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# Where are the children? An autoethnography of deception in dementia in an acute hospital

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**Where are the children? An autoethnography of 'deception in dementia' in an acute hospital**

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Manuscripts

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3 **Where are the children? An autoethnography of *deception in dementia* in an acute**  
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5 **hospital**  
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10 **Abstract**  
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12 An acute hospital environment is a confusing place for many patients requiring admission,  
13 especially when they are presenting as acutely unwell. This can be particularly difficult for  
14 people living with dementia. As cognition changes it is not uncommon for people living with  
15 dementia to have difficulties with their ability to orientate to time, place and person. These  
16 disorientating moments can lead to personal distress, and at times behavioural changes. As  
17 well as being distressing for the person living with dementia, it can also be emotionally and  
18 ethically challenging for acute hospital staff; including nurses. One area found to be  
19 particularly challenging is the concept of whether actively engaging with a person living with  
20 dementia's *living truth* is deceitful. This raises further questions of what forms of nurse  
21 responses to temporal disorientation might be constituted as a lying, colluding, or  
22 alternatively validating. This article uses autoethnography as a research methodology in  
23 which to explore a mental health nurse's lived experience of the challenges of responding  
24 *truthfully* to disorientation and distress in an acute hospital. This article is not attempting to  
25 offer conclusive answers to these challenging ethical questions. It is instead re-opening and  
26 re-visiting the discourse of what is *truth in dementia* from a personal and professional nurse  
27 perspective through a *lived narrative*. The conclusion to the concept of *truth in dementia* is  
28 complex, nuanced and individualised. However, it is essential that a nurse's response to  
29 disorientation and distress is always 'person focused', and not 'lie focused'.  
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54 **Keywords**  
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56 Dementia, Truth, Deception, Nursing, Care.  
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### Introduction to truth and deception in dementia

To consider the question of what is truth when caring for someone living with dementia one must first consider where time fits into the *truth concept*? Truth is often described as an objective and absolute everlasting singular fact or reality. Therefore, all opposing opinion must be false, or somehow and lie which is set out to deceive. However, this is not how many of us view the world. Our subjectivity allows us to change and grow, to become new, and to see the world in a different light. Deleuze writes that “philosophy creates concepts which are neither generalities nor even truths; they are rather of the order of the Singular, the Important, the New”.<sup>1</sup> As time changes, as does our concept of truth. Whether there is deception taking place is very much contextualised by a formulation of *Other* judgement. This leads to the question; is the observer of the perceived perpetrator of untruths driven by a will to judge, or by a will to create and formulate a new understanding?<sup>2</sup>

The use of deception in dementia across caring environments raises personal, professional and larger societal ethical questions and conundrums. Therefore, the topic is often difficult to address, challenge, or even discuss, and therefore never quite reaches an answer to the morality of its use<sup>3</sup>. Again, much of this indecision is down to the belief that deception is based upon lying to others as a direct act of maleficence in order to achieve some form of self-beneficence. In fact the majority of findings on studies into deception in dementia have concluded that the clinical decision of whether the perceived deceit was intentional, in the

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<sup>1</sup> Deleuze, G., & Lapoujade, D. (2006). *Two regimes of madness: Texts and interviews 1975-1995*. Los Angeles, CA: Semiotext (p.238)

<sup>2</sup> Smith, D. W. (2013). *Temporality and Truth*. *Deleuze Studies*, 7 (3): 377-389. doi:10.3366/dls.2013.0118

<sup>3</sup> Turner, A. Eccles, F. Keady, J. Simpson, J. & Elvish, R (2017)The use of the truth and deception in dementia care amongst general hospital staff, *Aging & Mental Health*, 21:8, 862-869, doi: 10.1080/13607863.2016.1179261

