

Truthfulness in dementia care

We value truth-telling, especially given its connection to the norms of honesty and accuracy. Lies and deception we regard as offensive, a boundary crossed only when a countervailing principle of sufficient seriousness can provide a legitimizing warrant. Yet truth-telling and non-deception are not always observed in the context of caring for and relating to people with dementia. For example, it is put aside when a carer falsely suggests that a loved one will visit them soon, or distracts a person who insists on leaving their care home, or by providing a robot toy kitten to be taken as real. There can be strong reasons supporting such deceptive practices typically deriving from a concern for well-being, but the routine suspension of truthfulness in speech and representation may have impacts on the moral standing of people with dementia, the authenticity and integrity of care relationships, as well as impacts on caregivers who may feel that suspending truthfulness is their best or only moral alternative, but nevertheless find it awkward or painful. In this special issue we explore these issues in six articles, and by a range of authors, including philosophers and practitioners in nursing, old age psychiatry, and mental health.

Several connected, and at times seemingly opposed, themes emerge from the articles that reflect both the complexity and difficulty of this topic, as well as different clinical and philosophical perspectives. Nevertheless, we think each of the essays significantly progresses the discussion and we are grateful to all of the authors for their thoughtful and important contributions. Some prominent themes emerge, that we briefly reflect on first, before introducing the papers.

The first, as brought to the fore by Julian Hughes (and questioned by Matilda Carter), is that truthfulness is in general seen as the appropriate default position, and deviations from this important norm derive their justificatory force from moral considerations, typically around comfort for distressed people, or to head off a situation where harm threatens. Connected to this theme is the importance, as Gary Hodge and Carter nicely bring out, of respectfulness in care via observance of the lived reality of those with dementia. Such respectfulness typically requires the default of truthfulness, but a norm that requires us to share the lived reality of a person with dementia, thereby eschewing cognitive ableism, enables us to re-describe *therapeutic* lies in a way that dilutes the moral offence of deception. A third theme is the need to understand the nature of the care relationship. For instance, as Jordan MacKenzie points out, formal caregiving typically lacks the context and history of informal caregiving relationships, where a spouse or close friend is involved. In close caregiving relationships, in fact we do occasionally permit deception in cases where our interests and values may be promoted.

This has implications for lies and deception within formal caregiving relationships. Finally, it is important to consider the nature of the mental states of those with dementia before presuming specific caregiving practices prompt false beliefs. Rhonda Martens and Christine Hildebrand invite us to consider that perhaps those who mistake robot toys for the real thing are not in a state of belief, but instead belief-like states that are 'automatic, affective, and arational'. If so, then, they claim, this brings into question those critical of robot pets as companions in dementia care who worry about the possibility of deception that would presuppose more full-blooded truth-bearing states like belief. We now provide brief summaries of the papers.

The UK Mental Health Foundation and the Nuffield Council on Bioethics both recommend that truthfulness should be the default position in dementia care, with deliberate lies the exception, after lesser deceptions have been tried and have failed to ameliorate distress or confusion. Julian Hughes defends this position, countering a trend towards justification of deception, especially 'so-called' therapeutic lies. His defence begins by tracing arguments for an absolute prohibition on lying from Aristotle to Tollefsen, Grotius and Kant, back to Aquinas, and then forward to Sissela Bok; he then describes positions countenancing emergency exceptions to this absolute prohibition, from Grotius, Tollefsen, Boenhoffer and Donagan. This sets out a longstanding tension between absolute prohibition and morally excusable exceptions, where the weight is nonetheless on truthfulness as a moral foundation of respect and where lies that avert emergency are morally excusable. Hughes then makes a case for a middle ground position between truthfulness and lying, in which the pragmatic intention of deceit is to comfort rather than mislead. He does this via a reading of Aquinas and on the notion of illocutionary force from J.L. Austin's speech act theory, suggesting that a compassionate and practically wise person will 'conform to the reality' of a person with dementia and in this way see that the overriding requirement in such circumstances is the provision of comfort and security. But, Hughes argues, the moral weight on truthfulness should remain, and lies should be avoided, except in emergencies, which in the case of dementia care may be extreme distress or the threat of immediate harm.

