

**Exploring truth and deception as strategies used within everyday communication by carers towards people with dementia**

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## Declaration

|                                     |   |
|-------------------------------------|---|
| <b>Title of degree programme</b>    | Professional Doctorate in Clinical Psychology |
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| <b>Initial date of registration</b> | September 2015                                |

### Declaration and signature of candidate

I confirm that the thesis submitted is the outcome of work that I have undertaken during my programme of study, and except where explicitly stated, it is all my own work.

I confirm that the decision to submit this thesis is my own.

I confirm that except where explicitly stated, the work has not been submitted for another academic award.

I confirm that the work has been conducted ethically and that I have maintained the anonymity of research participants at all times within the thesis.

Signed:

Date:

*Informative note: From April 2018 the author's surname changed from O'Leary to Di Franco. The thesis document refers to the author using the surname Di Franco.*

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## **Abstract**

Paper one, the literature review, considered the use of truth and deception within the care of people with dementia. Nine papers were included within the review, which explored the experiences of professional carers, informal carers and people with dementia. The studies identified continuing dilemmas about the use of truth or deception strategies within dementia care, for instance, when truthful strategies were less effective, due to characteristics associated with dementia, carers resorted to deceptive strategies, like lies, which were seen as least acceptable. The findings highlight the emotional impact of deceptive strategies, the impact on relational dynamics and issues about the lack of formal guidance. The review recommends that more research be undertaken to understand more about the use of truth and deception strategies within dementia care, especially for informal carers, who were under-represented. Clinical and research implications are discussed.

Paper two, the empirical paper, explored how informal carers made decisions about using truth or deception within everyday communication at home with a person with dementia. The study adopted Grounded Theory methodology to create a theory about the processes underlying carers' decision-making about using truth or deception. The findings revealed that in everyday life, carers' use of truth or deception strategies depended upon a number of triggers, motivations and conditional judgments. The core concept of the theory was that decisions about using truth and deception were ultimately made in the moment. This study adds to research by proposing a theory of decision-making for informal dementia carers. Clinical and research implications are discussed.

Paper three, the executive summary, describes the main features of the study alongside recommendations for clinical practice and future research. It is more accessibly written so that it can be easily disseminated with a diverse audience, which includes informal and professional carers of people with dementia.

Paper One: Literature Review

**A literature review of truth and deception as strategies used within  
everyday communication by carers in dementia care**

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**Target Journal:** Qualitative Health Research

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## **Abstract**

**Objectives:** The UK National Institute of Clinical Excellence (NICE) recommend that non-pharmacological interventions be used initially in order to manage complex and challenging presentations of dementia, often associated with behavioural and psychological symptoms of dementia (BPSD). This review aims to synthesise findings of research into the use of truth and deception by carers, which have been used to manage complex and challenging symptoms of dementia and offer an alternative to pharmacological interventions, which should be used as a last resort (NICE, 2006; Banerjee, 2009).

**Method:** A systematic search of the literature was conducted, influenced by systematic methods, and inclusion/exclusion criteria applied. A total of nine qualitative and mixed methodology studies were included. The selected literature is described and assessed in regard to quality using an appraisal tool influenced by the Critical Appraisal Skills Program Checklist for qualitative studies and the Downs and Black Index (Downs and Black; 1998 CASP, 2017). A narrative synthesis of the research findings is provided accompanied by further discussion, which includes limitations, implications for practice and suggestions for research.

**Results:** Studies generally achieved good quality ratings, however as the studies were dominated by qualitative methodology the findings are hard to generalise and any conclusions drawn should be tentative. The studies identify continuing dilemmas experienced by carers concerning the use of truth or deception strategies within dementia care, often in response to BPSD. These issues are not currently addressed by any formal guidelines therefore carers rely on professional or moral frameworks. It appears that when truthful strategies are less effective, due to characteristics associated with dementia, carers resort to variations of the truth or deceptive strategies, like lying, which are seen as least acceptable.

**Conclusion:** More research needs to be undertaken in this area to understand more about the use of truth and deception strategies within dementia care, especially for non-professional carers who were under-represented. The findings highlight issues around the emotional and practical impact of truth and deception strategies, issues about the lack of guidance available and the potential impact on dynamics between staff, families and people with dementia. There is evidence that the use of these strategies could provide an alternative to pharmacological alternatives if used sensitively and appropriately.

**Keywords:** Dementia, Carer, Professional, Family, Truth, Deception



## Introduction

Dementia is a progressive and largely irreversible, degenerative condition of the brain characterised by a widespread impairment of mental function (NICE, 2006). All types of dementia present with what are often referred to as behavioural and psychological symptoms of dementia (BPSD) that become more frequent over time as the disease progresses. Though not an exhaustive list such symptoms include memory loss, reduced insight, confusion, disorientation, aggression, wandering and hallucinations (Zanetti, Geroldi, Frisoni, Bianchetti & Trabucchi, 1999). In the UK, approximately 5% of people over 65 live with dementia. By the age of 80 this increases to 20% and of this total two-thirds live in their own homes and the remaining number live within care settings (Department of Health, 2009; Alzheimer's Society, 2017). Supporting people with dementia challenges the skills and capacity of those around them (Zarit & Anthony, 1986).

### *The role of carers*

There are an estimated 670,000 informal, family carers in the UK who provide regular on-going support to a person with dementia who is likely to present with a range of complex needs that include increasingly demanding BPSD, for instance, more frequent forgetting or confrontational behaviour (Alzheimer's Society, 2017). Professional carers, or staff, face similar challenges as management difficulties associated with caring for someone with increasing BPSD are often the reason that people with dementia move into formal care settings (Finkel, 2000). Staff are tasked with providing expert treatment alongside regular, on-going care to people who often have more advanced presentations and are managing increasingly complex and challenging presentations of dementia, often without training or supervision (Bender, 2007). All carers, family and professional, are considered within this review because of the lack of research within this area and in consideration of guidelines that suggest that all those supporting people with dementia work together to maximise the benefit for people with dementia and ensure person centred, consistent practice (NICE, 2006). For example, professional carers may act on family wishes in regard to truth telling or deception (Maestri-Banks & Gosney, 1997).

### *Interventions within dementia care*

The National Institute for Health and Care Excellence (NICE) provide national guidelines which are often used as a quality indicator for health and social care services across England. Their guidelines advise that people with dementia who develop complex or challenging BPSD be offered non-pharmacological interventions, starting with assessment, to establish person-centred factors that may generate, aggravate or improve behaviour (NICE, 2006). As a result, there is increasing interest in the use of communication strategies as non-pharmacological opportunities to manage BPSD, which includes the use of truth or deception (Schermer, 2007; Wood-Mitchell, Waterworth, Stephenson & James, 2006). Non-pharmacological interventions reduce the need for pharmacological interventions, in particular antipsychotic drugs, which should be the last option because the risks often outweigh any benefits (NICE, 2006; Banerjee, 2009).

Historical approaches to managing BPSD vary in their position regarding truth and deception. Reality Orientation (RO) was an early strategy, which aimed to bring people back from confused states, by presenting truthful information about time, place and person (Spector, Davies, Woods & Orrell, 2000). RO was criticised for being confrontational and insensitive; its value lessened due to the number of studies that reported increased psychological distress (Woods et al., 2012). Criticism led to the development of Validation Therapy (VT), which recommended that carers acknowledge that a person might be orientated within their past and approach this with empathy, as if what the person was talking about was happening in the present (Feil, 2004). There is insufficient evidence to suggest that VT reliably reduces distress and carers more regularly report using deceptive strategies rather than any other approach (Neal, Barton & Wright, 2003). For example, the concept of therapeutic lying emerged, based on the premise that trying to communicate the truth to someone with dementia can be futile and a therapeutic lie, which takes into account a person's life history, can reduce distress (Hasselkus, 1997; Culley, Barber, Hope & James, 2013). Ultimately, there is still insufficient evidence to suggest any approach is superior.

### *Defining truth and deception*

The universal definition of truth relates to that which is in accordance with fact or reality. Deception refers to the act of deliberately making somebody believe something that is not true (Oxford Dictionary, 2017). There are difficulties applying these definitions within a dementia context, for example, as dementia progresses people lose awareness of what constitutes reality and carers are faced with dilemmas about which reality constitutes truth, the objective or subjective reality (Shermer, 2007). Carers might also deceive without using factually incorrect information, for example, using exaggerations, half-truths and diversionary responses (Turner, Edgley & Olmstead, 1975). For the purpose of this review all relevant terms will be grouped under the terms truth or deception.

### *Truth or deception: a debate*

In dementia care, morality about deception might be determined by the consequences and there is a steady growth of evidence that suggests deception is used in best interests, for example, to avoid harsh facts which cause distress to a person with dementia (Hughes, 2002; Cunningham, 2005; Pendleton, 2006; The Alzheimer's Society, 2016). Deception, in particular lies, might also be used to achieve other consequences like improving compliance or saving time (Jackson, Cooney, Walsh & Coakley, 1991; Wood-Mitchell et al., 2006). Carers might justify deception within a consequentialist framework; as a reasonable means to achieve a positive consequence in the least restrictive way, for example, instead of using antipsychotics (Beauchamp & Childress, 2001; Jones, 2011). Carers using deceptive strategies report that they are also helpful in managing increasingly challenging BPSD, especially when strategies like truth telling and reasoning lose their effectiveness (Goffman, 1971).

Alternatively, carers might feel obligated to use the truth as deception may conflict with their personal morality or perhaps their professional values, where a patients' right to autonomy and open, honest care represent a fundamental ethical framework (General Medical Council, 2013). Deceptive practices, such as lie telling,

are seen as a form of treachery used to distract or manipulate people with dementia who deserve to know the truth, therefore can never be used in a person's best interests (Kitwood, 1997). As deception infringes a person's right to autonomy there are concerns that people with dementia are at risk of abuse when carers are enabled to make decisions on their behalf (Bakhurst, 1992; Schermer, 2007; Kosgarrrd, 2012). Due to diminishing capacity, carers might feel more able to use deceptive practices because it is less likely they will be found out, placing them in a potentially harmful position of power (Ekman, 1985). Person-centred approaches championed by NICE (2006) are violated because trust is broken and any true therapeutic relationship lost (Pool, 2007). Muller-Hergl (2007) concludes that lying is unethical, disrespectful and should categorically not replace using the truth.

### *Guidelines on truth and deception*

Though it is clear that deception is used regularly in dementia care, the use of deception is essentially unregulated and carers continue to face challenging dilemmas about choosing whether to tell the truth or deceive a person with dementia (Culley et al., 2013). There is little agreement within the present literature and no clear formal guidelines have been adopted or recognised formally for carers to refer to (NICE, 2006; Mental Health Foundation, 2014). The General Medical Council issued a statement, declaring that there are no plans to issue guidance, adding that professionals should decide on a case-by-case basis (GMC, 2013).

### *Aims*

Regardless of the terminology used or the position taken within the literature, decisions about whether to use truth or deception, especially in response to complex and challenging BPSD, is a common issue faced by people caring for people with dementia. The literature calls for continued investigation to determine the risks and benefits of truth and deception strategies (Culley et al., 2013). Therefore, the aim of this review is to synthesise and address the quality of research that explores the use of truth and deception as non-pharmacological, communicative strategies by carers of people with dementia.

## Method

### *Search strategy*

A systematic approach was taken to review the literature. The database host HDAS (Healthcare Databases Advanced Search) was used in order to access the following databases independently:

- AMED (The Allied and Complementary Medicine Database)
- BNI (British Nursing Index)
- CINAHL (The Cumulative Index to Nursing and Allied Health Literature)
- EMBASE (Excerpta Medica database)
- MEDLINE (Medical Literature Analysis and Retrieval System Online)
- PsycINFO

The search terms used were a result of an initial scope of the research and represent the most frequently used terms within relevant literature:

- Carer\* OR careg\* OR staff OR prof\* OR famil\* OR relative\*

AND

- Dementia\* OR Alzheimer\* OR "memory loss" OR "cognitive impairment" OR "cognitive-impairment"

AND

- Deception OR deceive\* OR lie\* OR lying OR truth\* OR withhold\* OR "truth telling" OR "truth-telling" OR honest\* OR covert OR distract OR divert

NOT

- Diagnosis

The search field was restricted to results where search terms appear within the title or abstract. The search was limited to papers written or translated into English. Where possible peer reviewed results were requested, although this would be confirmed during later screening. Research relating to the process of diagnosis was

excluded because this review focuses on strategies employed in response to BPSD, which are associated with moderate to advanced dementia rather than diagnosis, which is often associated with early stage dementia (NICE, 2006). There is also a body of literature that looks at issues specific to the use of truth and deception around diagnosis (Bamford et al., 2004). The initial search, conducted on 23<sup>rd</sup> May 2017 yielded 889 results across all included databases.

### *Inclusion and Exclusion criteria*

The titles and abstracts of all 889 results were screened to ensure that the terms relating to dementia, carers and either truth or deception in the abstract and title were featured appropriately, leaving 76 results. Then 43 duplicates were removed, leaving 33 results.

This review sought only to contain peer-reviewed, empirical studies. Full text reading excluded 9 studies that were not peer-reviewed or empirical leaving 24 studies. In consideration of NICE guidelines 8 studies and 1 review about pharmacological approaches, specifically covert medication, were removed leaving 15 results (NICE, 2006). Further exclusions were made where 7 results did not purposely aim to explore the concepts of truth or deception as non-pharmacological strategies used by carers within dementia care, leaving 8 results.

The search terms were searched within the Cochrane database, which identified no additional relevant reviews, as well as Web of Science to identify studies that may have been missed; one new result was found which was ruled out because although it looked at strategies it did not purposely explore truth or deception. Finally, a hand search was conducted through the bibliographies of relevant articles to see whether they contained references that were missed in the original search. Online database tools are not perfect and occasionally articles are missed; 1 study was found leading to 9 final studies for quality appraisal and inclusion in the literature review. Hand search also identified a review of qualitative studies that predate 2012, that explored the acceptability of deception in dementia care (Seaman & Stone, 2017). However, the current review includes additional mixed methods, recent studies that offer valuable evidence to the on-going debate on truth and

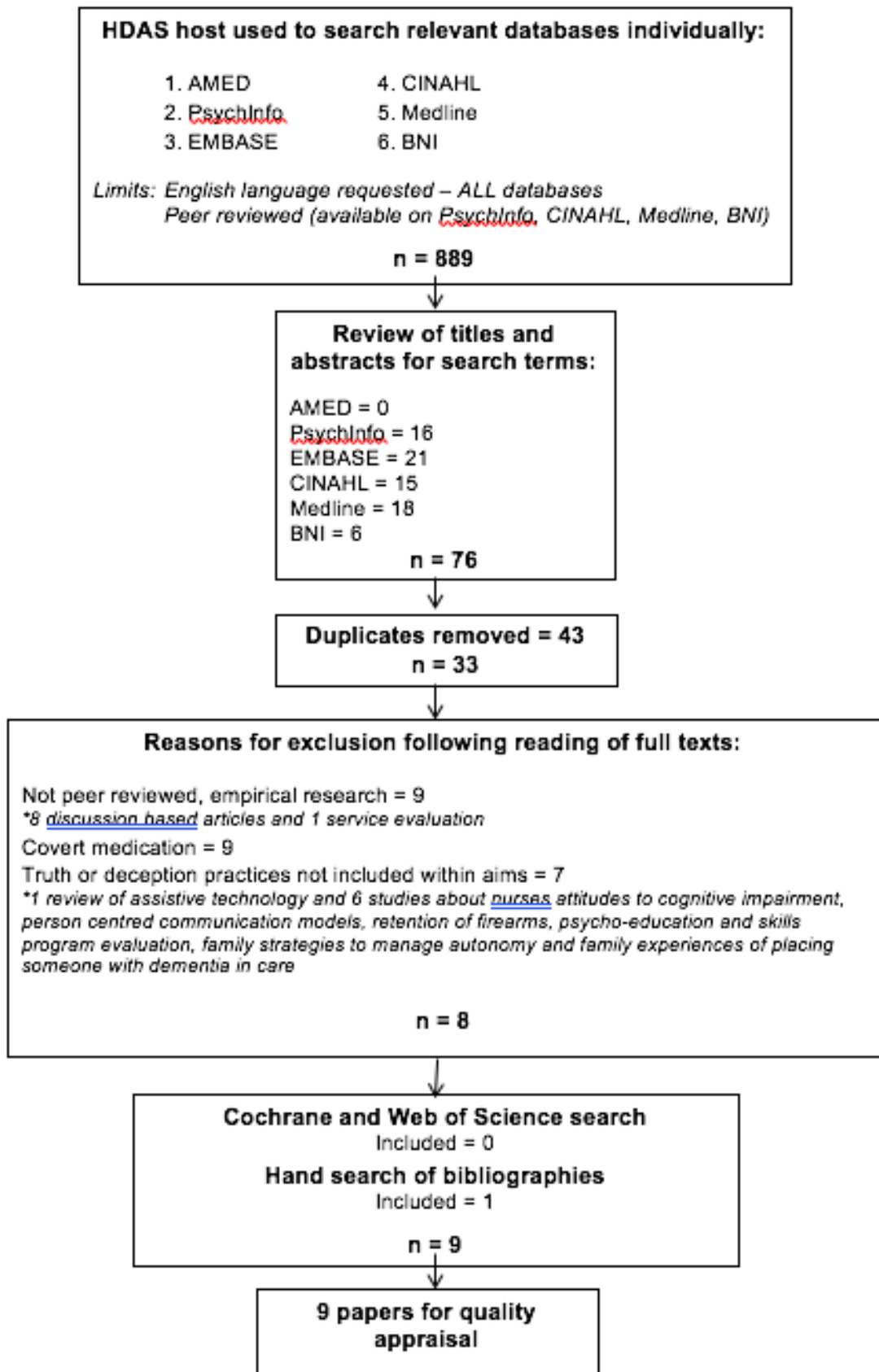
deception in dementia care. The search stopped on June 23<sup>rd</sup> 2017. A flow chart depicting the inclusion/exclusion process is provided (Figure 1).

### *Quality Appraisal*

The quality appraisal is influenced by systematic methods. Quality appraisal is essential because faults in design or conduct can result in bias and influence the validity of findings, which need to be addressed should research be used to influence decisions about practice beyond the realms of research (Steen & Roberts, 2011). The final nine studies represent qualitative and quantitative methods (Appendix 2). The majority of the studies utilize qualitative designs therefore a Critical Appraisal Skills Programme (CASP) checklist for qualitative research was chosen as the overarching framework for appraisal (CASP; 2017). CASP have developed a number of validated critical appraisal tools to ensure studies are assessed and appraised in a standardised way. However as two studies utilize mixed methodology, questions from the Downs and Black Index have been added into this framework to address quality issues related to quantitative methods (Downs & Black, 1998). The Downs and Black Index was chosen due to its validity ( $r = 0.90$ ), reliability (Cronbach alpha  $> 0.69$ ) and overall strong methodological rating (National Collaborating Centre for Methods and Tools, 2008). Quality appraisal of qualitative and quantitative designs may adopt different terminology, but concepts are 'translatable' (Lincoln & Guba, 1985). The combined quality-rating tool is provided (Appendix 1).

The studies are also assigned a rating to arbitrarily assess their overall quality, for the purpose of review, using a traffic light, point system according to the ten questions within the quality-rating tool (appendix 3). Studies that fully answered a question are coded as green (2 points), partially as yellow (1 point) and those that give sufficient, unclear information red (0 points). The total quality rating for each study is represented visually using the traffic light colours and numerically using the total score for each study (ranging from 0-20 points), which generates an overall percentage to indicate quality.

Figure 1: Overview of search strategy and selection for relevance.





## Results

### *Description of included papers*

The majority of the studies used qualitative methods to explore the use of truth and lies in dementia care. Two of the studies uniquely considered the perspectives of carers and people with dementia. Blum (1994) interviewed family carers who reported that they routinely used variations of deceptive strategies to manage BPSD and cope with caring. Day, James, Meyer and Lee (2011) explored deception from the perspectives of people with dementia. Generally, deception was considered acceptable if used in a person's best interests; a decision made by considering factors about the person with dementia, the person deceiving and the type of lies told.

The remaining studies all considered professional, or staff, experiences in regard to the use of truth and deception in dementia care. Hertogh, Mei The, Miesen & Eefstings (2004) explored moral and ethical tensions that existed for nursing home staff. Staff generally believed patients had a right to know the truth but struggled to uphold this in practice when faced with significant challenge and distress. Significant social events, like deaths, were never kept from patients however for day-to-day information, deemed as less significant, staff preferred to use techniques that withheld the truth or distraction. Tuckett (2006) explored truth telling in nursing homes. Generally, nursing staff determined the worth of truth telling by its outcome and there was an assumption that truth telling in full could be harmful, for example, nurses edited the truth to avoid causing distress to residents and families. In another study, Tuckett (2012) explored staff experiences of lying to people with dementia in residential care. Generally, lies were used when staff felt that residents with dementia lacked awareness and when the consequence justified the lie, for example, the resident became settled. Staff experienced moral distress when deciding if lies were appropriate and attempted to distinguish their actions as beneficent, where the aim was to help the person with dementia, from "out and out lying" (p.12). Tullo, Lee, Robinson and Allen (2015) interviewed medical students about deception. Students recognised that dementia raised unique ethical issues, for example, determining capacity, which introduced a difficult mediating factor to decisions about deception. Generally, students thought truth telling could worsen confusion or

be too confrontational. They believed a consensus should be reached with families and some justified using deception if this maintained family relationships. Turner, Eccles, Keady, Simpson and Elvish (2016) alone considered how staff within general hospital settings used truth and deception. They proposed a model of decision-making that considered what influenced staff decisions about using deception, for example, difficult questions, perceived responsibility or family presence. All staff wanted to act in the patient's best interests and generally preferred to avoid using truth or lies by "passing the buck" (p.5) or distracting a person.

Two studies utilised mixed methodology. James, Wood-Mitchell, Waterworth, Mackenzie and Cunningham (2006) explored lying in dementia care by requesting questionnaire responses from a large sample of staff. Lies were found to be pervasive across all settings; residential, specialist and hospital units. Generally, lies were used to reduce patient distress, carer distress and improve compliance. Staff saw problems associated with lying and the study suggests guidelines on how they should be used. Elvish, James & Milne (2010) developed the 25-item "Attitudes to Lying to People with Dementia" (ALPD) questionnaire to measure attitudes to lying in dementia care. This was administered to conference delegates, which included professionals within dementia care, who attended a workshop based around the concept of deception in dementia care. The ALPD, alongside other measures of change, showed that attitudes to lying were modifiable and delegates became more accepting of deception in dementia care.

