
A Tangled Web: Deception in Everyday Dementia Care

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Abstract: Care workers and families often engage in deception in everyday interactions with people affected by dementia. While benevolent deception can be justified, there are often more respectful and less risky ways to help people with dementia seeking to make sense of their lives.

Deception is pervasive in dementia care. Surveys and interviews reveal high rates of deception by health professionals and staff. In one survey, for example, just four percent of staff members said that they had never lied to a resident in their facility.¹ Families admit to using deception, too. Deception “becomes a way of life” in households where someone with dementia is living.²

At the same time, truth-telling is highly valued in modern Western society. This judgment applies to ordinary life and to health care, too. In health care, lies that were once seen as justified paternalism are now condemned as disrespectful and demeaning to patients. But the debate over deception in dementia care is unsettled. Does respect for persons with dementia require the truth-telling other people are owed? Or is it more respectful to support the subjective reality of someone with dementia, even when that reality is inaccurate?

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In this article, I describe the varieties of deception that exist in dementia care and the care theories underlying deceptive practices. I also describe ethical considerations bearing on these practices, with the goal of supplying guidance for the use of deception in this context. My focus is on “everyday life” deception, rather than deception related to diagnosis or other medical matters. Facts are essential in formal medical decision making, whether choices are being made by the patient with dementia or a surrogate decision maker, or through a collaborative process like supported decision making.³ Facts don’t necessarily have the same value, however, in other kinds of interactions involving people with dementia and health professionals, care workers, families, and community members.

Everyday life deception can have major effects on the welfare of people living with dementia, but the topic has attracted relatively little policy attention. Because formal law and policy fail to address the topic, guidance must come from empirical, clinical, and ethical literature considering deception in dementia care. Based on a review of this literature, I argue for a presumption against deception that can be overridden when telling the truth produces distress or other harm to a person with dementia. While benevolent deception can be justified, there are often more respectful and less potentially damaging ways to help people with dementia seeking to make sense of their lives.

The Practice of Deception

Deception in dementia care takes a variety of forms. It’s common for others to go along with the mistaken beliefs of people with dementia, such as a man’s idea that his caregiver is his office assistant⁴ or a woman’s impression that a robot is a real cat.⁵ Caregivers also

give people items associated with a past life that no longer exists, such as a tackle box for someone who once enjoyed fishing⁶ or coins for people worried about paying for food and services in their care facilities.⁷ Relatives sometimes record conversations to be used in simulated phone calls with people living in care facilities.⁸ Caregivers make false promises of upcoming visits from friends to encourage people to get dressed or cleaned up.⁹ Living facilities for people with dementia include deceptive design features, such as fake stores, bus stops, and nurseries with dolls instead of babies.¹⁰

Professional and family caregivers say that compassion motivates deceptive behavior like this. The short-term memory loss that affects people with dementia leads them to become disoriented, unable to make sense of their current circumstances. Long-term memories remain influential, which leads to “time-shifting.”¹¹ People think they are living and working as they did in the past, becoming anxious and distressed

method of social control, sometimes even a matter of “survival,” that helps caregivers meet the demands of maintaining a household or group residence.¹⁶

Moreover, deception isn’t always an effective remedy for distress and disruption, partly because caregivers can’t always judge whether a person with dementia is capable of detecting falsehoods. Although individuals with dementia lose insight and awareness over time, many have lucid periods in which they perceive dishonesty in others.¹⁷ People who don’t recognize or directly express their recollections can still possess what psychologists call “implicit memory,” which enables them to detect when someone is misleading them.¹⁸

Deception can generate distrust, anger, and further distress when people think they are being lied to. People with preexisting paranoia can become even more suspicious when they are deprived of truthful information.¹⁹ Deception can be experienced as “patronizing or demeaning,” leading people to lose confidence and think less of themselves.²⁰

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because features of their new lives don’t make sense to them. They wonder what is happening to them and why they aren’t seeing relatives and friends from an earlier time.¹²

Reminding people with dementia of their new situations doesn’t necessarily address the problem. When people believe in a different reality, accurate information doesn’t have the meaning that it ordinarily would.¹³ Telling the truth can instead provoke even more anxiety and distress. Caregivers find that effective reassurance often requires a response that reflects an individual’s subjective reality. When caregivers “tell them whatever they want to hear,” it makes the lives of people with dementia more bearable.¹⁴ Because deception can benefit people with dementia, caregivers say, deception is defensible in dementia care.

