taking part?

Taking part in this study will provide valuable information on people with dementia, carers and health care professionals experiences of dealing with situations when memory loss and cognitive impairment are evident. This information will be used to develop guidelines for carers and health professionals when caring for people with dementia.

What are the possible disadvantages of taking part?

The process of a Delphi study can be time consuming and may impinge on a busy work schedule but your expertise and contribution to this study will help to formulate guidelines on the best approach for carers to take for people with dementia when they ask questions or make statements that are false and it is hoped that you will find the process stimulating and motivational.

What happens at the end of the study?

You will be notified of the final consensus levels reached at the end of the study. A report will be published following completion of the entire study. Results from the data will be identified and published at conferences and in health care journals. Your name will not be included within this publication confidentiality and anonymity are ensured in the presentation of the research findings.
What happens if I change my mind during the study?
If at any time you wish to withdraw your participation from this study you may do so.

What if I have a complaint during my participation in the study?
If you have any concerns about this study and wish to contact someone independent and in confidence, you may contact the chairperson of the NUI Galway Research Ethics Committee, C/O Office of the Vice President for Research, NUI Galway, ethics@nuigalway.ie

If you have further concerns please contact .........................
Appendix 3

Reliability of the instrument

Following the pilot study a reliability test was undertaken in terms of homogeneity of the questionnaire and was measured by the use of Cronbach’s alpha coefficient. Cronbach’s alpha for each of the six sections was calculated individually in SPSS V22. The data output gave a list of item correlations, and alpha if that item was removed. Item by item correlations were examined and unreliable items removed. The results are reported below in the context of each section of the questionnaire and the measures taken are outlined.

Section A: Care Environment Influences

Alpha for this subscale was 0.42. Inspection of the items suggested that two items should be eliminated because of their low correlation with the test as a whole. The two items were removed and Cronbach’s alpha reliability test was then repeated and produced an alpha of 0.7483, which is acceptable.

Section B: Therapeutic Lying

Alpha for this subscale was 0.78. This was considered acceptable, and analysis indicated that there was no need to remove any items.

Section C: Validation Therapy

Alpha for this subscale was 0.71. This was considered acceptable, and analysis indicated that there was no need to remove any items.

Section D: Reality Orientation (RO) Therapy

Alpha for this subscale was 0.54. Inspection of the items suggested that one item should be eliminated because of its low correlation with the test as a whole. Following removal of the item a further reliability test then produced an alpha of 0.73, which was considered acceptable.

Section E: Information & Guidelines

Alpha for this subscale was 0.80, which was acceptable.
Appendix 4

Delphi Round One qualitative comments

SECTION A - CARE ENVIRONMENT INFLUENCES

Within this section many panellists commented on individual statements, therefore for ease of interpretation statements will be considered individually.

- Panellists were generally of the opinion that the person with dementia should be central to planning their own care; however this was dependent on the person’s stage of dementia, insight and capacity to make decisions which they suggested can be compromised depending on the stage of dementia.

Some panellists suggested that while the person with dementia should be central to planning their own care it can prove difficult for families to have this discussion with the person with dementia especially if the diagnosis is made late.

- Opinion among panellists was divided relating to the statement that support from external agencies such as GP, Social worker, carers agencies etc. has little impact on the family of the person with dementia. Some participants indicated that it is important for GPs and other external agencies to acknowledge the effort required of carers in caring for persons with dementia, that acknowledgement in itself can be a support.

A few panellists indicated that they had witnessed substantial support from GPs to families of persons with dementia and commented on the positive effect this had in reducing anxiety and increasing resilience.

Others suggested that the support should be good but lack of resources and understanding can mitigate against the quality of the support, with some panellists suggesting that they had observed very little external support and what was available was mainly nurse led services.

- Re: the statement ‘The main aim of psychosocial care for the person with dementia is to understand the person’s individual experience of dementia and employ strategies which optimise functioning’, some panellists suggested that this should include strategies that optimise wellbeing in a range of domains including: cognitive, physical and emotional functioning.

