

Jan Hartman

Department of Philosophy and Bioethics, Medical College, Jagiellonian University, Cracow, Poland

# In defence of telling the truth to patients with dementia

## Abstract

In this bioethics' paper, I oppose the arguments justifying lying and deceiving persons with dementia for their good or out of compassion. The goals achieved by lying and deception should be achieved in other ways. However, although in some extraordinary cases, a medical professional or caregiver can depart from the veracity rule, this cannot lead to the invalidation of truth-telling, being a *conditio sine qua non* of the respect for patient's dignity. In addition, the consequentialist argument that says that a person with dementia, while losing his or her discernment of the world, cannot be harmed when becoming the addressee of a lie is wrong. I argue that accepting deception is not only paternalist and contradictory to the principle of respect for patients but also harms the dignity of the caregiver community or care homes institutions. If a dementia patient is not able to take care of his or her status as an adult and a person worthy of respect, this task should be taken over all the more by caregivers. This is because dignity is a social value, constituted in social interactions (shared dignity). Truthfulness is often a harder choice to make, however, it should be given priority for the sake of human dignity, as well as for the authenticity of the personal relations among those who provide care to the patient — at home or in a care home. Avoiding the easier choice, which deception often is, requires an effort to build the communication skills necessary to give bad news in the least harmful way possible.

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## Assumptions

1. In principle, we are obliged to be truthful and to avoid lying and deceiving anyone. Certain actions (like giving evasive answers, giving incomplete information or declaring overly optimistic prognoses) may, at glance, look like lying or deceiving, however, on closer scrutiny, it may become clear that they are not contradictory with the goodwill to be truthful, frank and benevolent toward the addressee of such an action (resp. speech act). Cases of this kind do not provide us with sufficient

reason to perform a morally risky, as well as being discordant with the spirit of language, semantic manipulation and (for example) discern between lying (always bad) and deceiving (sometimes acceptable) [1]. Words like truth-telling, veracity, as well as benevolence and authenticity always refer to something good, desirable or mandatory, meanwhile, words like lie and deception always refer to something wrong. Therefore, it is better to use the expression an "apparent lie" or "departing from veracity" than to accept the idea that a lie (or deception) is sometimes justified. The difference

## Address for correspondence:

Jan Hartman

Department of Philosophy and Bioethics, Medical College, Jagiellonian University, Cracow, Poland,

Michałowskiego St. 12, 31–126 Cracow

e-mail: jan.hartman@uj.edu.pl



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between departing from veracity and lying is both in intention and scope. Concealment of facts or deforming them may be minimal, temporary or reversible, accepted as a necessary evil or in an extraordinary situation, forced by circumstances — in all these cases (if combined with protecting the other person's good or well-being), it is formally a deviation from the rule of telling the truth but not a lie. Analogically, using someone's else property in an extraordinary situation is treated as an appropriation but not as theft.

2. There are values greater than veracity, like security and protection of life. Subsequently, some ambiguous or borderline situations exist, when it is difficult to decide if the evil of departing from veracity might be accepted for the benefit of a higher value, namely the protection of the most essential interests and personal good of a deceived person. Nonetheless, veracity remains a *prima facie* principle and if by necessity it is not obeyed, it does not mean a lie.
3. Veracity cannot be separated from respect for others, at the same time as being an expression of the goodwill to do good (benevolence) as well as an expression of a more general attitude to life which we call authenticity. Authenticity is sincerity, frankness, simplicity in behaviour and speech, transparency of intentions and plans as well as some degree of spontaneity in expressing emotions and beliefs. Authenticity is also the readiness to protest against someone's harm or injustice as well as sensitivity to other people's pain. This set of virtues: benevolence, veracity, authenticity, empathy and integrity, is a consistent complex of moral qualities which should provide a universal ideal and commitment for medical professions. These virtues are quite incompatible with lying and deceiving patients.
4. Finally, I assume that paternalism is a term with pejorative connotations. In essence, paternalism is doctors' assigning to themselves some excessive rights in their relations with patients (especially the rights to actions that confine a patient's autonomy), justified by the attitude of carefulness and goodwill. A patient's autonomy, threatened by paternalism, is a *prima facie* principle, which

means that it should be enabled to the highest possible degree. In relation to partly incompetent patients, like those with dementia, it entails supporting them in their efforts to define and express their wishes, as well as in efforts to understand them better and to make communicating with them franker and more truthful.

### Paternalism — compassion — autonomy

Independently of aetiology, dementia is always connected with memory and cognitive impairment which often (however not necessarily<sup>1</sup>) causes traumatic experiences and deep suffering. Since a person with dementia is so much affected by his or her condition and subsequently so unhappy, the general principle which should guide us in our care of this person is compassion and support.