The Downsides of Deception

Not all deception is centered on the interests of people with dementia. The pressures of everyday life underlie some of the deception that occurs in dementia care.¹⁵ Families and professionals resort to deception to manage the challenges of caregiving. Deception is a

Deception can add to confusion, too, particularly when the information people are given doesn’t apply to their actual life history. Confusion is also exacerbated when people hear inconsistent answers from different caregivers. “Successful” lying requires knowing a person’s life story and a level of “collusion” among people interacting with that person.²¹

Not all caregivers are completely comfortable with their deceptive behavior. Deception seems disrespectful to the people they care for. Caregivers worry about the morality of engaging in conduct they would normally consider wrong. Professionals wonder whether they are violating their duties to patients, and families wonder whether they are betraying the people they love.²² Caregivers say they would prefer to tell the truth, but this is often not a kind or realistic option.²³

Dementia Therapies and Deception

Different therapeutic approaches to dementia care take different positions on deception. Until a few decades ago, reality based therapy was the dominant approach to dementia care. Caregivers were advised to correct the inaccurate beliefs of people with dementia.

But reality based care could be ineffective and even harmful. Because corrections were quickly forgotten, caregivers were constantly repeating them.²⁴ Corrections could inflict damage, as well. When people with dementia were repeatedly reminded of painful events like a loved one's death or the sale of a family home, each reminder could trigger a fresh episode of shock and grief.²⁵

Dissatisfaction with reality based therapy gave rise to a care model more attuned to the subjective realities of people with dementia. During the 1980s, social worker Naomi Feil introduced validation therapy, which encourages caregivers to accept, rather than correct, the ways that people with dementia see the world. Validation therapy supporters contend that engaging with a person's own reality makes it easier to communicate and determine how to help that person. They say it creates an opportunity for caregivers to discover what underlies a person's anxiety and distress, allowing them to provide emotional support and use techniques like redirection and distraction to soothe the individual.²⁶

Validation therapy doesn't condone direct lying to people with dementia, favoring more indirect methods of guiding people to more comforting situations. But other therapeutic approaches go further, endorsing direct lies when they are needed to support a person with dementia.²⁷ Some go so far as to say one should never contradict the false beliefs of people with dementia, for doing so is always unjustifiably damaging to them.²⁸

Therapies endorsing some forms of deception in dementia care have had a significant impact, for many caregivers find these therapies more workable and humane than reality based therapy. But the trend has its critics, too, many of whom question the ethics of this approach. In their eyes, therapies that countenance deception cannot be justified in any care setting.

Ethical and Legal Issues

Objections to deception in general often focus on the damage it does to individual autonomy. People cannot make good choices without accurate information about their situations.²⁹ Some say this reasoning applies in the dementia context, as well. The influential psychologist Tom Kitwood, who developed the person-centered approach to dementia, labeled deception as "treachery," an element of the "malignant social psychology" governing many interactions involving people with dementia.³⁰ Kitwood saw deception as a way to manipulate people with dementia, denying them the respect they are owed as persons.