- Panellist who disagreed with the statement ‘The type of dementia has a significant influence on appropriate strategies that can be used by carers’ suggested that an assessment of the level of dementia and the extent to which the person is living in a small or larger world matters more than the clinical cause of the dementia.
• Re: the statement ‘Discussion between family members is necessary to agree strategies that will be used when the person with dementia makes statements that are false.’

Panellists who disagreed with this statement felt that family members are not always well versed in the different approaches that are available to care for the person with dementia.

Panellists who agreed with the statement suggested that families of those with dementia require the support to make appropriate decisions are often critical of professions that do not support them in this endeavour.

• Re: the statement: The formal carer (i.e. health professional) should be the person who ultimately decides the most appropriate approach to take when the person with dementia make statements that are false.

Panellists who disagreed with the statement felt that decision-making required a collaborative approach between family and health professional to determine the most effective strategy.

Panellists who agreed with the statement also suggested that it is important that the health professional has the appropriate skills; knowledge and competency to make the decision in relation to the best approach to take. It was also suggested that it was critical for the health professional to ‘know’ the person with dementia in relation to them as a person as well as their diagnosis.

• Re: the statement: ‘The family of the person with dementia should ultimately decide the most appropriate approach to take when the person with dementia makes statements that are false.’

Many panellists disagreed with this statement and suggested that it was impractical as many family members would need to have sufficient insight into dementia in order to make the decision. It was also suggested that decision-making of this kind can be traumatic for the family and create an unnecessary emotional burden.

• Re: the statement: ‘Counselling support is necessary for families to facilitate them to make appropriate decisions regarding care of the person with dementia’.

Opinion on this aspect was divided. Some panellists suggested that the lack of counselling services can be an issue, resources were scarce and where available were episodic and transitory. Other panellists suggested that some families were more resilient than other and counselling requirements were quite individual rather than a required norm.

• Re: the statement: ‘The ability to proactively plan ahead for what to do when a person with dementia makes statements that are false is often impacted by the trajectory of the person’s dementia’.
Panellist who agreed with this statement suggested that the variety of developmental stages of the disease trajectory significantly impacted the ability to proactively plan.

- Re: the statement: ‘Discussion between family members is necessary to agree strategies that will be used when the person with dementia makes statements that are false’.

Panellists who agreed with the statement suggested that families also need to be informed of best practice in this regard to ensure informed decision-making. Other panellists suggested that it was dependant on the stage of dementia and the relationship dynamic.
Appendix 5

Delphi Round One qualitative comments

SECTION B – THERAPEUTIC LYING

Some panellists commented on the use of the term ‘therapeutic lying’ and its appropriateness. Some felt that it was a misnomer and some panellists had issues with its use in the context of dementia care considering it to have an undue negative undertone.

• Re: the statement: ‘Therapeutic lying is deceptive and should never be used’

  o Some participants felt that the terminology ‘Therapeutic lying’ suggested negative connotations. Others suggested that its use completely depended on the context but it needed to be a multidisciplinary approach.
  o Others suggested that previous experience of a person with dementia getting upset if they were told the truth should inform any decisions to use therapeutic lying.

• Re: the statement  ‘Therapeutic lying involves the carer ‘going along’ with what the person with dementia is saying rather than trying to re-orientate them’

One panellist suggested that therapeutic lying is a contradiction in terms as going with the flow has beneficence as its core ethos; lying; as a deliberate attempt to deceive; does not have this as its central ethos; but is self-protective despite the impact on the other.

• Re: the statement: ‘Therapeutic lying is acceptable if it reduces aggressive behaviour in the person with dementia’

  o Some panellists commented that therapeutic lying may not be the only strategy or approach that will support the person with dementia when aggressive behaviour is problematic.
• Re: the statement: ‘Therapeutic lying is acceptable if it helps the carer give treatment (e.g. medication, nutrition) to the person with dementia’

  o Some panellists who disagreed with this statement suggested that this would go against the patient’s right to refuse treatment.

