

## NOTHING BUT THE TRUTH? ON TRUTH AND DECEPTION IN DEMENTIA CARE

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### ABSTRACT

*Lies and deception are often used in the care for demented elderly and often with the best intentions. However, there is a strong moral presumption against all forms of lying and deceiving. The goal of this article is to examine and evaluate concrete examples of deception and lies in dementia care, while addressing some fundamental issues in the process.*

*It is argued that because dementia slowly diminishes the capacities one needs to distinguish between truths and falsehoods, the ability to be lied to also disappears. When the moral reasons to reject lying are explored, it becomes clear that most of them also hold where demented patients are concerned, though this also depends on the capacities of the patient. Lying, though prima facie wrong, can sometimes be justified with an appeal to well-being. The relationship between well-being and the truth is further explored. Two examples of deceiving demented patients for reasons of beneficence are discussed, from which it can be concluded that although in some cases beneficent lies or deception will not enhance patients' well-being, there are circumstances in which they do. In general, methods that enhance the well-being of the patient without deception or lies should be favored above options that use deceit, and methods of getting the truth across without hurting the patient should be favored above blunt honesty. Finally, it is important to note that not only the patient but also the nursing and medical staff can be affected by the use of lies and deception.*

### 1. INTRODUCTION

Lies and deception are often used in the contact with and care for demented elderly – and often with the best intentions. The truth can be painful and hard to bear and demented patients seem to have

lost touch with reality anyhow. From a moral point of view, the presumption is strongly against all forms of lying and deceiving. Kant even called deception, together with coercion, the most fundamental form of wrongdoing to others – the root of all evil. Kant has been criticized in turn for his

overly strict rejection of lying. In many situations lying may seem harmless or at least a lesser evil and the question whether or not to lie requires serious moral deliberation in such cases.

I will focus here on the care for and interaction with demented patients because problems of truth and deception loom large there. However, it is my ambition to contribute to a better understanding of the morality of deception and truth-speaking as well. The goal of this article is therefore twofold: to examine and evaluate concrete examples of deception and lies in dementia care; and, in the process, to address some more fundamental issues about lying, deception and the truth.

I will argue that what can be called deception, or a lie, changes over the course of dementia because dementia slowly diminishes the capacities one needs to distinguish between truths and falsehoods. Once these capacities are lost, the ability to be lied to is also gone. There are many reasons to reject lying, and I will argue that most of them also hold where demented patients are concerned, though not all remain equally strong. But even if lying is *prima facie* wrong, it can be justified in some circumstances, for example with an appeal to the well-being of the one lied to. I will discuss two examples of deceiving demented patients for reasons of beneficence, and examine the relationship between well-being and truth. I will argue that though in some cases beneficent lies or beneficent deception will not actually enhance people's well-being, there are some circumstances in which they do.

## 2. TWO EXAMPLES FROM PRACTICE

In the daily practice of dementia care, lies, falsehoods and deception can take different shapes. The following two examples will figure as 'cases' in the further analysis.

### Simulated Presence

Simulated Presence is a device developed for Alzheimer's patients. It is intended to manage behavior problems like agitation and withdrawal that are believed to indicate personal discomfort, and hence a lack of well-being. SimPres® is an audiotape that

includes a caller's side of a telephone conversation. The tape is made by a family member of the patient, who is trained in special communication techniques and has a list of previously selected cherished memories of the patient to talk about. The audiotape can be played through a recording device that looks like a telephone, or using a headset and auto reverse tape player enclosed in a hip pack. Patients respond to the tape as if they were having a real telephone conversation. They smile and talk back and thus appear to believe that they are actually on the phone with their family member. Because people with Alzheimer's disease have recent memory defects, audio taped messages can be played repeatedly and yet be perceived as fresh conversation each time.<sup>1</sup> An evaluation study showed that SimPres® improved agitated or withdrawn behaviors and appeared to make patients feel good and enjoy. The conclusion of the evaluation study is that: 'SimPres® appears to be a pleasurable activity when used as a complement to existing activity programs and even as a substitute for one-on-one interactions when staff must be involved with other residents'.<sup>2</sup>

### Tricks and white lies in everyday interaction

On many occasions in everyday interaction with demented people the question of speaking the truth or telling a 'white lie' comes up. Imagine a demented woman banging on the locked door of the ward, begging everyone in the neighborhood to open the door so that she can go and collect the children from school. Telling her that her children are long grown up and are not waiting for her only worsens her agitation and confusion. So one of the nursing aides takes her arm and says, 'come on Mrs. G. the children will not be out for another hour, let's go have a cup of tea first'.

