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Abstract

An acute hospital environment is a confusing place for many patients requiring admission, especially when they are presenting as acutely unwell. This can be particularly difficult for people living with dementia. As cognition changes it is not uncommon for people living with dementia to have difficulties with their ability to orientate to time, place and person. These disorientating moments can lead to personal distress, and at times behavioural changes. As well as being distressing for the person living with dementia, it can also be emotionally and ethically challenging for acute hospital staff; including nurses. One area found to be particularly challenging is the concept of whether actively engaging with a person living with dementia's *living truth* is deceitful. This raises further questions of what forms of nurse responses to temporal disorientation might be constituted as a lying, colluding, or alternatively validating. This article uses autoethnography as a research methodology in which to explore a mental health nurse's lived experience of the challenges of responding *truthfully* to disorientation and distress in an acute hospital. This article is not attempting to offer conclusive answers to these challenging ethical questions. It is instead re-opening and re-visiting the discourse of what is *truth in dementia* from a personal and professional nurse perspective through a *lived narrative*. The conclusion to the concept of *truth in dementia* is complex, nuanced and individualised. However, it is essential that a nurse's response to disorientation and distress is always 'person focused', and not 'lie focused'.

Keywords

Dementia, Truth, Deception, Nursing, Care.

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".[1] 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?[2]

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[3]. 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

[1] Deleuze, G., & Lapoujade, D. (2006). Two regimes of madness: *Texts and interviews 1975-1995*. Los Angeles, CA: Semiotext (p.238)
[2] Smith, D. W. (2013). *Temporality and Truth. Deleuze Studies*, 7 (3): 377-389. doi:10.3366/dls.2013.0118
[3] 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

person's best interest, or indeed ethically justifiable came down to time, place, and person specifics, and the overall judgement of the observer.[4]

Dementia describes a set of cognitive symptoms that due to a decline in brain function affects our capacity to think, remember, problem solve, and at times communicate. All of which can impact significantly of our day to day functioning. However, dementia is more than that, it is a subjective lived experience which draws upon transient and experiential "lived times".[5] These *lived times* can only be understood on a subjective temporal and emotional level, rather than through an objective *fact based* prism.[6] Although complex, and often neuro-specific, it is not uncommon for people living with dementia to have *lived event* chronology and other temporal challenges. Therefore, the theme this article explores is the nursing challenge of whether it is deceitful to assist a person living with dementia to reside in their *lived time*, in contrast to orientating them to an objective clinical hospital reality.

Background

"People with dementia are more frequently admitted to hospital than those without dementia, independent of physical comorbidities".[7] Not only has there been a marked increase of hospital admissions for people living with dementia but the average length of stay has also become more protracted.[8] An acute or emergency hospital admission for a person living with

[4] St Clair Tullo, E., Lee, R. P., Robinson, L. & Allan, L. (2015) Why is dementia different? Medical students' views about deceiving people with dementia, Aging & Mental Health, 19:8, 731-738, doi: 10.1080/13607863.2014.967173

[5] Van Manen, M. (1997). Researching lived experience: Human science for an action sensitive pedagogy. London, ON: The Althouse Press. (p. 101)

[6] Førsund, L. H., Grov, E. K., Helvik, A., Juvet, L. K., Skovdahl, K., & Eriksen, S. (2018). The experience of lived space in persons with dementia: A systematic meta-synthesis. BMC Geriatrics, 18(1). doi:10.1186/s12877-018-0728-0

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

[8] 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.[9] 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.[10] 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.[11] Any unsuccessful attempts to orientate to the new environment can interrupt long established psychosocial coping mechanisms, whilst also reigniting negative past experiences.[12]

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.[13] It is a form of storytelling; a "narrative inquiry that provokes

[9] 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

[10] 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

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

[12] 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

[13] 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

identification, feelings, emotions, and dialogue"[14]. It actively invites the reader to consider their own meaning and understanding of the narrative presented. To do this I refer to an incident that took place in my role as a mental health liaison nurse in a large general hospital. The name of the patient in the chosen vignette is a pseudonym in order to respect and protect their identity and dignity. The narrative offered is a self-reflexive account of an incident where it could be argued that *deceptive practice* was present. The vignette is a reflection of my thoughts, feelings, and actions as a nurse. Due to the nature of my chosen methodology my article will be written and presented in the first person.