#### *Quality of included papers*

All included studies clearly outlined aims to purposely explore carers' use of truth or deception within a dementia context. Though the studies adopted appropriate methodology less than half explicitly justified their methods, for example, by explaining that qualitative methodology obtained detailed experiences for interpretation (Greenhalgh & Taylor, 1997). The studies, which were dominated by interview methods (78%), described their designs with varying detail and justification. Though appropriate to qualitative research, interviews pose potential issues, for example, there can be differences between what participants say and do in practice and participants might have given responses they deemed desirable or

appropriate (Seidman, 2013). The two mixed method studies included used questionnaires to capture participant responses (James et al., 2006; Elvish et al., 2010). Though self-reported measures, like questionnaires, capture personal data they present similar limitations in regard to validity and reliability (Richardson, 2004).

Over half of the included studies (56%) omitted explicit details about their recruitment strategies. It is helpful to know recruitment strategies to allow for exact replication especially when strategies should relate to the overarching approach followed by the study, for example, Day et al. (2011) and Turner et al. (2016) used theoretic sampling, which relates to grounded theory and Tuckett (2012) used purposive sampling, which allowed the researcher to seek phenomenon specific data. It is also helpful to know sample sizes, especially in quantitative research, where a power calculation should be made to ensure sufficient participants are recruited. Elvish et al. (2010) were open about their sample size being “barely acceptable” (p.261) therefore their research presented tentative findings. All studies described data collection, though with varying levels of description and justification. A number of studies (56%) also reported multiple methods of data collection, for example, observations, field notes, focus groups, questionnaires and workshops. Utilizing more than one method can increase the robustness of the research and increase the validity and reliability of findings (Greenhalgh & Taylor, 1997).

Due to a dominance of qualitative methods, most of the included studies analysed their data using grounded theory or thematic methods (78%), however description was varied, limiting overall replicability. To support replication, two studies gave explicit detail about specific procedures related to their adopted approach, grounded theory, for instance, coding, constant comparison and negative case analysis (Day et al., 2011; Turner et al., 2016). Qualitative research is often criticised for lack of rigour, or evidencing consistency, however nearly all qualitative studies attempted rigour by adopting quality-rating tools, triangulation, field notes or negative case analysis (Noble & Smith, 2015). In reference to the mixed method studies, Elvish et al. (2010) provided in-depth description of their analysis, which allows for replication, detail that is lacking from James et al. (2006) due to this being formatted less formally as a research letter.

All of the qualitative studies presented clear findings and attempted to demonstrate credibility by illustrating their findings with embedded quotes, discussing negative cases and referring to relevant literature. Of the mixed method studies, both reported responses from the adopted questionnaires. Statistical tests were only relevant to the objectives of Elvish et al. (2010), who used statistical methods to develop a questionnaire, and these results are reported clearly. All of the studies highlighted practices in dementia care that utilised truth, variations or deceptions. Three studies provided new insight; into family carers, the perspectives of people with dementia and inpatient contexts (Blum 1994; Day et al., 2011; Turner et al., 2016). The majority of the studies discussed limitations alongside recommendations for future research or clinical practice (67%). This openness allows the reader to make an informed judgment about the dependability, or reliability, of the results and to cautiously consider the transferability of the study. For example, reported limitations, which included sample sizes and experimenter effects, make it difficult to transfer findings to other people and settings without some level of caution (Greenhalgh & Taylor, 1997). Research is increasingly subjected to scrutiny about ethical issues, so it is surprising that three studies omitted any consideration of ethical processes (Hayes, 1995). The remaining studies described ethical issues in varying detail; four clearly evidenced their ethical considerations by describing the ethical processes that influenced the study alongside additional considerations around design and participants, and three studies made more brief reference to ethical procedures including ethical approval, consent and debrief.

Demonstrating reflexivity, or influence on the research, is an important aspect of qualitative research because without evidence of the researchers' position or influence, readers are not assured that attempts have been made to separate these from the findings (Noble & Smith, 2015). Similarly, within quantitative studies, authors should remain objective in their interpretations of adopted measures (Downs & Black, 1998). Surprisingly the majority of the studies did not address reflexivity explicitly (89%). Only one study explicitly stated reflective diaries were used to identify influence and ensure inter-subjectivity (Hertogh et al., 2004). Four studies alluded to reflexivity by describing use of field notes, team discussions to agree upon

findings or reflection upon the impact of a researcher's influential profile (Tuckett, 2006; Elvish et al., 2010; Tuckett, 2012; Turner et al., 2016).

### *Individual characteristics*

Where detail was provided, female participants dominated the studies. Caring responsibilities in families tends to be adopted by females, for childcare and elderly parents, and women also tend to be in occupations that involve personal services (Carers UK, 2017). However, there is insufficient evidence to draw conclusions about the impact of gender differences on truth or deceptive strategies. Age is also not explicitly addressed within the research, but it would be interesting to identify generational differences regarding the use of truth or deception, especially as there is an increasing number of young carers (under 25) caring for people with dementia (National Children's Bureau, 2016). Finally, the studies reported the experiences of carers from the UK, America, Netherlands and Australia. Though these carers reported similar experiences, deception may be perceived differently within other cultural settings, for example, Elvish et al. (2010) refer to the systematic use of deception by Shaman community leaders.

## **Findings**

This review focused on the research findings, as interpreted by the authors of the research, which were synthesised in accordance with previous literature that explored the concepts of truth and deception as used by carers in dementia care. The studies generally achieved good quality ratings (45-90%) and seven studies fully met over half of the criteria (78%). However, as the studies were dominated by qualitative methodology, which due to small samples are generally hard to generalise, any conclusions drawn from these studies should be tentative.

### *Defining truth and deception*

All studies found that carers of people with dementia were using variations of truth and deception and their use partially depended upon how carers defined what constituted being truthful or deceptive. These concepts were defined differently

within the context of dementia, compared to other health and social contexts, seemingly because of specific difficulties associated with the characteristics of dementia. For example, for people with dementia it was less clear what constituted as true or false as they fluctuated between objective and subjective realities. Furthermore, truth and deception were used as umbrella terms, which defined a continuum of strategies in dementia care; from truth telling, which included edited or partial truths, to deception, of which lies were seen as the most extreme form. Carers felt more comfortable defining their actions as variations of truth rather than deception and proposed that the truth had layers (Tuckett, 2006). Similarly, for deception, blatant lies, which said something contrary to the truth, were defined differently to “white lies”, “porkies”, or “going along with someone” (Blum 1994; Day et al., 2011). Notably, though these strategies do not conform to the general definition of deception, carers were still not necessarily disclosing truths.

*Why are truth and deception used?*

*To enable carers to manage symptoms of dementia*

Carers used deception in order to cope with and manage complex and challenging BPSD, especially when other more truthful strategies failed. For example, instead of trying to reason with someone who was increasingly confused, carers told a lie. When seeking alternative strategies, carers used trial and error, experimental approaches, or they learned new strategies as a result of seeking support from other carers. Though they might not have envisioned using anything other than the truth, a number of carers reported using deception in order to survive the demands of their role (Blum, 1994).

*To achieve positive consequences*

A number of carers approached the use of truth or deception from a consequentialist position, where adapted truths or deceptions were justified as acts of compassion or beneficence and were used for the good of the person with dementia or in their best interests. Ideally, decisions about best interests were made collaboratively with family carers, not in isolation or based on preferences and assumptions of professional carers (Tuckett, 2006; Day et al., 2011). Adapted truths or deceptions were an attempt to achieve positive consequences, such as avoiding

distress, that was associated with telling a person with dementia the truth. Similarly adapted truths or deceptions were used to avoid physical risk, for example, to prevent people with dementia wandering in environments where they are vulnerable.

#### *To manage information*

Adapted truths or deceptions were used to manage information, especially by professional carers, for example, to manage difficult questions about the death of a spouse or to manage medical information, like a diagnosis (Tullo et al., 2015; Turner et al., 2016). Some carers were keen to always tell the truth about social life events, like births or deaths, but were less concerned about events that they perceived to be day-to-day events, like family visits, and for these they were more accepting of adapted truths or deceptions (Hertogh et al., 2004). A number of carers regularly made decisions to withhold information from families that they felt did not impact on overall care, for example, occurrences of aggression (Tuckett, 2006).

#### *In response to advancing dementia presentations*

Dementia raised unique ethical considerations around the use of truth and deception because of the characteristics associated with the disease, often referred to as BPSD, which included disorientation, agitation and reduced awareness of an objective reality. Truth was used when carers judged that people with dementia had awareness, whereas deceptive strategies were adopted when people were less aware and could not detect fiction from fact. Students believed that disclosure of truth in more advanced dementia would be futile and damaging (Tullo et al., 2015). Some carers found it difficult to gauge when a person's dementia has progressed to a point when non-truths were acceptable, especially when a person had fluctuating awareness (Hertogh et al., 2004). Carers who understood more about the characteristics of dementia were more open to using variations of truth or deception, for example, they accepted that acknowledging a persons' subjective reality was not deceitful (Tuckett, 2012).

#### *In line with professional and personal values*

The use of truth or deception strategies depended upon how acceptable they were perceived to be by individual carers and there appeared to be a continuum of attitudes, ranging from unacceptable to acceptable (Elvish et al., 2010). For example,

carers were reluctant to use verbal deceptions, like lies, but were more accepting of environment deceptions, like hiding keys. Due to a lack of formal guidelines professional carers described attempts to adhere to professional codes of conduct, for example, that staff should be open and sincere because patients deserve to know the truth (Hertogh et al., 2004). Non-qualified and family carers referred to moral frameworks, due to a lack of alternative guidance. Interestingly, professional carers would more likely be truthful around family members due to a fear of being judged by their moral frameworks (Turner et al., 2016). Professional and moral frameworks are both challenged within the context of dementia care; carers struggle to enforce these in practice and many carers reformulate their values when faced with challenging BPSD.

#### *Depending on the relationship*

The relationship with the person with dementia appeared to influence the use of truth and deception strategies. People with dementia felt that it was less acceptable for family carers to use deception because expectations of trust within these relationships are higher (Day et al., 2011). Despite reporting regular use of deception, family carers were reluctant to use deception with loved ones with whom they had trusting and intimate relationships (Blum, 1994). Professional carers with less direct contact with patients with dementia, like psychiatrists, believed that those with more regular contact, like nurses, were in a better position to use truth or deceptive strategies. However, some nurses wanted professionals with more clinical responsibility, like psychiatrists or psychologists, to make decisions about using truth or deception (Hertogh et al., 2004; Turner et al., 2016).

#### *How are truth and deception used?*

Truth and deception represented a range of approaches and the general consensus amongst carers was that decisions about what strategies to use should be person centred and consider both a person's subjective reality and individual needs instead of making something up entirely. Carers' strategies are presented as a continuum from truth to blatant deception, a concept suggested by Tuckett (2006), because the though the extremes of truth and deception were distinct there were also strategies in-between these extremes that varied in their use of truth and deception.



### *Truth telling*

A number of carers saw telling the truth as the correct response, however when faced with challenging BPSD many carers changed their approach. People with dementia believed that carers could continue to tell the truth but in a kind way (Day et al., 2011).

### *Variations of truth telling*

Carers used strategies that allowed them to withhold truthful information from the person with dementia. For example, they chose to limit truth by telling edited, filtered or partial truths, which they believed softened the information being shared (Blum, 1994; Tuckett, 2006; Tuckett, 2012).

### *Distraction and diversion*

Carers avoided the truth by distracting the person with dementia, for instance, by diverting them to other immediate happenings or activities. Carers also avoided the truth by passing the buck, or responsibility, to another person (Turner et al., 2016). Many carers viewed these strategies more positively because they were not perceived equally to lies.

### *Going along with*

Carers chose not to confront a person with dementia by going along with their subjective experiences instead of disagreeing with them. Acknowledging subjectivity was not seen as akin to deceptive lies, as this did not involve giving false information (Blum, 1994; Tuckett, 2012).

### *Deceptive acts*

Carers used deceptive acts, including tricks and subtle environmental changes, like hiding keys (Blum, 1994). Deceptive acts appeared to lie between truth and verbal deceptions, and carers were more accepting of these, perhaps because their discovery was predicted to be less distressing than the discovery of a lie (Day et al., 2011).

### *Lies*

Verbal deceptions, including white lies and porkies, were seen as the most extreme forms of deception as they involved giving false information (Blum, 1994; Hertogh et al., 2004; Day et al., 2011; Turner et al., 2016).

### *What are the risk or benefits?*

#### *Positive outcomes*

The use of truth variations or deception commonly resulted in reduced emotional distress, reduced physical risk or improved compliance in those with dementia. These strategies also led to positive outcomes for carers, by providing carers with alternatives in order to cope with and manage challenging BPSD when other strategies became less effective. There were concerns that if used regularly deceptive strategies would become routine, instead of an option, however if used inconsistently such strategies could also increase confusion (James et al., 2006; Tuckett, 2012).

#### *Carer uncertainty*

Carers did not have access to guidelines for making decisions about truth or deception, and often experienced uncertainty about adopting deceptive strategies. A number of carers, often-unqualified carers, felt they lacked information necessary to make decisions about using truth or deception, leaving them uncertain (Turner et al., 2016). A number of carers attempted to seek reassurance, for example, from other carers in support groups or from staff perceived to have authority (Blum, 1994; Hertogh et al., 2004; Turner et al., 2016). Medical students were apprehensive about applying strategies in practice because of complexities associated with dementia, for example, difficulties around fluctuating capacity (Tullo et al., 2015). Despite the reported regular use of deception strategies, there is a lack of open discussion about practices within dementia settings, perhaps due to societal taboo's around dementia, which make carers feel vulnerable to blame (Hertogh et al., 2004; Tuckett, 2012; Turner et al., 2016).

### *Emotional discomfort*

A number of carers experienced discomfort and guilt about having the power and responsibility for using non-truthful approaches with people with dementia, about the person finding out or being judged by others, like family, especially if this risked damaging relationships build on trust and honesty (Blum, 1994; Day et al., 2011; Hertogh et al., 2004; Tuckett, 2012; Turner et al., 2016). Some carers experienced distress about using approaches that contrasted with their professional or personal ethics, for example, that lying is wrong (Day et al., 2011; Turner et al., 2016). Carers struggled to withhold their beliefs in practice when confronted with challenges associated with dementia, including BPSD, and these beliefs did not easily function within dementia contexts. Carers were more likely to choose strategies that did not impact as greatly on their moral beliefs, for example, distraction (Hertogh et al., 2004).

### *Relationship tensions*

Truth and deception strategies appeared to cause tension between those with dementia, professional carers and family carers. Carers, especially family carers, worried about the impact of deception should it be found out as their family relationships were based on expectations of trust and intimacy (Blum, 1994). Over time, deception might impact on the networks surrounding people with dementia, as more people become involved in order to manage their needs (Blum, 1994). Eventually, this might involve professional carers if people enter care settings and power dynamics might evolve between professional and family carers, who both make assumptions about what strategies to use. Professional carers who disagree with family carers have difficulties managing opposing views, for example, professional carers were not happy following family wishes by telling lies about significant family events (Tuckett, 2012). However, professional carers might want to maintain good relationships with families and justify deception if this pleased family members (Tullo et al., 2015). Groups of carers, for example staff teams, might contain strong opposing views about the use of truth and deception and this created unhelpful, inconsistent care environments (Hertogh et al., 2004). Equally, staff avoiding discussions about strategies created a sense of unease about the use of truth or deception (Turner et al., 2016).

### *Role pressures*

The use of truth or deception strategies appeared to impact carers differently, depending on their role. Frontline staff within dementia care experienced frustrations about having to implement strategies first hand in comparison to staff who had less contact, like psychology. Nurses reported that they often took responsibility from unqualified staff who pass the buck to them, as well as psychiatrists who felt that nurses knew patients better (Turner et al., 2016). However, some nurses felt uncomfortable about making decisions without support from those deemed to have more authority, like psychiatrists or psychologists, especially for people for whom capacity fluctuated. Nurses also experienced frustration about having to manage the consequential distress of strategies, as they felt time limited in their abilities to do so (Hertogh et al., 2004). Non-qualified professional carers felt they lacked the information needed to make decisions about truth or deception, despite opinions that they had more time to manage distress, and many did not feel it was their responsibility to cause upset (Turner et al., 2016). Family carers often made decisions about using truths or deception alone, regularly through experimentation (Blum, 1994).

## **Discussion**

In response to the existing literature, which called for continued investigation, this review shares a number of risks and benefits associated with truth or deception strategies. Decisions about truth and deception put additional pressure on carers and created uncertainty, emotional discomfort and tension in their relationships. However, such strategies gave carers alternative ways to manage BPSD, especially when truth failed, in order to achieve positive outcomes including reduced distress. This review highlights the lack of guidelines available to support carers with the use of truth or deception strategies, which introduces further risk because instead carers are adopting practices that they learn through others or as a result of trial and error (Blum, 1994). Without guidelines, the use of such strategies is unregulated and people with dementia are in a vulnerable position because carers are entrusted to use these strategies appropriately (Ekman, 1985). Though not explicitly explored within the studies presented, it does not mean that these risks did not occur in practice.

The review confirmed that professional and family carers face similar challenges supporting people with dementia. Carers struggled with decisions to use deceptive strategies because of how these contradicted with their moral or professional values and changed their relationship with the person with dementia (Blum, 1994; Hertogh et al., 2004; Turner et al., 2016). Carers also struggled to define their actions as deception, especially lying, and instead found ways to avoid telling the truth without giving factually incorrect information (Blum, 1994; Hertogh et al., 2004; Tuckett, 2006; Turner et al., 2016). As suggested by Bender (2007), some professional carers did not feel they had adequate information, training or skills to make decisions about deception (Turner et al., 2016). The review suggests that this is also the case for family carers who often make decisions alone (Blum, 1994).

The studies confirmed that deceptive strategies are a way of life for many carers, used to manage challenging BPSD as well as day-to-day tasks (McElveen, 2016). As suggested by Goffman (1971), deception was helpful in managing worsening memory problems and confusion, especially when strategies like truth telling and reasoning lost their effectiveness, but also to manage information that could create distress, for instance, about diagnosis. This review challenges literature that states deception is never in best interests, because carers attempted to use strategies to achieve positive outcomes (Kitwood, 1997; Hughes, 2002; Cunningham, 2005). The positive outcomes suggested by the studies match those discussed in the literature, for example, to reduce distress, risk and improve compliance (Jackson et al., 1991; Beauchamp & Childress, 2001; Jones, 2011).

The studies highlight issues with recommendations proposed by NICE (2006) in practice, for example, none of the studies referred to formal assessment processes. NICE also recommend that all those supporting people with dementia work together, but the studies showed that professional and family carers occasionally have different approaches to truth and deception and that carers sometimes make decisions without consultation, in isolation (Hertogh et al., 2004; Tuckett, 2006). Issues also lie within professional care teams who are reluctant to talk about using deceptive strategies or take responsibility for fear of being judged or blamed (Turner et al., 2016).

The rationale for this review was to explore the use of truth and deception as communication strategies used by dementia carers, especially as these strategies offer non-pharmacological alternatives to pharmacological approaches, in particular antipsychotic drugs (NICE, 2006). Though the included studies did not comment on the impact of truth or deceptive strategies on pharmacological interventions, they do offer anecdotal evidence for how truth and deceptive strategies can reduce the BPSD that challenge carers.

### *Limitations*

A full systematic review would seek to include all published and non-published studies in order to reduce publication bias, however due to time constraints associated with student projects, this review included only published, peer-reviewed studies. Despite debate, the credibility and trustworthiness of peer-reviewed journals are often considered the gold standard (Bondas & Hall, 2007). Nevertheless, as a consequence of excluding non-peer-reviewed research some caution should be applied to these findings, as not all evidence is represented. Furthermore, the literature search strategy was conducted solely by the researcher, so it is possible that the search terms used could have been refined further.

Due to increasing interest in the use of truth and deception in dementia care, the evidence base is still growing. Currently, research is dominated by professional carer experiences and though professional carers appear to experience similar experiences to family carers, this is not conclusive with so little evidence. The studies are also dominated by qualitative methodology. Though this generates rich in-depth findings about carers' views and experiences, samples are often small; therefore, findings cannot easily be transferred to other people or settings (Ormston et al., 2014).

### *Clinical Implications*

#### *Improved communication*

The concept of deception appears to be a taboo amongst many carers, as well as the governing professional bodies, for a number of reasons. However, decisions about truth and deception should be discussed more openly, especially in formal care

settings where practice is at risk of becoming inconsistent (James et al., 2006; Tuckett, 2006). Carers often experienced uncertainty about whether their practice is correct, therefore should be encouraged to establish shared definitions about truth and deception within their setting, to improve their confidence and ensure practices are being used appropriately. Multi-disciplinary meetings, handovers, supervision sessions and individualised information sessions could provide ideal opportunities, especially for non-qualified carers who often lack both emotional and practical support, similarly to family carers, who should be involved in decision-making processes (Blum, 1994; NICE, 2006; Turner et al., 2016).

#### *Assessment of challenging dementia presentations*

NICE (2006) state that people with dementia should be offered assessment to establish factors that may influence their behaviours, especially should they present with challenging BPSD. The included studies, which explored professional carer experiences, showed that truth or deception strategies could influence behaviour; however, included no explicit reference to how such strategies were documented within an assessment context. Ideally, each patient should be offered assessment, which includes consideration of the use of truth or deception, which can be shared between carers and influence clinical practice.

#### *Supporting carers*

NICE (2006) make different recommendations for supporting professional and family carers; that professional carers access dementia-care training and family carers are offered psychological therapy. However, as the literature suggests professional and family carers face similar challenges around the use of truth or deception, perhaps a clinical implication should be about how carers can access whichever support best meets their needs. This could be dementia-care training, or it could be the opportunity to access psychological therapy or supervision (Blum, 1994; Hertogh et al., 2004; Tuckett, 2012).

#### *Future Research*

The literature is dominated by research about professional carers in formal care settings (78%) therefore more research is needed that considers the perspectives of

family carers alongside people with dementia within community settings. Research should employ more inclusive methods, for example, observation, so that people with advanced dementia can be involved (Day et al., 2011). The included studies also highlight opportunities to explore truth and deception within educational and health settings, for example, medical students and hospital settings (Tullo et al., 2015; Turner et al., 2016). A small number of studies (22%) looked at how decisions about the use of truth and deception were made by staff within hospital settings and by people with dementia. Future research could explore decision-making processes by professional carers in other care settings or by family carers (Day et al., 2011; Turner et al., 2016). Individual differences were not considered within the included studies, so future research should also explore how factors like gender, age and ethnicity impact on attitudes towards truth and deception as well as their usage.