Another example is that of a widower who keeps asking about his wife, and who is inconsolable every time when he is told that she has passed away. Why hurt such a patient by confronting him with the

<sup>1</sup> L. Camberg et al. 1999. SimPres: A Personalized Approach to Enhance Well-Being in Persons with Alzheimer's Disease. In *Enhancing the Quality of Life in Advanced Dementia*. L. Volicer and L. Bloom-Charette, eds. Philadelphia: Taylor & Francis: 126-140.

<sup>2</sup> L. Camberg et al. Evaluation of Simulated Presence: A Personalized Approach to Enhance Well-Being in Persons with Alzheimer's Disease. *J Am Geriatr Soc* 1999; 47: 451.

painful truth time and again? Why not just distract attention by a small lie and tell the widower his wife is out shopping?

### 3. WHAT IS TO COUNT AS A LIE?

Are the above examples instances of lying, or of deception? Does the fact that Alzheimer's patients sometimes 'live in their own world' and are often unable to distinguish between truth and falsehood make a difference for the classification and evaluation of such acts?

According to Sissela Bok in her famous *Lying*, a lie is 'any intentionally deceptive message which is stated'.<sup>3</sup> Lies are part of the broader category of deception, which includes all that we do or do not do, say or do not say, with the intention of misleading others. Misleading others means making them believe what we ourselves do not believe. So, anything that is stated (either verbally or in writing) with the intention to make someone else believe something that the person uttering the statement himself believes to be false is a lie. Anything done with the same intention, but without uttering a falsehood, is deception. Evading a question, withholding information or even a certain way of looking or gesturing can all be deceptive. The difference between lying and deceiving lies in the assertion, the statement, which is the characteristic of the lie. Jennifer Jackson, in her work on truth and trust in medicine, uses much the same definition. According to her a lie is 'the asserting of what one believes to be false in order to deceive someone', where deceiving is understood as getting others to believe what one believes to be false.<sup>4</sup>

With these definitions in mind, it is easy to classify the use of SimPres® as either a form of lying or a form of deceiving. SimPres® is clearly set up to make the patient believe he is actually on the phone, and most patients apparently do believe this since they respond to the tape talking and smiling. The device is constructed as to make patients believe something that is not true, and so it is an inherently deceptive technology. Whether or not it involves

*lying* to patients depends how it is introduced, on what is stated about it to the patient. If a nurse says: 'Here's something for you to listen to', she is not lying, but if she says: 'Here's your daughter on the phone', she clearly is. As long as she does not make it absolutely clear, however, that this is merely a tape, she is deceiving the patient.

This may not be all there is to say about it, however. When we examine the daily tricks and white lies used in nursing homes, another picture emerges. Though they often include the statement of falsehoods, it is not necessarily the case that one *intends* to make the demented patient *believe* these falsehoods. While some tricks or 'white lies' are clearly lies – falsehoods intended to mislead – there exist other forms of dealing with truth and falsehood that do not classify as lies. For example pretend play in children, jokes and jests, or exaggerations to 'spice up' a story are all practices that border on lying or deception but are not quite the same (although sometimes difficult to demarcate).

In the care for demented patients as well, one might ask whether telling falsehoods is always properly understood as deceptive. Frequently, falsehoods are not intended to create false beliefs but to distract patients or to reach them when they have become absorbed in their own 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.<sup>5</sup> In this approach, patients are addressed on an emotional rather than on a cognitive level. When a woman keeps banging the door to go to her children, a validating care-giver would not state that the children are long grown up (which is true) or that their school will be out a little later today (which is a lie). She will invite this woman to tell something more about her children and so address her feelings and emotions, not the cognitive content of her beliefs. Whether or not the conversation will contain true statements and give an accurate picture of reality is not the point; the point is to reach the patient and to establish a connection.

The question is whether it is accurate to discuss such practices in terms of truth, lying, reality and

<sup>3</sup> S. Bok. 1999 (originally 1978). *Lying*. New York: Vintage Books: 13.