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3 person's best interest, or indeed ethically justifiable came down to time, place, and person  
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5 specifics, and the overall judgement of the observer.<sup>4</sup>  
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10 Dementia describes a set of cognitive symptoms that due to a decline in brain function affects  
11 our capacity to think, remember, problem solve, and at times communicate. All of which can  
12 impact significantly of our day to day functioning. However, dementia is more than that, it is  
13 a subjective lived experience which draws upon transient and experiential "lived times".<sup>5</sup>  
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18 These *lived times* can only be understood on a subjective temporal and emotional level, rather  
19 than through an objective *fact based* prism.<sup>6</sup> Although complex, and often neuro-specific, it is  
20 not uncommon for people living with dementia to have *lived event* chronology and other  
21 temporal challenges. Therefore, the theme this article explores is the nursing challenge of  
22 whether it is deceitful to assist a person living with dementia to reside in their *lived time*, in  
23 contrast to orientating them to an objective clinical hospital reality.  
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### 35 **Background**

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37 "People with dementia are more frequently admitted to hospital than those without dementia,  
38 independent of physical comorbidities".<sup>7</sup> Not only has there been a marked increase of  
39 hospital admissions for people living with dementia but the average length of stay has also  
40 become more protracted.<sup>8</sup> An acute or emergency hospital admission for a person living with  
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49 <sup>4</sup> St Clair Tullo, E., Lee, R. P., Robinson, L. & Allan, L. (2015) Why is dementia different? Medical students'  
50 views about deceiving people with dementia, *Aging & Mental Health*, 19:8, 731-738, doi:  
51 10.1080/13607863.2014.967173

52 <sup>5</sup> Van Manen, M. (1997). *Researching lived experience: Human science for an action sensitive pedagogy*.  
53 London, ON: The Althouse Press. (p. 101)

54 <sup>6</sup> Førstund, L. H., Grov, E. K., Helvik, A., Juvet, L. K., Skovdahl, K., & Eriksen, S. (2018). The experience of  
55 lived space in persons with dementia: A systematic meta-synthesis. *BMC Geriatrics*, 18(1). doi:10.1186/s12877-  
56 018-0728-0

57 <sup>7</sup> Shepherd, H., Livingston, G., Chan, J., & Sommerlad, A. (2019). Hospitalisation rates and predictors in people  
58 with dementia: A systematic review and meta-analysis. *BMC Medicine*, 17(130). doi:10.1186/s12916-019-  
59 1369-7 (p.1)

60 <sup>8</sup> Torjesen, I. (2020). Figures show big increase in emergency admissions for dementia patients. *BMJ*, m249.  
doi:10.1136/bmj.m249

dementia brings with it a multitude of challenges. These include their ability to navigate around the setting and orientate oneself to time, place and person.

These challenges are often made even more difficult when co-morbid issues such as pain, acute illness, and secondary delirium arise.<sup>9</sup> It is important to understand that alongside any acute or chronic physical or cognitive disease or illness, the hospital environment itself can also be disorientating for the person living with dementia. Environmental factors such as lighting, noise, and a lack of stimulating activity can lead to increased confusion, which can in turn can trigger changes in behaviour.<sup>10</sup> These changes to behaviour arise as the person draws on their unique history and *lived experiences* to make sense of the setting they find themselves in.<sup>11</sup> Any unsuccessful attempts to orientate to the new environment can interrupt long established psychosocial coping mechanisms, whilst also reigniting negative past experiences.<sup>12</sup>

## Methodology

I have chosen autoethnography as a reflexive *first-person* methodology to consider the ethical and moral topic of *deception in dementia*. Autoethnography is a qualitative research methodology that systematically analyses personal lived experiences in order to understand cultural experiences.<sup>13</sup> It is a form of storytelling; a “narrative inquiry that provokes

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<sup>9</sup> Clissett, P., Porock, D., Harwood, R. H., & Gladman, J. R. (2013). The challenges of achieving person-centred care in acute hospitals: A qualitative study of people living with dementia and their families. *International Journal of Nursing Studies*, 50 (11): 1495-1503. doi:10.1016/j.ijnurstu.2013.03.001