• Re: the statement: ‘It is appropriate to use therapeutic lying when a person has a Clinical Dementia Rating (CDR) indicating moderate to severe impairment’

  o Some panellists who disagreed with this statement suggested that it was problematic to use CDR as a determinant of whether to use therapeutic lying or not. They advocated ongoing assessment of the situation to ensure that strategies are appropriate as adopting a blanket approach for such strategies is risky and can lead to disempowerment and potential loss of trust. Some panellists suggested that the deliberate creation of care environments mimicking a work or home environment of the person with dementia may be considered therapeutic lying as it is intended to reduce stress/distress in this person.

• Re: the statement: ‘It is appropriate to use therapeutic lying when a person has a Clinical Dementia Rating (CDR) indicating mild impairment only’

  o Panellists who disagreed suggested that the choice of strategy should be based on the individual and their interaction with their carers and not on a scale.

• Re: the statement: ‘Therapeutic lying is a specific communication strategy used in the best interest of the person with dementia’

  o Some panellists suggested that the choice of therapeutic lying should be dependent upon what is best and least upsetting for the person with dementia. The choice should involve short-term and long-term
considerations and needed to be agreed upon beforehand as a strategy and not used as an easy quick fix solution.

- Re: the statement: ‘It is acceptable to lie in a crisis situation when there is a risk that a person might harm themselves’
  
  - Some panellists suggested that not using outright lies but altering the way a question is answered is a more appropriate approach ensuring to treat the person as an individual.

  - Many panellists suggested that each situation should be assessed in its own merit and a judgement made depending on the assessment and background context.

- Re: the statement: ‘Carers should always tell the truth to a person with dementia’

  - The majority of panellists who commented on this statement suggested that each situation had to be assessed in its own. It was also felt that it depended on the stage of dementia and how well the carers are trained to care for someone with dementia.

- Re: the statement: ‘Carers should discuss the acceptability of therapeutic lying with the person with dementia while the person is in the early stages of dementia and has adequate memory’

  - Some panellists felt that this may not be possible because of late diagnosis of dementia and difficulties within families coming to terms with a diagnosis.
Appendix 6

Delphi Round One qualitative comments

SECTION D – REALITY ORIENTATION THERAPY

The majority of panellists were familiar with the use of Reality Orientation (RO) therapy. Panellists were generally in agreement with the statement that RO is most effective when delivered at the level of the individual. While some panellists agreed that RO is dependent on each individual others added that it may need to be a multidisciplinary team choice and suggested that it is influenced by the anticipated patient outcomes and it was acknowledged that not all patients with dementia will respond well to RO therapy.

- Re: the statement: ‘Cognitive stimulation therapy such as the use of word games, puzzles, group discussion and activities such as cooking and gardening is an effective therapy for persons with mild to moderate dementia’

Some panellists suggested that activities in general are beneficial for many different reasons for individuals but detailed assessment is necessary to determine what is best for the person where they are on their dementia journey. It was also suggested that the activities chosen needed to be matched to the individual and to their stage of dementia was an important aspect for consideration.

- Re: the statement: ‘I am familiar with the use of reality orientation therapy in the care of persons with dementia’

Some panellists commented that this strategy is employed without carers sometimes being aware that it has a formal name. RO encompasses activities that would be commonplace without them being formerly considered as a strategy or therapy.

Some panellists felt that RO should not necessarily be continual and may be used alongside validation therapy depending on the individual. Some panellists also suggested that RO is effective if it is incorporated into a care plan which has been agreed by the MDT and does not distress the individual.

- Re: the statement: ‘RO is effective when a person has a Clinical Dementia Rating (CDR) indicating mild impairment only’

Some panellists suggested that RO generally is more effective in earlier stages of dementia but it needed to be considered on an individual basis. The use of RO needs discussion at the MDT level to see if appropriate for the individual and an appropriate care plan in place.

- Re: the statement: ‘When RO is used with people with severe dementia it can result in increased levels of agitation’
A few panellists who commented on this statement suggested that the outcome of RO was dependant on the individual and how their dementia affects them rather than the strategy. There was very little commentary on the section on RO therapy. Some panellists commented that it was not a technique with which they were familiar. Some panellists who did comment on statement suggested that RO is seldom used in the care of persons with dementia.