Some of the studies attempted to propose guidelines for the use of truth and deception in dementia care and a tool, the ALPD, was also created to measure staff attitudes, towards lies specifically (James et al., 2006; Elvish et al., 2010; Tuckett, 2012). Future research should disseminate guidelines proposed within the research to see how these apply to practice within different contexts of dementia care. This could encourage open dialogues about the use of truth and deception and provide opportunities to gather quantitative data, for example, developing the ALPD tool, from which research could make more generalizable conclusions.

## **Conclusion**

Despite the absence of relevant guidelines, the studies in this review highlight the widespread use of strategies that adopt variations of truth and deception, by both professional and family carers in everyday practice. Though definition may vary, truth and deception represent a continuum of approaches including truth, variations of truth, acts of deception and verbal deceptions like lies. It appears that carers struggle to withhold the truth in dementia care and attempt to use what they deem to be variations of truth, like distraction, rather than deceptions, like lies, which conflict most with their professional and moral ethics. Generally, there is a consensus that the chosen strategy should adopt a consequentialist perspective and be in the best interests of the person with dementia, for example, carers commonly reported using



strategies to reduce distressing BPSD. However, despite good intentions a number of carers reported feeling guilty about the impact of their actions and vulnerable to judgment or blame, perhaps due to a lack of open communication about truth or deception in practice. The need to support carers with decisions about using truth and deception has been recognised; carers need opportunities to talk about strategies and receive support when they experience difficulties. Improving communication about truth and deceptive strategies could address the ongoing taboo in this area and offer carers alternative strategies should their existing approaches become less effective.

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## **Appendix**

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### Appendix one: Quality appraisal tool (non-validated measure)

| CASP question (qualitative appraisal concepts)                              | <i>CASP Prompts</i>  | <b>Downs and Black</b> (additional quantitative research concepts where appropriate)   |
|---|--|--|
| 1. Was there a clear statement of the aims of the research?                 | <p><i>What was the goal of the research?</i></p> <p><i>Why it was thought important?</i></p> <p><i>Its relevance</i></p>   | <p><i>Are the main outcomes to be measured clearly described?</i></p>  |
| 2. Is methodology appropriate?  | <p><i>Is methodology appropriate to address research goal?</i></p> <p><i>Is this discussed or justified?</i></p>   | <p><i>No additional questions.</i></p>   |
| 3. Was the research design appropriate to address the aims of the research? | <p><i>Has the design has been justified or decision-making discussed?</i></p>  | <p><i>Are measures reported as valid and reliable?</i></p> <p><i>Are confounders considered and defined?</i></p> <p><i>Is there significant power?</i></p> <p><i>If applicable, for questionnaires are example questions provided?</i></p> <p><i>Was the questionnaire adequately piloted in terms of the method and means of administration, on people who were representative of the study population?</i></p> <p><i>Was the questionnaire adequately piloted in terms of the method and means of administration, on people who were representative of the study population?</i></p> |
| 4. Was the recruitment strategy appropriate to the aims of the research?    | <p><i>Has the researcher explained how participants were selected?</i></p> <p><i>Has the researcher explained why the participants were chosen?</i></p> <p><i>Is there discussion around recruitment and drop out if relevant?</i></p> <p><i>If applicable, has the researcher has discussed theoretical sampling?</i></p> | <p><i>Is the sample random or representative?</i></p> <p><i>Was the sampling frame for the definitive study sufficiently large?</i></p>  |



|  |   |   |
|--|---|---|
| <p>5. Was data collected in way that addressed the research issue?</p>                         | <p><i>Is the setting for data collection justified?</i></p> <p><i>Is it clear how data was collected?</i></p> <p><i>Has the researcher justified methods chosen?</i></p> <p><i>Has the researcher made the methods explicit?</i></p> <p><i>Is the form of data is clear? (e.g. tape recordings, video material, notes etc)</i></p> <p><b>If applicable,</b></p> <p><i>has the researcher has discussed saturation of data?</i></p>                                    | <p><i>Are interventions clearly described?</i></p> <p><i>Questionnaires - Was the method of distribution and administration reported?</i></p> <p><i>Were response rates reported, including details of participants who were unsuitable for the research or refused to take part?</i></p> <p><b>If applicable,</b> were <input type="checkbox"/> participants randomly allocated to groups?</p> |
| <p>6. Has the relationship between researcher and participants been adequately considered?</p> | <p><i>Has the researcher critically examined their own role, potential bias or influence?</i></p>   | <p><i>Does the researcher discuss objectivity – how they may have confirmed results with others?</i></p> <p><i>Role within research design?</i></p>   |
| <p>7. Have ethical issues been taken into consideration?</p>                                   | <p><i>Are there sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained?</i></p> <p><i>Has the researcher discussed issues raised by the study e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study?</i></p> <p><i>Has approval has been sought from the ethics committee?</i></p> | <p><i>No additional questions.</i></p>  |
| <p>8. Was the data analysis sufficiently rigorous?</p>   | <p><i>Is there an in-depth description of the analysis process?</i></p> <p><b>If appropriate,</b> is it clear how categories/themes were derived from the data?</p>   | <p><i>Were appropriate statistical tests used?</i></p> <p><i>Were parametric or none parametric tests used?</i></p> <p><i>If appropriate, was loss of participants / missing data</i></p>   |

|   |  |   |
|---|--|---|
|   | <p><b><i>If applicable,</i></b></p> <p><i>has the researcher has discussed saturation of data?</i></p> <p><i>Does the researcher explain how data presented was selected from the original sample to demonstrate the analysis process?</i></p> <p><i>Is sufficient data presented to support the findings?</i></p> <p><i>To what extent contradictory data are taken into account?</i></p>   | <p><i>considered?</i></p>   |
| <p>9. Is there a clear statement of findings?</p> | <p><i>Are the findings are explicit?</i></p> <p><i>Is there is adequate discussion of the evidence both for and against the researchers arguments?</i></p> <p><i>Does the researcher discuss the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)?</i></p> <p><i>Are the findings discussed in relation to the original research question?</i></p>                                     | <p><i>Are quantitative results definitive (significant), and are relevant non-significant results also reported?</i></p> <p><i>Have probability values been reported?</i></p> <p><i>Have claims for validity been made, and are they justified? (Is there evidence that the instrument measures what it sets out to measure?)</i></p> <p><i>Have claims for reliability been made, and are they justified? (Is there evidence that the questionnaire provides stable responses over time and between researchers?)</i></p> <p><i>Does the study estimate distribution of the data? If not provided assumed estimates appropriate.</i></p> |
| <p>10. How valuable is the research?</p>          | <p><i>Does the researcher discuss the contribution the study makes to existing knowledge or understanding e.g. do they consider the findings in relation to current practice, policy or relevant research-based literature?</i></p> <p><i>Does the researcher identify new areas where research is necessary?</i></p> <p><i>Does the researcher discuss whether or how the findings can be transferred to other populations or</i></p> | <p><i>No additional questions.</i></p>  |

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|  | <i>considered other ways the research may be used?</i> |  |
|--|--|--|

## Appendix two: Summary of final studies

| Authors - reference                        | Title  | Participant sample  | Methodology & Statistical Analysis   | Main Findings   | Appraisal   |  |
|--|--|---|--|---|---|--|
|  |  |   |  |   | Strengths   | Limitations  |
| Blum (1994)                                | Deceptive practices in Managing a Family Member with Alzheimer's Disease   | 34 family carers from carers support group.   | <p>Part of a larger scale study.</p> <p><b>Four-year observation</b> of carers support group.</p> <p><b>In-depth interviews</b> with group members, group leader and office staff. 34 family carer interviews plus follow up totals 54 interviews.</p> <p>Interviews and groups tape-recorded.</p> <p><b>Analysis</b> - Grounded theory methodology (Glaser and Strauss 1967).</p>     | <p>For family carers deception becomes more routine and contextualised.</p> <p>For family carers deception is utilised for social control over information control.</p> <p>Diminishing capacity in people with dementia enables carers to use more extreme forms of deception.</p> <p>Carers struggle with dilemmas about having to violate relationships based on intimacy and trust with deception and experience a sense of betrayal.</p> <p>The intention of deception is not malevolent; carers use deception as a necessity to cope and typically believe it is in everyone's best interests.</p> | <ol style="list-style-type: none"> <li>1) Clear outline of aims</li> <li>2) Strong body of supportive literature presented</li> <li>3) Detail about participant characteristics</li> <li>4) Focus on family carers which have been underrepresented in research</li> <li>5) Use of embedded quotes to support findings</li> </ol> | <ol style="list-style-type: none"> <li>1) No examination of researchers role and influence</li> <li>2) No discussion about ethical processes or issues</li> <li>3) Omitted justification for methodology and procedures</li> <li>4) Insufficient detail or justification about sampling methods, recruitment and study procedures.</li> <li>5) No indication of research value or recommendations for replication.</li> <li>6) No discussion of limitations or discussion to support credibility / dependability.</li> </ol> |
| Hertogh, Mei The, Miesen & Eefsting (2004) | Truth telling and truthfulness in the care for patients with advanced dementia: an ethnographic study in Dutch nursing homes | <p>Two nursing homes (staff)</p> <p>Researcher one – 5 units; 80 patients, 2 doctors, 2 psychologists and 43 nurses.</p> <p>Researcher two – 4 units; 55 patients, 2 doctors, 2 psychologists and</p> | <p>Qualitative design – ethnographical field study.</p> <p>Two researchers observed in two nursing homes, which homed residents with dementia, which had differing levels of training.</p> <p>Data included observations, group discussions, formal interviews.</p> <p>Analysis (not explicitly stated) of themes similar to grounded theory / influences by Glaser and Strauss to</p> | <ol style="list-style-type: none"> <li>1) Staff believed that patients had a right to know the truth but struggled to uphold this in practice.</li> <li>2) Significant social events <b>were never</b> kept from patients e.g. weddings or deaths.</li> <li>3) Distraction by transformation of questions into other questions, which the nurses could answer, inviting the person to engage in an activity or drawing attention, was often used. Preferred</li> </ol>  | <ol style="list-style-type: none"> <li>1) Clear statement of aims and research question</li> <li>2) Descriptions of nursing home characteristics provided</li> <li>3) Methods and design justified.</li> <li>4) Clear efforts to ensure validity of findings using multiple data collection methods and triangulation</li> </ol>  | <ol style="list-style-type: none"> <li>1) Explicit analysis method not stated, but described in comparison to grounded theory.</li> <li>2) Limited information about sampling or recruitment</li> </ol>  |

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|--|--|--|--|---|---|--|
|  |  | 35 nurses)   | analysis data.   | <p>because the nurses didn't feel dishonest.</p> <p>4) Nurses were perplexed about what to do when patients were not 'far gone enough' as using truth or distraction was less straightforward.</p> <p>5) Nurses used concealment to encourage patients to take medication but had to try to be open about this i.e. not trying to 'trick' someone and only in best interests.</p> <p>6) Disagreement around deceptive acts, like giving patients money to hold; some agreed with giving subjective support others said this was 'taking advantage; to solve a problem.</p> <p>7) Staff wanted doctor/psychologist to make ultimate decisions.</p> | <p>5) Ethical principles considered</p> <p>6) Explicit reference to reflexivity through use of reflective diary.</p> <p>7) Findings supporting with embedded quotes.</p> <p>8) Discussion refers to relevant literature.</p> <p>9) Recommendations about transferability to other settings</p> <p>9) Acceptance of study limitations in regards to sample size and impact on overall validity.</p>  |  |
| James, Wood-Mitchell, Waterworth, Mackenzie & Cunningham(2006) | Lying to people with dementia: developing ethical guidelines for care settings | <p>112 staff working in elderly care settings</p> <p>4 occupational therapists, 6 doctors, 10 social workers, 31 unqualified staff and 61 nurses (112 total)</p> | <p><b>Exploratory survey</b> – questionnaire about lying care care settings, eliciting qualitative and quantitative responses, sent to staff working in residential homes, specialist units and hospital wards.</p> <p><b>Analysis (unclear)</b> – involved collation of quantitative responses to provide numerical feedback, and themes across qualitative feedback.</p> | <p>1) Lying is pervasive across all types of settings.</p> <p>2) Lying used to reduce distress, ease carer distress and promote compliance.</p> <p>3) Lies used to benefit staff less frequently used.</p> <p>4) Most participants saw problems associated with using lies including increasing confusion, issues with consistency, patient mistrust, and tension with family members.</p>  | <p>1) Clear statement of aims, to build on pilot work</p> <p>2) Recruitment of a large sample</p> <p>3) Participant professional characteristics shared</p> <p>4) Clear summary of findings</p> <p>5) Draft guidelines for use of lies suggested</p> <p>6) Researcher open about limitations, for example, social desirability effects.</p> <p>7) Clear about the need to expand research area.</p> | <p>1) Limited detail about methods, design, recruitment and analysis procedures however this was a research letter</p> <p>2) Ethical issues not fully considered</p> <p>3) Researchers role, or discussion of objectivity, not discussed</p> <p>4) No reference to power or sufficient sample size</p> <p>5) No explicit recommendations for replicability.</p> <p><b>*Note: research letter therefore extensive detail not necessarily expected</b></p> |

|                              |   |  |  |   |  |   |
|------------------------------|---|--|--|---|--|---|
| Tuckett (2006)               | Registered nurses' understanding of truth-telling as practiced in the nursing home: An Australian perspective | 5 nursing homes, all of which have a unit for dementia care<br><br>19 residents, 23 personal carers, 25 nurses (67 total)  | Findings derived from a larger scale study.<br><br><b>Data</b> collected through group discussions, personal journals, in-depth interviews, authors field notes.<br><br><b>Thematic analysis</b> partially using grounded theory practices.  | 1) Distinction between telling a full truth, partial, edited or tempered truth, to avoid harm.<br><br>2) Using edited truth eases burden of having to tell the truth, even if this titrates full truth.<br><br>3) Parts of the truth were omitted to protect family; important for staff to get to know and gauge family.<br><br>4) Staff justified actions; what is not said does not include untruths nor is the intention to convey false information.<br><br>5) Information judged easy to omit if it did not impact on care plan – “need to know” e.g. challenging behaviour   | 1) Clear statement of aims and research objectives<br><br>2) Multiple data collection methods listed.<br><br>3) Descriptions of rigour to support credibility; including negative case analysis, triangulation and member checking.<br><br>4) Guided by ethical principles.<br><br>5) Findings clearly summarised and supported by embedded quotes<br><br>6) Findings illustrate negative case analysis.<br><br>7) Attempts to advise nursing practice by advising staff to seek information about patient and family preferences about truth/deception. | 1) Nursing homes all include dementia units but resident characteristics unclear.<br><br>2) Limited detail or justification into method, design or procedures.<br><br>3) Setting described but sampling information limited.<br><br>4) Analysis methods specified but not justified.<br><br>5) Alluded to reflexivity, using field notes, but not explicit.<br><br>6) No discussion of dependability, limitations or recommendations about transferability. |
| Elvish, James & Milne (2010) | Lying in dementia care: An example of a culture that deceives in peoples best interests                       | <b>Phase 1:</b> 195 staff<br><br>32% psychologists, 19% nurses, 12% care workers, 9% social workers, 38% voluntary sector.<br><br><b>Phase 2:</b> 34 conference delegates (staff)<br><br>85% psychologists, 6% nurses, 9% other professionals from care settings | Classical test construction to develop questionnaire to measure attitudes to lying in dementia.<br><br><b>Phase 1:</b> 44 care home staff piloted 25-item questionnaire. Revised 16-item questionnaire given to 151 staff recruited through events and workshops between 2007-2008.<br><br><b>Phase 2:</b> Quasi-experimental, pre/post workshop design using 6 measures of change to assess if attitudes to lying were changed: 1) questionnaire including two ad hoc questions, 2) learning vignette 3) video clips, 4) hearing research 5) general discussion and 6) reflection. Participants given feedback form to rate above aspects of workshop using Likert acceptance scale and | <b>Phase 1 - Questionnaire construction:</b> All correlations above 0.5 and Cronbach alpha 0.94 suggesting good internal consistency. Factor analysis (varimax rotation) revealed two factors: themes related to person with dementia and themes related to participant's ethical stance on lies.<br><br>Item with most support suggests that lies most acceptable when people might injure themselves ( $x=3.52$ ). Least endorsed item suggested staff should be trained to lie effectively ( $x=2.49$ ).<br><br><b>Phase 2 – pre/post analysis:</b> using paired sample t-test. Significant change in scores and medium effect size – suggesting participants more accepting to use of lies. Additional measures showed participants admit to using lies | 1) Clear aims and justification for research design<br><br>2) Method and design are clearly explained, justified and limitations discussed, for example, participants who may have seen the video clips.<br><br>3) Validity of ALPD, additional measures and ANOVA shared.<br><br>4) Themes from qualitative evidence shared.<br><br>5) Findings discussed in relation to each phase and statistical test results provided including none significant results.   | 1) Recruitment context shared but sampling strategies less clear<br><br>2) Sample not entirely representative of dementia care but discussed by authors<br><br>3) Ethical considerations for research not explicitly discussed.   |

|                                |  |   |   |   |   |  |
|--------------------------------|--|---|---|---|---|--|
|                                |  |   | make qualitative comments.  | and finding them more acceptable. Six themes identified from qualitative comments consistent with this change. ANOVA using feedback form data suggests no one part of workshop made participants more/less accepting.   | <p>6) Discussion links findings to research, discusses limitations and makes recommendations for future research.</p> <p>7) Table of ALPD items alongside correlations, factor loadings and participant allocated ranks provided, which illustrates the ALPD well.</p> <p>8) Consider how the ALPD could be adapted for use across culture (generalizability).</p> <p>9) Reflection shared on impact of researchers influence on study findings.</p> <p>10) Recognise limited sample size</p> <p>11) Multiple methods of change adopted to increase validity of findings.</p> |  |
| Day, James, Meyer & Lee (2011) | Do people with dementia find lies and deception in dementia care acceptable? | 14 people with dementia recruited via older adults services | <p><b>Discussion group:</b> with 4 participants to develop interview schedule and vignettes.</p> <p><b>Phase 1:</b> One-to-one interviews with 10 new participants with vignettes to facilitate discussion.</p> <p><b>Phase 2:</b> Re-visit 10 participants to refine theory.</p> <p><b>Analysis:</b> Constructionist Grounded Theory methods (Charmaz) to develop themes, theory and accompanying process diagram.</p> | <p>1) The acceptability of lies varies according to whether it is in the person's best interests.</p> <p>2) Best interests decided by three categories: the person lied to, the person lying and the type of lie told.</p> <p>3) Lies were deemed less acceptable if the person was aware they were being lied to.</p> <p>4) Participants were concerned about the impact of lies on personal relationships and morals.</p> <p>5) Lies told in a more individualised and respectful manner were more acceptable.</p> <p>6) Lies more acceptable if no other</p> | <p>1) Clear aims presented in relation to existing research</p> <p>2) Justified decisions to use constructivist grounded methods</p> <p>3) Explicit details about design, recruitment procedures and sampling</p> <p>4) Participant demographics presented in table form</p> <p>5) Clear ethical considerations around design and process</p> <p>6) Analysis procedures outlines</p> <p>7) Clear findings supported by process diagram, embedded quotes,</p>  | <p>1) Unclear how the researcher considered their own role or influence.</p> <p>2) Participants awareness of diagnosis fluctuated, may have impacted on self-report.</p> |

|                |   |  |  |  |  |   |
|----------------|---|--|--|--|--|---|
|                |   |  |  | <p>alternatives/strategies work.</p> <p>7) White lies more acceptable than blatant lies, as blatant lies could cause more distress if discovered e.g. death of relative.</p> <p>8) The way a person defines lies influences how acceptable they may find them.</p>   | <p>existing research and contradictory research</p> <p>8) Discussion of limitations that impact credibility – impact of capacity.</p> <p>8) Research value discussed in relation to existing research and clinical implications i.e. advanced directives or guidelines.</p> <p>9) Considers unique perspective – people with dementia</p> <p>10) Clear research example of grounded theory according to Charmaz method.</p>  |   |
| Tuckett (2012) | The experience of lying in dementia care: A qualitative study | <p>5 nursing homes, all of which have a unit for dementia care</p> <p>19 residents, 23 personal carers, 15 nurses (57 total)</p> | <p>Findings derived from a larger scale study.</p> <p><b>Data</b> collected through group discussions, personal journals, in-depth interviews, authors field notes.</p> <p><b>Thematic analysis</b> partially using grounded theory practices.</p> | <p>1) Context nurses working in is generally one where residents do not have awareness or understand.</p> <p>2) Carer meaning of dementia is important to predict how they interact.</p> <p>3) Staff use consequentialism to justify their actions i.e. it settles residents.</p> <p>4) Confirming resident's reality, validation, was not seen as lying, as the aim is to accept and settle, not to deceive.</p> <p>5) Different seen between "out and out lying" and "coloured, calming, beneficent strategies.</p> <p>6) Moral distress amongst staff – where lies are used inconsistency, where there is disagreement with family, and because lying feels like a betrayal.</p> <p>7) Some staff felt memory problems should be prompted with the truth (not</p> | <p>1) Clear statement of aims and research objectives</p> <p>2) Clear description of sampling, using purposive sampling, alongside justification and sample characteristics table.</p> <p>3) Multiple data collection methods to improve credibility.</p> <p>4) Clear description of data collection including saturation as a result of constant comparison.</p> <p>5) Clear overview of analysis i.e. how themes were developed.</p> <p>6) Descriptions of procedures to ensure rigour including negative case analysis, triangulation and member checking.</p> <p>7) Guided by ethical principles including consent and</p> | <p>1) Limited justification for methodology and design.</p> <p>2) No explicit summary of findings, despite mention of field notes.</p> <p>3) No reflection on study limitations</p> |



|                                     |   |                                   |   |  |  |  |
|-------------------------------------|---|-----------------------------------|---|--|--|--|
|                                     |   |                                   |   | diagnosis specific)<br><br>8) Some extreme opposition where lies are seen as a form of abuse.  | confidentiality.<br><br>8) Clear findings supported by embedded quotes and relevant research<br><br>8) Presents four-stage communication strategy that includes truth and lies.<br><br>9) Offers direction for future research.  |  |
| Tullo, Lee, Robinson & Allen (2015) | Why is dementia different? Medical students' view about deceiving people with dementia. | 31 medical students               | <b>Qualitative design</b> within medical school context.<br><br><b>Focus groups</b> – 21 students<br><br><b>Interviews</b> – 10 students<br><br><b>Analysis</b> – shared between the research team using principles of constant comparison. | 1) Minority thought that dementia should not make a difference to ethical reasoning processes around truth and deception.<br><br>2) Majority believed that additional considerations were necessary for dementia.<br><br>3) Specific considerations to capacity, perceived vulnerability and family dynamics.<br><br>4) Ethical concerns aligned with Sokol's model despite additional concerns about complexity of decision making in dementia. | 1) Clear statement of aims with study objectives<br><br>2) Discussion of reasons for drop out<br><br>3) Clear data collection processes<br><br>4) Clear overview of analysis steps<br><br>5) Ethical principles followed clearly through design, recruitment and analysis.<br><br>6) Findings explore contrast and are supported by embedded quotes.<br><br>7) Discussion links to existing research, and provides implications and recommendations for further research.<br><br>7) Credibility discussed within limitations e.g. student sample<br><br>8) Considers medical students as alternative professional perspective. | 1) Qualitative methods and design are appropriate but not explicitly justified<br><br>2) Recruitment methods and setting outlined but sampling strategy not explicit<br><br>3) Limited evidence about how the research considered their own role and influence |
| Turner, Eccles, Keady, Simpson &    | The use of the truth and deception in dementia care                                     | 12 staff members recruited from 8 | <b>Semi-structured interviews</b> with staff with direct experience of  | 1) Staff described three triggers; difficult questions, attempts to manage behaviour that challenged including personal care   | 1) Clear aims<br><br>2) Explicit discussion and  | 1) Limited evidence about how the research considered their  |

|               |                                |   |   |  |   |  |
|---------------|--------------------------------|---|---|--|---|--|
| Elvish (2016) | amongst general hospital staff | inpatient wards<br><br>1 nurse, 1 student nurse, 3 support workers, 2 housekeeping staff, 1 ward clerk, 1 ward manager, 1 ward sister, 1 physiotherapist, 1 doctor (12 total) | dementia care.<br><br><b>Theoretical sampling:</b> 6 interviews initially followed by 6 additional interviews to develop theory and reach saturation.<br><br><b>Grounded theory</b> analysis methods (Charmaz) used to develop themes, theory and accompanying process diagram. | and sharing medication information.<br><br>2) Staff identified three factors that mediated their response; poor communication alongside lack of guidance, staff role/responsibility alongside knowing the patient and reference to ethical frameworks (personal or professional).<br><br>3) Staff suggested all responses should be in the patient's best interests.<br><br>4) Staff depended on four types of deceptive response; telling the truth, passing the buck, distracting and lying.<br><br>5) Staff would adapt their usual response by being more likely to use the truth if family were observing, or focusing on any way to calm patients down who were particularly distressed.<br><br>6) General lack of clarity amongst staff who would prefer not to use the truth or use a lie' distraction was most preferred. | justification throughout study of chosen grounded theory method, design, sampling strategy, data collection and analysis.<br><br>3) Analysis description is in-depth and it is clear how themes developed.<br><br>4) Findings clearly structured alongside process diagram, detailed narrative, supporting quotes, opposing arguments and relevant literature.<br><br>5) Clear links to existing research alongside clinical implications and future directions.<br><br>6) Acknowledges limitations and makes recommendations for replicability.<br><br>6) Clear research example of grounded theory according to Charmaz method.<br><br>7) Unique insight into ward environment. | own role and influence<br><br>2) Limited evidence about how the researcher ensured ethical standards and procedures. |
|---------------|--------------------------------|---|---|--|---|--|