The role of liaison psychiatry in an acute hospital

One of my roles within the hospital required that I visit wards to offer advice on how *confused patients* (often due to dementia and delirium) might be *managed*. A role which was activated by referrals with covert, or at times extremely overt messages, of; *we need to control this situation*. These messages where more often than not sent by senior medical and nursing staff, who were openly *uncomfortable* with their ward routine being disrupted by these subjectively judged *unruly* patients. Medical and nursing staff in general hospitals report a lack of confidence in not only treating, but also understanding and communicating with patients who present with confusion due to dementia and / or delirium.[15] This lack of confidence and competence often leads to the request for support from *so-called* specialist colleagues; which includes the consultation of liaison psychiatry.[16] I never really saw this as a clinical speciality, but more a humanistic necessity. Without valuing and validating that

[14] Maréchal, G. (2010). Autoethnography. In A. J. MillsG. Durepos, & E. Wiebe (Eds.), Encyclopedia of case study research (pp. 44-45).
[15] Griffiths, A., Knight, A., Harwood, R., & Gladman, J. R. (2014). Preparation to care for confused older patients in general hospitals: A study of UK health professionals. Age and Ageing, 43(4), 521-527. doi:10.1093/ageing/aft171
[16] Mujic, F., Cairns, R., Mak, V., Squire, C., Wells, A., Al-Harrasi, A., & Prince, M. (2018). Liaison psychiatry for older adults in the General Hospital: Service activity, development and outcomes. BJPsych Bulletin, 42(1), 30-36. doi:10.1192/bjb.2017.9

person's experience we are at risk of depersonalising them, leading to a "deterioration in human relations"[17] which cannot be fully recovered.

Where are the children?

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

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

People living with dementia are in my mind time travellers who are living a non-sequential storyline made up of their lived experiences. This unpredictable story is often prompted by emotionally significant events[18] arising from a *pure past* that unintentionally enters their *living present*.[19] Tom Kitwood presented a concept in which we have two aspects to our self and being, one that is made up of our experiences and feelings; the other that has been

[17] Kimura, H., Tamoto, T., Kanzaki, N., & Shinchi, K. (2011). Burnout and Characteristics of Mental Health of Caregivers of Elderly Dementia Patients. Journal of Rural Medicine, 6(2), 47-53. doi:10.2185/jrm.6.47 (p.52)
[18] Mackenzie, L., Smith, K. & James, I. (2015) How a time machine concept aids dementia care. Nursing Times. 22-28;111(17):18-21.
[19] Deleuze, G. (1994). Difference and Repetition. (Patton, P. Trans). New York: Columbia University Press.

contextually adapted by our societal position and roles, and our abilities to cope in any given situation. This *self* is highly and tightly socialised, particularly in relation to the performing of given roles.[20] Mrs Jones was clearly drawing on her *lived experiences*, but her *adapted self* was front and centre for anyone who wanted to take notice.

I looked directly at her and said, "Mrs Jones are you a teacher" (I just had a sense). "Head teacher my dear", came the response, "Do I know you"? I introduced myself to Mrs Jones and explained my role. However, none of my explanation either orientated or assured Mrs Jones that she need not worry. However, Mrs Jones was worried. She was concerned that the children had not returned from the school trip, and she needed to get out to find them. Looking directly at me with a fixed gaze she said, "All I want to know is; where are the children"? I suggested we take a walk, in my mind as a distraction, but also as a validation of Mrs Jones emotional distress and 'living present'… I had consciously become part of Mrs Jones's search party.