Panellists suggested that the use of validation therapy depended on the individual assessment and that it was the person with dementias care needs that should drive the choice of use of this strategy rather than a Clinical Dementia Rating (CDR).
Appendix 7

Delphi Round One qualitative comments

SECTION E – INFORMATION AND GUIDELINES

Many panellists suggested that care should be individually tailored and person centred but in addition there was still a requirement for guidance in relation to that care. It was suggested that guidance would enable carers to make better informed decisions and allow for the fact that differing health care professionals have differing opinions which are not always in the best interests of the person.

- Re: the statement: ‘Explicit guidance would have a positive impact on my practice in relation to the care of persons with dementia to make statements that are false’

Some panellists suggested that this was dependent on the nature of the guidance; and whether it is based on a biomedical view of dementia; or a bio-psycho-social approach.

Others suggested that explicit guidance is not realistic as the response must be person centred. However guidance to increase general awareness of the ethical issues associated with responses to untruths would be useful to support more informed decision-making for carers.

Some panellists suggested that training for carers should include all appropriate strategies and enforce the fact that not all strategies will work or continue to work for the person with dementia

- Re: the statement: ‘Explicit direction should be provided for carers regarding the best approach to take with persons with dementia who make statements that are false’

Some panellists suggested that the word ‘should’ be replaced with ‘could’ as otherwise it may lead to lack of individualisation in care planning.

Other panellists suggested that it was down to the individual carer and their experience. It was suggested that training for carers should include all appropriate strategies and enforce the fact that not all strategies will work or continue to work for the person with dementia at that time.

Some panellists suggested that education could be provided to improve carers care of individuals in relation to validation therapy in particular as RO was a more straightforward technique. Many panellists suggested that it was important to provide support to individuals, aids can be used i.e. communication passports to ensure individuals get the most out of their care.
• Re the statement: ‘Guidance should be available from relevant professional
governing bodies and/or local and national health service providers regarding
ethical issues for carers in the use of ‘untruths’ in the course of care delivery’

Several panellists suggested that there are significant ethical issues regarding care of
those with dementia which urgently need to be dealt with.
Figure 8: Round Two, Section A: Care Environment Influences

- The person with dementia should be central to planning their own care
- The main aim of psychosocial care for the person with dementia is to understand the person's individual experience of dementia and employ strategies which optimise functioning
- The type of dementia has a significant influence on appropriate strategies that can be used by caregivers
- The stage of dementia has a significant influence on the appropriate strategies that can be used by caregivers
- Discussion between family members is necessary to agree approaches to care for the person with dementia
- Discussion between family members is necessary to agree strategies that will be used when the person with dementia makes statements that are false
- In my opinion; support from external agencies such as GP; Social worker; carers agencies etc. has little impact on the family of the person with dementia
- Disharmony among the family can negatively affect strategies that will be used when the person with dementia makes statements that are false
- The formal caregiver (i.e. health professional) should be the person who ultimately decides the most appropriate approach to take when the person with dementia make statement that are false
- The family of the person with dementia should ultimately decide the most appropriate approach to take when the person with dementia makes statements that are false
- Counselling support is necessary for families to facilitate them to make appropriate decisions regarding care of the person with dementia
- The adoption of relationship centered approaches/interventions is critical in providing meaningful care for people with dementia and their families
- Support from external agencies such as GP; social worker; carers agencies etc. has little impact on the family of the person with dementia
- Treating a person with dementia in a person-centred manner aids their social interaction and connectedness
- The ability to proactively plan ahead for what to do when a person with dementia makes statements that are false is often impacted by the trajectory of the persons dementia

[Options: Strongly Disagree, Disagree, Neither Agree nor Disagree, Agree, Strongly Agree]
Figure 9: Round Two, Section B: Therapeutic Lying

