Open Access

OBM Geriatrics

LIDSEN Publishing Inc.

Research Article

Key Dimensions of Therapeutic Lies in Dementia Care: A New Taxonomy

Rachel Mills [1, †], Louisa Jackman [2, †], Mithila Mahesh [1], Ian James [3, †, *]

1. Doctorate in Clinical Psychology, University of Newcastle, United Kingdom; E-Mails: Rachel.mills@ntw.nhs.uk; m.v.mahesh2@newcastle.ac.uk
2. Leeds Teaching Hospitals Trust, United Kingdom; E-Mail: louisa.jackman@nhs.net
3. Campus of Ageing and Vitality, Northumberland Tyne and Wear (NTW) NHS, Westgate Road, Newcastle upon Tyne, United Kingdom; E-Mail: IanAndrew.James@ntw.nhs.uk

† These authors contributed equally to this work.

* **Correspondence:** Ian James; E-Mail: IanAndrew.James@ntw.nhs.uk

Academic Editor: Miyako Tazaki

Special Issue: Treatment of Dementia

OBM Geriatrics
2019, volume 3, issue 1
doi:10.21926/obm.geriatr.1901032

Received: December 12, 2018
Accepted: January 30, 2019
Published: February 12, 2019

Abstract

***Background*:** Research suggests that the use of lies and deception is prevalent within dementia care settings, despite ongoing debates raised about the ethics of this approach. There has been increasing exploration of when and why deceptive practices should be used, but the lack of clarity as to what constitutes a lie has caused difficulty in ensuring that lies are used ethically. The aim of this study was to widen our understanding of the key dimensions that underpin the use of lies, and further to use this information to develop a taxonomy of lies within dementia care settings.

***Methods*:** A mixed methods approach was used for the study, which consisted of three phases: (1) obtaining examples of lies from experienced clinicians, (2) using expert advisors to standardise the examples, (3) asking independent participants to sort the examples into similarly themed groups. Hierarchical cluster analysis was used to produce clusters which led to the development of the taxonomy.

***Results*:** The results indicated that lies are mainly used in the best interests of people with dementia, often to reduce distress or manage difficult behaviour. From the developed taxonomy, there were two overarching clusters: the larger cluster was concerned with the welfare or activity of a family member/friend, and the second cluster was concerned with the welfare or activity of the person themselves.

***Conclusions*:** These results highlighted that in order to use lies appropriately it was important for caregivers to have a good understanding of the person with dementia and their life experiences. An awareness of the potential problems in using deception is key, and it is recommended that communication training should be employed to support carers in the use of therapeutic lying as a person-centred and beneficial approach. The study also shows that lies are often used to deal with the needs of PWD who are expressing concerns about the wellbeing of others. This notion of the importance of 'other-directed' needs in PWD is a new and relevant finding.

Keywords

Dementia; therapeutic lies; communication; taxonomy

1. Introduction

Recent literature suggests that lying and deception are prevalent within dementia care settings, with 96% of care staff admitting to using lies [1]. In line with the Mental Capacity Act 2005 [2], James et al. (2006) developed guidelines for staff when using lies with people with dementia (PWD) [1, 2]. Literature suggests that when lies are used in care settings, it is generally judged as beneficial for the wellbeing of the PWD, and therefore in their best interests [1, 3, 4]. Lies are employed by carers in an attempt to communicate sensitively with PWD who have become time-shifted (i.e. viewing the past as the current reality). During such times, the person with dementia may believe certain altered realities, i.e. a deceased spouse is still alive, he is still working at a job, or she is living independently at home [5]. In such situations, lies may be deemed acceptable in order to prevent unnecessary distress [6].

Blum (1994) researched the types of lies used within family homes, and developed the only taxonomy in the area [7]. Her taxonomy consisted of four main classes of deception: "going along with an incorrect assumption", "not telling," "little white lies," and "tricks" [7].

Blum's work was helpful, but limited to the views of family carers [7]. Recent studies suggested that lies used in care settings may be different [8]. Indeed, the developing literature highlighted a lack of clarity and consistency regarding the nature of therapeutic lies employed in these settings [9]; hence, the need for the current study.