Some contemporary experts agree that deception unjustifiably restricts the autonomy of people

with dementia. Though people with dementia may lack the capacity for full autonomy, they should still be treated as "active agents" seeking "to make sense of their world, to cope with the threats of the disease and to resolve the emotional challenges posed by the dementia process."³¹ On this view, it is wrong to see their mistaken ideas as a product of disease instead of an understandable effort to deal with their current circumstances. Rather than withholding the facts from people with dementia, caregivers should be truthful and supportive, allowing people to experience sadness, confusion, and other upsetting emotions that are "part of being human."³² Such an approach can help people achieve "meaningful lives in the present, rather than ... keep them in nostalgic themes from the past."³³

But others contend that deception can be consistent with a broader conception of respect for persons with dementia, one that emphasizes their ongoing dignity, as well as their personal concerns. What people with dementia believe may not be real to others, but it is real to them. Accepting their versions of reality can be a way to respect who they are.³⁴ From this perspective, taking some leeway with the facts can promote a truth more attuned to the individual with dementia. One caregiver's story shows how this can work. This caregiver's wife, who lived in a dementia care facility, became quite upset when her husband said goodbye at the end of a visit. So instead, before leaving he would say he was going on a shopping trip. This alleviated her distress, he explained, because to her that meant that he would see her again soon. In this case, misleading her was a means to convey a more important truth in terms she could understand.³⁵

Another defense of deception comes from philosopher Maartje Schermer, who observes that the usual prohibition on deception presupposes a shared reality. When people with dementia are living in a different reality than others, they have lost the ability to know what is truth and what is fiction. In such cases, Schermer proposes, "the ability to be lied to is also gone."³⁶ Schermer also distinguishes intentional deception, which seeks to encourage someone else to believe in a falsehood, from the kinds of falsehoods validation therapy endorses, which seek to distract or relate to people with dementia. In the latter situation, she argues, deception is "part of a completely different practice, dealing with the emotional and not the cognitive level of interaction."³⁷

An additional consideration is the presence of deceptive behavior in other parts of ordinary life. Adults lie to and mislead each other out of self-interest or a desire to protect another person from unpleasant truths. Lying to children is even more common. Parents who believe strongly in the importance of teach-

ing their children to be honest nevertheless admit they use deception to comfort or control their children.³⁸ Indeed, parents sometimes boast about their successes with this strategy.³⁹ Such behavior may not be admirable, but it shows that the use of deception isn't reserved for people with dementia. If people accept deception in these situations, their use of deception in dementia care doesn't necessarily demonstrate a lack of respect toward people with dementia.

The law governing health care decision making offers relatively little guidance on whether deception can be acceptable in everyday dementia care. Some writers have suggested that "advance deception directives" offer a way out of the deception dilemma. Individuals choosing this option could include in their advance medical directives instructions on whether deception would be acceptable in future dementia care. This proposal has serious shortcomings, however. Not many people issue specific instructions on future health care of any sort, and those who do are unlikely to express preferences about the details of everyday dementia care.⁴⁰ Moreover, people won't necessarily know what they would prefer as a person with dementia. As someone with early dementia put it, "I don't want to be lied to, but I won't know how I might feel as the dementia develops."⁴¹ When people with dementia lose touch with the matters that were once important to them, their advance instructions can become irrelevant or even harmful.⁴²

Alternative standards for medical decision making supply a bit more guidance. The substituted judgment standard directs family members and other surrogate decision makers to consider what a particular individual living with dementia would prefer in the current circumstances, while the best interests standard directs decision makers to choose options likely to promote the welfare of the person with dementia.⁴³ Applying these standards requires caregivers to evaluate truth-telling's impact on a particular person and to consider whether measures like distraction, agreement with false beliefs, and other departures from the truth would be better ways to respect and protect that person.

Toward a Defensible Approach

Writers arguing that deception can be morally defensible in dementia care put conditions on its use. Deception can be justified, they say, only when it genuinely benefits a person with dementia. In many cases, alternatives to deception can confer similar benefits.