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<td>Therapeutic lying designed to ease the distress of the person with dementia is acceptable</td>
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<td>It is acceptable for the caregiver to use therapeutic lying if they have a good knowledge of the person and are aware of what approach works best with them</td>
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<td>The use of therapeutic lying is justified if it reduces challenging behaviour in the person with dementia</td>
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<td>It is acceptable to use therapeutic lying if you know from past experience that the person with dementia gets upset when told the truth</td>
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<td>Caregivers should always tell the truth to a person with dementia</td>
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<td>Therapeutic lying is acceptable if it reduces aggressive behaviour in the person with dementia</td>
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<td>The acceptability of therapeutic lying depends on the stage of dementia of the person</td>
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<td>Therapeutic lying could be considered as a person-centred strategy</td>
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<td>The acceptability of therapeutic lying depends on the type of dementia the person is suffering from</td>
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<td>Therapeutic lying is acceptable if it helps the caregiver give treatment (e.g. medication, nutrition) to the person with dementia</td>
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<td>Caregivers would need formal training to be able to carry out therapeutic lying appropriately</td>
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<td>Caregivers should discuss the acceptability of therapeutic lying with the person with dementia while the person is in the early stages of dementia and has adequate memory</td>
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- Strongly Disagree
- Disagree
- Neither Agree nor Disagree
- Agree
- Strongly Agree

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Figure 10: Round Two, Section C: Validation Therapy

1. I am familiar with the use of validation therapy in the care of persons with dementia.
2. Validation therapy puts emphasis on the emotional content of what the person with dementia is expressing.
3. Validation therapy is effective when a person has a Clinical Dementia Rating (CDR) indicating mild impairment only.
4. Validation therapy is effective when a person has a Clinical Dementia Rating (CDR) indicating moderate impairment.
5. Validation therapy is effective when a person has a Clinical Dementia Rating (CDR) indicating moderate to severe impairment.
6. Validation therapy involves the person with dementia and their caregiver retreating together into the past and by doing so; exploring the lived experiences of the person with dementia.
7. Living in the past is less demanding for the person with dementia than living in an unfamiliar present.
8. Using validation therapy can help the caregiver better understand the person with dementia’s entire frame of reference.
9. In my experience; validation therapy promotes better communication between the caregiver and the person with dementia.
10. In my experience; validation therapy promotes better interaction between the caregiver and the person with dementia.
11. In my experience; validation therapy has a positive effect of behavioural symptoms of the person with dementia.
12. In my experience; validation therapy is seldom used in the care of persons with dementia.
13. Caregivers would need formal training to be able to carry out validation therapy.

- Strongly Disagree
- Disagree
- Neither Agree nor Disagree
- Agree
- Strongly Agree
Figure 11: Round Two, Section D: Reality Orientation (RO)

Reality orientation (RO) is about continually presenting confused persons with information about time; place and person to help keep them in the "now".

RO is effective when a person has a Clinical Dementia Rating (CDR) indicating mild impairment only.

RO is effective when a person has a Clinical Dementia Rating (CDR) indicating moderate impairment.

RO is effective when a person has a Clinical Dementia Rating (CDR) indicating moderate to severe impairment.

When RO is used with people with severe dementia it can result in increased levels of agitation.

Reminiscence therapy is extremely effective as a RO strategy.

RO therapy never results in lowering of mood when used with people with severe dementia.

RO is most effective when delivered in a group setting.

RO is most effective when delivered at the level of the individual.

Discussion of recent events is an appropriate strategy for RO therapy.

Carers using RO therapy are more prone to frustration and stress.

Positive effects of RO therapy are long-lasting for the person with dementia.

I am familiar with the use of reality orientation therapy in the care of persons with dementia.

Cognitive stimulation therapy such as the use of word games; puzzles; group discussion; and activities such as cooking and gardening is an effective therapy for all persons with dementia.

Cognitive stimulation therapy such as the use of word games; puzzles; group discussion and activities such as cooking and gardening is an effective therapy for persons with mild to moderate dementia.

Cognitive stimulation therapy is more effective than RO therapy for persons with mild to moderate dementia.