Recent work suggests that therapeutic lies are consistent with Algase's (1996) notion of a 'needs-led' intervention [10]; that is a person centred intervention that attempts to meet the unmet needs of clients [11]. Therefore therapeutic lies can be regarded as person centred interventions to be used and documented in people's care plans [11]. Further, as person-centred care has become the ethos of the approaches delivered in 24hr care settings [12], it is important to further understand the types of lies being used and their roles in communication strategies. A

major review of lies as communication techniques has recently been undertaken by the Mental Health Foundation [6]. It concluded that there were five typical methods of responding to difficult questions posed by PWD: (1) telling the whole truth, (2) looking for an alternative meaning to the question and responding accordingly, (3) distracting the person from the question, (4) going along with PWD's perspectives, and (5) lying [6]. MHF recommended starting from position (1) whenever possible, and using lies as the last resort in order to prevent unnecessary distress [6].

The present study aimed to develop an empirically derived taxonomy of lies used within residential dementia care settings and to understand the key dimensions that underpin this. It is envisaged that the resulting taxonomy will be a useful tool to support the understanding of lies and could be used within care settings to develop effective communication with PWD.

2. Methods

2.1 Design

A mixed methodology was selected, enabling the researchers to obtain detailed information of participants' experiences of lies [13]. The study contained three data collection phases: (1) gathering examples of lies from experienced clinicians, (2) standardising 'examples' with support from experienced clinicians, (3) employing independent participants for a sorting task to place the 'examples' into piles of similarity. Analysis was then conducted using cluster analysis.

Phase One - The first phase consisted of a survey of lies witnessed in care home settings. The data was gathered from expert clinicians in dementia care with experience of observing lies in residential settings. They were recruited from Older Adult Challenging Behaviour Teams in Northumberland Tyne and Wear (NTW) NHS Foundation Trust. Through NTW, team managers approached clinicians to inform them of the study, and 17 participants consented to participate in this initial phase (15 female, 88%). All of these clinicians regularly worked into care homes with PWD, with a range of experience of 37-151 months working into such settings. Participants were asked to provide examples of lies that they had witnessed being told to PWD by care staff in residential homes. They were asked to record the lies using a specific format, to ensure that the required data was gathered from each lie. Participants were asked to describe: the situation requiring a lie, what was said, and the perceived intention of the liar. Each participant provided two to three examples, generating a total of 45 examples of lies.

Phase Two - The second phase consisted of content revision of the 45 examples by expert advisors, to standardise material in preparation for the sorting task in Phase Three. Two local female clinicians, different to those recruited in Phase One, were recruited as expert advisors from Older Adult services in the North East of England. Inclusion criteria was that participants had experience in the subject matter, but were not working within NTW Challenging Behaviour services. The expert advisors discussed standardising the examples with consideration toward relevant information required for unbiased sorting. The expert advisors also provided advice on whether data saturation had been achieved from the 45 examples.

Phase Three - The third phase included a sorting task in which participants were asked to read through the 45 examples and sort them into piles of perceived similarity. Trainee clinical psychologists from the Newcastle University Clinical Psychology Doctorate course were contacted by course directors via email with information regarding the current study. Following this, 10

trainees consented to participate (8 female). Inclusion criteria required trainees to have completed a placement within Older Adult services so they had experience in dementia care. Participants were asked to sort the lies into piles which were similar to each other in some way. Participants were asked to describe why lies had been placed in each pile, and to attach a concise label to each pile.

2.2 Analysis

A proximity matrix was developed from the piles provided by participants in Phase Three. This was done by calculating how often each lie was paired with each of the other 44. This process produced a number between 0 to 10 (0 being never paired, 10 being paired by all participants) in each column, showing how many times each lie had been paired with another (i.e. lie 1 with lie 34).

Hierarchical cluster analysis was employed. Analysis was conducted using the SPSS software program (Statistical Package for the Social Sciences; IBM, 2015). The cluster method used was average/between groups' linkage along with an interval measure of Euclidean distance.

2.3 Ethics

The project was approved by Newcastle University Faculty of Medical Sciences Ethics Committee and was registered with Northumberland Tyne and Wear Mental Health Trust Research and Development Department on 25th May 2016.

3. Results

Table 1 illustrates the variety of situations (and frequency) that lies occurred. From the 45 examples provided, 80% of situations were related to disorientation (to time and/or place) of the PWD. In addition, over half (64%) lies were related to the PWD being concerned for/about another person (i.e. wanting to collect their 'grown-up' children from school, asking for deceased parents).

