
COMMENTARY

Deception in Dementia: Adding Caregivers to the Equation

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Caregivers are responsible for providing non-medical care that assists individuals living with dementia in completing daily activities. Formal and informal caregivers balance obligations to the individual's objective best interests while simultaneously respecting their autonomy. These two values are not always aligned and may require difficult decisions — including those that are contrary to the individual's stated desires. While trust is a core value held between the caregiver and the individual receiving care, there is an accepted standard of deception in dementia care.¹ The dense literature evaluating and making sense of deception in dementia care focuses on the tensions that emerge between respect for persons, including autonomy, and the practical challenges associated with providing care.²

In her *JLME* article, Professor Dresser summarizes the ethical considerations regarding the appropriateness of deception in dementia care. She provides a critical foundation that includes a hierarchy of five degrees of deception, from the most acceptable to the least ethically supportable: (1) evaluation of whether deception is necessary, (2) distractive and redirection, (3) minor distortions, (4) deceptive claims, and

(5) outright lies. Professor Dresser's hierarchy reflects tenants of "least restrictive means" used in the clinical ethics literature, including physical and chemical restraints in medical care.³ Her foundational article prioritizes the individual living with dementia's values and interests. The article also focuses on the use of deception in the setting of memory impairment, a common symptom of Alzheimer's disease. Here, I will briefly build upon this foundation by considering the importance of underlying disease pathology and the relevance of caregivers' values, and particularly their interests in reducing caregiver burden.

Heterogeneity in Dementia

Dementia is an umbrella term for clinical syndromes defined by impaired cognitive and behavioral functions that impede daily activities and independence.⁴ Dementia is often the result of one or multiple neurodegenerative processes that affect cognitive and/or behavioral function. While there are overlapping features, each neurodegenerative disease leads to distinct symptoms. For example, individuals with Lewy Body Dementia (LBD) may experience sleep disturbances, visual hallucinations, and visuospatial impairment.⁵ Unlike Alzheimer's disease, LBD spares an individual's memory. The most common cause of young-onset dementia, Behavioral Variant Frontotemporal Dementia (BvFTD) is characterized by apathy, loss of empathy, and obsessive behaviors.⁶ Both of these are different from Alzheimer's disease, which most often leads to memory impairment, difficulty learning new information, poor decision making, and getting lost.⁷ In addition to the variable symptoms associated with the neurodegenerative causes of dementia, there is also heterogeneity in the progression of the disease — with dementia being the final stage. Neurodegenera-

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tive conditions are progressive in nature and typically begin with subjective or subtle cognitive impairment, typically not detectable by standard testing. As the individual's symptoms progress, the individual may experience Mild Cognitive Impairment (MCI). MCI indicates that the individual is experiencing impairment that results in performance below what would be expected within a normal range (objectively measured).⁸ Finally, an individual's symptoms meet diagnostic criteria for dementia if the individual's cognitive impairment impedes their independence.⁹

The underlying neurodegenerative disease and stage of cognitive and behavioral impairment both

cumstances.¹⁰ Third, the symptoms associated with different neurodegenerative conditions may determine the "effectiveness" of different forms of deception (i.e., will the individual "believe" the deception). For example, deception that relies on an assumption that the individual is suffering from memory impairment will not be successful with an individual with LBD. Instead, this type of deception may increase distrust and further complicate caregiving. Finally, because these diseases are progressive in nature and individuals' cognitive status can vary within a day or week, the ethical assessment of deception cannot be static. Deception predicated on safety to prevent an

Individuals living with dementia reported a range of factors informed whether they perceived the use of deception as acceptable, including the purpose of the deception. Here, I propose similar factors would be relevant: (1) the purpose of the deception, with the highest priority on safety for the individual or others; (2) the relevance to helping the individual better cope with their symptoms; (3) potential adverse effects for the individual living with dementia or harm to the caregiver-individual relationship; (4) the likelihood that deception will be effective; (5) the degree of deception necessary to accomplish its purposes (minimum necessary); and (6) bearing on caregiver burden. These factors, while not an exhaustive list, can build upon the hierarchy proposed by Professor Dresser while also accounting for differences that individuals living with dementia and their caregivers may experience based on the underlying neurodegenerative disease and the degree of symptom severity.

inform caregiving needs and shape the ethical appropriateness of deception in several ways. First, the underlying neurodegenerative disease affects the individual's areas of impaired functions and their retained capacities. These impairments translate into caregiving needs and individual abilities to understand and appreciate their illness. An individual suffering from hallucinations will have different caregiving needs than an individual who has behavioral symptoms that lead to aggressive outbursts. These differences are informative in evaluating the potential benefits and harms associated with deception. Second, the behavioral symptoms associated with some neurodegenerative conditions may cause an individual to be a risk to themselves or others.⁹ For example, one study has shown that individuals with BvFTD are more likely to have behavioral symptoms that result in criminal actions. In the context of deception, these behavioral symptoms may motivate deception to avoid risky cir-

individual with dementia from driving is no longer supportable if the individual is no longer physically capable of accessing the vehicle.