Many experts, as well as individuals living with dementia, contend that caregivers should begin with honesty. A presumption of truth-telling should apply in interactions with people with dementia, as it does

in other human interactions. Telling the truth with sensitivity and kindness is an ethical and compassionate response to a confused person with dementia. When people become distressed after hearing an accurate account of their situation, caregivers should empathize, then try to discover whether the distress is related to another need, such as a need to feel safe and secure. Such needs can often be addressed through means other than deception.⁴⁴

Examples come from cases involving people who continually ask about a missing spouse or other relative who has died. In one case, showing a woman the clothes she had worn to her son's funeral was a meaningful reminder of what had happened, one that stayed with her for some time.⁴⁵ Another woman gained a deeper understanding of events when caregivers showed photographs of her husband's life and talked with her about the funeral she had attended in his honor.⁴⁶ Conversely, failing to tell the truth about a serious event like this can backfire. For example, when staff in one facility followed a family's instruction to withhold from a resident the truth about her husband's death, the woman withdrew and died within the year. A regretful staff member reported, "whenever I saw her, I could almost feel her pain."⁴⁷

Whenever possible, caregivers should take advantage of options that don't rely on deception. Alternatives to deception focus on the existing interests and needs of people with dementia. For example, playing tapes of a relative's reflections on shared family experiences is a better alternative than using such tapes to orchestrate fake telephone calls.⁴⁸ Going for walks with people who were once avid hikers is a better alternative than giving them hiking boots to wear around the facility. Taking people to real stores, arranging visits with real schoolchildren, and allowing people to participate in cooking their meals are better alternatives than fake versions of these activities.

Activities and environments that don't rely on artifice are ethically superior to those that do. Although make-believe approaches can have positive effects, they also contribute to social isolation and stigma. When people with dementia can manage the real world, they should have opportunities to do so. As one group put it, "why aren't people with dementia afforded the same access ... to everyday 'real' activities, as other people are given?"⁴⁹

When someone with dementia refuses to cooperate with things like getting dressed, bathing, leaving the home, and other tasks of everyday life, caregivers should consider how important it is to complete that task.⁵⁰ Sometimes it's okay to skip a bath or wear pajamas all day. Sometimes the person will be more receptive in an hour or two. Alternatives like these are

preferable to using deception to secure the person's cooperation.

If measures like these don't work, distraction and redirection can be acceptable. If deception seems necessary, caregivers may resort to "white lies," "partial truths," concurrence with someone's false beliefs, and other minor distortions that fit into a person's subjective reality. But these measures should always be aimed at promoting the interests of the person with dementia. Deceptive claims involving false visits, travel destinations, and the like are acceptable only when completing a task is essential to the health and welfare of the person with dementia. Outright lies are justified only as a last resort, when they are the sole means available to protect someone with dementia from serious physical or psychological harm.⁵¹

Before resorting to deception, caregivers should understand which features of a person's past life are shaping that person's current subjective reality. Family and professional caregivers should share information about the person's past and current circumstances and agree on a consistent response to the person's questions and actions. Once they have tried a deceptive response, they should evaluate whether it is helping the person. If not, they should revise or reject it and develop a different strategy.⁵²

Determining when deception will promote well-being is a complicated process. As one caregiver put it, "You have to experiment."⁵³ It also takes "positive curiosity" about the individual life stories of the people whose care is at issue.⁵⁴ Professional and family caregivers ought to have opportunities to meet and discuss whether and how to adopt deception, as well as how to improve communication and maintain respect for the people they care for.⁵⁵

Conclusion

Truth-telling should be the preferred practice in everyday dementia care. But a blanket ban on deception would fail to serve the interests of people with dementia. A rule mandating truth-telling in every situation would be misguided and cruel. A rule against deception would also be pointless. Caregivers will inevitably choose deception when they find it the most humane and effective approach to reaching people with dementia. Empirical evidence, ethical analysis, and educational efforts can help them determine when this is the case.

I've described ways to increase the odds that deceptive techniques will actually enhance the well-being of people with dementia. At the same time it's disturbing to endorse "deception plans" for dementia caregivers to follow. We should hold on to our ambivalence about condoning deception in dementia care.⁵⁶ Without this

ambivalence, it could become too easy to resort to deception when there are better options.

