

Dementia – what is truth?

Exploring the real experience of people living with more severe dementia

A Mental Health Foundation national inquiry

A rapid literature review

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Summary

The aim of this rapid literature review was to identify key issues relating to people living with more severe dementia when they are experiencing confusion, disorientation or 'delusions', especially the debate around telling the truth or not to people having such experiences, in journal articles, grey literature, practice guidance and other media considered relevant to the Inquiry.

The reviewer identified 42 sources which were analysed in order to provide a conceptual picture of major issues involved in the discussion. The identified key issues included:

- The debate on 'truth-telling' or 'lying' in advanced dementia care is on-going. There is no agreement on this issue in the UK or elsewhere, and there are no static views among people living with dementia or their paid or family carers regarding acceptability of lying.
- A certain amount of deception motivated by reducing truth-related distress or other risks does occur in practice. Perceived acceptability of deception seems to vary under various circumstances, such as who the interlocutors are (i.e. the person living with dementia), and how, when, where and why a 'lie' is being told or the 'truth' avoided or reframed.
- Several alternative approaches to 'lying' were identified which consider challenging experiences as meaningful; as a manifestation of a person's physical, psychological or social needs. However there is a paucity of research into such approaches showing their effectiveness in particular circumstances.
- Research into the understanding of meaning and needs of people with more severe dementia and the attempts of professional and family carers to meet such needs seems to be at its infancy and requires further investment of time and resources.

- Successful communication and person-centred care are emerging as key issues in the debate. In order for person-centred care to become ingrained in advanced dementia care settings, more time for interpersonal caring and more training for staff is needed.
- Further discussion questions arising from the review were formulated.

Introduction and background

The Mental Health Foundation has been funded by the Joseph Rowntree Foundation (JRF) to conduct an 18-month inquiry investigating ways of reframing our understanding of some of the most challenging and distressing symptoms of dementia – *confusion*, *'hallucinations'* and *'delusions'* usually experienced by people with more severe dementia¹. This is part of JRF's programme of work *Reframing Dementia in the 21 century: challenging thinking and stimulating debate*.

The following are examples of experiences for people with most forms of dementia in the middle to late stage of the illness:

- Believing that a deceased parent is alive and wanting to visit them;
- Gaining comfort by holding a doll, believing it to be a real baby;
- Being convinced that a spouse or partner is an imposter or constantly deceiving them;
- Wishing to leave a care home and 'go home' when the care home is where they now permanently live;
- Seeking activities/roles that replicate jobs or activities the person did prior to developing dementia.

¹ For the purpose of the Inquiry, the terms 'hallucinations', 'delusions' and 'confusion' have been used as shorthand to capture a whole range of different experiences that people living with dementia may have – people may use very different words and phrases to describe these.

Such confusion or ‘delusions’ are usually complex and could be distressing not only for the person experiencing them but also for practitioners and carers who are supporting them. Knowing how to respond appropriately and helpfully is a constant challenge and at the heart of this is a debate around truth telling, distraction or lying.

These situations place staff and family carers in moral, ethical, practical and emotional dilemmas. If they decide to be honest it may be difficult or upsetting to tell the person truthful information because of the distress this is likely to cause (a key principle of medical ethics is non-maleficence – ‘do no harm’). However, lying or colluding with the person’s beliefs may be considered unethical, risky, disrespectful or simply wrong – it is certainly not an approach that is sanctioned in medical ethics or professionals’ codes of conduct.

Ethics, theory and practice will be considered and the evidence will be drawn together in an Inquiry report with key findings and recommendations for all stakeholders which will be disseminated at the end of the project.

The Inquiry involves a panel of experts, including people living with dementia and carers, which will consider evidence from a literature review, online survey, oral hearings, and site visits to explore these issues. This document presents a rapid literature review for the panel’s consideration and further discussion.

The aim of the literature review

The aim of this rapid literature review is to identify key issues relating to people living with more severe dementia when they are experiencing confusion, disorientation or ‘delusions’, especially the debate around telling the truth or not, in journal articles, grey literature, practice guidance and other media considered relevant to the Inquiry.

Method

The Research and Development Manager of the Mental Health Foundation was tasked with executing a rapid ten-day literature review. Key publications of UK and international dementia experts such as Dr Ian James and Dr Anthony Tuckett were identified by the lead of the project and communicated to the author. The author also performed an independent rapid literature search using keywords and Boolean operators in the following combinations: 'dementia AND truth AND hallucinations OR delusions', 'dementia AND lying AND hallucinations OR delusions' on the following databases: The Cochrane Library; Medline and PUBMED for white literature sources, such as peer-reviewed scientific articles. A literature search was carried out on Google for grey literature sources such as newspaper articles, blogs, unpublished manuscripts and practice guidelines under the author's supervision. In addition, one panel member alerted the author to a systematic literature review article on ethical issues in dementia care.