<sup>4</sup> J. Jackson. 2001. *Truth, Trust and Medicine*. London and New York: Routledge: 48.

<sup>5</sup> B.J. Benjamin. 1999. Validation: A Communication Alternative. In *Enhancing the Quality of Life in Advanced Dementia*. L. Volicer & L. Bloom-Charette, eds. Philadelphia: Taylor & Francis: 107–125.

the like. At least some everyday tricks and white lies in the care for demented elderly should probably not be defined as lies, because they are not intended to deceive. Put even more strongly: they should be understood as part of a completely different practice, dealing with the emotional and not the cognitive level of interaction. There may be a parallel with what Sissela Bok says about children: 'strict accuracy is simply not very high on the list of essentials in speaking with children'. With the youngest ones especially, the sharing of stories and fairy tales, of invention and play can suggest, in Erik Erikson's words, at its best 'some virgin chance conquered, some divine leeway shared' – leaving the conventionally 'accurate' and 'realistic' far behind.<sup>6</sup>

Second, not only the intention to mislead may be absent, but also the ability of the patient to form beliefs and hence to form false beliefs and to be misled. If someone is living in 'his own world' this does not mean that truth does not exist anymore. But the further on in the dementia process, the less it is possible for patients to entertain 'beliefs', either true or false ones. One can often predict that although a lie will give the patient a temporary false believe, this will be forgotten very quickly, perhaps in a few seconds. Perhaps only the emotional content will get through and no real cognitive 'belief' will be formed. Once patients reach a state in which concepts such as true and false, reality and illusion, or fact and fantasy do not mean anything to them anymore it becomes logically impossible to deceive them or to lie to them. Lying to someone requires a capacity of the one lied to to form and hold beliefs about what is true and what is not. One cannot lie to someone in a coma, or to a baby. Likewise, it is conceptually impossible to lie to people in the advanced states of dementia. When exactly the capacity to form beliefs and hence to be lied to is lost is a very complex empirical and theoretical question. That it is lost at some point seems clear.

#### 4. IF IT IS LYING, OR DECEPTION, IS IT WRONG?

While not all tricks, falsehoods and white lies in daily nursing home practice may constitute real

instances of deception or lying, some do. On what grounds, if any, can lies and deceptive practices towards demented residents be justified? SimPres®, for example, is deceptive but it is intended to make people feel better and improve their well-being. Can this weigh up to the deception involved? Or are lying and deceiving always morally wrong and should they be prohibited in all circumstances? In order to answer this question we should first have a look at reasons to believe that lying and deception are morally wrong, and then at how these reasons hold up where demented patients are concerned.

One frequently mentioned argument against lying is that it violates the autonomy of the person lied to. Lies and deception affect people's opportunities to make their own choices, because they affect the information they base their choices on or because they prevent choice altogether. This is an important argument against lying and deception in medicine, where respect for autonomy and informed consent have become cornerstones of good practice.

Apart from the ability to choose, autonomy is also manifested in the ability for authentic self-creation and self-manifestation. One of the problems with deception is that it makes it impossible for people to relate to reality and to react to it, while it is in doing so that people can both express and construct themselves – which is a form of autonomy. A good example is dealing with painful truths. Once we come to know some painful truth, we can start dealing with it – mourning it, accepting it, struggling with it, 'giving it a place in our lives' or whatever. For Alzheimer's patients in the later stages the painful truth – for example that their spouse has died – is new every time again. They cannot even start to 'deal with it' since they do not remember. New information cannot affect the demented patient's identity, his outlook on life, or his plans and goals anymore. This means that the truth or falsehood of this information loses its significance for the patient. So, in the later stages of Alzheimer's, capacities for authentic self-creation and manifestation may disappear and autonomy may no longer provide a reason against lying. The same goes for the capacity to make choices. When all these capacities have gone, the point is probably also reached where one cannot really be lied to anymore (as discussed above). However, as long as patients do have some capacity to

<sup>6</sup> Bok, *op. cit.* note 3, p. 206.

choose, and to express and construct their identity, lies that hamper the use of these capacities do infringe on autonomy.

