Truth that Matters: The Role of Family Caregivers in the Care of People with Dementia

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ABSTRACT

This research paper explores the family caregivers' role in resolving the ethical dilemma of deception in dementia care. Family members possess the unique capability to engage in "white lies" in a manner that both respects and upholds an individual with dementia's identity.

Keywords: Family Caregiver, Dementia, Autonomy, Truth, Identity, Ethical Deception, Personhood

INTRODUCTION

It was our usual family Shabbat dinner: golden flames flickered in crystal candleholders, and the smell of warm challah permeated the air. “Where is Elena?” my great-grandmother anxiously asked, scanning the doorway. “I am here, sitting right next to you, babushka!’’ my mother affectionately reassured her. Having raised my mother in Russia, my great-grandmother Tsilya, then in her early nineties, had resided in our Riverdale home for several years. “No, I know *you* are here, but where is the little Elena?” Any attempt to explain that “little Elena” had grown into an adult only agitated my great-grandmother. She eventually calmed down, distracted by the promise of a scrumptious meal. As Tsilya’s mind wandered back into the reality of her past, where my mother Elena was a young girl living in Tsilya’s modest flat in Leningrad, what we then believed was a temporary moment of confusion turned out to be the first glimpse into Tsilya’s future.

Over the next few years, as Alzheimer’s disease brought on Tsilya’s cognitive decline, erasing her memories and taking her identity with them, Tsilya’s concerns about the “little Elena” transformed into attempts at leaving the house to attend parties hosted by television celebrities. She would also cry and ask for her own mother at night. In the beginning, my mother always tried to uphold the truth and reorient my great-grandmother to the reality of her situation. However, as Tsilya’s cognitive decline advanced, my mother often had to redirect her attention to family photo albums or, in moments of extreme distress, resort to occasional “white lies” to validate some of her inaccurate beliefs. My mother’s actions provided such solace and felt so instinctive that I never questioned the legitimacy of her strategies to mitigate my great-

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grandmother's distress. Nevertheless, over the last two decades, the issue of truthfulness in dementia care has become the object of study and contemplation by both medical professionals and ethicists alike.

I. Person-Centered Care for People with Dementia

Most current discussions about the care of people with dementia begin with the principles of person-centered care, a revolutionary new philosophy of care introduced in the 1990s by Tom Kitwood, an English social psychologist and gerontologist. Rather than treating a person with dementia in a medical, protocol, and task-based fashion, Kitwood advocates approaching the care of such patients through a more holistic method that considers social and environmental factors, rather than only the patients' biochemical brain changes.[1] The main tenets of person-centered care include the awareness of the uniqueness and individuality of each person, the recognition of the subjective nature of experiences of people with dementia, and the maintenance of close relationships with people with dementia, allowing them to uphold bonds and lasting attachments to their loved ones.[2]

This philosophy of care highlights the importance of social interactions and interpersonal relationships in dementia care. "[T]o care for others," Kitwood writes, "means to value who they are; to honor what they do; to respect their unique qualities and needs; to help protect them from harm and danger; and – above all – to take thoughtful and committed action that will help to nourish their personal being."[3] Kitwood also emphasizes the need for people with dementia to have "a standing or status that is accorded by others."[4] However, the emphasis on conferring personhood onto individuals through their relationships with others introduces a challenge in implementing person-centered care. If a caretaker acknowledges and respects the subjective reality of a person with dementia, who may perceive a reality disconnected from their present, the caretaker may have to compromise their commitment to absolute truth-telling. On the other hand, if a caretaker solely adheres to the objective truth, they implicitly delegitimize the subjective reality and experiences of people with dementia.

II. Truthfulness versus Therapeutic Lying in Dementia Care

Scholars contemplating truthfulness versus therapeutic lying in dementia care hold different views. Some believe that maintaining the selfhood of people with dementia justifies occasional deception, while others claim that only uncompromised truth-telling can offer people with dementia the respect they deserve from others. This dichotomy of opinion presents a moral dilemma for individuals and institutions involved in the care of people with dementia. However, family members caring for individuals with dementia possess a unique capability to navigate this dilemma.[5] They have a profound understanding of their loved ones' identities and personal stories, allowing them to preserve the selfhood of people with dementia through occasional therapeutic lying without compromising the integrity of their relationships. As a result, the inclusion of family caregivers in the conversation about the permissibility of therapeutic lying in dementia care can facilitate the implementation of true person-centered care for people with dementia.[6]