<sup>10</sup> Scales, K., Zimmerman, S., & Miller, S. J. (2018). Evidence-Based Nonpharmacological Practices to Address Behavioral and Psychological Symptoms of Dementia. *The Gerontologist*, 58 (suppl\_1): S88-S102. Doi:10.1093/geront/gnx167

<sup>11</sup> Wicker, A. W. (2011). Perspectives on Behavior Settings. *Environment and Behavior*, 44(4), 474-492. doi:10.1177/0013916511398374

<sup>12</sup> Rouch, I., Dorey, J., Boublay, N., Henaff, M., Dibie-Racoupeau, F., & Krolak-Salmon, P. et al., (2014). Personality, Alzheimer’s disease and behavioural and cognitive symptoms of dementia: the PACO prospective cohort study protocol. *BMC Geriatrics*, 14 (1). doi:10.1186/1471-2318-14-110

<sup>13</sup> Ellis, C., Adams, T., & Bochner, A. P. (2011). Autoethnography: An Overview. *Forum: Qualitative Social Research*, 12 (1): 35–43. Retrieved from: <http://nbn-resolving.de/urn:nbn:de:0114-fqs1101108>

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2  
3 identification, feelings, emotions, and dialogue”<sup>14</sup>. It actively invites the reader to consider  
4  
5 their own meaning and understanding of the narrative presented. To do this I refer to an  
6  
7 incident that took place in my role as a mental health liaison nurse in a large general hospital.  
8  
9 The name of the patient in the chosen vignette is a pseudonym in order to respect and protect  
10  
11 their identity and dignity. The narrative offered is a self-reflexive account of an incident  
12  
13 where it could be argued that *deceptive practice* was present. The vignette is a reflection of  
14  
15 my thoughts, feelings, and actions as a nurse. Due to the nature of my chosen methodology  
16  
17 my article will be written and presented in the first person.  
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### 24 **The role of liaison psychiatry in an acute hospital**

25  
26 One of my roles within the hospital required that I visit wards to offer advice on how  
27  
28 *confused patients* (often due to dementia and delirium) might be *managed*. A role which was  
29  
30 activated by referrals with covert, or at times extremely overt messages, of; *we need to*  
31  
32 *control this situation*. These messages were more often than not sent by senior medical and  
33  
34 nursing staff, who were openly *uncomfortable* with their ward routine being disrupted by  
35  
36 these subjectively judged *unruly* patients. Medical and nursing staff in general hospitals  
37  
38 report a lack of confidence in not only treating, but also understanding and communicating  
39  
40 with patients who present with confusion due to dementia and / or delirium.<sup>15</sup> This lack of  
41  
42 confidence and competence often leads to the request for support from *so-called* specialist  
43  
44 colleagues; which includes the consultation of liaison psychiatry.<sup>16</sup> I never really saw this as a  
45  
46 clinical speciality, but more a humanistic necessity. Without valuing and validating that  
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53 <sup>14</sup> Maréchal, G. (2010). Autoethnography. In A. J. Mills, G. Durepos, & E. Wiebe (Eds.), *Encyclopedia of case*  
54 *study research* (pp. 44-45).

55 <sup>15</sup> Griffiths, A., Knight, A., Harwood, R., & Gladman, J. R. (2014). Preparation to care for confused older  
56 *patients in general hospitals: A study of UK health professionals*. *Age and Ageing*, 43(4), 521-527.  
57 doi:10.1093/ageing/aft171

58 <sup>16</sup> Mujic, F., Cairns, R., Mak, V., Squire, C., Wells, A., Al-Harrasi, A., & Prince, M. (2018). Liaison psychiatry  
59 *for older adults in the General Hospital: Service activity, development and outcomes*. *BJPsych Bulletin*, 42(1),  
60 30-36. doi:10.1192/bjb.2017.9

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3 person's experience we are at risk of depersonalising them, leading to a "deterioration in  
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5 human relations"<sup>17</sup> which cannot be fully recovered.  
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### 10 **Where are the children?**