Deception or validation: Where are the children?

Validation therapy is a recognised and person-centred approach to managing confusion for people living with dementia,[21] which in principle accepts, and does not challenge, the person living with dementia's personal truth, experience, or current reality.[22] It instead validates their experience by exploring their underlying emotional need by being non-judgemental and active listening to the person. However, attempts to offer a justification and firm evidence for

[20] Kitwood T. (1997). Dementia Reconsidered: The Person Comes First. Buckingham: Open University Press.
[21] Belser-Ehrlich J. & Bowers D. (2019) Validation Therapy. In: Gu D., Dupre M. (eds) Encyclopedia of Gerontology and Population Aging. Springer, Cham. https://doi.org/10.1007/978-3-319-69892-2_718-1
[22] Tuckett, A. G. (2012). The experience of lying in dementia care. Nursing Ethics, 19(1), 7-20. doi:10.1177/0969733011412104

validation therapy have proved inconclusive.[23] Nevertheless, it is perhaps more morally and ethically acceptable than truth telling or reality orientation for people living with dementia whose cognition and orientation have significantly deteriorated.[24]

This lack of certainty leads to the question of whether validation is a betrayal of the truth, and as such a deception towards the person living with dementia. Was I colluding with an untruth, or was I offering an empathic and lived experience response to distress that addressed Mrs Jones feelings.[25] These are not easy questions to answer, as each event will bring its own complexity and ethical challenges.[26] These challenges include whether a lie had indeed taken place, and for what purpose. My reflection led me to the conclusion that I had not told a lie, I had just joined Mrs Jones in her search, and in doing so appeared to offer her some comfort that she was not alone in her endeavour. Arguably, this was not my *lived experience* or *living present* in which to impose my truth. By validating Mrs Jones's *subjective experience*, and emotions "I am affected by a thought that is both mine and the thought of an Other".[27]

This validating moment of *Other truth* transcends my self-conscious reality of what *I* believe to be true, and allows me to enter a transient time lived only by Mrs Jones. Subjective reality (or perhaps in this case an *inter-subjective reality*) has been found to be successful in reducing distress in people living with dementia, but it is a skilled intervention that requires

[23] Neal, M., & Barton Wright, P. (2003). Validation therapy for dementia. Cochrane Database of Systematic Reviews. doi:10.1002/14651858.cd001394
[24] Mental Health Foundation Dementia (2014) What is truth? Exploring the real experience of people living with more severe dementia. A Mental Health Foundation national inquiry: A rapid literature review. London: Mental Health Foundation.
[25] Feil, N. (2012) The validation breakthrough: Simple techniques for communicating with people with "Alzheimer's type dementia." Baltimore: Health Professions Press
[26] Seaman, A. T., & Stone, A. M. (2017). Little white lies: Interrogating the (Un)acceptability of Deception in the Context of Dementia. Qualitative Health Research, 27(1), 60-73. doi:10.1177/1049732315618370
[27] Voss, D. (2013). Deleuze's Third Synthesis of Time. Deleuze Studies, 7(2), 194-216. doi:10.3366/dls.2013.0102 (p.196)

acceptance and understanding from any external observers; which in itself is challenging.[28] However, my experiences of hospital care for people living with dementia was one in which subjective reality was invalidated by a discourse bias that required an immediate reorientation towards an *institutional truth*.[29]

Search complete: A new story begins…

As we continued our search for the children we came across the wards 'quiet room' and there stood a bookcase. Mrs Jones commented that "this must be the library".