Compassion seems to be an ambiguous concept<sup>2</sup> since it can be used to justify a paternalist attitude. There is a danger that compassion and, more generally, a "good heart" attitude becomes an alibi for medical professionals and caregivers to deceive patients. It is not because lying sometimes facilitates caring but is also a result of a deeply embodied belief that caring for persons with dementia is analogous to childcare. If connected with another widespread belief (false) that a duty of truthfulness does not apply to our relations with children, it results in what we oppose here, that is deceiving people with dementia. Therefore, we need to put a spotlight on the popular stereotype of a person with dementia as a child-like old person, unveiling the potential of paternalism and disregard hidden behind this attitude. "Infantilizing" people with dementia only apparently helps to protect them, meanwhile, it opens the door to practising paternalism. Abandoning this attitude is, perhaps, challenging for carers. In order to do this, awareness of the patient's status as an adult person is necessary. Adulthood means, in this case, not having the capacity for self-control and responsibility for one's actions but possessing the biography and achievements of an adult person. Each person with dementia is worthy of respect because of what she or he used to be, what he or she has experienced and achieved but also because of what this person is nowadays, as someone who suffers.

<sup>1</sup> In Boer 2007 authors present a review of 50 papers on the subject. Many patients interviewed by different researchers in different countries bring authors to the conclusion that there is "no solid support to the widespread assumption that dementia is necessarily a state of dreadful suffering" (1021), however patients' experience of "negative emotions" may vary and stretch from a feeling of inadequateness and disintegration, through emotions dominated by fear as well as humiliation, to what is colloquially referred as "going mad".

<sup>2</sup> Cf. an analysis of the concept of compassion in Peterson 2011. Cf. also a consequentialist defense of discrimination between unacceptable lying and acceptable deceiving in Jackson 1991, as well as the counterargument in Bakhurst 1992.

Every person with dementia certainly is a living human. His or her reduced mental and communicative capacities or even atrophy of consciousness understood as self-awareness and separation from other beings may result in treating these patients as existing on the edge of life and death. This way of perceiving patients, namely as admittedly living a bodily life but deprived of spirit and personality, presents a serious risk to their dignity and rights.

### The temptation to lie and deceive

There are many different situations when medical professionals or carers abandon truthfulness for the sake of the patient.

1. The paradigmatic case is informing patients with dementia about their diagnosis and prognosis. Research shows that doctors tend to invoke the therapeutic privilege and prevent patients from hearing bad news [12]. Anyway, information obtained by a patient is going to be forgotten sooner or later. To keep a patient informed, doctors should renew the information from time to time. On the one hand, doctors are not inclined to do so and on the other hand — as research states — patients do not feel sufficiently informed about their health situation. We can assume that medical professionals and caregivers usually choose to avoid talking to the patients about their condition. Since the condition leads to deterioration and death, discussing it seems to be painful and useless. As a result, the situation can be resumed by two expressions: “there is nothing to talk about” or “we all know what the matter is”. The similar phenomenon of avoidance or evasion of the difficult subjects of suffering and death toward detailed questions about everyday care and treatment also concerns oncological patients and their communication with doctors [13]. The words “dementia” or “Alzheimer’s” are almost as emotionally loaded as the word “cancer”. Open talk about this issue seems to many people to be taboo, if not cruel. However, although the diagnosis and the challenge to accept information about dementia is an extremely difficult experience for anyone, it is necessary for the people involved, enabling them to fix and arrange their personal and legal issues during the first stages of the illness. At the same time, awareness of one’s own medical situation is a precondition for protecting one’s dignity and

“informed” cooperation with those who provide care. A person kept in the dark is *de facto* deceived and thus maintained in an asymmetric relationship with “knowing” ones. This asymmetry infringes a patient’s dignity, excluding him or her from the community of those who are “competent and rational”.