### Appendix three: Traffic light quality ratings for studies (none validated measure of quality)

**Green** = Fully    **Yellow** = Partially    **Red** = Unclear or no    **\*Grey** = Indicates mixed methodology study

|   | Blum (1994)               | Turner, Eccles, Keady, Simpson & Elviah (2016) | James, Wood-Mitchell, Waterworth, Mackenzie and Cunningham (2006)* | Day, James, Meyer & Lee (2011) | Tuckett (2006)             | Tuckett (2012)             | Hertogh, Mei The, Miesen & Eefsting (2004) | Elvish, James & Milne (2010)* | Tullo, Lee, Robinson & Allen (2015) |
|---|---------------------------|--|--|--------------------------------|----------------------------|----------------------------|--|-------------------------------|-------------------------------------|
| Clear statement of aims                 | 2 points                  | 2 points                                       | 2 points   | 2 points                       | 2 points                   | 2 points                   | 2 points                                   | 2 points                      | 2 points                            |
| Methodology appropriate?                | 1 point                   | 2 points                                       | 1 point  | 2 points                       | 1 point                    | 1 point                    | 2 points                                   | 2 points                      | 1 point                             |
| Research design appropriate?            | 1 point                   | 2 points                                       | 1 point  | 2 points                       | 1 point                    | 1 point                    | 2 points                                   | 2 points                      | 2 points                            |
| Recruitment strategy appropriate?       | 1 point                   | 2 points                                       | 1 point  | 2 points                       | 1 point?                   | 2 points                   | 0 points                                   | 1 points                      | 2 points                            |
| Data collection address research issue? | 1 point                   | 2 points                                       | 1 point  | 2 points                       | 2 points                   | 2 points                   | 2 points                                   | 2 points                      | 2 points                            |
| Examination of researchers role?        | 0 points                  | 1 point  | 0 points   | 0 points                       | 1 point                    | 1 point                    | 2 points                                   | 1 points                      | 0 points                            |
| Consideration of ethical issues?        | 0 points                  | 1 point  | 0 points   | 2 points                       | 2 points                   | 2 points                   | 2 points                                   | 0 points                      | 2 points                            |
| Rigorous data analysis?                 | 1 point                   | 2 points                                       | 0 points   | 2 points                       | 2 points                   | 2 points                   | 2 points                                   | 2 points                      | 2 points                            |
| Clear statement of findings?            | 1 point                   | 2 points                                       | 2 points   | 2 points                       | 1 point                    | 1 point                    | 2 points                                   | 2 points                      | 2 points                            |
| Research value discussed?               | 1 point                   | 2 points                                       | 1 point  | 2 points                       | 1 point                    | 2 points                   | 2 points                                   | 2 points                      | 2 points                            |
| <b>Total quality rating</b>             | 9/20 points<br><b>45%</b> | 18/20 points<br><b>90%</b>                     | 9/20 points<br><b>45%</b>  | 18/20 points<br><b>90%</b>     | 14/20 points<br><b>70%</b> | 16/20 points<br><b>80%</b> | 18/20 points<br><b>90%</b>                 | 16/20 points<br><b>80%</b>    | 17/20 points<br><b>85%</b>          |

## Appendix four: Sample of author guidelines from Qualitative Health Research

### WRITING TO PUBLISH IN *QHR*

Proper formatting will speed the peer-review process for your manuscript and will facilitate a smoother production process if it should be selected for publication. Refer to the guidelines below, and to the *Publication Manual of the American Psychological Association*, [APA] 5th edition. Improper formatting could result in burdensome revisions, lengthy delays in the review and production processes, and *the possible rejection of your manuscript*.

### ELEMENTS OF A MANUSCRIPT

The following elements are **required** for each manuscript, and should be compiled in the following order:

1. Title page
2. Abstract
3. Keywords
4. Main body of the manuscript ([main document"; beginning on p. 2]
5. References

The following elements **may** be included in your submission (they are *optional*):

- A. Notes/footnotes/endnotes [place after the main body of the text, before the reference list]
- B. Tables [place at the very end of the document]
- C. Figures [submit in a separate document]
- D. Appendices are published *only in certain circumstances*, at the editor's discretion [place after the reference list and before any tables]

### ORDER OF ELEMENTS

Compile the elements of your main manuscript document in the following order. Each element (except notes) should begin on a new page:

- A. Abstract and keywords - required
- B. Main manuscript text - required
- C. Notes/footnotes (if any)
- D. References - required
- E. Appendices (if any)
- F. Tables (if any)

### DOCUMENT SETUP (See also Sample Manuscript)

- Document file type: Submit only documents created in Microsoft Word, and only with the regular file extension of ".doc"; Word documents with ".docx" extensions, PDF files, or other types of documents cannot be accepted for consideration. *Do not add any special coding or formatting to your documents that is not described within these guidelines.*

- Margins: 1” on all sides \*\*\*\*\*
- Ellipses/Ellipsis Points: Almost every manuscript contains ellipses. They are used to indicate missing words in quotations, and are to be created in a very specific manner. *Do not* use the “Insert Symbol” function in Word to enter ellipses. The proper way to create ellipsis points is as follows: space/dot/space/dot/space/dot/space ( . . . ); that is, 3 dots, preceded, divided, and followed by spaces, like . . . this. If it is necessary to indicate missing words between sentences (instead of in mid-sentence), place a period (full stop) at the end of the first sentence, then format the ellipsis points as noted, and begin the next sentence (with a capital letter) immediately after the last space. Do not place ellipses within parentheses or brackets ( . . . ); the exception to this is in conversation analysis, when appropriate.
- Font Size: 11 point font, including font used for titles, regular text, section headings, and quotations; however, fonts between 8 and 10 points in size should be used in tables and figures
- Font Style, Main Manuscript: Use Times New Roman font. *Italics* should be used *only* (a) as appropriate in the reference list (see *APA*), or (b) to introduce new or non-English words, or new concepts (2 to 3 words), and then only when the new word or concept is first introduced in the manuscript; subsequent use of the same word(s) should be in regular Roman font. *QHR* does *not* use italics for emphasis, and does not use underlining for any purpose other than conversation analysis (conversation analysis does not refer to regular participant quotations). Bolded font may be used for section headings, as appropriate according to these guidelines, and (sparingly) in tables and figures.
- Font Style, Figures: For printing clarity and ease of reading, “sans serif” fonts are strongly recommended for figures; some common examples include Arial (this is the preferred style), Calibri, Franklin Gothic Book, Tahoma, and Verdana. It is recommended that only one font style be used in each figure, with possible variations introduced through bolding, italicizing, capitalizing, or underlining—all of which should be used *sparingly*. It is further recommended that all figures within a single manuscript be prepared with the same font style.
- Line Spacing: **Everything**, in all elements of the manuscript, from the title page through the references, must be (exactly) double-spaced. The only exception is text within a figure. To set double spacing, go to Format > Paragraph > Line spacing > Double. *Do not create double spacing with hard returns* (by striking the “enter” key twice).
- Text Justification: All text should be left-justified; *do not use full justification* for any portion of your manuscript. The text at the right margin *should be uneven*.
- Paragraphs: Indent the first line of every new paragraph by .5” (1/2 inch; do not use two, .25” indentations). Do not insert additional line spaces between paragraphs, or between paragraphs and headings; *the exceptions are (a) an extra line space (hard return) between the abstract and the keywords, and (b) after (not before) each excerpt/block quotation, numbered or bulleted list, or section of conversation analysis*. Use a blank line between block quotes/excerpts if you have placed two or more in a row. *Do not add any special*

formatting, such as increased line space before and after paragraphs, or before and after headings.

- **Headings:** *Do not follow APA guidelines for headings. QHR uses 4 distinct levels of headings (H = level), including:* **H1: Centered, Bold, Uppercase and Lowercase Text in Title Case** **H2: Flush Left, Bold, Uppercase and Lowercase Text in Title Case** **H3: Indented (.5”), Italicized, Uppercase and Lowercase Text in Title Case** **H4: Indented (.5”), italicized, lowercase text in sentence case and ending with a period.** At this level, the paragraph text begins immediately after the heading, instead of on the next line. Use at least two heading levels: For manuscripts with 2 heading levels, use H1 and H2 For manuscripts with 3 heading levels, use H1, H2, and **H4** For manuscripts with 4 heading levels, use H1, H2, H3, and H4

- **Quotation Marks:** In general, use double quotation marks (e.g., “Xxxx.”) to set off quotations appearing within regular paragraphs, and to set off words being used with “special” meaning (or unusual spelling to convey special meanings within the text; e.g., “busy-ness”). In regular paragraphs, use single quotation marks to set off a quote within a quote (e.g., “Xxx, ‘Yyy,’ xxxx.”). Do not use any quotation marks for block quotes *unless* there is a separate quote contained within the larger quote. In such a case, use double quotation marks (e.g., Xxxxxx, “Yyyy,” xxxxx.) only for the separate quote within the larger quote.

- **Spelling:** The spelling of English words varies among the many English-speaking countries of the world. *QHR* is published in *U.S. English*. Use Word’s spell check feature to ensure that you have used U.S. English spellings throughout your manuscript. Exceptions to this include (a) direct quotes from *written*, published material, and (b) as appropriate for titles in the reference list.

- **Manuscript Length:** There is no predetermined page or word limit. Provided they are “tight” and concise, without unnecessary repetition and/or irrelevant data, manuscripts should be as long as they need to be. The editor may require a reduction in length if the manuscript contains superfluous material that does not add anything useful to the topic being discussed. Limits might be imposed on the number/size/length of tables, figures, reference lists, and appendices.

Paper Two: Empirical Paper

**Truth and deception in dementia: a qualitative study of carer  
decision-making in the home environment**

Melissa Di Franco

Doctorate in Clinical Psychology

Faculty of Health Sciences, Staffordshire University

**Target Journal:** Qualitative Health Research

**Word count:** 7996

### **Preface**

#### *Introduction to the researcher's epistemological position*

The researcher's affiliation to a particular research paradigm will reflect their perspectives on ontology and their epistemological position, namely, what is knowledge and how does one access it (Guba, 1990). These concepts are important to discuss, as they suggest how the researcher will see themselves in relation to knowledge, an openness that supports the reader to make judgment about the credibility of the research. The researcher holds a constructivist approach to research, which proposes that there is no single reality or truth; therefore, research provides an *interpretation* of people's perceived reality, which they construct through their individual interactions with the world (Charmaz, 2006). Grounded theory, which is the chosen methodology within the following study, lends to a constructivist approach because methods seek to interpret individual social interactions and develop a theory that is grounded in individual experience (Carson, Gilmore, Perry & Gronhaugl, 2001). Grounded theory allows researchers to gain knowledge of specific social realities that are time and context bound; this study explores current decision-making processes of informal dementia carers, within a selected geographical location (Hudson & Ozanne, 1988). The aim of grounded theory is to understand and interpret meaning within subjective social experiences,



rather than to generalise and predict causes and effects of behaviour (Neuman, 2000).

### *A note on terminology*

This paper will refer to strategies that adhere to truth, which is universally defined as ‘that which is true or in accordance with fact or reality’ (Oxford Dictionary, 2017), and deception, which is universally defined as ‘deliberately causing a person to believe something that is not true’ (Oxford Dictionary, 2017). Though these are commonly accepted definitions within everyday life, this paper will explore how the definitions for these terms are less explicit within the realms of dementia care.

### **Abstract**

**Objectives:** A growing body of research explores the use of truth and deception within everyday communications in dementia care. Although there is no clear consensus about their use, research describes how both professional and informal carers (family or friends of people with dementia) use these strategies, though less is known about informal carers. This study aimed to gain a greater understanding of how informal carers make decisions about using truth or deception within everyday communication.

**Method:** This is a qualitative study, drawing on constructivist Grounded Theory methodology (Charmaz, 2006). Data was obtained from nine semi-structured interviews with informal carers of people with dementia. A model, grounded in carer experiences, was developed to represent carer decision-making processes.

**Results:** The study presents a model of in the moment decision-making by informal carers of people with dementia, about the use of truth and deception within everyday communication. The model connects key categories involved in decision-making; ‘pre-existing variables’, ‘triggers’, ‘motivations’ and ‘conditional judgments’. The core concept was that decisions were ultimately made in the moment. Carers decided upon an interaction, represented as a continuum of strategies from truth to blatant deception, and outcomes influenced future decision-making.

Conclusion: This study adds to research regarding the use of truth and deception in dementia care by proposing a theory of in the moment decision-making for informal carers. The findings implicate how services might support carers' decision-making about truth and deception or learn from their practices, alongside discussion about limitations and future research.

Key words: Dementia, carer, decision-making, truth, deception

## **Introduction**

### *Dementia*

Dementia is an umbrella term, which describes several progressive and largely irreversible conditions that are commonly identified by impairments in cognitive function and 'out-of-character behaviour', for example, memory loss, disorientation and personality changes (National Institute for Health and Care Excellence or NICE, 2006, p.5). An estimated 850,000 people have dementia in the UK and this is predicted to increase to 1,142,677 people by 2025 (Prince et al., 2014). Two-thirds of people with dementia in the UK live in their own homes and the remaining number within care settings, such as care homes (Alzheimer's Society, 2016). Most people with dementia want to stay at home as long as possible and nearly half believe this is possible with the support of family or friends, who become informal carers (Alzheimer's Society, 2014).

### *Informal carers*

An estimated 700,000 people are informal carers for people living with dementia in the UK (Lewis, Karlsberg-Schaffer, Sussex, O'Neill & Cockcroft, 2014). Around a third spend more than 100 hours per week caring for a person with dementia, which puts a strain on their own physical and mental health, and their social and financial opportunities (NHS Digital, 2018). Unfortunately, over half say they have had no support or not enough support and many feel isolated from social support networks (NHS Digital, 2018). Carers need support to manage negative experiences associated with their roles so those who want to continue caring are able to do so (Cowdell, 2008; Ornstein & Gaugler, 2012). Carers should be properly skilled to avoid overburdening (Hattink et al., 2015). They should have access to information, which supports them to make effective decisions about effective strategies (The Carers Trust, 2013).

#### *Economic impact of informal carers*

Dementia creates enormous costs to the UK economy, which are spread across healthcare and social care, however, most costs are compensated by informal carers (Prince et al., 2014). Informal carers save the UK economy an estimated £11 billion each year (Alzheimer's Society, 2014). The Department of Health (DOH) highlight the importance of spending money on ways to improve quality of life for dementia carers, envisaging this will save money and provide a better future for people living with dementia (DOH, 2009).

#### *Challenges in dementia*

Although there are different subtypes of dementia, the most common being Alzheimer's Disease and Vascular Dementia, global impairment of function is expected as dementia is degenerative process. All dementia subtypes present with behavioural and psychological symptoms of dementia or BPSD, that distress people living with dementia and challenge the skills and capacity of people caring for a person with dementia (Zarit & Anthony, 1986; Zanetti, Geroldi, Frisoni, Bianchetti, & Trabucchi, 1999; Hodges, 2007). Behavioural and psychological symptoms

include memory loss, confusion, disorientation, mood changes and problems with communication and reasoning, which progressively increase in frequency and severity (Alzheimer's Disease International, 2013). Dilemmas about how to respond to worsening symptoms of dementia include the use of truth and deception within everyday communication, for example, carers might believe that telling the truth to a person who is increasingly confused and forgetful is futile therefore they might explore other strategies, like deception.

Carers are tasked with providing regular, on-going care for people with increasingly complex and challenging BPSD, often without training (Bender, 2007). Over time people with dementia lose capacity, and carers take on increased decision-making responsibilities. Situations arise that create uncertainties about how to respond and carers have to decide if the person with dementia has capacity to be involved in decision-making or if a decision has to be made in their best interests (Samsi & Manthorpe, 2013). Though research has explored everyday decision-making in dementia care, for example, Livingston et al. (2010) considered everyday decisions by informal carers about accessing help, legal matters, physical health and long-term care decisions, no research has considered decision-making by informal carers about using truth or deception, to manage challenges associated with caring for a person with dementia.

### *Research into truth and deception*

#### *Defining truth and deception*

In dementia care there has been much debate around definitions of truth and deception, and though literature acknowledges both truth and deception are used, professional and informal carers attempt to avoid defining their actions as deception because they inherently 'believe in truth' over deception (Blum, 1994, p.26; Hertogh, The, Miesen & Eefsting, 2004). Blum (1994, p.27) proposed four categories to illustrate strategies used by informal carers who were reluctant to define their actions as deception; 'going along', which is about responding without challenge, 'not telling', which is about withholding information, 'little white lies', which involve an untrue statement, and 'tricks', which involve deceptive acts like hiding keys. Other studies identified similar terms used by professional carers to

define their actions differently to deception, such as passing the buck, distracting, pretending and bending the truth (Hasselkus, 1997; Cunningham, 2005; James, Wood-Mitchell, Waterworth, Mackenzie & Cunningham, 2006; Turner, Eccles, Keady, Simpson & Elvish, 2016).

### *Guidelines*

There are no formal guidelines in healthcare settings for the use of truth and deception, however attempts to propose guidelines recommend that cases be judged individually, and a response chosen that suits the specific situation (James et al., 2006; Culley, Barber, Hope & James, 2013; Alzheimer's Society, 2016b). These attempts suggest decision-making should consider biographical knowledge, underlying need or emotion, level of confusion, what is essential to be honest about and what is in the best interests of the person with dementia, for instance, to avoid distress. Both Wood-Mitchell et al. (2006) and Tuckett (2012) advise truth-telling first, then strategies that avoid confrontation, such as validation and distraction, and deception as a last resort.

### *Informal carers*

Blums' (1994) study illustrated carers' use of truth, as well as deceptions, such as "going along" and "not telling" to control the person's agitation, and "little white lies" and "tricks" to accomplish daily tasks, avoid risk to the person, others or valuables and occasionally to prevent their own exhaustion. Carers increasingly used deception as dementia progressed and truthful strategies became less successful, often in reaction to increased confusion, though having to use deception was a source of guilt. Hughes, Hope, Reader and Rice (2002) interviewed carers who believed consequences could justify deceptions, for example, reducing distress.

### *People with dementia*

Day, James, Meyer and Lee (2011) interviewed people with dementia, who believed deception in the best interests of people with dementia is acceptable, especially during later stages of dementia, when the person is less aware, truth is ineffective, and the carer has limited options. However, they were concerned about how deception could impact on their autonomy, self-worth and relationship with the carer, for example, should deception be discovered and trust lost.

### *Dementia care staff*

Research suggests that professional carers' decision-making about truth and deception is triggered by specific dilemmas, including responding to difficult questions, managing behaviour, personal care and decisions about sharing information (Tullo, Lee, Robinson & Allen, 2015; Turner et al., 2016). A number of studies show that professional carers attempted to differentiate their actions from deception, by emphasising beneficent intentions (James et al., 2006; Turner et al., 2016). Tuckett (2012) aligns such attempts with a consequentialist position, as professional carers believed strategies with the power to reduce negative consequences, for example, upset, were justifiable. Though generally motivated to act in the best interests of people with dementia, professional carers reputedly adopted strategies to reduce their own distress and improve compliance (James et al., 2006). Tuckett (2012) illustrated how professional carers experienced moral upheaval when deciding between truth, and deception, which conflicted with their personal and professional ethics. Professional carers generally believed patients with dementia had a right to know the truth, however struggled to uphold such beliefs in practice when faced with significant challenge and distress (Hertogh et al., 2004). Medical students interviewed by Tullo et al. (2015) predicted that as people with dementia become increasingly confused, truthful strategies become less helpful, as they might worsen confusion or be too confrontational. Elvish, James and Milne (2010) demonstrated that professional attitudes towards deception were modifiable, using the Attitudes to Lying to People with Dementia (ALPD) Questionnaire, following a workshop that encouraged reflection on deception in dementia care.