While a central argument for the necessity of uncompromised truth-telling to people with dementia rests on the importance of truth in maintaining human bonds, family members can uphold this value despite occasional deception. In her article "Truthfulness and Deceit in Dementia Care: An Argument for Truthful Regard as a Morally Significant Human Bond," Dr. Philippa Byers, an ethics researcher, rejects the validity of lying for therapeutic purposes in dementia care. Byers argues that truth-telling is a moral value that establishes trustful relationships and therefore should not be denied to people with dementia. She grounds her argument in the notion of "truthful regard," which she defines as the "regard for another person as one for whom truth matters, just as it does for oneself." As a result, Byers contends that lying must be avoided to maintain truthful regard, rather than paternalism or condescension, in the caretaker's relationship with a person with dementia. Despite her seemingly uncompromising stance, Byers does approve of refraining from truth-telling in interactions with a friend sharing the same story over and over again.[7] Byers claims that if one cares for their friend, one can forgo the truth-telling of informing the friend that one has heard the story before by making decisions "involving the judgment, discretion, and tact that is characteristic of (most) respectful communication with one another…without suspending our truthful regard" for the other person. In communicating with people with dementia, family caregivers embody the role of such friends. As a result, due to close social relationships with a person with dementia, family caregivers can eschew blunt truth-telling without compromising the truthful regard they hold for the person. When my great-grandmother would get upset and agitated in her desire to attend a party hosted by a television celebrity and when all efforts at redirecting her attention failed, my mother occasionally had to offer "white lies" in telling her that the host cancelled the party due to inclement weather. While not truthful, such statements did not undermine my mother's truthful regard for my great-grandmother but served as a measure of last resort to ensure my great-grandmother's safety by preventing her from leaving the house alone at night. Byers states that truthful regard for other people "does not require close affiliative bonds."[8] Yet, it is precisely the existence of such close bonds that imparts special privileges on family members in their relationships with people with dementia, similarly to the way Byers affords such privileges to close friends. Family caregivers, therefore, may introduce the necessary "white lies" if their respectful judgment demands them.

III. The Inclusion of Family Caregivers' Perspectives in Navigating Truth-Telling

Despite the demonstrated significance of family caregivers in navigating truth-telling in the care of people with dementia, current discourse on justifying deception in dementia care often overlooks the perspectives of family caregivers. Dr. Matilda Carter, a lecturer in philosophy at King's College London, claims that an insistence on truth delegitimizes the subjective experiences and undermines the current identities of people with dementia.[9] Carter contends that the norm of truth-telling to dementia patients, whose cognitive decline and memory loss lead them to exist in their own version of reality, is an ableist construction that disrespects the perceived realities of people with dementia. Therefore, Carter argues that "withholding the truth from and, in limited circumstances, lying to people living with dementia is not only morally permissible, but morally required." "Ethical deception" is morally justified as an act of respect in seeing people with dementia through the lens of "the type of person that they are." However, Carter's justification of ethical deception overlooks the significance of careful judgment in the use of deception in dementia care, violating the personhood of people with dementia.

An example illustrating Carter's perspective on ethical deception and the negative consequences of neglecting the voices of family members of individuals with dementia can be found in the medical case study "How Much a Dementia Patient Needs to Know" by Dr. Oliver Sacks.[10] In this short work, Sacks, a neurologist and a best-selling author, describes Mr. Q., a nursing home resident with dementia. Having been employed as a janitor in his earlier years, Mr. Q. continued performing his "duties" in the nursing home. While the nursing home staff realized that his adherence to his former identity was a delusion, they "respected and even reinforced" Mr. Q.'s identity by encouraging his actions and providing him with instruments and supplies for his janitorial duties. Initially questioning whether Mr. Q. should have been told the truth about the reality of his condition, Sacks ultimately concludes that the objective reality holds little meaning for Mr. Q and that truth-telling would be "pointless" and "cruel." The story of Mr. Q. aligns with Carter's concept of ethical deception, as the residential care facility staff knowingly upheld Mr. Q.'s erroneous identity.

However, Carter's philosophical framework overlooks the attitudes of family caregivers towards such ethical deception, considering the caregivers' deep understanding of the wishes and identities of their relatives. Mr. Q.'s facility caregivers could have encouraged his janitorial activities for their own convenience, such as to minimize the time needed to attend to his care. Additionally, Mr. Q. could have believed in holding onto the truth until the very end. If not for the nursing home staff's deception, Mr. Q.'s family could have had the opportunity to reorient him to reality. This highlights the importance of caregivers' meticulous deliberation on the use of deception in their interactions with individuals with dementia. Without such consideration, deception may be driven by ulterior motives or may disregard the wishes of people with dementia and their family caregivers.