As a result, 22 of the most relevant literature sources were identified and studied. Conventional, or 'white' peer-reviewed and commercially published literature (Di Cesare and Ruggieri, 2006) included 14 sources with three Cochrane reviews, six original research articles, and four articles discussing dementia practice guidelines and ethical issues. 'Grey' non-commercially published literature sources relevant to the topic included: ten newspaper or newsletter discussion articles and six Alzheimer and Dementia practice guidelines (Di Cesare and Ruggieri, 2006). The issue of telling the 'truth' in terms of disclosing an initial diagnosis of dementia to people and their relatives has not been included in the literature review, as it was beyond the remit of the current Inquiry which is concerned with experiences associated with more severe dementia. Other relevant sources referred to in the identified literature and suggested by the project lead were added. The final selection of 42 sources (see References) included 22 conventional 'white' literature sources such as Cochrane reviews and

original research articles, and 20 ‘grey’ literature sources such as practice codes and guidelines and electronic media sources (Table 1).

Table 1 Literature sources used for the review

<i>Conventional ‘white’ literature sources</i>		<i>‘Grey’ literature sources</i>	
Type	Number	Type	Number
Peer-reviewed articles	13	Practice codes and guidelines	11
Cochrane reviews	4	Electronic media	6
Books and book chapters	5	Online reports and conference proceedings	2
Total	22	Total	20

The contents of sources were analysed by the author in order to provide a conceptual picture of major issues involved in the discussion particularly around telling or not telling the ‘truth’ to people living with more severe dementia.

Please note that the rapid review does not represent a systematic or exhaustive review of literature but can be regarded as a scoping document aimed at identifying and flagging useful concepts, circumstances and issues capable of provoking further panel discussions and formulating questions for further inquiry.

To ‘lie’ or not to ‘lie’: overview of major issues

Currently, no official guidelines in the UK justify ‘lying’ or ‘not telling the truth’ to any patients or to people living with more severe dementia (Culley et al, 2013). In fact, lying in any way or form to a person living with dementia is considered unethical and damaging the person’s right to autonomy (Müller-Hergl, 2007) and trust (Kitwood, 1997). For example, the Nursing and Midwifery Council (2008) urges nurses and midwives to ‘be open and honest, act with integrity and

uphold the reputation of your profession' (p.2), and warns that 'failure to comply with this code may bring your fitness to practise into question and endanger your registration' (Nursing and Midwifery Council, 2008: 2). In addition, the most recent regulations of the General Medical Council underline that as a professional a doctor must 'be honest and trustworthy in all your communication with patients and colleagues' (General Medical Council, (2013):21).

Despite the absence of any formalised published guidelines on circumstances where not telling 'the truth' to people living with dementia may be justifiable, studies of views of people living with dementia (Day et al, 2011), nurses and staff (Wood-Mitchell et al, 2006), psychiatrists (Culley et al, 2013) and informal carers (Hughes et al, 2002) show that lying is pervasive and sometimes considered justifiable in dementia care by both people living with dementia and their family carers (Nuffield Council of Bioethics, 2009). Examples of 'untruths' include not telling someone that their loved one was dead when they were asking for them, or colluding with delusions to reduce distress and agitation and thus avoiding behaviour that challenges (e.g. agitation, aggression).

Moreover, some practitioners introduce informal guidelines for the use of 'therapeutic lies'. For example, a 12-item set of guidelines on the use of 'therapeutic lies' was compiled by Dr Ian James (James et al, 2006; Culley et al, 2013). It is worth noting that the set of guidelines was originally designed by Dr James in response to the Mental Capacity Act 2005 as a means of ensuring that the mental capacity of a person was assessed, prior to considering if any form of 'lying' in dementia care was appropriate. Debates in the literature regarding the appropriateness of providing any sort of guidelines for 'lying' in dementia care were identified. The arguments against 'deception' guidelines include not only ethical and professional issues discussed earlier, but also the issue of the impracticality of lying as it may involve a lot of effort and paperwork for staff to ensure 'lying' consistency, and could potentially lead to abuse and coercion of people with dementia (Müller-Hergl, 2007; Culley et al, 2013).

The introduction of guidelines for ‘therapeutic lying’ has also been condemned by the Alzheimer’s Society which viewed them as encouraging people to live in a ‘false reality’ (Pemberton, 2013). Interestingly, some of the guidelines of the Alzheimer’s Society pertaining to sight, perceptions and hallucinations in dementia (e.g. when a person fails to recognise another person or an object and does not accept an explanation provided by a carer) recommends ‘ignoring the mistake’ for the sake of maintaining the person’s confidence and sustaining effective communication in the future:

‘If they do not accept this explanation, try not to argue with them. Ignore the mistake and listen to what they are trying to say. Being corrected can undermine a person’s confidence and they may become reluctant to join in conversation and activities’ (Alzheimer’s Society, 2013c: 7)

In this respect one could argue that this recommendation in itself can be viewed as a type of deception categorised by Blum (1994) as ‘going along’ [with], by not challenging factually incorrect ideas (Wood-Mitchell, et al 2006). Therefore, the boundaries of ‘truth’ and ‘lies’ seem blurred in some situations.