### *Ethical concerns about deception*

There are concerns that deviations from truth, regardless of complications associated with dementia, are always morally wrong because they disregard a person's right to autonomy and involve a misuse of power (Bakhurst, 1992; Korsgaard, 2012). Such arguments state that deceptive practices place people with dementia at risk of their personhood and dignity being disrespected, for example, lying to a person infantilises them and contests their right to the truth (Kitwood, 1998; Schermer, 2007).

### *Aims of the current study*

Though research acknowledges that informal carers use truth and deception strategies there is limited research detailing their experiences, despite the increasing number of people who are taking on informal caring roles for people with dementia (Mental Health Foundation, 2014). This study aimed to explore the experiences of informal dementia carers to understand more about how they make decisions to use truth or deception within everyday communication with people with dementia in a home environment. This study set out to generate a theory about the processes underlying decision-making, which is grounded in participant experiences (Charmaz, 2006).

### **Method**

This study adopted constructivist Grounded Theory (GT) methodology, based on Charmaz (2006). Traditional realist GT approaches (e.g. Glaser & Strauss, 1967) propose that research embodies objective truths that are testable and verifiable, however Charmaz (2006) suggests research is an interpretation of realities that are constructed through people's interactions with the world. Charmaz defines GT as "systematic, yet flexible guidelines for collecting and analysing qualitative data, to construct theories from the data themselves" (Charmaz, 2006, p.1). Inductive processes within GT allow the researcher to generate theory that is grounded within the data.

GT has methodological strengths in developing theory within an area where no theory exists. Day et al. (2011) and Turner et al. (2016) used GT to develop theory about the use of truth and deception with people with dementia and general hospital staff respectively. This study will propose a theory about family carers' use of truth and deception and capture their unheard experiences (Anderson & Goolishian, 1992). GT methods are best suited to research questions that seek to explore processes underlying human behaviour, for instance, how carers make decisions about using truth and deception, as opposed to methods that seek to describe an

experienced phenomenon, for example, what are carers' experiences of truth and deception (Charmaz, 2006). Developing a theory about carers' use of truth and deception is important because though we know that carers use both strategies, we do not understand what processes underlie their decision-making and we have no framework that might predict carers' decision-making. GT methods allow the researcher to generate a theory to explain differences in decision-making about truth and deception and conceptualise the underlying processes that might predict carers decisions. The researcher will make clinical recommendations based on the named processes, about how services can support carers' decision-making as well as ideas for further research and theory development (Office of Behavioural and Social Science Research, 2018).

### *Design*

Interviews adopted a semi-structured approach, where the role of the researcher was to facilitate a conversation, which encouraged participants to share their individual experiences. Interview methods were chosen to gather rich data, grounded in participant experiences, allowing for detailed descriptions and identification of the processes underlying decision-making (Willig, 2001). The initial interview schedule (Appendix E) was influenced by a study that explored truth and deception with general hospital staff (Turner et al., 2016). The semi-structured design allowed the researcher to adapt the schedule throughout data collection, by adding questions to pursue gaps in the data and areas of interest, which would develop the emerging theory. The researcher gathered descriptive data using a demographic questionnaire (Appendix F) and scores on the Attitudes to Lying to People with Dementia Questionnaire (ALPD) to describe the attitudes represented in the sample (Appendix G), which was adapted with permission from the author (Elvish et al., 2010). The ALPD was originally created to capture the attitudes of professional healthcare staff towards the use of deception in dementia care, therefore any reference to 'staff' on the original questionnaire was changed to 'you' so that the questions applied to family carers. Responses to the APLD were considered as part of the study methodology, where varied attitudes indicated saturation. The APLD was also



included within the findings, where the responses to the questions were recorded and transcribed alongside interview data, in following with GT methodology that states everything learned can serve as data (Glaser, 2002).

### *Participants*

Participants were identified through two National Health Service (NHS) dementia services in the West Midlands. The initial sample was opportunist; participants identified by staff had current experience of caring for a person with dementia who was living at home and receiving support from dementia services. Participants were required to speak English, as this study did not have resources to recruit interpreters. In accordance with GT methodologies a theoretical sampling strategy was then adopted, which involves recruiting participants to develop an emerging theory. Therefore, following five initial interviews, a further four participants were recruited to explore ideas that had emerged within the theory development (Charmaz 2006). In total, staff identified seventeen carers and nine carers agreed to be interviewed. Recruitment ended when the researcher determined that saturation had been reached because the final interviews revealed no new insights (Dey, 1999).

The participant sample comprised of nine participants; five females and three males, ranging from 60 to 83 years old (Table 1). The majority of carers were spousal carers, only one carer was an adult child. The majority of carers cared for a person with Alzheimer's Dementia, with one reported Mixed Dementia diagnosis, and caring experiences ranged from 10 months to 9 years. Scores on the APLD ranged from 50.5 to 68, which crudely suggests a range of attitudes towards deception, where higher scores were indicative of being more accepting of deception. A range of attitudes is tentatively indicative of saturation, referencing GT methods that state a saturated sample should represent a variation of data (Charmaz, 2006).

### *Procedure*

The researcher displayed posters to advertise the study to staff within two team bases, attended team meetings to introduce the study and then distributed study

materials by email; a participant information sheet (Appendix C), consent form (Appendix D) and opt in slip (Appendix B). Staff were advised that they could distribute study materials to carers. Alternatively, if staff gained consent from the carer, the researcher could make contact by telephone or send materials by post to inform them about the study.

Carers were sent a recruitment pack, which included a participant information sheet (Appendix C) and consent form (Appendix D) and were advised to return the opt in slip (Appendix B) using the enclosed stamped addressed envelope if they wished to be contacted about taking part. Participants were informed that the researcher could be contacted with any queries using contact details on the participant information sheet. Before saturation was reached, staff identified seventeen carers who were all sent recruitment packs in the post. Nine carers returned an opt in slip. Once an opt in slip was received, the carer, potential participant, was contacted and an interview arranged. Interviews were carried out in a setting chosen by the participant, either Trust based clinical rooms or within participant's homes, following risk assessment which adhered to Trust lone working policy procedures. Informed consent was taken prior to interview by reviewing and co-signing the consent form.

*Table 1*  
*Participant sample (In order of recruitment)*

|   | Gender | Pseudonym*<br>(Used to protect identity) | Age<br>(years) | Ethnicity     | Relationship<br>(to person with dementia) | Diagnosis             | Time in caring role (estimated in years/months) | ALPD score |
|---|--------|--|----------------|---------------|---|-----------------------|---|------------|
| 1 | Female | April                                    | 67             | White-British | Wife                                      | Alzheimer's -Dementia | 3 years   | 64         |
| 2 | Male   | Bill                                     | 69             | White-British | Husband                                   | Mixed Dementia        | 18 months                                       | 66         |
| 3 | Male   | Colin                                    | 83             | White-British | Husband                                   | Alzheimer's -Dementia | 5 years   | 61         |
| 4 | Male   | Dennis                                   | 66             | White-British | Husband                                   | Alzheimer's -Dementia | 4 years   | 51         |
| 5 | Female | Enid                                     | 77             | White-British | Partner                                   | Alzheimer's -Dementia | 10 months                                       | 60         |

|   |        |        |    |               |          |                       |                  |      |
|---|--------|--------|----|---------------|----------|-----------------------|------------------|------|
| 6 | Female | Freyja | 69 | White-British | Wife     | Alzheimer's -Dementia | 2 years          | 63   |
| 7 | Female | Gail   | 61 | White-British | Wife     | Alzheimer's -Dementia | 4 years 9 months | 50.5 |
| 8 | Female | Helen  | 67 | White-British | Partner  | Alzheimer's -Dementia | 1 year           | 59   |
| 9 | Female | Ingrid | 60 | White-British | Daughter | Alzheimer's -Dementia | 9 years          | 68   |

### *Data collection*

#### *Interview procedures*

The semi-structured interviews lasted between 45 and 90 minutes. Within this time the researcher also supported the participants to complete a brief demographic questionnaire and the ALPD. The APLD was completed after the semi-structured interview by discussing and marking answers to each question. All interviews, which included the discussed responses to the ALPD, were digitally recorded and transcribed verbatim.

#### *Memos*

GT encourages the researcher to explore ideas, or hunches, about the data by writing about these in the form of preliminary analytic notes called memos, which are included as data within analysis (Glaser, 2002; Charmaz, 2006). The researcher recorded memos throughout data collection and analysis, making note of ideas or observations that felt important or helpful to data collection, analysis or building the emerging theory (Appendix I).

### *Data analysis*

The process of transcribing interviews and re-reading transcripts allowed the researcher to become familiar with the data. The first stage of open coding analysed transcripts in sentence-by-sentence detail, by allocating gerunds, verbal nouns, to describe each sentence. The researcher selected open codes that appeared most frequent or significant to produce focused codes, which synthesised the data by attaching labels to describe larger segments of data together with the underlying

processes taking place. From this, the researcher raised conceptual categories, which ultimately represent the processes underlying carers' decision-making. For example, a number of carers described attempts to keep the person with dementia in a 'good place', which was about feeling happy, calm or at peace. The researcher allocated an open code to this data which was called 'keeping the person in a good place'. This combined with other relatable open codes, for instance, about protecting or engaging a person, to produce a focussed code that described a larger amount of data called 'achieving positive responses'. The researcher compared this focussed code to other codes that were about responses, for example, avoiding negative responses, and raised this as a conceptual category about carer 'motivations' (Appendix H).

The researcher adopted constant comparative methods, which are non-linear and iterative, comparing data with data to find similarities and differences, moving back and forth between data collection and analysis so that each interview informed the process of the next interview (Glaser & Strauss, 1967). For instance, by interviewing participants gradually and constantly comparing codes within the data, the researcher was able to gather further data to check and refine the emerging categories. This process continued until the final participant was interviewed, whereby it was felt that no more theoretical concepts would emerge. The categories that emerged from the data, combined with the researcher's memos, formed the emerging theory and accompanying diagram. Diagramming is an intrinsic part of GT, as it provides a visual representation of categories and their relationships (Charmaz, 2006).

### *Credibility*

As the researcher and participants are mutually interactive, the researcher's influence on data collection and analysis was important (Hudson & Ozanne, 1988). Researchers are obligated to be reflexive about relevant experiences, beliefs and assumptions, to distinguish these from participant data (Charmaz, 1990). Alongside memos, supervision is important, and supervisory discussions were used to reflect on any preconceptions that might have been placed upon the data, to protect the credibility of the study. The researcher shared segments of transcripts with supervisors to ensure that interpretations and theoretical concepts were agreed upon and authentic.

### *Ethical considerations*

Ethical issues were considered in consultation with project supervisors. Particular consideration was given to ensuring carers felt comfortable discussing a sensitive topic and reflecting upon their practices, for instance, the researcher reminded them they could stop the interview at any time. Carers were advised that the information they share about their experiences will be treated confidentially and kept securely in accordance with University guidelines and the 'Data Protection Act 1998' (2015). However, if any information they share suggests that anyone, carer or cared for, is at risk that this information would have to be passed on to the appropriate professionals or services. Carers were advised that the study might be published however assurances were given that the information they share will be anonymised to ensure that they are not be identifiable within the final report, for example, by use of pseudonyms. The study was approved by Staffordshire University and an NHS Research Ethics Committee (Appendix L; Appendix M).

## **Findings**

### *Introduction to the theory*

This study presents a theory of in the moment decision-making by informal carers towards the person with dementia with whom they live at home. The data revealed that in everyday life, carers adopted either a truthful or a deceptive communication style depending upon a number of triggers, motivations and conditional judgments. The accompanying model (Figure 1) connects the key categories involved in decision-making through the use of arrows. Decision-making was influenced by 'pre-existing variables', which are individual differences between carers that influenced their decision making. 'Triggers' are events that elicited decision-making, which related to 'motivations' to achieve desired outcomes. Decisions were modified by 'conditional judgements', which encompassed judgments about the current situation and person with dementia. The 'core concept' of the model is that due to the variability of conditional judgments, decisions are ultimately made in the moment. Carers chose an 'interaction', represented as a continuum of strategies from

truth to blatant deception. Interaction outcomes influenced future decisions about truth or deception.

### *Pre-existing variables*

#### *Knowing a person well*

As seen in figure 1, carers emphasised that ‘knowing a person well’ was crucial to decision-making, because, “everyone is different” (April). Carers had in-depth knowledge of the person with dementia, that had been acquired through close longstanding relationships and shared biographical histories, “We’re together all the time. . . she’s told me stories all her life” (Ingrid). Knowing a person’s personality influenced decision-making; carers were at ease responding to “easy going” (Colin) personalities but were apprehensive about responding to changeable personalities because they feared a ‘bad’ reaction, “you tell the truth and they would erupt” (Freyja). Knowing a person well helped carers to make decisions that met a persons’ needs “You know your partner and what they require” (Dennis), and know what strategies work, “The truth at the moment works” (Enid). Carers had reservations about strategies they had no previous experience of, “I’ve never done [deception] so I don’t know what his reaction might be” (Enid).

#### *Moral beliefs*

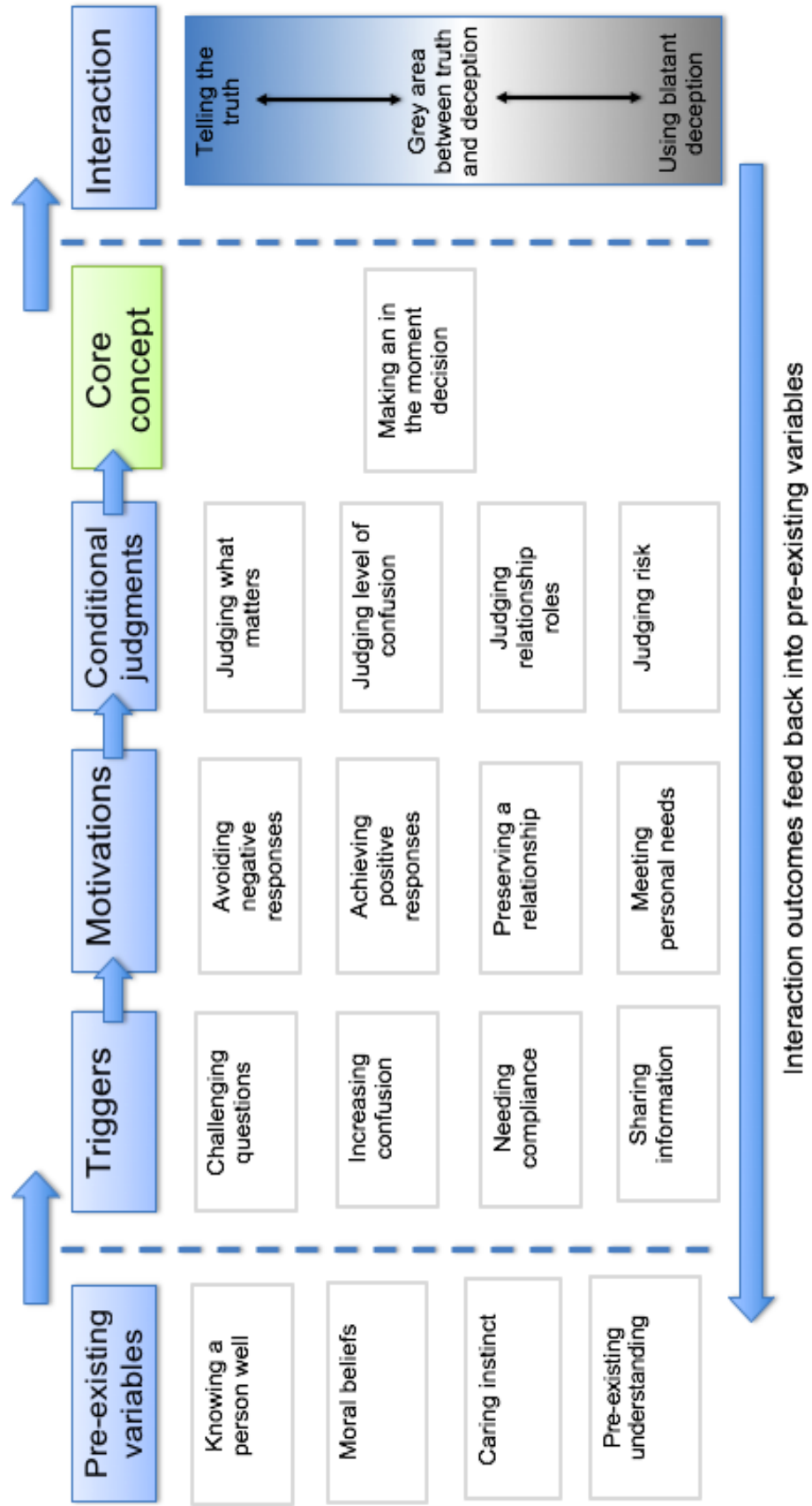
Carers were guided by moral beliefs about truth and deception, including those shared with the person with dementia, “throughout our marriage we’ve told the truth” (Gail). Dementia challenged moral beliefs about being truthful as carers were forced to reevaluate their beliefs should truth not work, “Truth has always been a big deal. . . it’s a shock when you can’t be” (Dennis). Some maintained a moral stance against deception, “My moral code is that I don’t tell lies” (Gail). Others were more flexible, justifying that deceptions are not uncommon within everyday life, “we all lie a little bit” (Bill). Some carers perceived ethics within dementia care differently to everyday ethics, “I don’t think I lie naturally but I don’t think I’d object if [deception] had to be” (Colin).

#### *Caring instinct*

Carers’ believed that caring naturally varied between people, for instance, “Not everyone has it. . .” (Bill) and identified that individual “instinct” (Freyja) supported

decision-making. Some carers believed instinct would lead to decisions to use non-truths, “I would do the alternative without taking much notice” (Enid). Carers identified empathy as a significant decision-making tool, “The secret. . . is to put yourself in their shoes” (April), and believed empathy varied according to gender, “Some men aren’t as in touch as women are at understanding and empathy” (April) and age, “When you're middle aged or older you have more empathy” (Bill). Carers who were accepting of living with dementia, “They can’t change the diagnosis it’s going to get worse. . . why not face it. . .” (April), were more open to deception compared to carers who did not want life to change and struggled to accept an unfixable condition, “I’ve always been Mr Fix-It. . .” (Bill).

Figure 1  
*Truth or deception in everyday communication at home: a grounded theory model of in-the-moment decision-making by carers of people with dementia*





### *Pre-existing understanding*

Knowledge and experience of dementia influenced carers' understanding of dementia and informed decision-making. Knowledge was acquired from websites, books, formal training opportunities and advice from other dementia carers, "For ideas that work. . . the best ideas we have had is from other carers" (Dennis). Decisions were informed by experiences working in adult care settings, caring for people with other long-term health conditions, knowing others who have had dementia alongside current experiences, "I've learnt a lot about dementia living with it" (April). Experiences observing others using truth or deception also influenced decisions, for instance, "I hear her say things and think I wouldn't do it like that" (April). Carers without experiences to draw upon felt less informed in decision-making, "I have no experience of anybody else suffering with this so I have no idea. . ." (Colin).

### *Triggers*

#### *Challenging questions*

Decisions were triggered by challenging questions, which included emotive questions, such as asking to go "home. . . to where she was born" (Ingrid) or asking for deceased people, "his mother whose been dead ten years" (April). Challenging questions included practical requests for something the carer was dubious of, "She was adamant I want a phone. . . we knew she couldn't have one" (Freyja) or did not want, "he asked are we going to so and sos and I don't want to go" (April). People with dementia sometimes asked to help the carer, who predicted this would be unhelpful, "That doubles the work, she makes a mess of things" (Dennis). Carers had to decide whether to answer challenging questions truthfully or with a deception.

#### *Increasing confusion*

Decisions were triggered by increasing day-to-day confusion, such as forgetting events, repeating conversations and confusion that impeded upon pastimes, daily living tasks, such as cooking, and personal care, such as dressing. Carers described how the person with dementia became increasingly disorientated, for instance, muddling life events, "sometimes he knows he's retired. . ." (Gail), regressing to childhood, "saying her uncle owned this place because when she was a child her

uncle had a farm” (Colin) or struggling to recognise family members, “. . . I don’t fit with her image of her daughter” (Ingrid). Carers had to decide whether to address confusion with truth or deception.

#### *Needing compliance*

Decisions were triggered by tasks that carers perceived as essential and strategies were adopted to get things done, for example, personal care, attending appointments, taking important medication or general errands. Carers had to decide whether to be truthful, for instance, openly helping or talking about necessary tasks, or use a deception, for instance, covertly helping or making excuses to get things done. Compliance seeking efforts were sometimes rejected by the person with dementia, “she won’t let me help. . . she becomes very cross” (Colin), and strategies were used to manage resistance, for example, “instead of saying anything shrug your shoulders and say nothing” (Colin).

#### *Sharing information*

Decisions were triggered by dilemmas about sharing or withholding information. Carers believed that certain information was irrelevant to the person, “If he can manage without knowing why tell him?” (April), or should only be shared when necessary, “till he needs to know” (April). Irrelevant information included seemingly trivial information, such as “daily conversations” (Helen), but largely referred to potentially upsetting information, for instance, family “upheavals” (April). Carers sometimes withheld their feelings, for instance, they withheld their frustrations to avoid causing upset, “sometimes I get exasperated. . . a normal reaction that I feel bad about” (Freyja). Some carers withheld information to prevent the person sharing what they should not due to an increasing lack of inhibition, “I couldn’t say to him don’t say anything. . . he’s lost that control” (April).

#### *Motivations*

##### *Avoiding negative outcomes for the person*

Carers were motivated to use truths or deceptions that avoided negative outcomes for the person with dementia, described as “avoiding a bad place” (April). Carers avoided strategies that would create negative feelings, for example, worry,

frustration, low self-esteem or additional confusion. Carers avoided strategies that would lead to negative behaviours, for example, disengagement, aggression, or self-harm, “Having seen what she goes through when she beats herself up, you’d want to avoid that” (Dennis). Some carers were motivated to avoid upset through any means, including deception, “If it was going to make him feel really bad I would lie through my teeth” (Helen).

#### *Achieving positive outcomes for the person*

Carers were motivated to use truths or deceptions that achieved positive outcomes for the person with dementia, described as a “good place” (April). Carers favoured strategies that helped the person to feel “happy” and “at peace” (Ingrid). Carers sought to make the person “feel good all the time” (Enid), by choosing strategies that prioritised their needs, “It’s about doing what’s right for the person. . .” (Gail), and gave them a sense of achievement, “I try and give her job satisfaction” (Dennis). Carers were also motivated by responsibilities to protect the person’s overall wellbeing, such as, “power of attorney over her health, wellbeing and finance” (Dennis), and had to decide whether to be truthful or deceptive about such responsibilities.