A 2020 study demonstrated that telling a "white lie" was found acceptable if intended solely to minimize harm to a person with dementia and particularly if introduced by a caregiver who really "'kn[e]w the person.'"[11] This acceptance was rooted in the belief that "the deep knowledge [caregivers] had about the person, their past, and their current experience allowed them to use lying in a genuinely caring and respectful manner."[12] Even more significantly, people with dementia emphasized the importance of consulting family members in decision-making during later stages of disease because these family members "knew what mattered to them the most."[13] Since there are no clear references to Mr. Q.'s personal beliefs or his family's wishes, one cannot fully confirm the moral validity of the nursing staff's approach. Conversely, my mother's extensive years of caring for my great-grandmother, coupled with her understanding of her beliefs, provides moral justification for her use of ethical deception to ensure my great-grandmother's safety. Therefore, family caregivers' profound understanding of the identities and circumstances of individuals with dementia allows them to utilize deception in a manner that upholds the selfhood of people with dementia without diminishing the importance of truth.

IV. Artificially Constructed Realities for People with Dementia

Regardless of the caregiver's type or intentions, some critics reject deception on the grounds that it leads to the construction of artificial realities for people with dementia.[14] Such critics claim that deception inherently contradicts the innate human desire for experiences grounded in true reality, a philosophical idea developed by American political philosopher Robert Nozick.[15] Nozick introduces the concept of an "experience machine," a device that would provide desired experiences through targeted brain stimulation. Nozick claims that while the machine can allow people to feel good "'from the inside,'" people would reject it because they want to "*do* certain things, and not just have the experience of doing them… to *be* a certain way, to be a certain sort of person."[16]

Proponents of Nozick's ideas might draw a parallel between Mr. Q.'s existence and a person hooked up to the experience machine since the nursing home staff's treatment of Mr. Q. is not grounded in objective reality. However, people with dementia already live in their own subjective realities due to cognitive decline and frequent reversion to past identities. Therefore, upholding these realities differs from constructing them de novo. Furthermore, while the experience machine offers a passive existence, Mr. Q. can physically attend to the expected responsibilities of his believed identity. As a result, when artificially constructed realities are introduced with the well-being of individuals with dementia in mind, and by those who understand what that well-being entails, they offer genuine experiences that enable people with dementia to realize their individuality within the bounds of their cognitive abilities.

Artificially constructed realities and the importance of family caregivers in upholding the personhood of individuals with dementia living within such realities come into focus in De Hogeweyk, the first dementia village for people with advanced dementia.[17] De Hogeweyk, which opened its doors in Weesp, Netherlands in 2009, is a gated community with a single entrance and exit where its residents receive twenty-four-seven care.[18] The village aims to maintain continuity with the residents' past lives by grouping them into themed homes based on their previous lifestyles and by offering familiar social events and physical activities.[19] Through thoughtful planning and design, the founders of De Hogeweyk have integrated all the "deceptive" aspects of their institutional reality into the village's infrastructure, including residences that look like real homes, a supermarket that does not use money, and a restaurant and hair salon staffed by trained caregivers who do not require payment for their services.[20] Although it is a closed facility, De Hogeweyk welcomes both family members and outside volunteers of all ages to interact with its residents.[21]

While critics of De Hogeweyk have likened it to *The Truman Show*, multiple family members report their satisfaction with De Hogeweyk's model of care.[22] Ada Picavet, whose husband Ben is a resident at De Hogeweyk, shares her experience of visiting him daily, playing the piano, and singing songs together. These activities serve as an attempt to preserve a sense of normalcy and continuity with their life before his dementia diagnosis.[23] While some might claim that their relationship is deceptive due to Ben's limited cognitive abilities, Ada's visits demonstrate a profound respect for her husband's subjective reality. She recognizes that his dementia shapes his perception of the world and maintains the continuity of his identity by allowing him to engage in activities they enjoyed together in the past, such as singing. By portraying Ada and other family members visiting their loved ones at De Hogeweyk as true partners in care, Dr. Sanjay Gupta, in his CNN report on De Hogeweyk, underscores the importance of family caregivers in addressing the moral dilemmas in dementia care through their understanding of the personal preferences and experiences of their loved ones with dementia.