As shown by the identified literature, currently there is no agreement among carers, practitioners or people living with dementia on ethical acceptability of the use of ‘lies’ in dementia care. However some conditions under which certain kinds of ‘lies’ can be regarded as ‘appropriate’ have been identified. Table 2 presents a matrix of issues, circumstances and stakeholder relations influencing the decision-making of telling or not telling the truth.

Table 2 ‘Truth’ versus ‘Lie’: Issues, stakeholders and circumstances

<i>Circumstances and conditions</i>	<i>Issues for people living with dementia</i>	<i>Telling a ‘lie’ versus telling the truth</i>	<i>Issues for practitioners and carers</i>
<i>Who?</i>	Beliefs and memory status; mood status	Relationships: close friends? Relatives? Paid or unpaid carers?	Beliefs and training; formal and informal guidelines
<i>When? (stage and timing)</i>	‘Confused’ or ‘lucid’ stage? Mild or severe dementia? Capable of remembering or making decisions?	Have communication and trust been established? Are advanced directives possible?	Do I know the person and their previous history? Has mental capacity been assessed? Are there any advanced directives?
<i>How (the spectrum of truth and ‘lies’)</i>	‘Blatant’ or ‘white lie’? Hurtful or pacifying truth?	Spectrum between ‘truth’ and ‘lie’: telling; reality checking; validation therapy; reframing; hiding; avoiding; distracting; etc.	‘Going along’ with; ‘not telling’; ‘little white lies’; ‘tricks’;
<i>How (manner of communication)</i>	Individualised and respectful manner; dignity	Body language, communication; kindness; alternative to ‘lie’: Y/N?	Underlying respect and dignity; communication guidelines
<i>Why? (purpose of ‘lies’)</i>	Best interests; avoidance of distress; kindness; dignity and respect	Effectiveness of communication (quality and quantity, trust)	Best interests; quality of life; fulfilling perceived needs; comfort; compliance
<i>Where? Home or residential care</i>	Familiar or confusing environment? Pleasant or disturbing surroundings?	Balance of physical and social needs? Balance of risk and wellbeing? Financial implications?	Time and resources constraints; lack of understanding of meaning of experiences and/or communication skills
<i>What? Meaning and needs based alternatives</i>	Unmet needs: Y/N? Which needs?	Needs analysis, dolls therapy, habilitation therapy, functional analysis, SPECAL, etc?	Trying to understand meaning: Y/N? Training? Guidelines? Knowledge of person’s history?

Although such circumstances and conditions are presented in Table 2 in a somewhat linear fashion, in the literature they are interrelated and often overlap.

Who? Personalities, roles and relationships

As suggested by people living with dementia, the appropriateness of being ‘lied’ to, first and foremost depended on the beliefs of people themselves and their carers, and their family or professional relationships (see Table 3).

Table 3 - Who? Personalities, roles and relationships

<i>Issues for people living with dementia</i>	<i>Telling a ‘lie’ versus telling the truth</i>	<i>Issues for practitioners and carers</i>
Beliefs and memory status; mood status	Relationships: close friends? Relatives? Paid or unpaid carers?	Beliefs and training; formal and informal guidelines

A minority of family carers in the study of Day et al (2011) believed that they should always be told the truth as it will always ‘emerge’. Interestingly, ‘lies’ were considered less acceptable if they were initiated by friends or family members, as it somehow violated the higher level of trust established by closer relationships bonds as opposed to those of professional carers. The champion of person-centred care, Tom Kitwood, was very critical of deceptive practices in ‘Alzheimer culture’ which he labelled ‘malignant social psychology’ (Kitwood, 1997). Similarly, some practitioners and carers believe in the value of truth more than others, and may feel pressurised when their superiors condone the use of ‘lies’ even in exceptional cases (Tuckett, 2004).

Another distinctive feature influencing the perceived acceptability of ‘lying’ was the level of awareness of a person living with dementia of

being 'lied to', which depended on the level of their cognitive impairment, memory state, and the authenticity of behaviour of the carer. If a person was not aware of being 'lied' to due to lack of memory, the 'deception' was viewed as less threatening and potentially beneficial.

In addition to personal beliefs a lot seems to depend on professional training and qualifications. For example, a study of James et al (2006) which mostly included nurses and care staff showed a higher percentage of claims of resorting to 'lies' (96%) as opposed to a later study among psychiatrists (Culley et al, 2013) which identified that only 69% of them ever resorted to any 'lies'. In the latter study, the existence of formal or informal guidelines on 'therapeutic lying' were viewed by psychiatrists as useful for training and discussion purposes, but less so for ethical or practical purposes as they were perceived as too difficult to implement in a meaningful way and could vary from case to case.

When? Stages and timing

Although it is beyond the scope of this paper to discuss philosophical dimensions of 'objective' or 'subjective' truth, it may be helpful to distinguish the notion of 'objective' truth of shared reality from the notion of what a person believes is true at a particular moment (Tuckett, 2004).

One of the arguments against 'telling a lie' or 'going along' with unusual experiences of people with dementia is the fluctuating nature of the condition whereby periods of 'lucidity' can alternate with times of 'confusion' (see Table 4).