Table 2 demonstrates the perceived intention of the liar as judged by the clinicians providing the examples in Phase One. In some situations, there was more than one perceived intention (i.e. to reduce distress when meeting personal care needs). 96% of intentions were in the best interest of the PWD, 4% were perceived to be for the benefit of someone else (i.e. to reduce distress of family). There were no instances in which phase 1 participants judged carers to be employing lies for their own benefit.

Phase 1 participants revealed that 13 of the 'examples' of lies were included in a care plan for the PWD.

Table 3 shows the results of the cluster analysis. There were two primary clusters, with five sub-clusters within these. After examination of lies in these clusters, themes were extrapolated. Labels were assigned to each of the five sub-clusters to categorise the type of lies incorporated within each cluster. These labels were given by the first author, with guidance from the co-authors, and were not obtained directly from 'wording' from the data sets.

Table 1 Overview of examples of situations where lies were used in care homes.

Situation that triggered lie	Examples of lies	Frequency of occurrence	Percentage (%)
PWD wants to see/contact deceased relative	Resident pacing, dressed to go out and asking to go and see her mother (deceased)	15	33
PWD believes their children are still school-age	Resident wanting to leave care home to pick up children from school	7	16
PWD wants to see or contact family	Resident repeatedly requesting to telephone wife (several times daily)	5	11
PWD not allowing staff to provide personal care	Resident requesting to telephone wife (several times daily)	4	9
PWD believes they are still employed and wants to go to work	Resident thinking she still had to go to work every day, trying to leave care home	4	9
Delusion relating to perception of objects	Resident had a toy cat – he interacted with the cat as though it was a living pet; feeding it food from the dining table, naming it.	4	9
PWD believes they still live at their previous home and wishes to return	Resident wanting to go home (no longer lives at home, permanent resident in a care home)	3	7
PWD believed themselves to be a prisoner in the care home	Resident becoming agitated/aggressive as asking to use phone to contact police as being kept as a prisoner	2	4
Visiting family were leaving	Family were leaving and the resident was becoming distressed	1	2
		45	**100**

Table 2 Overview of perceived intentions of lies from Phase one participants.

Perceived intention	Frequency	Percentage (%)
Reduce agitation of the PWD	27	37
Provide reassurance to the PWD	15	21
Management of BtC of the PWD	14	19
To reduce anxiety/worry of the PWD	10	14
To ensure that personal care needs of the PWD were met	4	5
To reduce distress of a relative of the PWD	3	4

Table 3 Categories of lies developed from analysis in Phase three.

Primary Cluster Separation	Sub-cluster – category label	Explanation	Examples of lies included	Perceived Intention of type of lie
1 Non-client related (lies concerning actions or well-being of another person)	**1.1 Delayed fulfilment of request**	Putting off requests by the client to see a person (often deceased)	"Your dad is coming to get you at 9.30am tomorrow"	Reducing immediate distress and managing subsequent BtC.
	1.2 Providing reassurance of well-being	Assuring client that a specific person is safe, when often deceased (or now grown children)	"The bairns are at school and will be home soon, they're safe"	Reducing distress by providing reassurance to the PWD that the person in question is safe.
	1.3 Explanation for absence	False account of where an (often deceased) relative is	"Your mam's not at home at the moment, she's gone to the shops"	Reducing distress and managing of BtC (i.e. aggression) were intentions. This type of lie uses a more direct (and less reassuring) mechanism for care staff to diffuse a difficult situation.
2 Client related (lies concerning activity or well-being of the client)	**2.1 Enactment**	Performing a false role or story to match the client's reality	Staff engaged with toy cat as though it were real, e.g. putting food out for it at request of resident "No need to go to work this morning, you're on holiday."	Meeting PWDs' personal care needs, and reducing their anxiety and behaviours such as wandering.
	2.2 Fobbing off	Excuses as to why something can't happen	"You can't use the phone because its broken"	Used for the benefit of others, rather than for the PWD, employed to reduce distress for visiting relatives.