Again. I was being mindful not to respond with a "therapeutic lie"[30] but simply replied, *"shall we take a look at the books".* Yet, here I was still actively engaged in a search for the children, perhaps in an attempt to avoid "truth-related distress".[31] Therefore, I question myself was I engaged in a deception. Something Tom Kitwood would define as a form of treachery; using deception to distract or manipulate a person into compliance. It is my nursing duty to act in the best interest of a patient in my care. A *therapeutic lie* is unethical and immoral, and in some cases unlawful, and yet they continue to exist on a day to day basis in dementia care.[32]

Mrs Jones was disappointed at the content of the bookcase shelves, particularly as there are no ladybird books – "the children are doing their ladybird reading, these won't do". At

[28] Erdmann, A., & Schnepp, W. (2016). Conditions, components and outcomes of integrative validation therapy in a long-term care facility for people with dementia. A qualitative evaluation study. Dementia, 15(5), 1184-1204. doi:10.1177/1471301214556489
[29] Amino, K. (2020). Validation, invalidation, and negative speech acts in dementia care discourse. Frontiers in Communication, 5. doi:10.3389/fcomm.2020.00020
[30] Feil N & Altman R (2004) Letter to the editor: validation theory and the myth of the therapeutic lie. American Journal of Alzheimer's Disease and Other Dementias.19, 2, 77-78. (Title)
[31] Day, A.M, James, I.A, Meyer, T.D, Lee, D.R. (2011) Do people with dementia find lies and deception in dementia care acceptable? Aging and Mental Health. 15, 7, 822-829. (p.825)
[32] 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.

which point she made her way out of the room with me following. "It's been very nice to meet you dear, but now I need to get out of this place" at which point Mrs Jones returned to her ward bay. Mrs Jones pulled up a chair in the centre of the bay, got the attention of the other patients, all of which had a cognitive impairment or a confusion of some kind, and began to teach them her first lesson of the day. Mrs Jones was back doing what she loved. Some engaged, others slept, but harmony appeared to have been regained.

Interestingly, by this point none of referring clinicians who had raised grave concerns about Mrs Jones previous behaviour were at all perturbed by her impromptu middle of the ward *classroom lesson*. Mrs Jones appeared contented, the patients were settled, and in turn the anxieties of the ward team evaporated. Providing acute hospital care for people living with dementia is complex and at times personally and professionally challenging, not only from a physical and psychological aspect, but also an ethical one.[33] These times of ethical challenge are perhaps where the need for specialist intervention, including liaison psychiatry, is required. If not in terms of a solution, but perhaps as a respite or as a mediatory to what has essentially become an unseen and unwanted moral dilemma.

Once again, we revisit the opposing arguments of what is truth in dementia. On the one side there is the championing for a "Dementia Orientated Reality"[34] which focuses on a subjective lived narrative, the other a "Reality Orientation for Dementia"[35] argument, which suggests

[33] Alzheimer Europe (2014) *Ethical dilemmas faced by carers and people with dementia*. Luxembourg: Alzheimer Europe. https://www.alzheimer-europe.org/Ethics/Ethical-issues-in-practice/2014-Ethical-dilemmas-faced-by-carers-and-people-with-dementia

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

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

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

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

Conclusion

What is constituted deceptive practice, versus a validating response to a distressing or disorientating moment can surely only by measured by its intent? It has been argued that deceptive practice cannot replace truthfulness, even when the intention is benevolent, and thought to be in the best interest of the person living with dementia.[37] However, in cases where the deceptive practice is more nuanced; i.e. when the response is "person focused" and not "lie focused", clinicians have found it more acceptable.[38] It is evident that lying to a person living with dementia in which to deceive or to benefit is immoral, unethical, and is against all nursing and healthcare codes of practice. However, what is considered beneficent

[36] Eichbaum, Q. (2014). Thinking about Thinking and Emotion: The Metacognitive Approach to the Medical Humanities that Integrates the Humanities with the Basic and Clinical Sciences. The Permanente Journal. 18 (4): 64-75. doi:10.7812/tpp/14-027 (p.71)
[37] Lorey, P. (2019). Fake bus stops for persons with dementia? On truth and benevolent lies in public health. Israel Journal of Health Policy Research, 8(1). doi:10.1186/s13584-019-0301-0
[38] 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)

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