Table 4 - When? Stages and timing

<i>Issues for people living with dementia</i>	<i>Telling a 'lie' versus telling the truth</i>	<i>Issues for practitioners and carers</i>
'Confused' or 'lucid' stage? Initial or advanced stage of dementia? Capable of remembering or making decisions?	Have communication and trust been established? Are advanced directives possible?	Do I know the person and their previous history? Has mental capacity been assessed? Are there any advanced directives?

Some argue that we cannot know if a person who is unaware of being 'lied' to at the moment will remember about it later, thus damaging relationships of trust with the carer (Müller-Hergl, 2007; Alzheimer Society, 2013b,c; Kitwood, 1997).

As can be seen from Table 4, both people living with dementia, practitioners and carers, seem to agree that 'lies' could be harmful for those who are in the initial stages of the condition and whose short-term memory functions better than at the advanced stages:

'...well that very much depends on how bad the dementia is. If it comes to an occasion where you've told a person that it's not safe to do a thing and you find out she's doing it, then I think it would be satisfactory to use deception.' (quote from a person living with dementia, Day et al, 2011: 825).

As previously mentioned, the first condition of the 12-step guidelines suggested by James et al (2006) and Culley et al (2013) presupposes the establishment of mental capacity of the patient.

James and colleagues advise that any 'lies' told to a person should be properly documented (James et al, 2006). In addition, the role of advanced directives, i.e. documenting the person's wishes for their future care, regarding potential 'deception' can be considered by

practitioners and carers at early stages of care when the person still has mental capacity (Hughes et al, 2002).

A Cochrane review of studies of the effectiveness of *validation therapy* (VT) has been identified (Neal & Wright, 2009). VT is based on the acceptance of the reality of personal truth and experience, however disturbed it may seem. The essence of therapy is non-judgemental empathy and person-oriented techniques. The therapy also takes into consideration the continuum of cognitive impairment.

Different validation and reality checking techniques are suggested for different stages; for example reality orientation (Spector et al, 2000), i.e. trying to bring the person 'back' into shared reality can be more appropriate during the early stages, whereby validation of the person's reality can be viewed as being more appropriate as cognitive impairment progresses.

Unfortunately the review did not find enough evidence in support of the effectiveness of VT in terms of improving people's cognition, behaviour, emotional state, or activities of daily living. The reviewers underlined paucity of research in the area and the low quality of identified studies. Validation therapy may be a promising alternative to 'truth telling' but requires further discussion, evaluation and adaptation to specific circumstances (Neal and Wright, 2009).

In addition, decision making can be influenced by the length of time the practitioner or carer knows the person. For example, the establishment of trust requires a certain amount of time, and knowledge of the person's previous history can be helpful in understanding the best course of action:

'The abilities and behaviour of people with dementia are influenced by personal histories, social interaction and social contexts. This is where life story and reminiscence therapy are valuable. The process of gathering information about a person and their situation should involve the individual as well as family and carers.' (SCIE, 2013: 5).

How? The spectrum of truth and lies

The identified literature points out that the degree of distortion of truth can also influence views on the appropriateness of ‘lying’ for both people living with dementia and their carers (see Table 5).

Table 5 - How? The ‘spectrum of ‘truth’ and ‘lies’

<i>Issues for people living with dementia</i>	<i>Telling a ‘lie’ versus telling the truth</i>	<i>Issues for practitioners and carers</i>
‘Blatant’ or ‘white lie’? Hurtful or pacifying truth?	Spectrum between ‘truth’ and ‘lie’: telling; reality checking; reframing; hiding; avoiding; distracting; etc	‘Going along’ with; ‘not telling’; ‘little white lies’; ‘tricks’; etc.

For people living with dementia, an important distinction was whether it was a ‘blatant lie’ (e.g. saying ‘you have agreed to take this medication’ when the person has not) or a ‘white lie’ (e.g. ‘your relative is not here at the moment’ used as a euphemism instead of ‘your relative has passed away’):

‘...well I think there is a sort of continuum of degrees of deception. When you get to the point where you’re explicit, you say something that is simply false, I think it falls into a slightly different category.’
(quote from a person living with dementia, Day et al, 2011: 826).

The degrees of deception emerging from the literature can vary and can be schematically represented by the following figure:

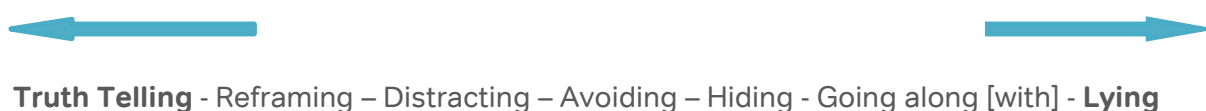


Figure 1 The spectrum of ‘truth’ and ‘lies’

Wood-Mitchell et al. (2007) quote Blum’s (1994) categories of deceptive practice such as ‘going along’ with, ‘not telling’, ‘little white lies’ and ‘tricks’, such as using mirrors to prevent the wandering of residents in nursing homes. People living with dementia also identify various deception practices of their carers and practitioners such as avoiding the truth or environmental deception e.g. hiding the house or car keys (Day et al, 2011).