A second important argument against lying is connected to the autonomy-argument, but goes a bit further by invoking the human dignity of the one lied to. It claims that lying to someone is a severe form of disrespect. As Christine Korsgaard explains this Kantian point of view: 'According to the Formula of Humanity, coercion and deception are the most fundamental forms of wrongdoing to others – the roots of all evil.'<sup>7</sup> Like coercion, deception implies treating someone as a means only, and not as an end in himself. To treat people as ends in themselves, to respect them, is to treat them always as free rational beings. We ought, morally, to ascribe free will and rationality to others and thus treat them as ends and not merely as means. By withholding them the opportunity to make free rational choices one does not treat them as ends. This violates the respect we owe humanity (either in our own person or in that of others). That is why lying is, according to Kant, one of the two most fundamentally wrong things you can do to others.

However, this does not imply that there is never any excuse for lying. Korsgaard argues convincingly that there is a difference between the world of pure practical reason and the actual world we live in.<sup>8</sup> The free will and rationality of Kant are ideal concepts of pure practical reason. They are not natural attributes of persons and they do not match seamlessly with any actual properties of people. In the real world, according to Korsgaard, we find a continuum of more or less imperfectly free and rational beings. Kant's theory sets a moral ideal to live up to. We should treat others as if they were free and rational as much as possible. But paternalistic deception can be justified if the person lied to is not free and rational, and the ends of the deception are ones we can fairly presume that this person would hold if he were rational. Who we should count as free and rational and who not, where we should draw the line between those who we should treat as free rational beings and those we need not treat as such, is a matter of decision. We should decide on

the best possible grounds but we cannot derive such a judgment directly from Kantian ideal concepts, says Korsgaard.

The autonomy-based argument allowing lies to non-autonomous people such as severely demented patients is therefore in itself correct, but the Kantian duty of respect for human dignity urges us to be very careful in using it.

Another important argument against lying and deception is that both undermine trust. This is mostly stated as a utilitarian argument that suggests lying is all right as long as no-one finds out. I do not believe that this is the case, but as an additional argument to the former ones the trust-argument is very important. Especially in the relationship between caregiver and care receiver, trust is a crucial component and lying or deceiving patients can severely damage trust and so undermine the care relationship. In the case of demented residents it may be the case that the damaging effects of lying and deception are not always a serious problem, since many demented people do not notice or find out subtle lies and forms of deception or quickly forget about them. On the other hand, lying can increase the confusion and disorientation characteristic of Alzheimer's. Apart from trust within individual relationships, lying can also damage public trust in an entire practice. While a decline in trust between the demented patient and the caregiving staff may not always result from the use of a technology like SymPres®, or from white lies, public trust in professional care might be damaged if lying and deception were known to be common practice. People might feel uncomfortable with the idea that once their faculties decline, caregivers would start deceiving them.

The trust-argument can also be understood in a more Kantian way. Regardless of any actual decline in trust caused by lies or deceptive practices, it can be argued that lying and deception are always wrong, because they can never serve as universal principle of action for all. As Onora O'Neill explains: 'It cannot do so because one standard effect of widespread, let alone universal, deception would be severe and widespread damage to trust. This damage to trust would undercut or damage an indispensable prerequisite of any deception: if a principle of deception is widely, let alone universally, adopted some – or many – people will find that

<sup>7</sup> C.M. Korsgaard. 1996. *Creating the Kingdom of Ends*. Cambridge: Cambridge University Press: 140.

<sup>8</sup> Ibid: 335–361.

others will not accept their words or deeds as trustworthy, so that they are unable, or less able, to deceive. Deception cannot therefore be a principle of action for all.<sup>9,10</sup>

A final argument against lying, which gains its validity from the former arguments, concerns the effects of lying on the liar himself. Bok has argued that lying may easily become a habit, entrapping the liar in an ever more complex web of lies and falsehoods, corrupting him and damaging his integrity and credibility. According to Kant, lying destroys the human dignity of the liar himself. Even when deceptive practices and white lies in the care for demented patients prove to be harmless or beneficial to those patients, the effects of lying on the caregivers should be considered as well. Caregivers may well be bothered by what they perceive as being dishonest, deceptive or untruthful. Even if they do so from good intentions, and even if they know it actually is beneficial to patients, it may still bother them and be perceived as compromising their personal integrity, or violating basic moral rules. Although there is little research in this area, there are some indications that caregivers actually find this aspect problematic.<sup>11</sup>