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12 Following one these *call to arms*, I arrived on the ward to find Mr Jones behind the  
13  
14 electronically locked door, surrounded by nursing staff who were trying to direct her away,  
15  
16 and back toward her hospital bed. Getting into the ward required what amounted to a stealth  
17  
18 like manoeuvre; a swift swipe of my key card, a crab like sidling shuffle through the  
19  
20 miniscule gap, whilst always keeping one eye on Mrs Jones in an attempt to protect her from  
21  
22 coming to any harm as she attempted to make her escape.  
23  
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27

28 *Mrs Jones was getting very irritated, bordering angry; "let me go, I need to get out" she said*  
29  
30 *as I entered the ward. Mrs Jones was a 78-year-old woman. She was dressed conservatively*  
31  
32 *in a black skirt, a white blouse with a pearl necklace and a beige cardigan (although all her*  
33  
34 *clothes were now a little unkempt). She stood upright with a sense of position and pride, and*  
35  
36 *spoke eloquently, although by this time was a little flustered and distressed.*  
37  
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41

42 People living with dementia are in my mind time travellers who are living a non-sequential  
43  
44 storyline made up of their lived experiences. This unpredictable story is often prompted by  
45  
46 emotionally significant events<sup>18</sup> arising from a *pure past* that unintentionally enters their  
47  
48 *living present*.<sup>19</sup> Tom Kitwood presented a concept in which we have two aspects to our self  
49  
50 and being, one that is made up of our experiences and feelings; the other that has been  
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56 <sup>17</sup> Kimura, H., Tamoto, T., Kanzaki, N., & Shinchi, K. (2011). Burnout and Characteristics of Mental Health of  
57 Caregivers of Elderly Dementia Patients. *Journal of Rural Medicine*, 6(2), 47-53. doi:10.2185/jrm.6.47 (p.52)

58 <sup>18</sup> Mackenzie, L., Smith, K. & James, I. (2015) How a time machine concept aids dementia care. *Nursing Times*.  
59 22-28;111(17):18-21.

60 <sup>19</sup> Deleuze, G. (1994). *Difference and Repetition*. (Patton, P. Trans). New York: Columbia University Press.



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3 contextually adapted by our societal position and roles, and our abilities to cope in any given  
4  
5 situation. This *self* is highly and tightly socialised, particularly in relation to the performing of  
6  
7 given roles.<sup>20</sup> Mrs Jones was clearly drawing on her *lived experiences*, but her *adapted self*  
8  
9 was front and centre for anyone who wanted to take notice.  
10  
11

12  
13  
14 *I looked directly at her and said, "Mrs Jones are you a teacher" (I just had a sense). "Head*  
15  
16 *teacher my dear", came the response, "Do I know you"? I introduced myself to Mrs Jones*  
17  
18 *and explained my role. However, none of my explanation either orientated or assured Mrs*  
19  
20 *Jones that she need not worry. However, Mrs Jones was worried. She was concerned that the*  
21  
22 *children had not returned from the school trip, and she needed to get out to find them.*  
23  
24 *Looking directly at me with a fixed gaze she said, "All I want to know is; where are the*  
25  
26 *children"? I suggested we take a walk, in my mind as a distraction, but also as a validation*  
27  
28 *of Mrs Jones emotional distress and 'living present'... I had consciously become part of Mrs*  
29  
30 *Jones's search party.*  
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### 38 **Deception or validation: Where are the children?**

39  
40 Validation therapy is a recognised and person-centred approach to managing confusion for  
41  
42 people living with dementia,<sup>21</sup> which in principle accepts, and does not challenge, the person  
43  
44 living with dementia's personal truth, experience, or current reality.<sup>22</sup> It instead validates their  
45  
46 experience by exploring their underlying emotional need by being non-judgemental and  
47  
48 active listening to the person. However, attempts to offer a justification and firm evidence for  
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56 <sup>20</sup> Kitwood T. (1997). *Dementia Reconsidered: The Person Comes First*. Buckingham: Open University Press.