How? Manner of communication

As can be seen from Table 6, people living with dementia and professionals agree that often it is not what is said but how it is said that matters for the perceived acceptability of a ‘lie’ (Day et al, 2011; Alzheimer’s Society, 2013b).

Table 6 - How? Manner of communication

<i>Issues for people living with dementia</i>	<i>Telling a ‘lie’ versus telling the truth</i>	<i>Issues for practitioners and carers</i>
Individualised and respectful manner; dignity	Body language, communication; kindness; alternative to ‘lie’: Y/N?	Underlying respect and dignity; communication guidelines

Most important was the perception of preserving the person’s respect and dignity at the time of communication: ‘...*but he says it in a nice way, you know, he doesn’t say “ah your daff”*’ (quote from a person living with dementia p. 826 Day et al, 2011).

One of the main criticisms of the *reality orientation* (RO) approach is that people living with dementia are constantly contradicted and re-educated in order to be brought to the shared reality of practitioners or carers. Some argue that RO approach was ‘being applied in a mechanical, inflexible, insensitive and confrontational manner’ (Woods et al, 2012: 3). The reported short-term benefits of RO on cognition

and memory, identified for people living with mild dementia may have been less noticeable and valued because of cases of psychological distress also reported by some RO studies (Spector et al, 2000). One can argue that it could have been due to the manner of communication and the blanket approach to individual needs that RO fell into disrepute over the years (Woods et al, 2012).

It is worth mentioning that RO gave birth to at least two new approaches to dementia care: validation therapy discussed earlier, which in its essence is opposite to RO in terms of 'truth telling' and is often recommended for caring for people with severe dementia; and cognitive stimulation approach recommended for mild and moderate dementia which focusses on memory stimulation and social interaction as opposed to constant re-educating of people living with dementia (Woods et al, 2012; Neal and Wright, 2003; Alzheimer's Society, 2013b). It would seem that good communication skills and some key principles of person-centred care should underlie any approach to truth-telling or interventions benefitting quality of life or cognitive resources of people living with dementia.

Tom Kitwood put forward a theory of dementia care emphasising the importance of personhood and wellbeing of people living with dementia (Kitwood, 1992). He argues that the frame of reference of dementia care should be changed from 'person-with-DEMENTIA' to 'PERSON-with-dementia', recognising the importance of humanity and personhood of men and women who live with dementia (Kitwood, 1997:245). Kitwood argues that some degree of cognitive functioning can be retained through social interaction, and that the brain is capable of structural regeneration in a care environment that promotes activity and cooperation (Kitwood, 1992).

Various guidelines provide similar advice on successful communication with people with dementia. For example, the Alzheimer's Society's guidelines on communication state: *'Don't talk about people with dementia as if they are not there or talk to them as*

you would to a young child – show respect and patience. (Alzheimer’s Society, 2013a: 4)

Other tips on successful communication in dementia care provided by the Alzheimer’s Society include: making an eye-contact with the person; speaking clearly and calmly; using short, simple sentences; trying to be positive; avoiding speaking sharply or raising one’s voice; using humour to relieve the pressure and to bring the person and carer closer together (Alzheimer’s Society, 2013a).

Why? Purpose and motivation of ‘lies’

One of the major factors influencing the use of ‘deception’ in caring for people living with more severe dementia seems to be its purpose and perceived consequences for all parties involved (Table 7).

Table 7 - Why? Purpose and motivation of ‘lies’

<i>Issues for people living with dementia</i>	<i>Telling a ‘lie’ versus telling the truth</i>	<i>Issues for practitioners and carers</i>
Best interests; avoidance of distress; kindness; dignity and respect	Effectiveness of communication (quality and quantity, trust)	Best interests; quality of life; fulfilling perceived needs; comfort; compliance

As can be seen from Table 7, such motivators as avoidance of distress, dignity and respect, kindness, and perceived ‘best interests’ of the person in terms of minimising potential risks and maximising benefits to the person’s physical and psychological well-being were quoted by both people living with dementia, practitioners and carers.

Table 8 presents various arguments for and against ‘lying’ emerging from the published studies of views of different stakeholders. Please note that the list is not exhaustive and can be further modified.

Table 8: Arguments for and against ‘lying’

<i>Stakeholders</i>	<i>For ‘lying’</i>	<i>Against ‘lying’</i>
People living with dementia (Day et al 2011)	‘Best interests’: to reduce truth-related distress; to sustain dignity and respect; kindness	Not in the ‘best interests’: produces distress; distrust; devalues the person
Nurses and care workers (Tuckett 2004; 2007)	Happiness and comfort; autonomy; physical or psychological benefit	Unethical, devalues truth; reduces autonomy; physical or psychological harm
Psychiatrists (Culley et al 2013)	‘Best interests’: to reduce distress or aggression; to increase compliance; to improve communication	Not in the ‘best interests’: potential abuse; unethical; more research is needed

It is important to note that in the identified literature most people and professionals did not have static views regarding the appropriateness of ‘lies’ and often underlined that such acceptability differed for each particular person under particular circumstances discussed earlier, such as who, how, when, where and why (Culley et al, 2013; Day et al, 2011; Tuckett, 2004, 2007).