Drawing on her previous work and on critical disability studies, Matilda Carter suggests the moral duty to tell the truth, as understood in the Kantian tradition where truth-telling respects others as 'moral equals', includes an implicit 'cognitive ableist' bias that downgrades the lived reality, or 'parallel subjectivity', of persons who live with dementia. It may indeed fail to respect individuals for 'who they are' with a range of abilities, some of which no longer meet normative standards for cognitive abilities. In opposition to positions,

held by the UK Mental Health Foundation and the Nuffield Council on Bioethics, as defended by Julian Hughes, where truth-telling is a moral default position and where deceptions and lies are the exception, Carter suggests the customary elevation of truth as a moral norm can be exclusionary, and thus a source of injustice, when seen through the lens of a relational egalitarian view of justice. She suggests that while many lies are unnecessary, or contrary to the interests of persons with dementia, or can be dominating, carers can engage in 'ethical deception' to discerningly engage with a person's parallel subjectivity, giving it moral weight, as opposed to viewing it as disturbed or confused according to ableist norms. In Carter's view, this allows for investigation of, and sensitive responses to, a person's unmet needs, while fostering 'egalitarian care relationships'. Carter describes a range of strategies involving mild to moderate deception—by omission, by distraction, and by immersion in a person's parallel subjectivity—with three thorny cases, which are fictional but realistic. The case studies demonstrate how people living with dementia can be treated as equals and respected for who they are whilst being deceived. Accordingly, in Carter's view, if deception fosters equality between carers and care recipients, with their differing abilities, and respects people with dementia for who they are, then carers' deceptions are neither oppressive, nor unjust.

Person-centred care (PCC), as inspired by psycho-gerontologist Tom Kitwood, shifted the emphasis in dementia care from treating symptoms and managing challenging behaviours to viewing them as responses to unmet social needs. Matthew Tieu focuses on the central insight that under PCC, such needs can be addressed via those interactions that promote what he calls the 'continuity and maintenance' of a person's selfhood. He describes the use of skilled and subtle diversionary techniques that meet a person's needs, for example, an anxious woman's need for reassurance that her young children are safe, even though these children are now middle-aged. Such techniques may affirm an 'out-of-date' role identity, that the woman is a mother of young children, but do not involve direct lies. Tieu argues that such techniques are morally justified when they serve care recipients, rather than serving the interests of carers. He then describes how the difference between these two sets of interests can be hard to discern. Kitwood described certain pervasive carer practices that were damaging to personhood as arising from and perpetuating a 'malignant social psychology'. Drawing on this idea, Tieu describes and criticizes under-staffed and under-resourced care settings, where time-pressured carers may, quite understandably, use diversion. In such cases, completing care tasks is prioritized, rather than delivering PCC. This suggests that the ethical use of diversionary tactics requires more than the person-centred attitudes of carers, it also requires resource and staffing levels that allow care staff to prioritize persons in care, and, in so doing, the continuity and maintenance of their selfhood.

Gary Hodge's article is an autoethnographic study from an acute care setting in a large hospital where he works as a mental health liaison nurse. He describes hospital environments as frightening and confusing places for people living with dementia that often induce or exacerbate anxiety, distress and disorientation to time and place,

which, in turn is challenging for hospital staff. He has observed that going along with the perceptions of a disoriented patient, say by confirming a false belief, does not always sit well with nursing staff. Although well-being based ethical justifications for such deceit in terms of therapeutic lies are available, Hodge questions their pre-suppositions. At the very least, he suggests, we should consider 'truth in dementia' to better understand the perspectives of disoriented patients, and he investigates this through a first-person narrative of his own encounter with a woman who seemed disoriented to time and place, and was demanding to be 'let out'. After a few questions, Hodge discovered that she was, or rather had been, a head teacher. Her distress arose because she wanted an answer to a simple question: 'where are the children?'. He describes an interlude where he stepped into her world and within a short space of time she began to 'conduct a class' in the middle of the ward. Some patients looked on; others continued sleeping; she became calm. The moment of crisis had passed. Hodge suggests that his engagement with the woman's 'lived present' was not a case of therapeutic lying done for the sake of achieving an effect, in this case, calming her down. It was an encounter that, at least for a few moments, achieved a middle place between her disorientation and pressing institutional demands within acute care settings. It was a shared reality in which he and she met one another.