57 <sup>21</sup> Belser-Ehrlich J. & Bowers D. (2019) Validation Therapy. In: Gu D., Dupre M. (eds) *Encyclopedia of*  
58 *Gerontology and Population Aging*. Springer, Cham. [https://doi.org/10.1007/978-3-319-69892-2\\_718-1](https://doi.org/10.1007/978-3-319-69892-2_718-1)

59 <sup>22</sup> Tuckett, A. G. (2012). The experience of lying in dementia care. *Nursing Ethics*, 19(1), 7-20.  
60 doi:10.1177/0969733011412104

1  
2  
3 validation therapy have proved inconclusive.<sup>23</sup> Nevertheless, it is perhaps more morally and  
4  
5 ethically acceptable than truth telling or reality orientation for people living with dementia  
6  
7 whose cognition and orientation have significantly deteriorated.<sup>24</sup>  
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10  
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12 This lack of certainty leads to the question of whether validation is a betrayal of the truth, and  
13  
14 as such a deception towards the person living with dementia. Was I colluding with an untruth,  
15  
16 or was I offering an empathic and lived experience response to distress that addressed Mrs  
17  
18 Jones feelings.<sup>25</sup> These are not easy questions to answer, as each event will bring its own  
19  
20 complexity and ethical challenges.<sup>26</sup> These challenges include whether a lie had indeed taken  
21  
22 place, and for what purpose. My reflection led me to the conclusion that I had not told a lie, I  
23  
24 had just joined Mrs Jones in her search, and in doing so appeared to offer her some comfort  
25  
26 that she was not alone in her endeavour. Arguably, this was not my *lived experience* or *living*  
27  
28 *present* in which to impose my truth. By validating Mrs Jones's *subjective experience*, and  
29  
30 emotions "I am affected by a thought that is both mine and the thought of an Other".<sup>27</sup>  
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38 This validating moment of *Other truth* transcends my self-conscious reality of what *I* believe  
39  
40 to be true, and allows me to enter a transient time lived only by Mrs Jones. Subjective reality  
41  
42 (or perhaps in this case an *inter-subjective reality*) has been found to be successful in  
43  
44 reducing distress in people living with dementia, but it is a skilled intervention that requires  
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51 <sup>23</sup> Neal, M., & Barton Wright, P. (2003). Validation therapy for dementia. Cochrane Database of Systematic  
52 Reviews. doi:10.1002/14651858.cd001394

53 <sup>24</sup> Mental Health Foundation Dementia (2014) What is truth? Exploring the real experience of people living with  
54 more severe dementia. A Mental Health Foundation national inquiry: A rapid literature review. London: Mental  
55 Health Foundation.

56 <sup>25</sup> Feil, N. (2012) The validation breakthrough: Simple techniques for communicating with people with  
57 "Alzheimer's type dementia." Baltimore: Health Professions Press

58 <sup>26</sup> Seaman, A. T., & Stone, A. M. (2017). Little white lies: Interrogating the (Un)acceptability of Deception in  
59 the Context of Dementia. Qualitative Health Research, 27(1), 60-73. doi:10.1177/1049732315618370

60 <sup>27</sup> Voss, D. (2013). Deleuze's Third Synthesis of Time. Deleuze Studies, 7(2), 194-216.  
doi:10.3366/dls.2013.0102 (p.196)

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2  
3 acceptance and understanding from any external observers; which in itself is challenging.<sup>28</sup>  
4  
5 However, my experiences of hospital care for people living with dementia was one in which  
6  
7 subjective reality was invalidated by a discourse bias that required an immediate reorientation  
8  
9 towards an *institutional truth*.<sup>29</sup>  
10  
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### 15 **Search complete: A new story begins...**

16  
17 *As we continued our search for the children we came across the wards 'quiet room' and*  
18  
19 *there stood a bookcase. Mrs Jones commented that "this must be the library".*  
20  
21  
22