3.1 Non-Client Related (Lies Concerning Actions or Well-Being of Another Person)

The key emerging theme was that all of the lies were used to assuage distress and anxiety resulting from disorientation of the PWD regarding the current status of someone important to them, i.e. whereabouts of a deceased family member. This was the larger of the two primary clusters.

3.1.1 Delayed Fulfilment of Request.

The five lies in this cluster concerned the PWD being told that a fictitious event would be occurring. These events were all linked to requested contact with a relative (often deceased), where the PWD was told that they would see that person at a specified time in the near future.

3.1.2 Providing Reassurance of Well-Being

The eight lies in this cluster related to reassuring the PWD of the safety and whereabouts of a relative they were concerned about (often already deceased or now grown children). In these cases, the PWD's distress were underpinned by a belief that they still held caring roles for the relative in question, and their absence meant they were not protecting and/or ensuring their safety.

3.1.3 Explanation of Absence

The nine lies in this category also linked to the PWD's anxiety and concerns related to the whereabouts of a relative, but the lies employed in these situations lacked the element of safety reassurance of the previous sub-cluster.

3.2 Client Related (Lies Concerning Activity or Well-Being of the Client)

Lies within this cluster were concerning issues regarding the PWD themselves rather than someone else, i.e. completion of personal care needs, or believing that they were still employed in their previous jobs. Situations requiring lies were related to disorientation of the PWD and consequent distress, but not in relation to a third person.

3.2.1 Enactment

The eight examples of lies here were the most varied regarding the approach used by care staff, but all encompassed a similar theme. Staff appeared to engage in the reality of the PWD to a greater degree in order to meet any of the specific needs of the PWD. For example, informing a PWD who wanted to go to work that he was on holiday.

3.2.2 Fobbing Off

The nine examples of lies in this cluster appeared to demonstrate less engagement with the subjective reality of the PWD, unlike the previous sub-clusters. These examples concerned the PWD wanting something (i.e. to use the telephone, looking for their car) and being given false information and/or promises to quickly 'shut down' the request. This is the only sub-cluster where

the use of lies were for the benefit of others (e.g. for visiting relatives) rather than the PWD directly. The term 'fobbing off' was devised by the first author as she felt it best explained the theme; however, it was not a term that came up in vivo from the data.

4. Discussion

This study examined the key dimensions that underpin the use of lies in dementia care settings with the aim of developing a taxonomy of these lies. The majority of the situations in which care staff felt that deception was required was linked to the issue of disorientation of the PWD, and the disparity between their subjective reality and current reality. Within this disorientation, situations where deception was used were largely related to misplaced beliefs by the PWD, such as asking for deceased relatives. These findings support previous literature examining situations in which lies are often employed with PWD [14].

Perceived intentions of care staff when using lies with PWD were varied, but the reduction of agitation was judged to be the major theme, alongside providing reassurance, managing BtC and reducing anxiety of the PWD. These results suggest that for the most part, phase one participants perceive that care staff use lies to enhance well-being of the PWD with their best interests in mind; therefore, these types of lies could be viewed as therapeutic [3, 4, 15].

For the small proportion of lies that were judged as less therapeutic or beneficial, perceived intentions were management of either BtC or the distress of relations. The only concerning category that emerged in the cluster analysis was 'fobbing off,' which suggested there were a category of lies used for the carers' benefits. Fobbing-off is likely to reflect the busy caregiver attempting to avoid complex interactions and explanations in order to allow themselves to get on with their own work. This notion would be consistent with anecdotal evidence of environments termed 'task focused cultures.'

It was argued in a previous study that those lies that can be regarded as 'therapeutic' should be termed 'person-centred' [16] because the lies are attempting to enhance the wellbeing of people with dementia. In the same article it was argued that staff should be trained to deliver therapeutic lies which meet the needs of PWD [16]. This needs-led approach to interventions is highlighted in many of the national dementia strategies [17]. However, when needs-led interventions are normally discussed, the foci of the need is always the person with dementia. Interestingly, the present study suggests that clinicians should throw their nets wider when using needs-led perspectives, taking account of the person's perceived needs of 'others' (ie. family and friends). An awareness of this feature is crucial because it is the PWD's concerns about the wellbeing of others that seem to be activating their queries and possible distress that ultimately lead to the use of lies.