#### *Preserving a relationship*

Carers were motivated to use strategies that preserved their relationship with the person with dementia, “That’s the biggest thing just keeping our relationship” (Gail). For some carers this was about preserving shared values about being truthful and they worried that deception would damage their relationship, “He has always known that I tell the truth. . . so if I suddenly start telling lies that trust has gone” (Gail). Some carers believed that attempts to preserve the relationship were futile because dementia had changed the person, “It can’t work because he’s not the same” (Helen) and were more open to using non-truths. Seeing glimpses of the person as they were prior to dementia increased motivations to preserve the person, “part of the old her is still there” (Dennis), and carers adopted strategies to engage that person, truth or deception, “She always has loved crosswords... I’ll try and organise it so she’ll hone in on the answer more quickly” (Dennis).

### *Meeting personal needs*

Carers were motivated to meet their own needs, acknowledging that caring depended heavily on their wellbeing, “If the carer goes downhill the patients had it” (April). Carers connected positive outcomes for the person with dementia with their own wellbeing, “If she was happy we were happy” (Ingrid). Carers believed that strategies, truth or deception, that led to positive outcomes for the person made day-to-day life easier, “I’ve got to live with him. . . so it’s better for me to keep him in that good place by using lies or deception” (April) and allowed them to avoid experiencing negative emotions vicariously, because, “[Her upset] cuts you like a knife” (Colin). Some carers were motivated to use deceptive strategies to save time and avoid inconvenience, “To avoid awkward situations. . . I don’t have to waste time...” (Dennis).

### *Conditional judgments*

#### *Judging what matters*

Carers made a judgment about what matters, which was about being truthful when something was important, “If you’re going to put something into their brain you want it to matter” (Enid). Things that did not matter, for which truth was less important, included seemingly trivial facts, “It doesn’t matter what today’s called” (Gail), any mistakes, “If you don’t get peas. . . you say it doesn’t matter” (Bill), or anything with the potential to cause upset, “Why upset her when there’s no need to?” (Ingrid). Impairment caused by dementia influenced this judgment, as carers placed less importance on sharing truths that would be forgotten, “There’s no point because it will be gone in five minutes” (Colin), or challenging people who were seen as unaccountable for their behaviours, “. . . She can’t help it so what’s the point in pursuing it?” (Colin). Should the person with dementia become disorientated to time, though their reality is not factual, generally carers judged “their truth” as what matters (Gail).

#### *Judging level of confusion*

Carers made a judgment about the person’s level of confusion, which included judging “Good and bad days” (Freyja). Good days were when the person was judged to be less confused and more lucid. Bad days were when the person was more

confused or confrontational. Carers connected using truth with early stages of dementia, “I’m not using that [deception] right now because he’s so early on. . . he knows [the truth]” (April). Carers predicted that increasing confusion would moderate decision-making because “Truth becomes less and less relevant” (Ingrid). Carers predicted that deceptive strategies were relevant to later stages of dementia, “Further down the line, maybe 8-10 years into the diagnosis” (April).

#### *Judging relationship roles*

Carers made judgments about their relationship dynamic with the person with dementia. They reflected on the loss of a person with dementia, “that’s not the lady I married” (Dennis), loss of an equal relationship, “I’ve got to take charge of everything” (Dennis) and the burden of “thinking for one and a half people” (Bill). Carers likened their roles to a “boss” (Helen), parent or “untrained carer” (Dennis). Judging dynamics was difficult because the person with dementia fluctuated, “You treat her like a child. . . but other times she’s not” (Dennis), and was seen as less accountable because of deficits associated with dementia, “With a child who made a mess you’d tell the child. . . but you can’t do that because it’s not going to get any better” (Dennis). Carers who perceived the person with dementia as less accountable were more likely to withhold truths, “I think I should have handled that, she knows no different now” (Dennis).

#### *Judging risk*

Judging risk was a significant variable within decision-making because all carers reported that they would use any strategy, truth or deception, to manage risk to the person or others, “only if he was in danger or put someone else in danger” (Gail). Carers recognised that caring alone might mean they are also vulnerable to risk, “if you knew the truth was going to make them violent then I would totally agree that a lie could be used” (Ingrid).

#### *Core concept*

##### *In the moment decisions*

Decisions about using truth or deception were made in the moment, which was day and time specific, “Sort of split second but taking her on that particular day, at

that time. . .” (Ingrid). In the moment decisions considered the person with dementia, “. . . a judgment call and it depends on the person” (Freyja) and their reactions, “I’m led by his responses” (Gail). In the moment decisions were contextual, “every time it depends on [the circumstances]” (April). Carers felt pressured to make “instant” (Ingrid) decisions that “deal with [the trigger] straight away” (April).

### *Interaction*

#### *Truth*

Some carers always used truth or reverted to truth when possible, “If you can, you should try to tell the truth” (Freyja). Carers provided the person with truthful accounts, for example, “tell the whole story” (Gail), or truthful prompts to help the person to remember. Some carers gave the truth but waited till what was perceived to be the right time, for example, “till absolutely necessary” (April), which was about reducing the likelihood of worry, “the less time he’s got to worry the better” (Enid). Carers acknowledged different ways to tell truth; by adjusting tone, “how you say it” (Freyja) and being positive, “dress the truth nicely” (Gail). Carers avoided blunt truth, which was seen as a “cold. . .bitter pill” (Gail).

#### *Grey area strategies between truth and deception*

Carers referred to strategies that did not adhere to definitions of either truth or deception as “stuff in the middle” (April) or the “grey area” (Gail). These were not seen as akin to deception because the carer had not used an untruth. Some carers regularly avoided or omitted truth, for instance, “shying away” (Dennis) or “failing to admit” (Freyja), or used distractions and excuses to “bypass” the truth (Ingrid), for instance, using validation to, “move towards feelings and away from truth” (Gail). Carers sometimes altered truth by, “softening” (Enid), “twisting” (Ingrid) or “embellishing” (Freyja) to make truth less upsetting. Some carers engaged in the reality of people who were disorientated by “playing along” (Ingrid) with their beliefs, for instance, “we’ve walked to school if that’s what he believes” (Gail). Some carers provided subtle interventions, for instance, to “give the impression” of achievement, “when her back is turned I put everything right” (Dennis).

### *Deception*

Carers defined deception as intentionally telling non-truths, “making [him] believe something that isn’t true” (Gail). Intention was significant, as carers emphasised their deceptions were not intentional, for instance, “not deliberately doing something underhand” (Ingrid). Carers described using “minor lies or deceptions” (Dennis), in benevolent ways to avoid upset, “A lie because I haven’t made a phone call, but I know going there will upset him” (April), and pacify, “We kept saying we’re going to get someone to come to placate her” (Enid). Carers distinguished between “white lies”, which were for the good of the person, and “black lies”, which were for the good of the carer (Colin). Carers were least accepting of “blatant” deception (Freyja), though acknowledged these as a last resort, “if nothing else works you’ve got to lie” (April).

### *Outcomes*

Carers experiences using truth or deception influenced their future decision-making, “you learn from the last one” (Helen). Carers were less likely to change strategies that were successful, “If it’s not broken don’t mend it” (Enid), and more likely to change ineffective strategies that led to unwanted outcomes, such as distress, “for some reason if that strategy no longer suited. . . I would find another one” (Ingrid).

## **Discussion**

This study offers insight into how informal dementia carers use truth or deception within everyday interactions with people with dementia, by proposing a theory about the processes underlying their decision-making. The findings largely complement existing research that has explored the use of truth and deception in dementia care and add to research exploring everyday decision-making within dementia care (Livingston et al., 2010). The theory emphasises that decisions about using truth and deception are made in the moment, in keeping with literature about daily care decisions in dementia care, that are made by ‘weighing up’ judgments about the situation and the capabilities of the person with dementia (Sampson & Clarke, 2015). However, carers in this study did not consult the person with dementia in decisions

about using truth and deception, contrasting with decision-making about daily care, such as what to wear (Whitlatch & Menne, 2009).

A significant finding was that decision-making about using truth and deception was influenced by biographical knowledge of the person with dementia, in keeping with research that explores daily care decisions by informal dementia carers (Smebye, Kirkevold & Engedal, 2012). Notably, the daughter in this study had comparable in-depth knowledge to the spousal carers, which contrasts with Samsi and Manthorpe (2013) who proposed that spousal carers are most equipped with biographical knowledge. Like informal carers in Blum's (1994) study, decision-making was also informed by knowledge gained from other informal and professional carers. Carers who lacked knowledge or experience of dementia felt less confident about decision-making, similar to general hospital staff in Turner et al's. (2016) study, who reported limited opportunities to discuss truth and deception strategies left them uncertain of their practice.

Carers' moral beliefs, that adhered to truth-telling, mirrored moral beliefs reportedly held by informal and professional carers (Blum, 1994; Elvish et al., 2010). However, moral beliefs in this study were reinforced by familial relationship, for instance, carers were driven to maintain historically shared standards about being truthful, which staff would not possess. Similar to professional carers, carers found moral beliefs hard to maintain in practice when faced with increasing confusion (Hertogh et al., 2004). Carers' instinctual decision-making approaches echoed informal and professional carers in Smebye et al's. (2012) study, who made intuitive decisions about daily care. Carers believed that empathy was significant within decision-making, which resonates with literature that recommends identifying unmet needs (Tuckett, 2012) and the 'message behind' behaviours (Alzheimer's Society, 2016b, p.10) when choosing truth or deception strategies. Carers who struggled to accept dementia also struggled to deviate from truth-telling, a similar finding to Smebye et al. (2012, p8), who found informal carers who had not accepted dementia continued using ineffective strategies, hoping life would 'continue as before'. Such hopes resonate with Goffman's (1955) theory of 'saving face', because as people with dementia lose the ability to consciously present with a capable 'face', carers might compensate with increasing efforts to keep things the same.



Triggers for decision-making (Figure 1), were comparable to triggers experienced by professional carers, for instance, difficult questions, increasing confusion, non-compliance for care and dilemmas about sharing personal information (Tuckett, 2012; Tullo et al., 2015; Turner et al., 2016). Triggers were also comparable to triggers experienced by informal carers, who described using deceptive practices in response to ‘growing disorientation’ within everyday tasks (Blum, 1994, p.25). Carers’ motivations, to choose strategies that achieved positive outcomes and avoided negative outcomes, are in keeping with motivations underlying use of truths or deception reported by informal carers (Blum, 1994) and professional carers (James et al., 2006; Elvish et al., 2010). Like family carers in Blum’s (1994) study, some carers were motivated to avoid deceptions that could damage their relationship by breaking trust. Some carers were motivated to use any strategy that avoided negative outcomes, which resonates with consequentialist perspectives held by informal and professional carers, who believed that any deceptions that reduced negative outcomes, including risk, were justifiable (Hughes et al., 2002; Elvish et al., 2010; Tuckett, 2012). Carers were sometimes motivated to meet their own needs, similar to professional carers in James et al.’s. (2006) study, by occasionally using deception for personal advantage, for example, avoiding inconvenience.

In this study, carers’ decision-making was influenced by continuous judgments of the fluctuating capacity of the person with dementia, which also featured within professional carers’ decision-making (Tuckett, 2012). Like informal carers (Blum, 1994), professional carers (Tullo et al., 2015) and people with dementia (Day et al., 2011), carers associated deception with later stages of dementia, when awareness was lost. Carers in this study, comparably to professional carers in Tuckett’s (2012) study, respected the truth of people with dementia who become increasingly confused, “*what is in (the resident’s mind) is real*” (p.9). Carers’ beliefs that seemingly trivial information mattered less over time, corresponds with literature describing how trivial everyday truths become less meaningful to people with dementia as confusion increases (Vittoria, 1998). Some carers did not share any information that was likely to cause distress or when it was likely that the person with dementia would forget due to increasing confusion, like the family carers within Blum’s (1994) study. This contrasts with professional carers who reportedly would

consistently share information even if this caused distress (Hertogh et al., 2004; Tuckett, 2012). Professional carers within Tullo et al's. (2015) study, reasoned that informal carers were more entitled to make decisions to withhold meaningful information because of their significant relationship status.

The findings support research that illustrates loss of equality within relationships following dementia diagnosis (Sampson and Clarke, 2015). Carers' increased decision-making responsibilities, correspond with literature that illustrates how people with dementia become less active decision-makers because of diminishing capacity (O'Connor and Purves, 2009). Carers' concerns about increased decision-making responsibilities, mirror informal carers in Blums' (1994) study, who felt disturbed about taking control over their family member. Such findings about power inequalities within decision-making resound with ethical concerns that decisions made without people with dementia are malevolent, as they involve a corruption of power (Kitwood, 1997). However, carers in this study, similar to informal and professional carers, emphasised benevolent intentions, where what was best for a person with dementia was the driving process behind decision-making (Blum, 1994; Hertogh et al., 2004).

Carers' strategies are represented within a continuum from truth to blatant deception (Figure 1), a concept also shared by Tuckett (2006). Truthful strategies in this study mirrored truthful strategies by informal carers within literature, such as 'stalled' truth-telling (Blum, 1994), and beliefs of people with dementia about respectful truth-telling (Day et al., 2011). Carers struggled to define some strategies within the categories of truth or deception (Appendix K), in keeping with a number of studies where informal and professional carers adopted different terms to describe their interactions (Blum, 1994; Tuckett, 2012; Turner et al., 2016). Like professional carers in Hertogh et al's. (2004) study, carers did not see strategies that avoided or withheld truth as akin to deception, as no untruth had been told. Mirroring informal carers in Blums' (1994) study, carers were least accepting of deception, which was seen as a last resort, and developing truth and deception strategies as a result of experimenting from one situation to the next.

### *Clinical implications*

Within the proposed theory, carers' in-depth knowledge of the person with dementia was significant within their decision-making. This insight is valuable as it directs clinical services to learn from carers' knowledge for clinical practice. There is evidence to suggest that such knowledge is desired by professional carers who believe that person-centred insights would better inform their practice, including decisions about truth and deception (Turner et al., 2016). All staff within dementia services should seek opportunities to learn from carers' knowledge. This will ensure that clinical decisions, such as whether to use truth or deception, are informed by knowledge of individualised, personal needs (Mitchell & Agnelli, 2015).

Carers' decisions were influenced by assumptions about what strategies were in the best interests of the person with dementia. However, within the research on best interests in dementia care there are queries about whether such assumptions accurately reflect what people with dementia would want (Whitlash & Menne, 2009). Therefore the importance of ascertaining the preferences of people with dementia is paramount, to increase the likelihood that carers are acting in best interests. De Boer et al. (2007) suggest that advanced statements could be utilized for such purposes, for instance, recording preferences towards the use of truth and deception to guide carers' decisions within future care. Any professional within a dementia service could facilitate conversations about advanced statements with a person with dementia who has capacity to express their wishes. Though advanced statements are not legally binding, they allow people with dementia to record their wishes about their future care and guide within future decision-making.

Carers integrated knowledge from peers and professionals to inform decision-making, though opportunities to meet with peers or professionals are not always available (Livingston et al., 2010). Clinical psychologists offer leadership in organisational development and are trained to design, implement and evaluate interventions that enhance well-being (BPS, 2014). They are well placed to facilitate opportunities for carers of people with dementia to meet together alongside staff, to share experiences and develop effective strategies, a recommendation shared with

NICE (2006). Ensuring carers are skilled and emotionally supported will reduce the likelihood of carer breakdown (Hattink et al., 2015).

Carers believed that empathy was significant within decision-making. Clinical psychologists provide face to face therapy for individuals and groups as well as supervision so that other staff can provide psychological treatments (BPS, 2014). Clinical psychologists should consider how empathy can inform therapeutic interventions, for example, to encourage carers to see things from the person with dementia's position, think about their needs, then decide if these are best met with truth or deception. There are specific assessment frameworks, such as 'The Newcastle Model' proposed by James (2011), that encourage people to adopt empathy in order to understand the thoughts, feelings and behaviours of people with dementia in terms of unmet needs before developing effective strategies.

### *Limitations*

Carers of people with more advanced dementia might have been unable to take part because of challenges associated with severe presentations, for example, people who are severely confused or physically dependent might need consistent support. Future research should consider ways to overcome these challenges, by using data collection methods that allow for easier engagement, such as telephone or written accounts of experiences.

The topic of truth and deception is sensitive, and carers might have struggled to talk openly about their strategies due to concerns about being judged (Festinger, 1962). Future research should consider introducing alternative methods to capture data, that encourage carers to be open and confident about sharing their experiences. For example, non-face-to-face approaches like written accounts or supportive peer discussions within the format of a focus group.

Despite the researchers' attempts to protect credibility of the study, for instance, by being reflexive about relevant experiences, beliefs or assumptions to distinguish these from participant data, a GT study will contain some degree of influence because the findings are the researchers' interpretation (Charmaz, 1990). In order to

ensure that the interpretations were as authentic as possible, the researcher reflected upon any preconceptions within memos and supervisory discussions.

### *Future research*

This study confirms that dilemmas about truth and deceptions continue to challenge carers and the topic warrants continued consideration. The theory compliments existing GT research that provides theory for decision-making about using truth and deception for people with dementia (Day et al., 2011) and general hospital staff (Turner et al., 2016). However as these were the first attempts to propose such a theory, future research should develop these theories and include groups that are not represented, for example, inpatient and residential dementia staff.

Generalisation is complicated within qualitative research because such methods aim to provide rich, contextualised understanding of specific human experiences that are not necessarily applicable within other contexts. In accordance with GT methods, this study provided a theory about the use of truth and deception that is grounded within carers' experiences; however, the theory could be strengthened or revised by exploring experiences of more informal carers (Stebbins, 2001).

The study was largely representative of spousal carers of people diagnosed with Alzheimer's Disease. Future research should identify whether decision-making processes of other family carers, such as adult children, or different diagnoses', such as Vascular Dementia, would lead to different theory of decision-making. The study was culturally representative of White British adults therefore future research should identify cultural differences in decision-making. For example, African-American communities believe that elders should be cared for by family, therefore decision-making may reflect family discussion (Alzheimer's Association, n.d).

## Conclusion

This study offers additional insight into the everyday experiences of family dementia carers. Similar to findings from previous research about truth and deception in dementia care, family carers in this study predominantly used truthful responses, however predicted deceptive strategies would become more relevant as the person with dementia becomes more confused and truth is less effective. Findings support research that proposes decision-making within dementia care is a result of weighing up options in the moment, based on the person with dementia and the situation. This study contributes a unique theory that conceptualises the underlying processes that influence family carers' decision-making about the use of truth or deception. Though there appear to be key processes that influence carers with a family relationship, for example, a longstanding relationship and knowledge of the person with dementia, the number of processes involved with the theory confirms that decisions about using truth and deception are complex. It is hoped that future research will develop the proposed theory and that clinical services will take direction from the identified processes, for instance, considering how key process like the use of empathy, experience and knowledge can influence the design of effective interventions to support family carers.

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## Appendix

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## Appendix A: Poster

Version 1.0, 31/1/17

IRAS project ID: 217300

Poster



### **PARTICIPANTS NEEDED FOR RESEARCH ABOUT CARERS IN DEMENTIA**

We are looking for volunteers to take part in a study about how people who care for those with dementia make decisions about what to do when the person with dementia appears confused, disorientated or distressed. We are specifically interested in how carers manage dilemmas around telling people with dementia the truth or a lie in response to their distress.

Your participation would involve *one* interview and *two brief* questionnaires, which may last approximately between 30-60 minutes.

The location for the interview is flexible and can take place somewhere where you feel comfortable and familiar e.g. community building or your home if appropriate.

This study aims to develop the research that involves carers, as despite the number of carers who are caring for people with dementia in our communities; little research in this area has involved them.

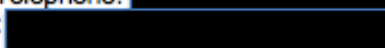
For more information about this study, or to volunteer for this study, please contact:



Telephone:



Email:



Or let a member of the dementia team know if you would like more information about volunteering for the study.

## Appendix B: Opt in slip



### Opt in slip

I agree to be contacted about taking part in the following study:

**Truth and deception in dementia: a qualitative study of carer decision-making in the home environment**

**Name:**

Please provide at least one telephone number in order for the researcher to contact you. The other fields are optional.

Please use the enclosed stamped addressed envelope to return this slip.

**Telephone number:**

**Mobile number:**

**Email:**

**Postal address:**

Many thanks

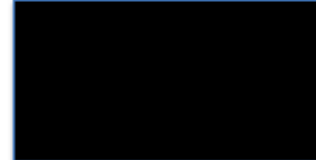


## Appendix C: Participant information sheet

Version 2.0, 28/7/17

IRAS project ID: 217300

Participant Information Sheet



### **Truth and deception in dementia: a qualitative study of carer decision-making in the home environment**

#### **Invitation and brief summary**

You have been invited to take part in this study because you are a carer for someone with dementia. This research study is about how carers, that is family or friends who support someone with a diagnosis of dementia regularly, may choose to use truth or a lie when communicating with them. This research is being undertaken by me, RESEARCHER, as part of my clinical psychology doctoral thesis at Staffordshire University. This information is provided to give you more information about the study; taking part is your choice.

#### **Who has reviewed the study?**

This study has been reviewed by NHS England through the Wales Research Ethics Committee 6. It has also been assessed by an ethics panel at Staffordshire University.

#### **Explanation: purpose of and background to the research and invitation**

Over time it is common for people with dementia to experience confusion and disorientation. Sometimes they may also appear to be re-living emotional times in their past. This can be upsetting for them as well as any carers who are trying to support them. Sometimes, as a result of this confusion and disorientation, carers are faced with a dilemma about having to choose whether to use the truth or a lie when communicating with the person they care for. For example, imagine you are caring for a person with dementia who is adamant that they have to go to work. You might choose to tell them the truth, perhaps, "You're retired now", or you might choose to use a lie, perhaps, "You don't have to go to work today". Or maybe imagine you are caring for a person with dementia who believes they need to pick up their children from school when in fact their children are now grown up. You might choose to tell them the truth, perhaps, "They're grown up now", or you might choose to use a lie, perhaps, "They're safe I picked them up for you". Another example might be telling a person with dementia who wants to drive their car the truth, "You can't drive anymore", a lie, perhaps, "The car needs to be fixed", or even hiding the car keys. There are many reasons why someone who looked after a person with dementia might choose to use a lie, and though examples of lies may vary, generally a lie is seen as something that is not factually correct or where information is withheld on purpose. The purpose of this research study is to explore how carers make this decision.