Where? Home or residential care

The importance of environment for understanding and reducing challenging experiences of people living with dementia emerged from grey literature. Table 9 presents main issues associated with home or residential care environment.

Table 9 - Where? Home or residential care

<i>Issues for people living with dementia</i>	<i>Telling a ‘lie’ versus telling the truth</i>	<i>Issues for practitioners and carers</i>
Familiar or confusing environment? Pleasant or disturbing surroundings?	Balance of physical and social needs? Balance of risk and wellbeing? Financial implications?	Time and resources; lack of understanding of meaning of experiences, communication skills

Home care

It is worth mentioning that apart from one Cochrane review of the effectiveness of needs analysis for people living with more severe dementia (Moniz Cook et al, 2012), very little literature related to the issue of truth-telling to people residing in their own homes was identified. This is in line with the findings of SCIE (2013): '*There is not much research on communication with people with dementia in the community settings, such as in people's own homes or in day care settings*' (SCIE, 2013: 1).

Alzheimer's Society guidelines on sight, perception and hallucinations in dementia suggest that 'illusions' or 'misperceptions' may be caused by deterioration of main or peripheral vision of people, and recommend a visit from an occupational therapist for home assessment (Alzheimer's Society, 2013c). For example, more lighting can minimise shadows; mirrors or shiny surfaces can be removed if they cause confusion or distraction; bright patterned curtains may create a 'distortion' of reality and should not be used in advanced dementia care.

One small qualitative study looked at ethical dilemmas faced by unpaid carers (families and friends); the issue of deception emerged from several participants of the study (Hughes et al, 2002). One carer shared his experience of deceiving the person with dementia by telling her they were going for a ride in the country when taking her to respite care. Others disclosed that in some cases they had to resort to deception or coercion when handling the people's financial matters or persuading them to take medication, and felt that such actions were often justified as practical solutions to difficult situations.

On the other hand, as discussed previously in the review, people living with dementia expected close friends and relatives to tell them the truth more often than e.g. practitioners (Day et al, 2011). This thorny issue highlights another avenue for discussion and investigation.

In some cases carers referred to the past judgements of people living with dementia when deciding the best course of action in a current situation. For example, a daughter decided not to hire additional paid help as her mother had not wished her to do so in the past. Views of other family members, e.g. spouses or in-laws were sometimes clashing with the views of main carers and had to be somehow accommodated.

The issue of 'best interests' brought up by the informal carers pertained not only to the people living with dementia but also to the carers' 'best interests', although this wasn't congruent with the legal definition of best interests (Department for Constitutional Affairs, 2007). For example, one carer underlined that her husband's best interests were her own best interests and thus informed her decision-making.

Residential care

Whereas home surroundings can be more familiar to people, residential facilities require certain adaptation and may cause orientation difficulties (Alzheimer's Society, 2013c.). Various environmental modifications have been mentioned earlier and require further investigation regarding their appropriateness or effectiveness in advanced dementia care (Price et al, 2001; Hall, 2012; Henley, 2012).

Some extreme examples of environmental modifications which can be considered as 'creating fake reality' in order to decrease anxiety and increase emotional wellbeing of people living with dementia include Hogewey care home in the Netherlands (Henley, 2012) and 'Dementiaville' in Switzerland (Hall, 2012).

The village of Hogewey near Amsterdam hosts over 150 residents who are cared for by over 250 qualified staff plus local volunteers. It has 23 houses decorated according to different tastes and styles, and 25 clubs where residents can sing, bake, do arts, bingo or cycle. Residents can also do gardening, shopping, laundry or visit cafes. The

total cost of its construction was over £15 million, most of which was funded by the Dutch state plus sponsors and local fundraising.

As one of the Hogewey managers admitted, occasionally the residents get confused and realise that the life in the village is not quite 'normal', for example when they try to pay the hairdresser and realise they have no money. However the residents seemed to be relatively active, fit and took less medication compared to people living with severe dementia in other more traditional homes (Henley, 2012).

Dementiaville near Berne in Switzerland is following the example of Hogewey in the Netherlands and is being constructed in the style of 1950s. It will comprise 23 homes for 150 people with dementia and will include a cinema, shops and other facilities run by carers disguised as gardeners, hairdressers and shop assistants. It will cost about £17 million to construct, and the plan is to open the village to residents by 2017 (Hall, 2012).

The Cochrane review identified various artificial exit modifications in buildings, used to prevent 'wandering' of people who are cognitively impaired (Price, Hermans & Grimley, 2009) such as mirrors and camouflage which can be considered as 'tricks' aimed at 'distorting' the shared reality. The Cochrane review concluded that there was no evidence of the effectiveness of such exits modification on the reduction of wandering frequency.

However the authors underline that the existing studies defined effectiveness only in terms of reducing the frequency of wandering but did not consider other factors such as improvement of quality of life or well-being. In addition, the degree of severity of dementia has not been addressed by the existing studies. Therefore more research, evaluation and discussion are needed in order to make any conclusions on the usefulness or appropriateness of various environmental modifications in advanced dementia care.