Having discussed these main arguments against deception and lying, I will adhere to the common opinion in bioethics that lying is *prima facie* wrong and not absolutely wrong. Probably no philosopher or ethicist would be willing to argue that lying is absolutely wrong in *all* circumstances. Even Kant, who is often considered to defend this position, would probably not do so in 'the real world' as Korsgaard has shown. In the case of demented patients, some arguments against lying or deceiving do not always count fully, depending mainly on the loss of capacities of the patient. Loss of trust or infringement of autonomy, for example, may not always be present. Even so, there is enough reason

to believe lying to be wrong *prima facie* and to require some justification.

One of the possible justifying reasons to lie or deceive a patient is that it will prevent harm, or even promote well-being. It may do so, for example, by giving hope, by sparing from pain or distress or by maintaining self-respect. If beneficence is invoked to justify deceptive practices, it should be clear that the well-being of the dupe is indeed being protected or promoted by the deception. Is this the case with SimPres®, and with everyday white lies? The focus of the argument shifts here from deception and lying as morally relevant actions, to the value that truth and reality have in human life.

## 5. DOES SIMPRES REALLY IMPROVE WELL-BEING?

From a scientific evaluation of SimPres® it appears as if SimPres® does make demented people 'feel good'. It helps resolve agitated and withdrawn behavior, produces happy facial expressions and in general appears to be enjoyed by the patients as a pleasurable experience.<sup>12</sup> From a philosophical point of view one might ask, however, what the value is of such deception-based positive feelings. Does it really add to a patient's well-being, understood as the all-encompassing assessment of how well life is going for the individual whose life it is? Does it contribute to what might be called a 'good life' for demented elderly?<sup>13</sup> On this point theorists concerned with well-being have no consensus. While most theories acknowledge that pleasant experiences can add to a person's well-being, there is no agreement on the question of whether pleasant experiences can enhance well-being when they are based on illusion, falsehood or deception. In the discussion about preference theories of well-being, for example, this question is discussed in terms of the necessity or

<sup>9</sup> O. O'Neill. 2002. *Autonomy and Trust in Bioethics*. Cambridge: Cambridge University Press: 98.

<sup>10</sup> However, it has also been argued that according to Kant some exceptions to the rule 'never to lie' are possible. A maxim allowing lying to deceivers, for instance, is universalizable. Korsgaard, *op. cit.* note 7, p. 137.

<sup>11</sup> C. Hertogh et al. Truth Telling and Truthfulness in the Care for Patients with Advanced Dementia: an Ethnographic Study in Dutch Nursing Homes. *Soc Sci Med* 2004; 59: 1685–1693.

<sup>12</sup> Camberg, *op. cit.* note 2.

<sup>13</sup> In the following I will assume that demented people enjoy SimPres because they believe they are having a conversation with a relative. This may not be a correct assumption, however. Maybe people simply enjoy the familiar voice – just like religious music or songs from childhood can be soothing – without having any 'beliefs' about what is going on. If people enjoy SimPres not as a conversation but simple as an enjoyable stimulus, I do not see anything wrong with it. As mentioned earlier, it is not really deceptive in such cases.

superfluity of a ‘reality requirement’. If well-being is defined by the fulfillment of preferences, is it necessary to stipulate that this fulfillment must be a *real event in the world*, or is the subjective experience of its fulfillment enough? In this discussion a famous thought experiment from Robert Nozick is frequently invoked to strengthen the argument in favor of a reality requirement.<sup>14</sup> In the experiment known as the Experience Machine, Nozick asks his readers to imagine a machine that can be directly attached to the brain and can provide any kind of experience one wants. Would people choose to be hooked on to such a machine for the rest of their lives, guaranteeing a life consisting of their preferred experiences? According to Nozick, people would not want this, because they do not only want to experience certain things but also to *do* things, to *be* a certain kind of person and to live in *contact with reality*.