Integrating Caregiver Burden

Professor Dresser's framework primarily relied on the benefit or harm to the individual as a driver for whether deception is ethical. However, in the context of dementia, caregivers are critical stakeholders with significant interests at risk. Caregivers of individuals living with dementia report the highest level of caregiver burden and distress compared to caregivers of other diseases, including cancer.¹² There is evidence that the behavioral and psychiatric symptoms associated with atypical dementias, including BvFTD, may further increase caregiver burden.¹³ Caregiver burden can lead to negative health outcomes for both the individual living with dementia and the caregiver. As a result, mitigation of caregiver burden is an important

interest when considering ethical approaches to caregiving, including the use of deception. It also raises the question of how to add consideration of the caregivers' interests to the balance between an individual living with dementia's best interests and their autonomy.

A Factors Based Assessment

While a hierarchy of appropriateness is helpful, I suggest that caregivers would benefit from factors to evaluate whether deception is appropriate in the context of their circumstance. This is consistent with prior studies showing that staff and individuals living with dementia consider several factors when they report on their comfort or acceptance of deception.¹⁴ For example, individuals living with dementia reported a range of factors informed whether they perceived the use of deception as acceptable, including the purpose of the deception.¹⁵ Here, I propose similar factors would be relevant: (1) the purpose of the deception, with the highest priority on safety for the individual or others; (2) the relevance to helping the individual better cope with their symptoms; (3) potential adverse effects for the individual living with dementia or harm to the caregiver-individual relationship; (4) the likelihood that deception will be effective; (5) the degree of deception necessary to accomplish its purposes (minimum necessary); and (6) bearing on caregiver burden. These factors, while not an exhaustive list, can build upon the hierarchy proposed by Professor Dresser while also accounting for differences that individuals living with dementia and their caregivers may experience based on the underlying neurodegenerative disease and the degree of symptom severity.

Note

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References

1. R. Elvish, I. James, and D. Milne, "Lying in Dementia Care: An Example of a Culture that Deceives in People's Best Interests," *Aging & Mental Health* 14, no. 3 (2010): 255-262.
2. R. Dresser, "A Tangled Web: Deception in Everyday Dementia Care," *Journal of Law, Medicine & Ethics* 49, no. 2 (2021): 257-262.
3. P. Crutchfield, T. Gibb, M. Redinger, D. Ferman, and J. Livingstone, "The Conditions for Ethical Application of Restraints," *Chest* 155, no. 3 (2019): 617-625.
4. "2020 Alzheimer's Disease Facts and Figures," *Alzheimer's Dementia* 16, no. 3 (2020): 391-460.
5. Z. Walker, K. L. Possin, B. F. Boeve, and D. Aarsland, "Lewy Body Dementias," *The Lancet* 386, no. 10004 (2015): 1683-1697.
6. J. Deleon and B. L. Miller, "Frontotemporal Dementia," in *Handbook of Clinical Neurology* 148 (2018): 409-430.
7. M.C. Carrillo, R. A. Dean, F. Nicolas, D. S. Miller, R. Berman, Z. Khachaturian, L. J. Bain, R. Schindler, and D. Knopman, "Revisiting the Framework of the National Institute on Aging-Alzheimer's Association Diagnostic Criteria," *Alzheimer's & Dementia* 9, no. 5 (2013): 594-601.
8. *Id.*
9. *Id.*
10. *Id.*
11. *Id.*
12. M. Liljegen, G. Naasan, J. Temlett, et al., "Criminal Behavior in Frontotemporal Dementia and Alzheimer Disease," *JAMA Neurology* 72, no. 3 (2015): 295-300.
13. R. Harding, W. Richard, G. Wei, et al., "Comparative Analysis of Informal Caregiver Burden in Advanced Cancer, Dementia, and Acquired Brain Injury," *Journal of Pain and Symptom Management* 50, no. 4 (2015): 445-452.
14. A. Uflacker, M.C. Edmondson, C.U. Onyike, and B.S. Appleby, "Caregiver Burden in Atypical Dementias: Comparing Frontotemporal Dementia, Creutzfeldt-Jakob Disease, and Alzheimer's Disease," *International Psychogeriatrics* 28, no. 2 (2016): 269-273.
15. See Elvish, *supra* note 1; A.M. Day, I.A. James, T.D. Meyer, and D.R. Lee, "Do People with Dementia Find Lies and Deception in Dementia Care Acceptable?" *Aging & Mental Health* 15, no. 7 (2011): 822-829.