23  
24 Again. I was being mindful not to respond with a "therapeutic lie"<sup>30</sup> but simply replied,  
25  
26 "*shall we take a look at the books*". Yet, here I was still actively engaged in a search for the  
27  
28 children, perhaps in an attempt to avoid "truth-related distress".<sup>31</sup> Therefore, I question  
29  
30 myself was I engaged in a deception. Something Tom Kitwood would define as a form of  
31  
32 treachery; using deception to distract or manipulate a person into compliance. It is my  
33  
34 nursing duty to act in the best interest of a patient in my care. A *therapeutic lie* is unethical  
35  
36 and immoral, and in some cases unlawful, and yet they continue to exist on a day to day basis  
37  
38 in dementia care.<sup>32</sup>  
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45 *Mrs Jones was disappointed at the content of the bookcase shelves, particularly as there are*  
46  
47 *no ladybird books – "the children are doing their ladybird reading, these won't do". At*  
48  
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50  
51 <sup>28</sup> Erdmann, A., & Schnepf, W. (2016). Conditions, components and outcomes of integrative validation therapy  
52 in a long-term care facility for people with dementia. A qualitative evaluation study. *Dementia*, 15(5), 1184-  
53 1204. doi:10.1177/1471301214556489

54 <sup>29</sup> Amino, K. (2020). Validation, invalidation, and negative speech acts in dementia care discourse. *Frontiers in*  
55 *Communication*, 5. doi:10.3389/fcomm.2020.00020

56 <sup>30</sup> Feil N & Altman R (2004) Letter to the editor: validation theory and the myth of the therapeutic lie. *American*  
57 *Journal of Alzheimer's Disease and Other Dementias*.19, 2, 77-78. (Title)

58 <sup>31</sup> Day, A.M, James, I.A, Meyer, T.D, Lee, D.R. (2011) Do people with dementia find lies and deception in  
59 dementia care acceptable? *Aging and Mental Health*. 15, 7, 822-829. (p.825)

60 <sup>32</sup> Culley, H., Barber, R., Hope, A., & James, I. (2013) Therapeutic lying in dementia care. *Nursing Standard*  
28(1):35-9. doi: 10.7748/ns2013.09.28.1.35.e7749.

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2  
3 *which point she made her way out of the room with me following. “It’s been very nice to meet*  
4 *you dear, but now I need to get out of this place” at which point Mrs Jones returned to her*  
5 *ward bay. Mrs Jones pulled up a chair in the centre of the bay, got the attention of the other*  
6 *patients, all of which had a cognitive impairment or a confusion of some kind, and began to*  
7 *teach them her first lesson of the day. Mrs Jones was back doing what she loved. Some*  
8 *engaged, others slept, but harmony appeared to have been regained.*  
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19 Interestingly, by this point none of referring clinicians who had raised grave concerns about  
20 Mrs Jones previous behaviour were at all perturbed by her impromptu middle of the ward  
21 *classroom lesson*. Mrs Jones appeared contented, the patients were settled, and in turn the  
22 anxieties of the ward team evaporated. Providing acute hospital care for people living with  
23 dementia is complex and at times personally and professionally challenging, not only from a  
24 physical and psychological aspect, but also an ethical one.<sup>33</sup> These times of ethical challenge  
25 are perhaps where the need for specialist intervention, including liaison psychiatry, is  
26 required. If not in terms of a solution, but perhaps as a respite or as a mediatory to what has  
27 essentially become an unseen and unwanted moral dilemma.  
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42 Once again, we revisit the opposing arguments of what is truth in dementia. On the one side  
43 there is the championing for a “Dementia Orientated Reality”<sup>34</sup> which focuses on a subjective  
44 lived narrative, the other a “Reality Orientation for Dementia”<sup>35</sup> argument, which suggests  
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54 <sup>33</sup> Alzheimer Europe (2014) *Ethical dilemmas faced by carers and people with dementia*. Luxembourg:  
55 Alzheimer Europe. [https://www.alzheimer-europe.org/Ethics/Ethical-issues-in-practice/2014-Ethical-dilemmas-](https://www.alzheimer-europe.org/Ethics/Ethical-issues-in-practice/2014-Ethical-dilemmas-faced-by-carers-and-people-with-dementia)  
56 [faced-by-carers-and-people-with-dementia](https://www.alzheimer-europe.org/Ethics/Ethical-issues-in-practice/2014-Ethical-dilemmas-faced-by-carers-and-people-with-dementia)