At first sight, SimPres® has some traits in common with the Experience Machine since one is attached to it and then has an experience of something that is not real, namely a telephone conversation with a relative. There are, however, important differences with Nozick’s thought experiment. First, as opposed to the definitive character of the choice for the Experience Machine, SimPres® is only a *temporary* escape from reality just like losing oneself in a film, a computer-game or a fantasy is. However, with these common escapes from reality, the person enjoying them knows that it is ‘not real’ – he is deliberately seeking the illusion. With SimPres®, the demented patient is not aware of the illusory character of the experience just like the person hooked onto Nozick’s machine. Still, the fact that SimPres® is a temporary intervention and a not a perpetual one like the Experience Machine does, I believe, make an important difference. The Experience Machine shows that there is more to the good life than merely experiences. Well-being comprises more than just ‘feeling good’. But this does not necessarily show us that illusory pleasant experiences have no value at all, or that they have nothing to contribute to well-being or to a good life whatsoever. It does not tell us that ‘false experiences’ can *never* count for anything. Although often invoked for that purpose, the Experience Machine has actually nothing

<sup>14</sup> R. Nozick. 1974. *Anarchy, State and Utopia*. New York: Basic Books: 42–45.

to say about this. As Wayne Sumner has rightly commented: ‘Our attitudes toward delusion, deception, and fantasy are more complex and ambiguous than the experience machine story allows for.’<sup>15</sup>

Sumner himself argues that the question about the ‘worth’ of illusionary experiences should be left to the person concerned. ‘When we reassess our lives in retrospect, and from a superior epistemic vantage point, *there is no right answer to the question of what our reaction [to illusory experiences, MS] should be* – that surely is up to us. Because a reality requirement stipulates a right answer – any happiness based on illusion can make no intrinsic contribution to our well-being – it must be rejected as presumptuously dogmatic. [. . .] Who are we to dictate that the solace someone else finds in a comforting fantasy should count for nothing?’<sup>16</sup>

The extent to which the illusoriness of the experience *matters* for an individual’s well-being therefore depends, according to Sumner, on the extent to which he decides to *make* it matter. When it comes to judging something like SimPres®, this is not a very practical solution, however, because obviously a demented patient is not in a position to decide how to evaluate the illusory character of the telephone call. Nevertheless, I believe it is fair to conclude that temporary illusory experiences *may* add to well-being, and so a strict reality requirement is not necessary.

However, the vocabulary introduced by the Experience Machine, is not precise enough in expressing what is problematic about SimPres® and its contribution to well-being. Rather than framing this in terms of mental state versus state of the world or illusion versus reality, I would suggest we see it as a matter of authentic versus fake. The problem is not that there is some experience with no substrate in the real world, but rather that the thing that is experienced is not ‘the real stuff’, but a fake. And some things cannot be fake without losing their essential nature and (thus) their value. This goes, for example, for art.<sup>17</sup> Imagine an art lover who succeeds in purchasing an early Van Gogh for his collection. If

<sup>15</sup> L.W. Sumner. 1996. *Welfare, Happiness, and Ethics*. Oxford: Oxford University Press: 96.

<sup>16</sup> Ibid: 159.

<sup>17</sup> And according to some, also for nature. See R. Elliot. 1997. *Faking Nature. The Ethics of Environmental Retoration*. London and New York: Routledge.

some years later the Van Gogh proves to be a fake, it's value for the collector will reduce dramatically however much he enjoyed it before. Just like art, human relationships and conversations between loved-ones appear to be the kind of things that depend on their 'authenticity', their 'truth' or 'sincerity' for their value. In meaningful human contact mutuality, reciprocity, interaction, sincerity and trust are important, hence fake interaction loses its value *as* interaction. SimPres® is faking something that derives its value from being real. It fakes interaction – a meaningful contact with another human being. Because at least part of the value of such interaction lies in the interaction itself, fake interaction cannot have the same value as real interaction.<sup>18</sup>

So, if people are enjoying SimPres® because they believe they are having a real telephone conversation with a loved-one, can it add to well-being? Yes and no. The pleasant feelings a fake call invokes can add to well-being just like other things that make one 'feel good' can. It is not clear, however, whether this weighs up to the deceptive character of the technique. Moreover, if interacting and conversing with loved-ones count as things that add to a good life, things that are valuable in their own right, then it seems that fake conversations do not add to well-being in the way real conversations would.<sup>19</sup> They simply are not the kind of thing one values having for itself, even if one is unaware of it at the time. This implies that SimPres may have a positive effect on well-being through the inducement of pleasant feelings, but that it does not add to well-being in the way real interaction does. The same effect on well-being could thus be reached by any other method that provides pleasant feelings, while these could avoid the deceptive and fake character of the Sim-

<sup>18</sup> It may not always be easy to make a sharp distinction between real and fake. Definitions of what 'real' interaction is, and of the value of interaction may change under the influence of new social or technological developments. For example, in robotics and human-computer interaction the boundaries seem to shift. People may interact with computers as if they were real people.