Despite the use of lies in dementia care remaining controversial [18, 19], growing literature indicates that it is prevalent in these settings [1]. The findings of the current study suggest potential clinical implications around the use of lies. Firstly, in order to use lies in a person-centred way, care staff need to have a good understanding of the PWD and their unique experiences [20]. It may be beneficial for care home management to ensure that any use of lies are discussed and agreed upon within their clinical team as well as are fully documented and used consistently through use of care planning [6]. The current study found that a large proportion of lies relied on the PWD being unable to remember information at a later date; however, as awareness can fluctuate in PWD [6, 21] this should not be assumed. As communication is deemed one of the

most important factors in provision of quality care [22], it may be useful for staff to receive specific training on the use of lies [23]. James and Caiazza have shown that clinical psychologists have particular skills in delivering such training programmes [16].

Though the developed sub-themes were in line with Blum's results [7], our taxonomy suggests two larger meta-themes: non-client related (lies concerning actions of well-being of another person i.e. family member); and client related (lies concerning actions of well-being of the PWD). This difference in findings may reflect the difference in settings in which the studies were conducted. Indeed, because the Blum study was conducted in family settings, there may have been less of a need for the PWD to enquire about the whereabouts of their family members [7]. Therefore, future directions may involve recruiting participants across a variety of health care settings and other environments, i.e family homes, to validate examples provided from the current study's taxonomy and understand if they are applicable and generalizable to other populations.

A major strength of the study was that the methodology used enabled inclusion of information regarding PWD in the later stages of the disease; a population who are often excluded from research [24]. Since, it is in the later stages of dementia that people are more likely to be lied to [25], it is important for this population to be represented within research on deception. The various limitations in the current study must also be noted. For example, the first phase of data collection was based on clinicians' responses, the accuracy of which obviously cannot be cross-checked. Additionally, though the current study maintained high standards of anonymity when collecting data, there could still have been a potential response bias in reporting because the clinicians may have been worried about being identified owing to the small number of participants. Therefore this may have led some clinicians to omit reporting of instances when lies were used when working with PWD. For instance, participants may have omitted examples of poor practice. In terms of analysis, the deterministic quality of hierarchical cluster analysis prevents reassessment after items are grouped together and clusters can be difficult to define if no clear separation exists [26], which was an issue within this study. As a result, identification of clusters relied on a subjective interpretation of the dendogram leaving results open to unconscious bias.

Owing to some of the concerns mentioned above about the biases in the use of 'reported' data, in the next phase of our work we are attempting to observe lies being used in-vivo. A Northumbria University PhD. student/qualified mental health nurse is currently collecting 'live' data as part of her postgraduate degree, and will be reporting her findings in the next two years.

5. Conclusions

This study explored the key dimensions underpinning the use of lies in dementia care settings to develop a taxonomy of lies. Findings indicated that lies are primarily used in the best interests of disoriented PWD, largely aiming to improve well-being by reducing distress and BtC. However, there were a group of lies which involved PWD being 'fobbed-off,' perhaps in an attempt to save carers' time and resources. The taxonomy identified two overarching clusters concerning the welfare of others and that of the PWD, containing five sub-clusters between them. The identified sub-clusters demonstrated the importance of understanding the unique perspective and experiences of each PWD, and how this can be used when employing lies.

Acknowledgments

The authors wish to thank the participants of this study, and the staff of the Doctorate Course in Clinical Psychology, University of Newcastle who assisted with the development of the original proposal.

Author Contributions

Rachel Mills prepared the study for ethics, collected and analysed the data, and submitted a version of the study for her doctoral thesis.

Louisa Jackman contributed to the theoretical ideas and supervised the project.

Ian James had the original idea for the study and supervised the project.

Mithila Mahesh assisted with revisions to the original thesis, and undertook the editing and preparation for submission.

Funding

This project was undertaken in part fulfilment of the Doctorate in Clinical Psychology, and no funding was sought.

Competing Interests

The authors have declared that no competing interests exist.