De Hogeweyk aligns with Kitwood's person-centered care model that emphasizes the recognition of individuality, dignity, and well-being of individuals with dementia. The infrastructure and social environment provided at De Hogeweyk contribute to an immersive world that resonates with the residents' personal histories and identities. Despite the constructed nature of the residents' world, its depth and significance come from the interpersonal connections between residents and their family members outside the dementia village. As a result, family caregivers can occasionally employ carefully considered acts of beneficent deception without undermining the importance of truth-telling in dementia care. They can also transcend the limitations of cognitive decline by providing love and dedication as the fundamental truths that matter.

CONCLUSION

At the end of her life, my great-grandmother Tsilya could no longer recognize or communicate with family members. She would sit quietly, staring at the wall. Yet, my family members and I continued to spend time with her every day, simply holding her hand or stroking her hair. While it may be true that these visits might not have mattered to my great-grandmother, who no longer had an awareness of the outside world, they upheld her selfhood in the eyes of our family and to everyone else around her. Family caregivers, like my mother, have the knowledge and experience to navigate moral dilemmas surrounding truth and deception in dementia care. As the number of people suffering from dementia continues to rise, future studies should examine new ways to engage family caregivers in helping to establish the true meaning of person-centered care.

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[1] Matthew Tieu, "Truth and Diversion: Self and Other-Regarding Lies in Dementia Care," *Bioethics* 35, no. 9 (2021): 858, https://doi.org/10.1111/bioe.12951.

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[2] Tom Kitwood, "The Concept of Personhood and Its Relevance for a New Culture of Dementia Care.," in *Care-Giving in Dementia: Research and Applications*, ed. Bere M.L. Miesen and Gemma M.M. Jones, vol. 2 (Routledge, 1997), 10-11.

[3] Kitwood, 3.

[4] Kitwood, "The Concept of Personhood and Its Relevance for a New Culture of Dementia Care," 4, 11.

[5] See "Holding One Another (Well, Wrongly, Clumsily) in a Time of Dementia," an essay where Hilde Lindemann, a philosopher and a bioethicist, examines the role of family caregivers in upholding their loved ones with dementia's identities.

[6] This essay is specifically concerned with informal family caregivers, such as children, close relatives, or romantic partners, as opposed to formal paid caregivers in the medical establishment. For people with dementia who have no informal caregivers and end up in institutional care early on, the lessons learned from family caregivers can contribute to creating guidelines for institutional person-centered care. See the United Kingdom's Mental Health Foundation 2016 report "What is Truth: an Inquiry about Truth and Lying in Dementia Care" for a further discussion regarding the necessity for non-family caregivers to understand the life stories and values of people with dementia.

[7] Byers, "Truthfulness and Deceit in Dementia Care: An Argument for Truthful Regard as a Morally Significant Human Bond," 231-232.

[8] Byers, 234.

[9] Matilda Carter, "Ethical Deception? Responding to Parallel Subjectivities in People Living with Dementia," *Disability Studies Quarterly* 40, no. 3 (2020), .

[10] Oliver Sacks, "How Much a Dementia Patient Needs to Know," *The New Yorker*, February 25, 2019, www.newyorker.com/magazine/2019/03/04/how-much-a-dementia-patient-needs-to-know.

[11] Dympna Casey et al., "Telling a 'Good or White Lie': The Views of People Living with Dementia and Their Carers," *Dementia* 19, no. 8 (2020): 2583.

[12] Casey et al., 2593-1594.

[13] Casey et al., 2595.

[14] Robert Sparrow and Linda Sparrow, "In the Hands of Machines? The Future of Aged Care," *Minds and Machines* 16 (2006): 155, https://doi.org/10.1007/s11023-006-9030-6.

[15] Sparrow and Sparrow, 155.

[16] Richard Nozick, *Anarchy, State, and Utopia* (Basic Books, 1974), 42-43.*CNN's World's Untold Stories: Dementia Village* (CNN, 2013), www.youtube.com/watch?v=LwiOBlyWpko.

[17] *CNN's World's Untold Stories: Dementia Village* (CNN, 2013), 02:00-02:13, www.youtube.com/watch?v=LwiOBlyWpko.

[18] *CNN's World's Untold Stories: Dementia Village*, 03:45-03:53.

[19] CNN, 05:10-06:00.

[20] CNN, 14:45-15:30.

[21] CNN, 20:20-20:40

[22] CNN, 06:50-07:55.

[23] CNN, 10:20-12:20