Most of the identified literature underlines the importance of establishing effective communication and trust for decision-making

about telling the truth, 'going with the person' or understanding the needs of people living with more severe dementia. However worrying statistics emerged from some studies on the very limited amount of time both practitioners and carers spend on social interaction, with practical tasks such as eating or bathing taking most of the time (Tuckett, 2007).

Some of the barriers to person-centred care included low pay, professional self-distance, lack of links between beliefs, training and care delivery, and care based on tasks and physical needs alone (Sheard, 2004). For example, a report of Alzheimer's Society (2007) found that only two minutes per day was spent on social interaction with people with dementia living in care homes.

The SCIE review of research in the UK and elsewhere on communicating well in dementia also highlights some workforce difficulties such as access to training, lack of resources and a focus on practical tasks at the expense of interpersonal communication with residents of care homes (SCIE, 2013).

What? Meaning and needs based alternatives

A useful alternative to telling a hurtful truth or a potentially unethical 'lie' may be treating unusual experiences as meaningful to the person, and by trying to understand their *unmet needs* and addressing these to the best of one's abilities and within constraints of particular circumstances. Among the 'unmet needs' approaches and models identified by this review were needs analysis, use of dolls, habilitation therapy (HT), functional analysis and Specialised Early Care for Alzheimer's (SPECAL) (see Table 10).

Table 10 - Meaning and needs based alternatives

<i>Issues for people living with dementia</i>	<i>Alternative models and approaches</i>	<i>Issues for practitioners and carers</i>
Meaning: unmet needs: Y/N? Which needs exactly, and how to meet them?	Needs analysis, dolls therapy, habilitation therapy, functional analysis, SPECAL	Trying to understand meaning: Y/N? Training? Guidelines? Knowledge of person's history?

The Social Care Institute for Excellence (SCIE) review of research on dealing with challenging behaviour of people with dementia such as agitation, aggression and distress identified a major problem of overprescribing of medication in challenging situations (SCIE, 2013).

The *unmet needs*, or *needs analysis* model is presented as a helpful alternative to medication. For example, agitation or aggression can indicate unmet physical, psychological or social needs, such as pain or discomfort, environmental stressors, social isolation, lack of verbal or cognitive stimulation in the person's surroundings (SCIE, 2013).

The Alzheimer's Society guidelines on unusual behaviour provide tips on how to learn to understand the meaning behind such actions as repetitive behaviour, restlessness, shouting and screaming, hiding things, sleeplessness among other (Alzheimer's Society, 2013d). For example, repetitive phrases, movements and restless actions can indicate boredom, lack of stimulation or social interaction, pain or other discomfort. Fidgeting and restlessness can be a sign of hunger, thirst, pain or boredom. Recommendations include trying to find the reason behind behaviour, providing reassurance, taking the person for a walk or giving them something to do with their hands e.g. a soft toy or worry beads.

In order to try and understand people's needs, it may be more productive to concentrate on their feelings and emotions rather than the specific contents of what is being said:

'If the person says something you know to be incorrect, try to find ways of steering the conversation around the subject rather than contradicting them directly. Try to see behind the content to the meaning or feelings they are sharing.' (Alzheimer's Society, 2013a: 4)

The use of dolls, or *dolls therapy* in residential care of people with dementia has been suggested by some as an alternative to overmedication, distracting or 'lying' to people in order to satisfy their social needs of feeling useful or caring for someone (Mackenzie et al, 2006). A calming effect of using dolls was most pronounced, which could indicate that people had been given a sense of purpose or focus. Other observed benefits included a reduction in wandering, improvement of speech and communication with other residents and care staff.

However one of the perceived downsides of using dolls was the perception of relatives and staff that it was 'demeaning' and leading to 'infantilisation' of people with dementia, i.e. being treated like children as opposed to adults with a life-time of experiences. On some occasions, residents with dolls became over stimulated and tired. The authors concluded that the use of dolls needs further research, evaluation and further adaptation to specific personal needs and circumstances.

Other example of needs-based approaches in advanced dementia is *habilitation therapy* (HT) (Raia, 2011). HT can be viewed as a specific way of thinking about dementia rather than a therapeutic model. The aim is not to restore people living with dementia to their previous functioning level, but to maximise their existing functional independence and morale in terms of positive emotion and socialising (Raia, 2011). The ultimate goal is to promote and maintain positive emotion as long as possible.

One of the main strategies of HT is to exclude the use of the word 'no' and to use instead the techniques of 'refocusing' and 'redirecting', e.g. suggest having a cup of tea first if a person wants to go home. Another strategy is based on the principle of travelling to the person's

reality as opposed to trying to bring the person back to shared reality of the carer: *'Perhaps the hardest [strategy] to learn and apply, is that one never brings a midstage patient back to our sense of reality; rather, the caregiver must go where the patient is.'* (Raia, 2011 p.3).