2. Another paradigmatic case, when it comes to paternalist manipulation, is the process of acquiring a patient’s informed consent for medical intervention. When the cognitive capacities of a patient are impaired, informed consent may be handled in a simplified way, sometimes with too automatic a reference to his or her advance directives. Meanwhile, some effort put into better communication might result in a better understanding of the doctor’s message by the patient and, subsequently, in more informed consent.<sup>3</sup>
3. Patients with dementia, depending on the stage of their condition, are capable of some self-sufficiency activities in cooperation with medical staff or carers. Getting patients to cooperate in everyday activities requires some special means and methods, sometimes including deception, like empty promises or lies about the presence or interest on the part of loved ones. It is common, but not necessary. J. Chalmers’ paper provides quite detailed information about methods of proceeding with demented patients (in a vulnerable field of dentistry) to win their consent and cooperation; there are no references to any sort of deception in what is applied or recommended [11].
4. Persons responsible for demented patients are supposed to take care of their well-being in physical, psychic and moral terms. One of the natural consequences of this commitment is a tendency to conceal sad or painful facts from patients. If a patient is always talking or calling someone whom she or he loves, is it fair to remind this patient that the loved one is not interested anymore or has died? In some cases, it would be cruel, in other cases, it would be a better choice. Each patient has his or her internal world of imagination, partially replacing what has been forgotten. It is the right of the patient to keep his or her internal world relatively safe, together with its internal truth (even if emotional only and far from reality) and this right should be respected<sup>4</sup>. It sometimes requires a compromise with truth-telling. How to

<sup>3</sup> For the good practice of informing cf. Fields, Calvert 2015

<sup>4</sup> In Karlawish 2021 we find a convincing idea that demented persons create their own worlds, often very beautiful, and carers can join it and be helpful in these creations. This participation, with accordance with the rules defined by a patient, cannot be qualified as lying

shape this compromise in order not to harm the trust of the practice of care and the dignity of a patient and a carer is a question to be answered in every individual case. The answer should include good knowledge of the given patient as well as involve the psychological competencies of the caregiver<sup>5</sup>. However, it must be remembered that the danger of the so-called slippery slope exists and that which at the beginning is only respect for a patient's emotional safety may soon turn into deception<sup>6</sup>. We find a very good example of this risk in Schermer's article mentioned above. The author analyses ways and consequences of using a device simulating telephone talks with relatives (SimPres<sup>®</sup>), which helps to maintain a better mood for patients with dementia. He illustrated the difference between referring to the patient's word and lying through two possible expressions used by a nurse proposing the use of the device to her patient: "Here's something for you to listen to" and "Here's your daughter on the phone". It cannot be denied that, in certain cases, it is in the patient's best interest that those who provide their care depart from veracity but, in all such cases, it should be conceived as an extraordinary action. Making a "white lie" into a routine action leads to regular lying and must be considered as serious deformation of the personal relations between patient and caregiver. As Schermer puts it: "Outright lies to demented patients should be avoided if possible because they compromise the liar, as well as threatening to undermine trust in the whole practice of care. Where possible, the best solution may be to get an important yet painful truth across without hurting the person involved" [1].

### Is it possible to deceive someone who does not understand?

It seems that only a person having full mental capacity can be harmed by the deception. If he or she does not have this capacity, consequently they have no access to any reliable picture of reality, and thus live in unknowledge and illusion. No matter what you tell such a person — a lie or the truth — it makes no difference because a cognitively impaired person does

not conceive the world anyway. This argument seems to be consistent with a consequentialist attitude, requiring actions to be judged by their consequences.

However, the very example of deceiving a person with dementia provides an argument against consequentialism itself. Apart from the fact that the easiness of lying always has a destructive influence on the liar's morals as well as their relations with others (which constitutes a good consequentialist argument in favour of strict truth-telling), lying and deceiving do not cease to be what they are even if the recipient of the given message cannot be misled. An act of lying is a spoken act driven by its inherent intention to communicate what is false, even in the case when the subject of this act is convinced that the lie at stake is in the addressee's best interests. The lie does not cease to be a lie when the liar's act of lying is coupled with the conviction that the recipient of this lie cannot be deceived in any way, since the order of truth and falsity (illusion, lie) is not accessible to him.

There are two kinds of arguments justifying this attitude. First, our conviction that the given patient is too demented to be able to be deceived does not state any fact but expresses an opinion and a "decree" excluding someone from the community of dissent and rational communication. This sort of exclusion is wrong as such, damaging a given community as a realm of safety and solidarity. Secondly, every act of speech, even if directed to only one recipient, is indebted in the language as a social good and participates in the ongoing permanent social process of communication. Whether or not an addressee of a message can understand it and has an idea of the truth (resp. falsehood), the very act of lying (deceiving) is sufficient for the moral infringement to occur. A lie not only harms the person lied to but is (as in other cases of transgression) a social evil, a corruption infiltrating some realm of the social life. It is wrong not only because of its wrong intentions but also because of its consequences. Therefore, if some very special circumstances occur in our contacts with demented patients that justify manipulation and departing from veracity, special care should be taken to prevent oneself from lying. We cannot define the deadline<sup>7</sup>. Certainly, it is a question of protecting the patient from