57 <sup>34</sup> Caiazza, R. & James, I.A. (2015). Re-defining the notion of the therapeutic lie; Person-centred lying. Faculty  
58 of the Psychology of Older People (FPOP) Newsletter, pp 23-9 (p.26)

59 <sup>35</sup> Spector, A. E., Orrell, M., Davies, S. P., & Woods, B. (2000). Reality orientation for dementia. Cochrane  
60 Database of Systematic Reviews. doi:10.1002/14651858.cd001119.pub2 (Title)

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2  
3 the *re-learning and orientation* to an environmental or institutional time, place, and person;  
4  
5 irrespective of the person's *living-present*.  
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7  
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9

10 It is traditional for reality orientation to be used in a hospital environment, in direct contrast  
11 to dementia reality orientation. This is more often than not due to the fact that the  
12 protagonists of these *lived times* are playing their part in the institutional script out of sync.  
13  
14 The story is moving unpredictably between chapters, and the plot that is unfolding does not  
15 fit neatly with the book written by the institutional authors. However, I counter argue that if I  
16 am unable to acknowledge and validate the person's *lived perspective of reality* then I am  
17 missing an opportunity to move my position as a nurse from an institutional "self-centredness  
18 toward an other-centredness"<sup>36</sup> guided by an empathic *curiosity of Other*.  
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### 31 **Conclusion**

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33 What is constituted deceptive practice, versus a validating response to a distressing or  
34 disorientating moment can surely only be measured by its intent? It has been argued that  
35 deceptive practice cannot replace truthfulness, even when the intention is benevolent, and  
36 thought to be in the best interest of the person living with dementia.<sup>37</sup> However, in cases  
37 where the deceptive practice is more nuanced; i.e. when the response is "person focused" and  
38 not "lie focused", clinicians have found it more acceptable.<sup>38</sup> It is evident that lying to a  
39 person living with dementia in which to deceive or to benefit is immoral, unethical, and is  
40 against all nursing and healthcare codes of practice. However, what is considered beneficent  
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55 <sup>36</sup> Eichbaum, Q. (2014). Thinking about Thinking and Emotion: The Metacognitive Approach to the Medical  
56 Humanities that Integrates the Humanities with the Basic and Clinical Sciences. *The Permanente Journal*. 18 (4):  
57 64-75. doi:10.7812/tpp/14-027 (p.71)

58 <sup>37</sup> Lorey, P. (2019). Fake bus stops for persons with dementia? On truth and benevolent lies in public health.  
59 *Israel Journal of Health Policy Research*, 8(1). doi:10.1186/s13584-019-0301-0

60 <sup>38</sup> Elvish, R., James, I., & Milne, D. (2010). Lying in dementia care: An example of a culture that deceives in  
people's best interests. *Aging & Mental Health*, 14(3), 255-262. doi:10.1080/13607861003587610 (p.258)

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3 versus maleficent practice is often down to the observer. A personal judgement made on an  
4 interrelational response that is taking place in a *lived time* exchange. A response of which the  
5 observer is no part, or indeed presence within that transient *living reality*. Instead, they can  
6 only observe from the vantage point of a *hospital or institutional reality* in apparent *real time*.  
7  
8 This is perhaps why deception in dementia remains such a contentious and complex issue.  
9  
10 Therefore, there is no straightforward answer, no magic solution, and very little in terms of  
11 research on what might be the ethically correct way to approach *truth in dementia*. Therefore,  
12 I conclude by asking myself, is my reality as a nurse more important than that of the person  
13 living with dementia; or is there a middle place, time and *reality* where we can both meet?  
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