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References

1. I.A. James et al., "Lying to People with Dementia: Developing Ethical Guidelines for Care Settings," *International Journal of Geriatric Psychiatry* 21 (2006): 800-801.
2. N.S. Blum, "Deceptive Practices in Managing a Family Member with Alzheimer's Disease," *Symbolic Interaction* 17, no. 1 (1994): 21-36, 22.
3. For discussion of these topics, see M. Marzanski, "Would You Like to Know What Is Wrong With You? On Telling the Truth to Patients With Dementia," *Journal of Medical Ethics* 26, no. 2 (2000): 108-113; M.A. Drickamer and M.S. Lachs, "Should Patients With Alzheimer's Disease Be Told Their Diagnosis?" *New England Journal of Medicine* 326, no. 34 (1992): 947-951; M. S. Wright, "Dementia, Autonomy, and Supported Healthcare Decision Making," *Maryland Law Review* 257, no. 2 (2020): 257-324.
4. See C.B. Bursack, "Playing Along with a Dementia Patient's Realities," *Aging Care*, available at <<https://www.agingcare.com/articles/playing-along-with-dementia-realities-121365.htm>> (last visited April 6, 2021).
5. See M. Jackson, "Would You Let a Robot Take Care of Your Mother?" *New York Times*, December 13, 2019.
6. See P. Belluck, "Giving Alzheimer's Patients Their Way, Even Chocolate," *New York Times*, December 31, 2010.
7. See C.M.P.M. Hertogh et al., "Truth Telling and Truthfulness in the Care for Patients with Advanced Dementia: An Ethnographic Study in Dutch Nursing Homes," *Social Science & Medicine* 59 (2004): 1685-1693.
8. See M. Schermer, "Nothing but the Truth? On Truth and Deception in Dementia Care," *Bioethics* 21, no. 1 (2007): 13-22.
9. See A. Kirtley and T. Williamson, "What Is Truth? An Inquiry about Truth and Lying in Dementia Care," Mental Health Foundation, 2016, at 18, available at <<https://www.mental-health.org.uk/publications/what-truth-inquiry-about-truth-and-lying-dementia-care>> (last visited April 6, 2021).
10. See L. MacFarquhar, "The Comforting Fictions of Dementia Care," *The New Yorker*, October 1, 2018, available at <<https://www.newyorker.com/magazine/2018/10/08/the-comforting-fictions-of-dementia-care>> (last visited April 6, 2021).
11. Kirtley and Williamson, *supra* note 9, at 12.
12. A. Turner et al., "The Use of Truth and Deception in Dementia Care Amongst General Hospital Staff," *Aging & Mental Health* 21, no. 8 (2017): 862-869.
13. *Id.*
14. A.G. Tuckett, "The Experience of Lying in Dementia Care: A Qualitative Study," *Nursing Ethics* 19, no. 1 (2012): 7-20, 12. Even people with dementia say deception can be justified if it prevents distress or provides other benefits to affected individuals. A.M. Day et al., "Do People with Dementia Find Lies and Deception in Dementia Care Acceptable?" *Aging & Mental Health* 15, no. 7 (2011): 822-829.
15. See A.T. Seaman and A.M. Stone, "Little White Lies: Interrogating the (Un)acceptability of Deception in the Context of Dementia," *Qualitative Health Research* 27, no. 1 (2017): 60-73.
16. Blum, *supra* note 2, at 25.
17. See Kirtley and Williamson, *supra* note 8, at 25; C. Muller-Hergl, "Distress Does Not Justify Lying," *Journal of Dementia Care*, July-August 2007, at 16, 17.
18. S.R. Sabat, *Alzheimer's Disease & Dementia: What Everyone Needs to Know* (New York: Oxford University Press, 2019).
19. See Kirtley and Williamson, *supra* note 9, at 30.