<sup>5</sup> It their interesting focus study Casey 2019 authors unveil a predominant opinion among patients and caregivers that "white lies" can be accepted under condition that they are rooted in a very good personal knowledge of a patients. Lying cannot be rhapsodic or accidental since it is serious. The focus study participants tend to grant "right to lie" rather to the informal/unpaid carers than to the professionals

<sup>6</sup> Daniela Cantone and her collaborators (Cantone 2017) show in their psychological focus study how real the effect of slippery slope can be. Almost all (90%) of interviewed nurses admitted that they sometimes lie to the demented patients — mostly in order to calm them and avoid aggression

<sup>7</sup> In seeking this „deadline“ Rebecca Dresser (Dresser 2021) refers to the concept of making sense of once life. If you are deceived being a vulnerable or helpless person, your attempts to protect your dignity and make sense of your life are undermined

psychic pain of the sort considered unacceptable by his or her caregiver. However, it is not only psychic pain that matters. The internal world of a patient must also be protected. It is a question of compassion coupled with respect for the patient. Does not everyone have his or her internal world which could be objectively evaluated as illusory? As Schermer puts it: "Frequently, falsehoods are not intended to create false beliefs but to distract patients or to reach them when they have become absorbed in their inner world. In the therapeutic approach known as 'validation', the quintessence is acceptance and confirmation of the patient's feelings and experiences regardless of their level of reality. In this approach, patients are addressed on an emotional rather than on a cognitive level" [1].

### **The covenant to care and shared dignity**

Persons with dementia are not fully able to take care of themselves, including protecting their dignity. They also need help with the latter. If we also justify the importance of truthfulness in relations with cognitively impaired patients by referring to the social dimension of the value of truthfulness, then we use an argument that is certainly insufficient, for it overlooks a patient as a person. Therefore, this argument must be completed in a way that includes the self of a patient. The self of a patient is certainly weakened. However, none of us proves to be so strong as a subject without constantly repeated acts of recognition performed by other subjects. Others continuously include us in the web of communicative and social relations, again and again confirming our status as persons who are intelligent and capable of deciding for themselves. In normal conditions, we can reciprocate this "gift of inclusion", meanwhile a person with dementia is unable to do so.

Because of the cognitive and communicative deficiency affecting each demented patient, caregivers, to respect his or her dignity and status as an adult person, not only need to see this patient as she or he is right now (a suffering person, stricken by misfortune) but also as how she or he used to be, in terms of biography, status and achievements. The past cannot be cancelled as a precondition for the general style of communication and attitude toward the patient. And yet each patient is somebody — a mother or a father, a former employee, an expert... And is still alive... Respect for who the patient used to be and respect for suffering are two factors protecting a patient's dignity. Of course, under the condition that his or her environment aspires to constitute an authentic community of solidarity and a covenant to care. Owing to the common effort of those who "convened" to provide care and protect sick persons, their vulnerable

and fragile dignity can be maintained. What cannot be done by demented patients on their own, should be taken and shared by their carers. A patient's dignity protected in this way becomes a common achievement of the medics and other persons who show a sincere concern for him or her. In other words, the dignity of a patient with dementia is a result of multilateral cooperation, proving to be a social value.

Preventing oneself from lying and deceiving patients with dementia is not only a duty. It is also a necessary condition for maintaining an ethical community inside a care home. Caregivers, as empathic, caring and respectful people, recognize and support their dignity when they practice sane, authentic relations, uplifting their moral existence to a higher plane. Inclusion of those afflicted with dementia in the solidary moral community of decent people of goodwill means giving priority to authenticity and veracity over the paternalist protectionism justified by solicitude. As a result, an emotional shield protecting a demented person cannot be entirely impermeable. To treat a sick person seriously means allowing for the possibility that, in certain circumstances, he or she may feel psychic pain as a result of some bad news. The truth, as we know, can be difficult and painful. However, we share it with others since they often have the right to it, on moral and practical grounds. Also, those who suffer from dementia have the right to the truth and to be taken seriously — to such an extent that is accessible to them and not less than that.

If we wish to frankly practice authenticity and solidarity, subsequently avoiding deception and lying to the patients, we make real efforts to elaborate an appropriate style of communication with each of them, suitable for him or her on cognitive and emotional grounds. It applies both to the family and institutional wards. Analogically to therapy and nursing, everyday care also requires communication and cooperation among the persons involved, who should elaborate a covenant to care and treat their patient. Part of this moral and practical challenge is considering truthfulness in communication with the patient. Protecting patients from deception should be reasonably and deliberately balanced with keeping them safe from intensive psychic pain. Willingness to take on this challenge is a measure of the goodwill, authenticity and morals of the caring institution.

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