References

1. James IA, Wood-Mitchell AJ, Waterworth AM, Mackenzie LE, Cunningham J. Lying to people with dementia: Developing ethical guidelines for care settings. Int J Geriatr Psych. 2006; 21: 800-801.
2. The Stationery Office Limited. Mental Health Capacity. London: Queen's Printer of Acts of Parliament. 2005. https://www.legislation.gov.uk/ukpga/2005/9/contents
3. Tuckett AG. Stepping across the line: Information sharing, truth telling and the role of the personal carer in the Australian nursing home. Qual Health Res. 2007; 17: 489-500.
4. Tuckett AG. The experience of lying in dementia care: A qualitative study. Nurs Ethics. 2012; 19: 7-20.
5. Gibbons L, Keddie G, James IA. Investigating the phenomenon of time-shifting. Aust J Dement Care. 2018; 7: 32-34
6. Kirtley A, Williamson T. What is truth? An inquiry about truth and lying in dementia care. Mental Health Foundation. 2016. www. mentalhealth.org.uk.
7. Blum NS. Deceptive practices in managing a family member with Alzheimer's disease. Symbolic Interaction. 1994; 17: 21-36.
8. James I, Jackman L. Understanding Behaviour in Dementia that Challenges, Second Edition. London: Jessica Kingsley Publishers. 2017.
9. Caiazza R, James IA. Re-defining the Notion of the Therapeutic Lie: Person-centred Lying. FPOP Bulletin: 2015. 2015.

10. Algase DL, Beck C, Kolanowski A, Whall A, Berent S, Richards K, et al. Need-driven dementia compromised behaviour: An alternative view of disruptive behaviour. Am J Alzheimers Dis. 1996; 11: 12-19.
11. O'Conner E, Caiazza R, James I. Use of the needs hierarchy framework to assist with the telling of person centred lies. J Dement Care. 2017; 25: 22-25.
12. Brooker D. What is person-centred care in dementia? Rev Clin Gerontol. 2003; 13: 215-222.
13. Michie S, Richardson M, Johnston M, Abraham C, Francis J, Hardeman W, et al. The behavior change technique taxonomy (v1) of 93 hierarchically clustered techniques: Building an international consensus for the reporting of behavior change interventions. Ann Behav Med. 2013; 46: 81-95.
14. Kartalova-O'Doherty Y, Morgan K, Willetts A, Williamson T. Dementia – what is truth? Exploring the real experience of people living with more severe dementia. Mental Health Foundation. 2014.
15. McElveen T. Lying to people with dementia: treacherous act or beneficial therapy? Royal College of Psychiatrists, e-newsletter (September). 2015.
16. James IA, Caiazza. Untruths in dementia care: ethical decision making process. Signpost: J Dement Mental Health Care of Older People. 2016; 22: 6-9.
17. Pini S, Ingleson E, Megson M, Clare L, Wright P, Oyebode JR. A needs-led framework for understanding the impact of caring for a family member with dementia. Gerontologist. 2018; 58: e68-e77.
18. Edwards P. Lies, damned lies and dementia. J Dement Care. 2008; 16: 14.
19. Wood-Mitchell A, Waterworth A, Stephenson M, James I. Lying to people with dementia: Sparking the debate. J Dement Care. 2006; 14: 30-31.
20. Caiazza R, James IA. Re-defining the notion of the therapeutic lie: Person-centred lying. FPOP Bulletin: 2015. 2015.
21. Woods B, Pratt R. Awareness in dementia: Ethical and legal issues in relation to people with dementia. Aging Ment Health. 2005; 9: 423-429.
22. James IA. The use of CBT in dementia care: A rationale for Communication and Interaction Therapy (CAIT) and therapeutic lies. Cogn Behav Therapist. 2015; 8: e10.
23. James IA, Caiazza R. Therapeutic lies in dementia care: Should psychologists teach others to be person-centred liars? Behav Cogn Psychother. 2018; 46: 454-462.
24. Wilkinson H. The perspectives of people with dementia: Research methods and motivations. Jessica Kingsley Publishers. 2001.
25. Day AM, James IA, Meyer TD, Lee DR. Do people with dementia find lies and deception in dementia care acceptable? Aging Ment Health. 2011; 15: 822-829.
26. Augen J. Bioinformatics in the post-genomic era: Genome, transcriptome, proteome, and information-based medicine. Addison-Wesley Professional. 2004.

Enjoy *OBM Geriatrics* by:

1. Submitting a manuscript
2. Joining in volunteer reviewer bank
3. Joining Editorial Board
4. Guest editing a special issue

For more details, please visit:
http://www.lidsen.com/journals/geriatrics