### **What would taking part involve?**

Before you decide whether to take part in the study it is important that you understand what the research is for and what you will be asked to do. Please take time to read the following information and discuss it with others if you wish. It is up to you to decide whether or not to take part. If you decide to take part you will be asked to sign a consent form, but you can change your mind up until the point that the data is analysed (estimated December 2017) and withdraw from the study without giving a reason. Please note that any support you receive from the dementia team will not change whether or not you decide to take part in this study.

The study will involve you taking part in an individual interview. If you choose to take part I will organise a location for the interview that is convenient for you. I would like to ask questions about what it is like for you in your caring role and your thoughts and feelings about how you would choose to tell truths or lies. For example, I will ask if you have had to make a decision about telling the truth or a lie when communicating with the person you care for. It would be helpful to hear about how you made your decision and what the outcome of your decision was for you and the person you care for. I will also ask about how supported you feel to make decisions about using truth or lies to people with dementia.

The interview will take approximately 30 – 60 minutes. Following the interview you will be asked to complete a short questionnaire that asks your gender, age, relationship to the person you care for, their diagnosis and how long you have cared for them. You will also be asked to complete a brief questionnaire about your attitudes to telling lies to people with dementia in order for the researcher to see how attitudes may vary. We can complete the questionnaire together if you would prefer.

### **What are the possible benefits of taking part?**

The information gained from this research will be used to learn more about people who care for people with dementia. Previous research has looked at how employed carers may make decisions about using lies in dementia care but this research will offer valuable insights into the experiences of carers supporting people in the community. The results of the study may lead onto further studies into carers' experiences.

### **What are the possible risks and disadvantages of taking part?**

Attending an interview may disrupt your caring and personal routines; therefore, as lead researcher, I will strive to be flexible in arranging interviews at times and locations that suit your needs. I recognise that talking about the person you care for and ways you may cope in difficult situations may be upsetting for you, and the questions I ask during the interview may cause you to feel anxious, distressed or uncomfortable.

It is important that you know you are free to stop the interview at any time if you do not wish to continue. If the interview upsets you and you would like additional help after the interview, or you leave the interview and find that you are reflecting on your own practices and experiencing negative feelings, please refer to the contact details on this information sheet. You could also contact your GP if you feel you need support for your own wellbeing. Please also be aware that if any information is shared that suggests that you or the person cared for is at risk, it is my duty to pass this information on.

### **What will happen to the information I provide?**

It is important that you know how any information you share for this research will be kept and used. The information you supply will be securely held by Staffordshire University and treated confidentially in accordance with the Data Protection Act (1998). All interviews will be digitally recorded and transcribed onto a computer. The recordings will be stored securely at all times and computer data will be password protected. All recordings will be destroyed at the end of the study. The questionnaires will be scanned onto computer and saved in a password-protected file. Personal information will be kept confidential; any data you provide will be identified only by code numbers or false names. All interviews will be analysed by me as lead researcher however parts of the data will also be accessed by my supervisors where appropriate. At the end of the research a report will be written and the results may be published in peer-reviewed journals. Again, no person will be identifiable within any publications. If you wish to request a final copy of the report, you would be welcome to contact me. The current policy at Staffordshire University is that all research data should be stored for ten years before being destroyed (estimate 2027), for use in further research or audit where appropriate.

If you would like to take part in this research, please complete the opt in slip to state that you are happy for me to contact you and **return the opt in slip within two weeks**. There is a stamped addressed envelope included for you to use. I will then know if you want me to make contact with you to talk further, to answer any questions and to arrange a suitable date to meet.

Please contact me if you need further information, using the following contact details. There are also alternative contact details provided if you would like to contact another member of the research team. Please note that these contact details have been provided in relation to this research. **If you need any immediate or on-going support for your own wellbeing please contact your GP or local out of hours service.**

Yours sincerely,



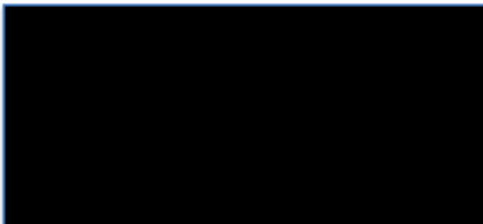
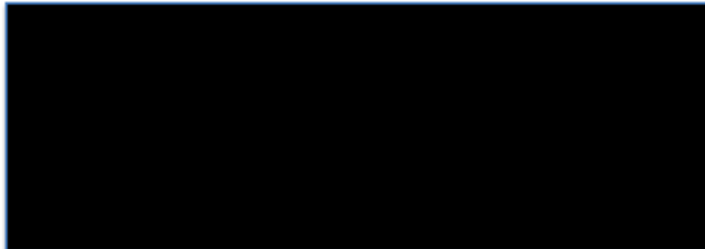
(Contact details on following pages)

**Contact details**

If you would like more information, to ask any questions or share any concerns you can use the following details:

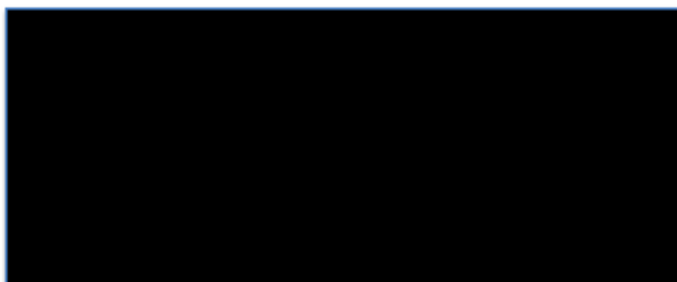


If you would like to contact an alternative member of the research team, you could contact the following people:



**Complaints**

If you wish to make a complaint or if you have any comments about this study or dementia services, you can speak to the Patient Advice and Liaison Service (PALS). PALS are an independent contact for complaints procedures. All comments to PALS are treated in a confidential manner and will not affect your current or future treatment:



### **Information and support**

If you want to talk about any concerns, worries or troubles these are some services that you might find helpful:

**The Samaritans** are a free, 24-hour telephone service if you want to talk about any concerns, worries or troubles that you are experiencing. If you don't want to call, you could send them an email or letter, or take a look at their website.

**Telephone:** 116 123 (call free from any phone)

**Email:** [jo@samaritans.org](mailto:jo@samaritans.org)

**Post:** Freepost RSRB-KKBY-CYJK, PO Box 9090, STIRLING, FK8 2SA

**Website:** <http://www.samaritans.org>

**The Alzheimer's Society** have a National Dementia Helpline if you are looking for information, support or advice about dementia. They can also tell you about local support in your area. If you don't want to call, you can use their website to send them an email. They have a lot of helpful resources on different dementia related topics on their website.

**Telephone number:** 0300 222 11 22 (charged at the national call rate)

**Helpline opening hours:**

Monday – Wednesday: 9:00am – 8:00pm

Thursday – Friday: 9:00am – 5:00pm

Saturday – Sunday: 10:00am – 4:00pm

**Website:** <https://www.alzheimers.org.uk>

**Dementia UK** provide support through Admiral Nurses. Admiral Nurses are specialist dementia nurses who give expert support to families living with dementia to help them cope. They can also tell you about local support in your area. If you don't want to call, you can send them an email, a letter, or you can take a look at their website.

**Telephone number:** 0800 888 6678 (Freephone number)

**Helpline opening hours:**

Monday – Sunday: 9:00am – 5:00pm

Wednesday – Thursday evenings: 6:00pm – 9:00pm

**Email:** [info@dementiauk.org](mailto:info@dementiauk.org)

**Post:** Dementia UK, Second Floor 356 Holloway Road London N7 6PA

**Website:** <https://www.dementiauk.org>

**AGE UK** is a charity that works with older people. They have a free advice line and a website where you can find out about local services available to you. They have information about a wide range of topics, and their trained advisors can support you with information and advice.

**Telephone number:** 0800 678 1174 (Freephone number)

**Advice line opening hours:**

Monday – Sunday: 8:00am – 7:00pm

**Website:** <http://www.ageuk.org.uk/no-one/we-provide-advice/>

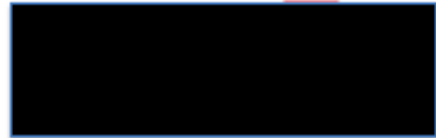


## Appendix D: Consent form

Version 2.0, 28/7/17

IRAS project ID: 217300

Consent form



### CONSENT FORM

**Study title:** Truth and deception in dementia: a qualitative study of carer decision-making in the home environment

**Name of Researcher:** Melissa O'Leary

Please read the following and sign if you agree to take part in this research.

*Please initial box:*

1. I confirm that I have read the information sheet for the above study (Patient Information Sheet, Version 2.0, 28/7/17), have had the opportunity to ask questions and have had them answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw up until the point that the data is analysed without giving any reason.
3. I understand that the information I provide will be taken from one interview, two questionnaires that ask for brief demographic information and ask about my attitudes.
4. I understand that the information I provide in will be used anonymously, will be kept in a secure location and that original data sources i.e. recording and paper questionnaire will be destroyed when the study is complete.
5. I understand that if any information is shared that suggests that myself or the person I care for is at risk, it will be passed on to the appropriate safeguarding services.
6. I understand that the information I provide may be used anonymously within a final research report, may be used anonymously to support other research in the future, and may be shared anonymously with other researchers.
7. I understand that the final research report may include things that I have said in my interview as verbatim quotes to support the research findings. These quotes will not include any identifiable data so that participants remain anonymous.
8. I agree to take part in the above study.

\_\_\_\_\_  
Participant name                      Date                      Signature

\_\_\_\_\_  
Person taking consent                      Date                      Signature

## Appendix E: Interview schedule

Version 1.0, 31/1/17

IRAS project ID: 217300

Interview schedule



### Interview schedule

**Research title:** Truth and deception in dementia: a qualitative study of carer decision-making in the home environment

This interview schedule has been developed using findings from previous research that explores the use of truth and lies in dementia care as well as guidance about how to construct grounded theory by Charmaz (2006). The initial questions take influence from Turner (2016) as Turner's research also considered the decision-making process of truths or lies, though from the perspectives of staff within dementia care in hospital settings.

The interviews will take a semi-structured approach, where the questions are designed to explore carers' experiences, but also the processes involved in their decision-making as well as any outcomes (Charmaz, 2006). Providing an interview schedule within grounded theory research is difficult, as the researcher may need to adapt the questions in order to develop the emerging theory based on the participant responses. Charmaz (2006) recognises that this is problematic during the process of seeking ethical approval, and suggests that researchers provide example of the kinds of questions that will be asked so that reassurances can be made that participants will come to no harm. The researcher will also be looking to identify when the data gathered from the interviews has reached saturation (Charmaz, 2006). This should be the point in which no new information is being gathered in order to develop the theory. If this point is not reached the researcher will need to consider conducting more interviews and further adapting the interview schedule.

#### **Sample questions:**

*Can you tell me a bit about your caring role, and how you support someone with dementia?*

*Can it be challenging?*

*Prompt: What kind of challenges do you face?*

*Prompt: What makes it more or less challenging?*

*When did you first experience having to make decisions about telling the truth or a lie to the person you care for?*

*Can you describe a situation where you have had to use a truth or a lie?*

*Prompt: What do you consider to be a truth or lie?*

*What led up to you having to make that decision?*

*How did you decide whether to tell a truth or a lie?*

*Prompt: What were you thinking about?*

*Prompt: What helped you make the decision?*

*Prompt: How much time did you have to decide?*

*Prompt: Did you talk about it to anyone else?*

*What was the outcome of your decision about using a truth or a lie?*

*Prompt: Was it a successful or unsuccessful outcome?*

*Prompt: How did you feel?*

*Prompt: How did the person you care for react?*

*What do you think now about your decision?*

*Prompt: Are you pleased or do you regret your decision?*

*Prompt: Would you change it?*

*Prompt: What was happening in your life then?*

*What have you learnt from your experiences?*

*Prompt: How would you make decisions about using truths or lies in future?*

*Prompt: Have your views changed?*

*Prompt: What helps you manage?*

*Prompt: What types of problems do you think you might encounter?*

*Are there times you think the use of lies is more acceptable?*

*Prompt: Can you share examples?*

*Prompt: Are there different types of lies?*

*Prompts: Are there things that make lies more or less acceptable?*

*Do you get to talk about how you making these decisions with anyone?*

*Prompt: Do you talk to family or friends?*

*Prompt: Do you get support from any teams?*

*Prompt: Has talking today impacted on you?*

*Do you feel you have enough support and guidance to make these decisions?*

After the interview, the researcher will talk the participants through a brief questionnaire called the Attitudes Towards Lying to People with Dementia (ALPD) initially created by Elvish et al (2010) for use with staff. This questionnaire has been adapted with the author's permission, not for statistical use within this research, but as a way of ensuring that the participants represent a range of attitudes, and as a way of supporting the saturation of the interviews.

After the questionnaire, participants will be given the opportunity to ask any questions and the researcher can signpost them to further support services if necessary.



## Appendix F: Demographic questionnaire

Version 1.0, 31/1/17

IRAS project ID: 217300

Demographic questionnaire



### Participant demographic questionnaire

1. What is your gender? (Circle your response)  
Male       /       Female
  
2. What is your age? (In years)
  
3. What is your relationship to the person with dementia that you care for?
  
4. What is their diagnosis? (If known)
  
5. How long have you cared for them? (In years or months)

***Thank you for completing this questionnaire***

*For researchers use:*

*Participant number*

**Appendix G: Attitudes to Lying to People with Dementia Questionnaire (ALPD)**

Version 1.0, 31/1/17

IRAS project ID: 217300

ALPD

**Attitudes to Lying to People with Dementia Questionnaire (ALPD)**  
**Ruth Elvish, Ian James and Derek Milne (2010)**  
*Adapted with permissions from the author*

Please rate how much you agree or disagree with the following statements using the scale where:

- 5 = totally agree
- 4 = agree
- 3 = neither agree/disagree
- 2 = disagree
- 1 = strongly disagree

|   | Question   | Rating (1-5) Please circle your response |   |   |   |   |
|---|--|--|---|---|---|---|
|   |  | 1  | 2 | 3 | 4 | 5 |
| 1 | Lies of any form are always wrong  | 1  | 2 | 3 | 4 | 5 |
| 2 | The use of a lie can be justified if it reduces a person's challenging behaviour   | 1  | 2 | 3 | 4 | 5 |
| 3 | Lies should be used when you know from past experiences that the truth is likely to upset the person                                 | 1  | 2 | 3 | 4 | 5 |
| 4 | It is acceptable to lie if you have a really good knowledge of the person and are aware of what approach usually works best for them | 1  | 2 | 3 | 4 | 5 |
| 5 | It is acceptable to lie if you have weighed up the situation and decided the lie is in the best interest of the person               | 1  | 2 | 3 | 4 | 5 |
| 6 | It is acceptable to lie if you believe that the person will behave in an aggressive way if told the truth                            | 1  | 2 | 3 | 4 | 5 |

|           |   |   |   |   |   |   |
|-----------|---|---|---|---|---|---|
| <b>7</b>  | It is possible for a lie to be regarded as a person-centred strategy  | 1 | 2 | 3 | 4 | 5 |
| <b>8</b>  | It is acceptable to lie if it is the only way to get a person to take important medication                              | 1 | 2 | 3 | 4 | 5 |
| <b>9</b>  | Certain types of lie are more acceptable than others  | 1 | 2 | 3 | 4 | 5 |
| <b>10</b> | Lies designed to ease the distress of the individual are acceptable   | 1 | 2 | 3 | 4 | 5 |
| <b>11</b> | It is acceptable to lie in an emergency when there is a risk that a person might injure himself?                        | 1 | 2 | 3 | 4 | 5 |
| <b>12</b> | It is acceptable to lie if you have tried other strategies that have not worked (e.g. distraction, validating feelings) | 1 | 2 | 3 | 4 | 5 |
| <b>13</b> | Lies are sometimes acceptable   | 1 | 2 | 3 | 4 | 5 |
| <b>14</b> | It is acceptable to lie to prevent a person from harming himself  | 1 | 2 | 3 | 4 | 5 |
| <b>15</b> | You should be trained in how to lie effectively in order to meet the needs of the person                                | 1 | 2 | 3 | 4 | 5 |
| <b>16</b> | You should always tell the truth  | 1 | 2 | 3 | 4 | 5 |

***Thank you for completing this questionnaire***

*For researchers use*

*Participant number:*

*Total:*

## Appendix H: Example of open and focussed coding

| Transcript excerpt   | Example of open codes →   | Example of focussed codes →  | Conceptual category  |
|--|---|--|--|
| <p><i>Participant 1 (April):</i></p> <p>That's the whole thing about being a carer, is to keep the person in a good place.</p>   | Keeping the person in a good place  | Achieiving positive responses  | Motivation   |
| <p><i>Participant 2 (Bill):</i></p> <p>Well I know the basis of what you're doing and so they're all minor lies or deceptions in the sense of if things don't go quite right to belittle that event if you see what I mean. It's like if she writes down what we write down for tea, well she's not going to get it all if you know... then if it doesn't happen then you just poo poo it you know, you say it doesn't matter. There's a lot of "don't matters".</p> | <p>Using minor lies to avoid belittling</p> <p>Saying it doesn't matter when wife forgets</p> <p>Using a lot of 'don't matters'</p> | <p>Deception</p> <p>Avoiding negative responses</p> <p>Judging what matters</p> <p>Deception</p> | <p>Interaction</p> <p>Motivation</p> <p>Conditional judgments</p> <p>Interaction</p> |
| <p><i>Participant 9 (Ingrid):</i></p> <p>"Sometimes I do kind of sit down with her and say look, it's a long way, wev've got to get into the car and its four or five hours, it will take a long long time to get there ... when we get there, you wont know the people in that house because your mum and dad, theyre dead now... and she'll say, oh are they? You know she was expecting her mum and dad to be there waiting for her.</p>                          | <p>Using truth to put Mum off request</p> <p>Using a gentle reminder of parents death</p> <p>Reconising Mums confusion</p>          | <p>Using excuses</p> <p>Using gentle truths</p> <p>Judging level of confusion</p>                | <p>Interaction</p> <p>Interaction</p> <p>Conditional judgments</p>                   |

## Appendix I: Example of memos

| Memos   | Date of Memo &<br>Transcript to Refer to:              |
|---|--|
| <p>In my first interview with April, the concept of a ‘good place’ stood out and I intended on asking future carers about their definitions and experiences of staying in a good place or avoiding a bad place for the cared for.</p>   | <p>Date noted: 25/11/17<br/>Participant 1 (April)</p>  |
| <p>I made assumptions about what carers may struggle with from personal and professional experience in dementia. I found that my assumptions have been proven wrong, for example, so far carers have largely stuck with the truth or grey area practices and lies were not as depended upon as I expected. Speaking with Dennis made me realise how powerful morals about telling the truth, specially within the context of a marriage, can be. I also wondered if the presentations of people with dementia in the community, are less advanced compared to people living in dementia care settings, so perhaps strategies that involve deceptions are less relevant.</p> | <p>Date noted: 30/11/17<br/>Participant 4 (Dennis)</p> |
| <p>In regard to my theoretical sampling and saturation, I worry about missing something, but maybe this is based on my preconceptions about the use of deception because the informal carers interviewed so far all seem to be communicating similar experiences. Perhaps because of their close family relationship, truth is prioritized much more and the carers all describe attempting to stick with the truth, more than my experiences of observing staff practice in care who use deception regularly.</p>  | <p>Date noted: 5/12/17<br/>Participant 7 (Gail)</p>    |

## Appendix J: Author guidelines from Qualitative Health Research

### WRITING TO PUBLISH IN QHR

Proper formatting will speed the peer-review process for your manuscript and will facilitate a smoother production process if it should be selected for publication. Refer to the guidelines below, and to the *Publication Manual of the American Psychological Association*, [APA] 5th edition. Improper formatting could result in burdensome revisions, lengthy delays in the review and production processes, and *the possible rejection of your manuscript*.

### ELEMENTS OF A MANUSCRIPT

The following elements are **required** for each manuscript, and should be compiled in the following order:

6. Title page
7. Abstract
8. Keywords
9. Main body of the manuscript ([main document"; beginning on p. 2]
10. References

The following elements **may** be included in your submission (they are *optional*):

- E. Notes/footnotes/endnotes [place after the main body of the text, before the reference list]
- F. Tables [place at the very end of the document]
- G. Figures [submit in a separate document]
- H. Appendices are published *only in certain circumstances*, at the editor's discretion [place after the reference list and before any tables]

### ORDER OF ELEMENTS

Compile the elements of your main manuscript document in the following order. Each element (except notes) should begin on a new page:

- G. Abstract and keywords - required
- H. Main manuscript text - required
- I. Notes/footnotes (if any)
- J. References - required
- K. Appendices (if any)
- L. Tables (if any)

### DOCUMENT SETUP (See also Sample Manuscript)

- Document file type: Submit only documents created in Microsoft Word, and only with the regular file extension of ".doc"; Word documents with ".docx" extensions, PDF files, or other types of documents cannot be accepted for

consideration. *Do not add any special coding or formatting to your documents that is not described within these guidelines.*

- ·Margins: 1" on all sides \*\*\*\*\*
- ·Ellipses/Ellipsis Points: Almost every manuscript contains ellipses. They are used to indicate missing words in quotations, and are to be created in a very specific manner. *Do not* use the "Insert Symbol" function in Word to enter ellipses. The proper way to create ellipsis points is as follows:  
space/dot/space/dot/space/dot/space ( . . . ); that is, 3 dots, preceded, divided, and followed by spaces, like . . . this. If it is necessary to indicate missing words between sentences (instead of in mid-sentence), place a period (full stop) at the end of the first sentence, then format the ellipsis points as noted, and begin the next sentence (with a capital letter) immediately after the last space. Do not place ellipses within parentheses or brackets ( . . . ); the exception to this is in conversation analysis, when appropriate.
- ·Font Size: 11 point font, including font used for titles, regular text, section headings, and quotations; however, fonts between 8 and 10 points in size should be used in tables and figures
- ·Font Style, Main Manuscript: Use Times New Roman font. *Italics* should be used *only* (a) as appropriate in the reference list (see *APA*), or (b) to introduce new or non-English words, or new concepts (2 to 3 words), and then only when the new word or concept is first introduced in the manuscript; subsequent use of the same word(s) should be in regular Roman font. *QHR* does *not* use italics for emphasis, and does not use underlining for any purpose other than conversation analysis (conversation analysis does not refer to regular participant quotations). Bolded font may be used for section headings, as appropriate according to these guidelines, and (sparingly) in tables and figures.
- ·Font Style, Figures: For printing clarity and ease of reading, "sans serif" fonts are strongly recommended for figures; some common examples include Arial (this is the preferred style), Calibri, Franklin Gothic Book, Tahoma, and Verdana. It is recommended that only one font style be used in each figure, with possible variations introduced through bolding, italicizing, capitalizing, or underlining—all of which should be used *sparingly*. It is further recommended that all figures within a single manuscript be prepared with the same font style.
- ·Line Spacing: ***Everything***, in all elements of the manuscript, from the title page through the references, must be (exactly) double-spaced. The only exception is text within a figure. To set double spacing, go to Format > Paragraph > Line spacing > Double. *Do not create double spacing with hard returns* (by striking the "enter" key twice).