Rhonda Martens and Christine Hildebrand examine the use of robot pets to comfort and reduce the loneliness and anxiety of people who live with dementia. Studies have shown that people with dementia are not the only ones who respond to robots, and to robot pets, as if they have mental states. But the *persistent* lack of understanding that people with dementia have raises ethical issues. They are being offered a counterfeit companionship, rather than a genuinely reciprocated one based on mutual affection and understanding, and this is potentially demeaning. In response to the argument that these persistent false beliefs encourage self-deception Martens and Hildebrand suggest an alternative explanation. Functionally normal beliefs are affirmed when the belief is true, and discounted, when a person responds to contradictory evidence against it. But persons with dementia may not be in such states. Rather, they may be in the mental states described by Tamar Gendler as 'aliefs'. When a person with dementia holds a robot pet the response may be, instead, 'automatic, arational, emotional and behavioural'. Unlike a functionally normal belief, it is not subject to truth norms. This alief hypothesis also provides a useful means to assess the benefits and risks of using robot pets in dementia care. In terms of benefits, alief responses are not seen as pathogenic, and that is because we all have them. Some people experience arational fears, for example, when walking on vertigo-inducing glass-floored skywalks. This too is an alief. And just as we understand this response, as many of us share it, we can understand and respect the alief response to a robot pet. Still, some risks remain and Martens and Hildebrand worry that robot pets may be over-used as substitutes for human companions, and that sustained aliefs, with continued use of robot pets, may encourage sustained disconnection from reality. Alief responses to high walkways may not produce other disconnections between what we believe and

how we emotionally respond, but this may not be the case for people who live with dementia. Good dementia care should offer and seek to maintain human and real-world connections, but if these potential risks are considered, Martens and Hildebrand suggest the benefits of robot pets outweigh the risks.

Jordan MacKenzie investigates some permissible limits to truth-telling obligations within informal caregiving relationships when a loved partner, parent or friend has dementia. In these relationships, obligations to foster the interests and values of a person we care for are longstanding and shaped prior to dementia onset. MacKenzie proposes that irrespective of dementia, informal caregiving relationships include 'moral allowances' such as the entitlement to assume hypothetical consent to deceive a loved one to honour their interests and values, and, at times, to facilitate a carer's self-interest. To motivate the proposal of an allowance to hypothetical consent, she describes a case in which her partner withholds information thereby preventing knowledge of a minor domestic crisis, until a writing commitment is completed. Her partner understands and values her interests, in his valuing of her, and this affords an allowance, or moral excuse, for him to promote her interests by deception, even though the obligation to tell the truth is typically stricter in close relationships than in others. Against this framework, MacKenzie draws on contractualism to suggest that the moral norms governing interpersonal relationships depend on the non-abstract nature of particular relationships. With a careful analysis of examples of deception our general truth-telling obligations can be seen to give way under conditions where moral allowances to deceive are justified by care that advances the interests of the care recipient. But since different relationships generate differences in what is owed, formal caregiver relationships do not include the same allowances as informal ones. In addition, self-interest is a far more limited avenue for justifying deceit in these cases. Importantly, formal caregivers typically do not share a relationship with those they care for that justifies the kind of reciprocal concern that conditions the possibility of hypothetical consent for deceit. The knowledge needed for that is unavailable; but an informal caregiver knows and values their loved one's interests, as their interests and their loved one's interests have long been entwined.

Our authors uniformly agree that lying to people with dementia must seem 'ineludible', not just convenient, as Julian Hughes puts it. Gratuitous lying could all-too-easily become a habit, and the exchanges in care lose their moral seriousness. As Jordan MacKenzie points out, whether to lie to a person with dementia is often a complicated thing, giving rise to situations where the moral quicksand here calls for swift, nuanced decisions, but which are nevertheless governed by the principles and values of person-centred care. It is important to see the issue as embedded in care practices governed by, and informed through moral virtue, as opposed to mere

workplace requirements. Many of our authors develop nuanced and sophisticated elements of person-centred care in which the cared-for are able to participate in genuine ways, and where caregiving is not motivated merely by comfort provision but involves respect for the values, beliefs (and aliefs) of those cared for. Carers' awareness of a person's genuine incapacity should not give way to a deterioration that reinforces a 'relational injustice', as Carter puts it. This connects again with the important realization that disorientation and distress start with the perspective of a person struggling to make sense of things, and to ignore that carries the risk of invalidation. As Gary Hodge asks 'is there a middle place, time, and reality where [the carer and cared-for] can both meet?'. A 'shared reality' framework provides a reminder that ham-fisted applications of care that is 'person-centred' will miss what is properly at stake in PCC, since the correct notion of personhood must recognize, as Matthew Tieu states it, the promotion of a 'continuity or maintenance of selfhood'. Deception occurring under this approach can only occur if it promotes the interests of those in care, and not as a convenience to caregivers. And as Tieu says at the end of his piece,

...what is at stake is no less than the proper fulfillment of the moral imperative to ensure some of the most vulnerable people in our community are able to live a good life in their final years. The real ingenuity and innovation in dementia care will only come from genuine recognition of this moral imperative.

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