An interesting point is made from the application of HT surrounding the meaningfulness, usefulness and need of delusional thinking among people living with dementia is made in an article by Deborah Bier:

'Take our example of the 80-year-old woman who believes she is [aged] 8 and waiting for her mother after school: She is making an important communication about how she feels and what she needs. This is information that, when decoded and used strategically, can help prevent difficult behaviors, and allow her to function at her best.

To decode this information, care partners need to know something about her life. In this example, it turns out that going home after school at age 8 to milk the cows made her feel she was fulfilling an important, grown-up function in her family. Connecting with and living in that time in her life may be the only way she can still communicate today how she feels and what she needs.'(Moore, 2009 quoted in Bier, 2012: 2).

The effectiveness of *functional analysis* (FA) (Wilson & Murrell, 2002; Cook et al, 2012), another needs-based approach for 'challenging' behaviour in dementia, was addressed in a recent Cochrane review in 2012 (Moniz et al, 2012). FA strives to establish the antecedent of behaviour and its consequences (ABC) (Wilson and Murrell, 2002) and understand the meaning or function behind the person's distressed behaviour. Most of the studies included in the review took place in domestic settings. Some proposed that behaviour that challenges in dementia indicates distress or suffering of the person, or distress of the carer, and can be interpreted as an attempt of a person to express psychological or physiological need.

Positive results of FA were shown for the reduction of frequency of the person's behaviour and for the perceived improvement of caregiver's reaction to them. However FA is a time-consuming intervention which requires involvement of a professional therapist and an individually designed package for both the person living with dementia and the carer of the person.

Specialised Early Care for Alzheimer's (SPECAL) approach is based on the following three 'golden rules': ask direct questions; listen to the experts (the people) and learn from them; don't contradict (Contented Dementia Trust, 2014). The SPECAL approach strives to 'make a present of the past' of a person with dementia through using the SPECAL Photograph Album to draw on their personal memories of past events and circumstances.

Although one can argue that the SPECAL approach is person-centred as it relies on the personal histories of people, it has also been heavily criticised by some for suggesting 'a blanket approach to deception of people with dementia' (Alzheimer's Society, 2012: 1). There was no research identified on the effectiveness of SPECAL approach for psychological wellbeing or cognitive resources of people living with dementia.

The identified needs based models and approaches require excellent communication and listening skills and ability to perceive emotional state of a person and the meaning of their experiences. In general, research into understanding meaning and needs of people with advanced dementia and the attempts of professional and home carers to meet such needs seems to be at its infancy and requires further investment of time and resources (Moniz Cook et al, 2012; Neal and Varton Wright, 2003; SCIE 2013; Contented Dementia Trust, 2014).

Some conclusions and further questions

- The debate on ‘truth-telling’ or ‘lying’ in advanced dementia is on-going. There is no agreement on this issue in the UK or elsewhere, and there are no static views among people with dementia or their paid or informal carers regarding acceptability of lying. However certain amount of deception motivated by reducing truth-related distress or other physical or psychological risks does occur in practice. Perceived acceptability of deception seems to vary under various circumstances, such as who are the interlocutors, and how, when, where and why a ‘lie’ is being told or the truth avoided or reframed. Every case seems to represent a unique interplay of personal, professional and environmental factors.
- There is a paucity of research, evaluation or advice pertaining to truth-telling issues in advanced dementia, especially in the community and home care to inform practices.
- Alternative approaches to ‘lying’ which consider challenging experiences meaningful as a manifestation of a person’s physical, psychological or social needs. Such approaches include Validation therapy, Habilitation therapy and Functional analysis of needs. However there is a paucity of research into such approaches showing their effectiveness in particular circumstances.
- Research into understanding meaning and needs of people with advanced dementia and the attempts of professional and home carers to meet such needs seems to be at its infancy and requires further investment of time and resources.
- Successful communication, person-centred care and needs-based approaches are emerging as key issues in the debate. In order for person-centred care to become ingrained in advanced

dementia settings, more time for interpersonal caring and more training for staff is needed. Financial and human resources restrictions may need to be addressed in advanced dementia care. In general, awareness of issues can inform better caring and communication.

- There are currently no formal guidelines on ‘lying’, only ‘truth telling’ whereby professional codes underline the obligation of practitioners to tell the truth, with the opposite potentially endangering professional registration or licence. However there are some informal guidelines for ‘lying’ in case when a person does not have mental capacity, and practical guidelines on how to avoid or minimise the need for lying in dementia care.
- There have been views expressed in the literature that specific guidelines for lying may be impractical, as they will require a lot of effort and paperwork and could potentially lead to abuse of people with dementia. Therefore, further questions arise:
 - Do we need guidelines and if yes, which and for whom?
 - If yes, who should be responsible?
 - If not, what do we need?
 - How can we advance our understanding of the meaning of unusual experiences (e.g. ‘confusion’, ‘hallucinations’ or ‘illusions’) so that we can provide appropriate responses to people’s needs?

As stated in the MHF proposal, even if the Inquiry does not come to any firm conclusions or find answers to all the emerging questions, it will provide an opportunity to raise awareness and create conversation about these issues at a national level for the benefit of people with dementia, practitioners and carers.

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