Caregivers would need formal training to be able to carry out RO therapy.
Appendix 12

Figure 12: Round Two, Section E: Information and Guidelines

- The approach to take with persons with dementia who make statements that are false requires no further clarification
- The governing body to whom I am accountable / my employer / my local and/or national healthcare provider provides adequate guidance for my practice in relation to the care of persons with dementia who make statements that are false
- Education should be provided for caregivers in relation to strategies such as RO and validation therapy
- Explicit direction should be provided for caregivers regarding the best approach to take with persons with dementia who make statements that are false
- Guidance should be available from relevant professional governing bodies and/or local and national health service providers regarding ethical issues for caregivers in the use of "untruths" in the course of care delivery
- Guidance should be available from relevant professional governing bodies regarding accountability issues for caregivers in the use of "untruths" in the course of care delivery
- Guidance would not be of benefit in the care of persons with dementia who make statements that are false because care should be tailored to the individual and be person-centred
- Explicit guidance would have a positive impact on my practice in relation to the care of persons with dementia to make statements that are false
- Knowing the person / life stories aids the delivery of therapeutic strategies
- Greater provision is required for carer education around understanding of dementia
- Guidance for carers is required on ethics in decision making for people who do not have capacity

- Strongly Disagree - Disagree - Neither Agree nor Disagree - Agree - Strongly Agree
Acknowledgements

We would like to express our appreciation and thanks to all the carers and persons with memory problems/dementia who took time from their busy lives and participated in the focus groups. Thank you all for sharing your experiences and feelings with us. Your insight has enriched our understanding of the complexities involved in dementia care.

We would also like to extend our sincere thanks to all the policy Delphi panellists, who willingly committed to the process and remained steadfast throughout the three rounds.

Below is a list of the panellists who completed the three rounds and consented to having their names added to this final report.

Miss Vicki Leah, Nurse Consultant Older People
Dr Jane M. Robertson, Lecturer in Dementia Studies
Dr. Robert F. Coen PhD, MIRA Memory Clinic
Mr. Gerry Monahan, Mental Health Social Worker
Ms. Claire O’Tuathail, Lecturer (Nursing)
Miss Esther-Ruth Beck, RN (Dementia & Palliative care)
Ms. Sharon Richardson, Senior Occupational Therapist
Ms. Deborah Coleman, Pathway Leader Care of Older Persons
Geoffrey Shepherd (Chair Young Dementia Homes UK)
Dr Mia McLoughlin, Old Age Psychiatry, Carlow/Kilkenny
Ms Blanaid McCabe, CNS Gerontology Outreach
Ms Laura Dempsey, Lecturer (Palliative Care/dementia)
Mrs. Finola McColgan, Assistant Director of Nursing
Mr. Cliff Kilgore, Consultant Nurse Intermediate Care
Ms Mary Mannix, Dementia Nurse Specialist
Mrs Janet Crowley, Clinical Nurse Manager
Ms Maria Mullan, Msc Dementia Studies Programme Development Manager
Ms Elizabeth Breslin, Nursing & Midwifery Planning & Development
Dr Corinna Dwan, Academic Lead and Project Manager
Ms. Phil Canny Lynch, Nurse Manager
Mr. Keith McAllister, Lecturer
Dr Gráinne O’Malley, Consultant Geriatrician
Ms. Marion Van Der Wel, Nurse Manager, Residential Care
Mrs Pamela Frazer, Dementia Friendly Communities Support Manager, Alzheimer’s Society
Mr Adrian Friell, Services Manager Alzheimer’s Society.
Ms Helena Morrison, RNID, End Stage Dementia Unit
Liz Foley, Director of Nursing, Long Stay Care
Diane Donnelly, Carers Development Officer
Eileen Braddock, Senior Social Worker, Mental Health Service for Older People
Fiona Rigney, Director of Nursing, Community Nursing Unit.
Edel Shiel, Clinical Nurse Manager 2, Dementia Care
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Professor Ainna Fawcett-Henesy, Limerick (Chairperson),
Mr John Grant, Western Alzheimer’s,
Ms Heather Gately, Dementia Research Education Advocacy in Motion (D.R.E.A.M),
Ms Michelle Harrison, Carers Department, HSE West, Galway PCCC,
Ms Amanda Leith, Formerly Director Dementia Services, Northern Ireland,
Ms. Bev Todd, Advocacy officer Alzheimer’s Society, Northern Ireland

Finally special thanks to Carol Farnan for sharing her powerful poems which we believe encapsulate the day to day reality of living for carers and people with dementia.