20. Day et al., *supra* note 14, at 825.
21. See T. Williamson and A. Kirtley, "Dementia Truth Inquiry: Review of Evidence," Mental Health Foundation, 2016, at 99-100, available at <https://www.mentalhealth.org.uk/sites/default/files/dementia-truth-enquiry-roe_0.pdf> (last visited April 6, 2021); Seaman and Stone, *supra* note 15; I.A. James and R. Caiazza, "Therapeutic Lies in Dementia Care: Should Psychologists Teach Others to Be Person-Centred Liars?," *Behavioural and Cognitive Psychotherapy* 46 (2018): 454-462.
22. Turner et al, *supra* note 12; Kirtley and Williamson, *supra* note 9, at 24.
23. R. Elvish et al., "Lying in Dementia Care: An Example of a Culture that Deceives in People's Best Interests," *Aging & Mental Health* 14, no. 3 (2016): 255-262.
24. Blum, *supra* note 2, at 26-27.
25. T. Yang-Lewis and R. Moody, "The Forgetful Mourner," *Hastings Center Report* 25, no. 1 (1995): 32-33.
26. See Kirtley and Williamson, *supra* note 9, at 46; MacFarquhar, *supra* note 10.
27. Kirtley and Williamson, *supra* note 9, at 46-47.
28. Seaman and Stone, *supra* note 15; MacFarquhar, *supra* note 10.
29. See generally S. Bok, *Lying: Moral Choice in Public and Private Life* (New York: Vintage, 1979); Schermer, *supra* note 7.
30. T. Kitwood, *Dementia Reconsidered: The Person Comes First* (Berkshire, United Kingdom: Open University Press, 1997): 46.
31. Hertogh et al., *supra* note 7, at 1686.
32. Kirtley and Williamson, *supra* note 10, at 23-24. See also Day, *supra* note 14, at 825 (in interviews, people with dementia "emphasized that lying could reduce their autonomy").
33. MacFarquhar, *supra* note 10, at 47.
34. See Sabat, *supra* note 18, at 50-82.
35. Nuffield Council on Bioethics, "Dementia: Ethical Issues" (London: Nuffield Council on Bioethics, 2009), at 105.
36. Schermer, *supra* note 8, at 14.
37. *Id.* at 16.
38. G.D. Heyman, D.H. Luu and K. Lee, "Parenting by Lying," *Journal of Moral Education* 38, no. 3 (2009): 353-369.
39. See for example, "Tiny Victories," *New York Times Parenting*, available at <<https://www.nytimes.com/interactive/2020/parenting/parenting-newsletter.html>> (last visited April 6, 2021).
40. See R. Dresser, "The Limited Value of Dementia-Specific Advance Directives," *Hastings Center Report* 51, no. 2 (2021): 4-5.
41. Williamson and Kirtley, *supra* note 21, at 98.
42. Kirtley and Williamson, *supra* note 9, at 18-19; MacFarquhar, *supra* note 10, at 51-52.
43. See R. Dresser, "Beyond Cruzan: Dementia and the Best Interests Standard," *SMU Law Review* 73, no. 1 (2020): 71-90; R. Dresser, "Substituted Judgment in Real Life," *Journal of Medical Ethics* 41, no. 9 (2015): 731-732.
44. Schermer, *supra* note 8; Kirtley and Williamson, *supra* note 9; Tuckett, *supra* note 14.
45. Yang-Lewis and Moody, *supra* note 25.
46. Kirtley and Williamson, *supra* note 9, at 29.
47. Tuckett, *supra* note 14, at 13.
48. Schermer, *supra* note 8, at 20.
49. Kirtley and Williamson, *supra* note 9, at 32.
50. *Id.* at 18, 35.
51. Kirtley and Williamson, *supra* note 9; James et al., *supra* note 1; Tuckett, *supra* note 14.
52. Kirtley and Williamson, *supra* note 8; James et al., *supra* note 1.
53. Blum, *supra* note 2, at 25.
54. Kirtley and Williamson, *supra* note 9, at 37.
55. Kirtley and Williamson, *supra* note 9; James and Caiazza, *supra* note 21; Tuckett, *supra* note 14.
56. Jackson, *supra* note 5.