- Text Justification: All text should be left-justified; *do not use full justification* for any portion of your manuscript. The text at the right margin *should be uneven*.

- Paragraphs: Indent the first line of every new paragraph by .5" (1/2 inch; do not use two, .25" indentations). Do not insert additional line spaces between paragraphs, or between paragraphs and headings; *the exceptions are (a) an extra line space (hard return) between the abstract and the keywords, and (b) after (not before) each excerpt/block quotation, numbered or bulleted list, or section of conversation analysis*. Use a blank line between block quotes/excerpts if you have placed two or more in a row. *Do not add any special formatting*, such as increased line space before and after paragraphs, or before and after headings.

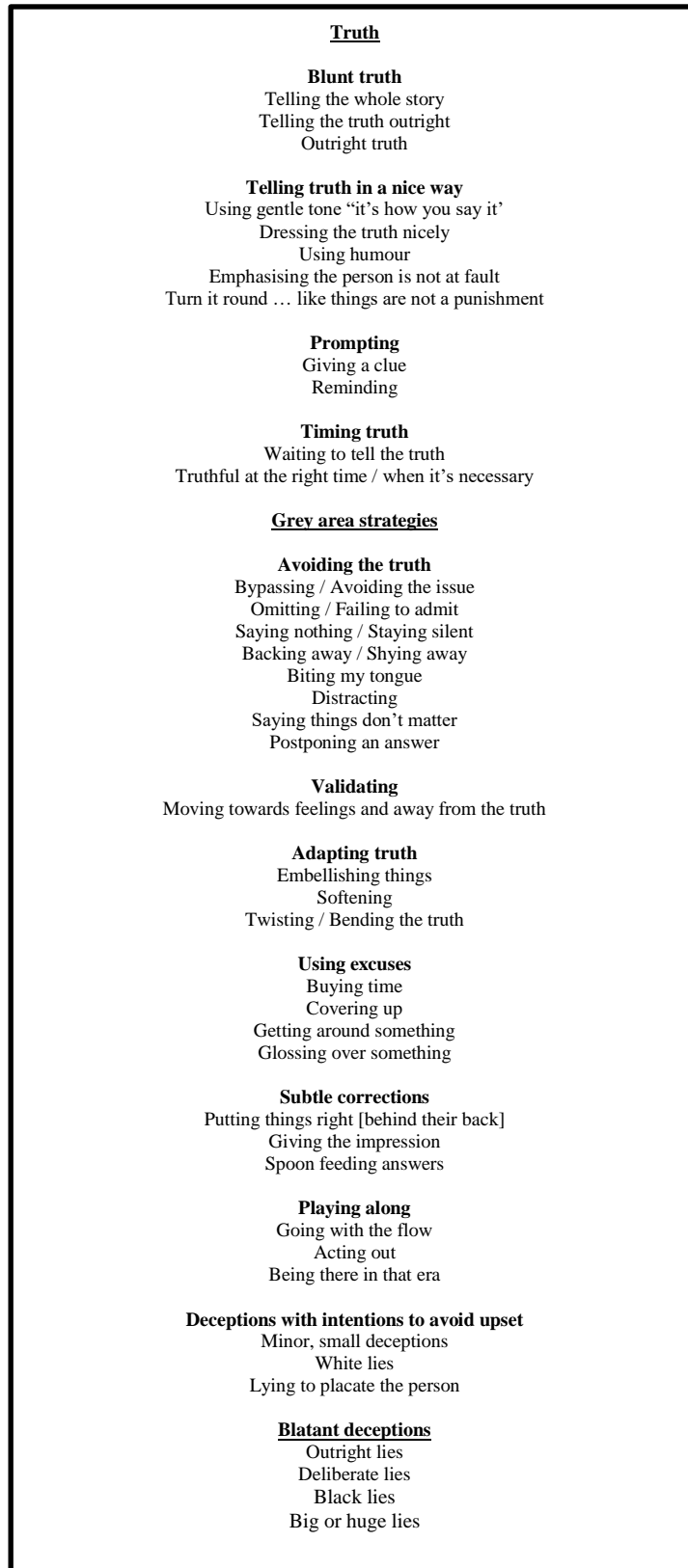
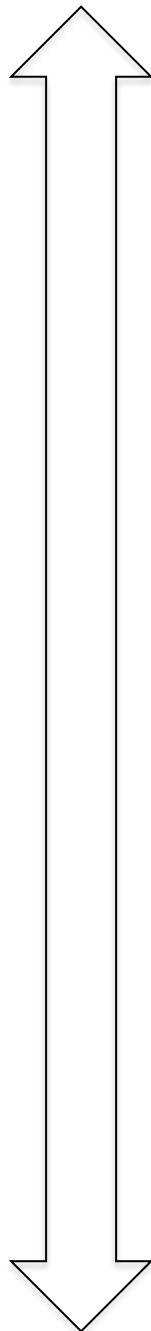
- Headings: *Do not follow APA guidelines for headings*. QHR uses 4 distinct levels of headings (H = level), including: **H1: Centered, Bold, Uppercase and Lowercase Text in Title Case** **H2: Flush Left, Bold, Uppercase and Lowercase Text in Title Case** **H3: Indented (.5")**, *Italicized, Uppercase and Lowercase Text in Title Case* **H4: Indented (.5")**, *italicized, lowercase text in sentence case and ending with a period*. At this level, the paragraph text begins immediately after the heading, instead of on the next line. Use at least two heading levels: For manuscripts with 2 heading levels, use H1 and H2 For manuscripts with 3 heading levels, use H1, H2, and **H4** For manuscripts with 4 heading levels, use H1, H2, H3, and H4

- Quotation Marks: In general, use double quotation marks (e.g., "Xxxx.") to set off quotations appearing within regular paragraphs, and to set off words being used with "special" meaning (or unusual spelling to convey special meanings within the text; e.g., "busy-ness"). In regular paragraphs, use single quotation marks to set off a quote within a quote (e.g., "Xxx, 'Yyy,' xxxx."). Do not use any quotation marks for block quotes *unless* there is a separate quote contained within the larger quote. In such a case, use double quotation marks (e.g., Xxxxxx, "Yyyy," xxxxx.) only for the separate quote within the larger quote.

- Spelling: The spelling of English words varies among the many English-speaking countries of the world. QHR is published in *U.S. English*. Use Word's spell check feature to ensure that you have used U.S. English spellings throughout your manuscript. Exceptions to this include (a) direct quotes from *written*, published material, and (b) as appropriate for titles in the reference list.

- Manuscript Length: There is no predetermined page or word limit. Provided they are "tight" and concise, without unnecessary repetition and/or irrelevant data, manuscripts should be as long as they need to be. The editor may require a reduction in length if the manuscript contains superfluous material that does not add anything useful to the topic being discussed. Limits might be imposed on the number/size/length of tables, figures, reference lists, and appendices.

**Appendix K: Continuum of strategies including examples shared by participants**



## Appendix L: Independent Peer Review approval feedback letter

Health Sciences



### INDEPENDENT PEER REVIEW APPROVAL FEEDBACK

**Researcher Name** Melissa O'Leary  
**Title of Study** Truths and lies in dementia: understanding carers' decision-making when communicating with people with dementia  
**Award Pathway** D Clin Psych  
**Status of approval:** **Approved**

Thank you for forwarding the amendments requested by the Independent Peer Review Panel (IPR)

#### Action now needed:

You must now apply to the Local NHS Research Ethics Committee (LREC) for approval to conduct your study. You must not commence the study without this second approval.

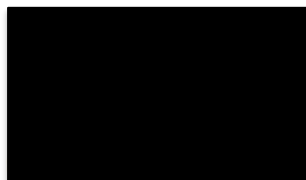
Please forward a copy of the letter you receive from the LREC by email to [HealthScienceEthics@staffs.ac.uk](mailto:HealthScienceEthics@staffs.ac.uk) as soon as possible after you have received approval.

Once you have received LREC approval you can commence your study. You should be sure to do so in consultation with your supervisor.

You should note that any divergence from the approved procedures and research method will invalidate any insurance and liability cover from the University. You should, therefore, notify the Panel of any significant divergence from this approved proposal.

When your study is complete, please send the Ethics Committee an end of study report. A template can be found on the ethics BlackBoard site.

#### Comments for your consideration:



Date: 16.06.2017

Chair of the Health Sciences Ethics Panel

## Appendix M: HRA approval letter



Miss Melissa R O'Leary  
Trainee Clinical Psychologist

Email: [hra.approval@nhs.net](mailto:hra.approval@nhs.net)



08 August 2017

Dear Miss O'Leary,

### Letter of HRA Approval

|                         |   |
|-------------------------|---|
| <b>Study title:</b>     | Truth and deception in dementia: a qualitative study of carer decision-making in the home environment |
| <b>IRAS project ID:</b> | 217300  |
| <b>REC reference:</b>   | 17/WA/0225  |
| <b>Sponsor</b>          | Staffordshire University  |

I am pleased to confirm that **HRA Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

#### Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

*Appendix B* provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. **Please read *Appendix B* carefully**, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

It is critical that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details and further information about working with the research management function for each organisation can be accessed from [www.hra.nhs.uk/hra-approval](http://www.hra.nhs.uk/hra-approval).

### Appendices

The HRA Approval letter contains the following appendices:

- A – List of documents reviewed during HRA assessment
- B – Summary of HRA assessment

### After HRA Approval

The document *“After Ethical Review – guidance for sponsors and investigators”*, issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

In addition to the guidance in the above, please note the following:

- HRA Approval applies for the duration of your REC favourable opinion, unless otherwise notified in writing by the HRA.
- Substantial amendments should be submitted directly to the Research Ethics Committee, as detailed in the *After Ethical Review* document. Non-substantial amendments should be submitted for review by the HRA using the form provided on the [HRA website](http://www.hra.nhs.uk), and emailed to [hra.amendments@nhs.net](mailto:hra.amendments@nhs.net).
- The HRA will categorise amendments (substantial and non-substantial) and issue confirmation of continued HRA Approval. Further details can be found on the [HRA website](http://www.hra.nhs.uk).

### Scope

HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found at <http://www.hra.nhs.uk/resources/applying-for-reviews/nhs-hsc-rd-review/>.

If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.

**User Feedback**

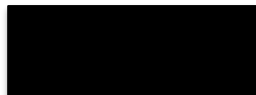
The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: <http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>.

**HRA Training**

We are pleased to welcome researchers and research management staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

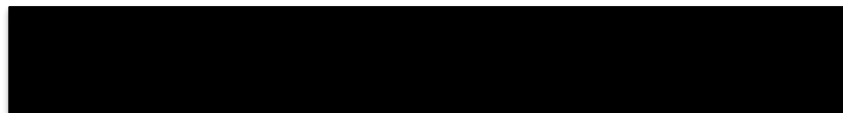
Your IRAS project ID is **217300**. Please quote this on all correspondence.

Yours sincerely



Email: [hra.approval@nhs.net](mailto:hra.approval@nhs.net)

Copy to:



Paper Three: Executive summary

**Truth and deception in dementia: a qualitative study of carer  
decision-making in the home environment**

Melissa Di Franco

Doctorate in Clinical Psychology

Faculty of Health Sciences, Staffordshire University

**Word count:** 2520

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## **Introduction**

The research described in this document focused on how family carers use truth and deception to manage everyday challenging situations when caring for a person with dementia at home. Truth refers to telling a person facts and deception refers to deliberately telling a person something untrue or acting in a misleading way to make a person believe something untrue (1, 2). For example, a person with dementia might ask to drive a car when they are no longer able to; a carer might tell the truth, “You can’t drive anymore”, use a deception like a lie, perhaps, “The car needs to be fixed”, or a deceptive act like hiding the car keys.

## **Background**

### *What is dementia?*

Dementia is the name for a number of conditions that worsen over time and are commonly identified by symptoms such as memory loss, difficulties with thinking, language and changes in behaviour. Dementia is caused when the brain is damaged by diseases, such as Alzheimer’s Disease or Vascular Dementia, which are the most common causes of dementia but not the only ones (3).

### *Caring for someone with dementia*

An estimated 850,000 people have dementia in the UK and a large number are supported by friends or family carers at home (4). Caring for someone with dementia is increasingly complicated and challenging because symptoms gradually worsen, for example, as people with dementia become increasingly confused and disorientated, carers might have to provide increasing amounts of emotional and practical support (5). Carers do not always have support to manage their caring role but should be supported to be able to carry on caring if they want to.

### *Decision-making in dementia*

Over time, people with dementia lose capacity and carers take on increased responsibility for making decisions. Situations arise when carers have to decide whether to tell a person with dementia the truth, which carers worry might cause upset and confusion, for example, reminding someone that a relative has died. Research shows that professional and non-professional carers, such as family and friends, sometimes use a deception to handle difficult situations, for example, lying about a person having died to avoid upset (6-8).

### *Truth and deception in dementia care*

In recent years there has been increasing interest in how carers of people with dementia use truth and deception to handle everyday challenging situations. Research shows that as well as using truth and deception, such as a lie, to manage challenging situations, carers use strategies that they did not define as a truth or a deception, for instance, “going along with”, “not telling” or using “little white lies”, which are for the good of the person with dementia (6-16). Such research has provided insights into why carers might use deception, for instance:

- when the truth did not work to manage difficult situations
- when people with dementia became more confused
- to achieve positive outcomes, for example, to reduce distress
- to get things done, like caring tasks or everyday jobs
- to prevent themselves from becoming upset or worn out

Research shows that carers experienced conflict in their decision-making about truth and dementia, because:

- using deception went against personal or professional morals to tell the truth
- using deception felt disrespectful to their relationship and could break trust
- there were no relevant official guidelines to support carers to make decisions

## **Aims**

Despite the increasing number of family carers who are caring for people with dementia, a lot of research on this topic is about professional carers (17), so the aims of this research were:

- To understand more about the truth and deception strategies that family carers use within everyday challenging situations when caring for a person with dementia at home
- To understand how carers make decisions about using truth or deception strategies to manage challenging situations when caring for a person with dementia at home

## **Method**

In order to find out more about carers' experiences, specifically how they make decisions about using truth or deception when caring for a person with dementia at home, a Grounded Theory approach was taken (18). This is a method that attempts to create a theory about a specific experience, for example, using truth and deception, by asking people about their personal experiences. Grounded theory methods enabled the researcher to create a new theory about the processes involved in carers' decisions to use truth and deception in everyday situations with people with dementia.

### *Recruitment*

Participants were identified through two National Health Service (NHS) dementia services in the West Midlands. The study was advertised using posters and by asking staff to identify carers with current experience of caring for a person with dementia living at home. Carers interested in participating were contacted by the researcher to arrange an interview. Interviews were carried out either on NHS premises or

participants' homes. Recruitment ended when the researcher believed that the interviews provided no new or different data.

### *Design*

The researcher gathered data in three ways:

- The researcher digitally recorded nine interviews with carers of people with dementia. During the interviews, the researcher developed ideas for a theory by asking questions to find out how carers' experiences of making decisions about truth and deception were similar or different.
- The researcher asked questions from a questionnaire called the Attitudes to Lying to People with Dementia Questionnaire (ALPD), which was used because the questions helped to find out more about carers' attitudes to truth and deception (19).
- Participants (the carers) were also asked their age, their relationship to the person with dementia, how long they have been supporting the person with dementia and the person's diagnosis. This information was collected so that the researcher could describe some of the characteristics of the carers included in the study. This information might be of interest to readers or other researchers who might want to do a similar study.

### *Participants*

Five female and three male carers took part in the study, and their ages ranged from 60 to 83 years old. Eight carers were spousal carers and one carer was an adult child. Eight carers cared for a person with Alzheimer's Dementia and one reported a Mixed Dementia diagnosis, which is when someone is diagnosed with both Alzheimer's and Vascular dementia.

### *Data analysis*

The researcher analysed the following:

- *Interviews* – The researcher transcribed each interview, by making a written copy of each digital recording. Each interview was read a number of times so that the researcher was familiar with each carer’s experience. This meant that the researcher could assign a label to every sentence, to describe what the carer was saying or what the researcher believed was happening, for instance, ‘avoiding telling the truth’, a process called coding.
- *Memos* - The researcher kept a written record of any ideas about the data as they occurred, for instance, ideas about how carers experiences fitted in or contrasted with an emerging theory of decision-making, or thoughts about how the data related to the researcher’s own ideas and personal experiences, for example, from working with people with dementia.

The researcher went back and forth between the data, selecting interview codes and memos that were most common or best described the processes involved in carers’ decisions about using truth and deception. In grounded theory this is called constant comparison (20). This process helped the researcher to decide upon a theory that best explained how carers made decisions about using truth and deception. A visual diagram, or model, to show what factors are part of the theory of carers’ decision making is given in the Appendix.

### **Key findings**

The theory that emerged from carers’ experiences in this study suggested that carers’ decision-making was influenced by their knowledge of the person with dementia, their moral beliefs about telling the truth, their understanding of dementia and their natural instinct towards caring. For example, some carers believed that they used empathy more than others, to put themselves ‘in the shoes’ of the person with dementia before making a decision about truth or deception.

The theory proposed that in everyday life, carers’ decision-making about using truth or deception was in the moment, depending upon a number of triggers, motivations and how carers weigh up a number of judgments about the person with dementia and the situation, which were variable and changed day-to-day. Triggers

were challenging situations that carers were faced with, that led to them making a decision about using truth or deception:

- Challenging questions, for example, asking for people who have died
- Increased confusion, for example, forgetting people or conversations
- Needing the person's compliance to get things done, for example, everyday tasks like attending appointments
- Having information about everyday things or upsetting things, like family bereavements, and being unsure about what to share

Carers were motivated to use any strategy, truth or deception, that led to outcomes that they desired, which included:

- Avoiding negative feelings for the person with dementia, such as upset
- Avoiding negative behaviours for the person with dementia, such as aggression
- Ensuring the person with dementia felt good about themselves
- Maintaining a positive relationship with the person with dementia
- For convenience, for example, saving time or to avoid dealing with problems, by 'making excuses' or 'bypassing' the person with dementia

Carers were more likely to use a deception, instead of truth, if they judged that:

- the truth was not important, for instance, carers believed that trivial truths like 'what day it is today' did not matter
- the truth would be upsetting, for instance, telling someone about a family bereavement
- the person with dementia would not understand or remember the truth because of increasing confusion associated with dementia
- there was any risk to the person or other people, such as risk of harm

Carers experimented with strategies in order to find what worked. They used strategies that ranged from truth to deception. Carers who told the truth generally

tried to tell the truth in a gentle way or time telling the truth to avoid causing worry. Carers who used deception, like lies, emphasised that these were ‘white lies’, to protect the person with dementia’s feelings. Carers also described strategies that avoided using truth or deception, for example, some carers chose to say nothing, or they used a distraction. Some carers told only parts of the truth that they believed would be least upsetting, which they called softening or twisting the truth. Some carers described playing along with the person with dementia, such as when people appeared to be re-living memories from their past they joined in and acted like this was reality.

### **Conclusion**

This study offers additional insight into the everyday experiences of family dementia carers and findings are comparable to previous research about truth and deception in dementia care, for example, that deceptive strategies are used when truth becomes less effective and that decision-making is a result of weighing up options in the moment. This study contributes a unique theory that names the processes that influence family carers’ decision-making about using truth or deception. Though there appear to be key processes that influence carers with a family relationship, for example, their longstanding relationship and knowledge of the person with dementia, the number of processes involved with the theory confirms that decisions about using truth and deception are complex. It is hoped that future research will develop the theory and that dementia services consider how the processes, such as empathy, experience and knowledge, can influence the design of effective interventions to support family carers.

### **Clinical recommendations**

Dementia services are often multi-disciplinary, which means that they are made up of teams of professionals, including doctors, nurses, occupational therapists and clinical psychologists. Teams should work together to implement findings from this research.

- All team members should learn from carers' in-depth knowledge of people with dementia so that decisions about care, including whether to use truth or deception, are informed by individualised, person-centred knowledge.
- Team members, especially those who make decisions about what interventions a service provides like Clinical Psychologists, should think about interventions that promote carers' empathy skills. This research suggests that encouraging carers to see things from the person with dementia's position and think about what they might need, will help them to make decisions about whether truth or deception will best meet their needs.
- Clinical Psychologists, should create opportunities for family and professional carers to come together and talk about their experiences of using truth and deception strategies in everyday life. This will give carers opportunities to support each other emotionally and develop effective strategies to use in their everyday caring role.
- All professionals should facilitate discussions with people with dementia about their wishes for their future care, which includes their preferences about the use of truth and deception. These kinds of discussions are called advanced statements and can take place at any time as long as the person with dementia has capacity to express and record their wishes. This means that carers' future decisions about using truth or deception will respect the preferences of people with dementia.

### **Research recommendations**

Decisions about truth and deception continue to challenge carers, therefore the topic warrants continued consideration.

- Future research should compare the theory proposed by this research with the experiences of other family carers, to see if this accurately represents the processes that underlie carers' decisions about truth and deception
- The carers in this study were predominantly spouses, therefore future research should consider how the decision-making processes of other family



carers, such as adult children, are similar or different to carers who are the spouse of people with dementia.

- Future research should consider how cultural differences in how dementia is managed influence decision-making processes, for instance, African-American communities believe elders should be cared for by family, therefore decision-making might reflect family discussions (23).

### **Limitations**

- Some carers might not have been able to take time away from the person with dementia to take part in an interview
- Some carers might have worried about being completely forthcoming about using deception, which is commonly seen as something morally wrong
- Despite the researcher's efforts to be neutral when analysing the data, the findings are an interpretation, therefore the reader should hold in mind that another researcher might have had a different interpretation.

### **Dissemination**

The aim is to share this research with a number of audiences, including:

- Carers who took part in the study, who might share the findings of the study with the people with dementia they care for, if appropriate
- Dementia teams where recruitment for this research took place, in order to share the outcomes of the research
- Relevant commissioners in the NHS Trust where recruitment for this research took place because these commissioners will make decisions about what support dementia services offer
- Relevant charitable organisations, like the Alzheimer's Society, who may be interested to hear about new research about dementia care
- A relevant research journal that might publish this research so that it can inform other readers and researchers.

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*Appendix:  
Truth or deception in everyday communication at home: a grounded theory model of in-the-moment decision-making by carers of people with dementia*