<sup>19</sup> If we also count having meaningful (family) relationships as things that contribute to a good life, we should look how these fake conversations should be placed in the maintenance of the relationship as a whole. Is it a mere substitute, provided by family members who do not bother to come in person and see SimPres as an easy way out? Or is it a tool to help maintain and strengthen the relationship, keep memories awake, be virtually 'present' when one cannot always really be present? If SimPres fits in a good family relationship and helps to maintain or strengthen it, it may add to overall well-being.

Pres® 'phone call'. Alternatives are therefore preferable. It seems perfectly possible to use some of the principles of SimPres® (pleasant personal memories related by a familiar voice of a loved one) *without* the deceptive side. Why fake a telephone call, if a narration can do the same? And, more importantly, why not invest more time and attention in real interaction with demented patients? SimPres® and related technologies might all too easily become substitutes for true attention.

## 6. THE VALUE OF TRUTH AND THE SOLACE OF LIES

Can lies, falsehoods and tricks be beneficial to demented patients? Can they, for example, spare people unnecessary distress and grief and are they therefore justified?

Many people would argue that the truth, however painful, is always important to know. Living 'in the truth' is worthwhile in itself and even a harsh reality may be preferred above blissful ignorance. The Experience Machine story can be interpreted as showing exactly this – that what people want is to live in the truth, to be able to react to the outside world, and to live life in a meaningful relationship with their environment. So, lying to people to protect them from grief or guilt may not actually enhance their well-being. A good life is not necessarily a life without distress, but one in which we can mourn our losses, learn to deal with our pain, and find ways to show remorse. The less grief and pain in a life the better, perhaps, but this does not mean that denying or avoiding pain is always the best way to enhance over-all well-being.

This conclusion is relevant for dealing with truth and deception in the care for demented elderly because being demented *is* in a sense like living in the experience machine. As Ben Rich says: 'on the experience machine, and, one might also argue, in the third stage of Alzheimer's dementia, we have essentially lost touch with reality. Such a loss should concern us profoundly if what we desire is to live our lives while being in touch with reality'.<sup>20</sup> Many

<sup>20</sup> B.A. Rich. Prospective Autonomy and Critical Interests: A Narrative Defense of the Moral Authority of Advance Directives. *Camb Q Health Ethics* 1997; 6: 143.



people will subscribe to this statement and agree that one of the dramatic aspects of the disease is this loss of contact with reality. Even those approaches in dementia care that claim to focus exclusively on the subjective sense of well-being of the patient do, on closer analysis, show real concern for maintaining some contact with reality.<sup>21</sup>

Because we value contact with reality as a good thing in life our treatment of and interaction with demented people is generally aimed at maintaining some contact with reality as long as possible. The value we attach to living life in contact with reality also means we should not deliberately make people with dementia lose touch even further by way of deceptive practices or lies. Truth and sincerity can help maintain a connection to reality and thus add to well-being. However, for patients who have irreversibly lost the capacity to actively *relate* to reality the value of truth changes, as discussed earlier. Once painful truths do not add anything to the person's life anymore but pain, time and again, they lose their meaning and their value. When there is only pain and no capacity left to deal with that pain, to really understand or come to grips with it, nor even to remember it for very long, then the truth cannot contribute to a good life in any way anymore. The conclusion is that sparing patients from painful truths is right to do in situations in which these truths cannot add anything to the patient's life anymore.

Outright lies to demented patients should be avoided if possible because they compromise the liar, as well as threaten 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. A good example of this is a case of a demented woman whose son had died but who could not remember this. Every time she asked how he was doing she was devastated when they told her that he was dead. Finally one of the nurses dressed her in the clothes she had worn to his funeral and this apparently made her remember and enabled her to mourn. Afterwards, she did not ask for her son anymore, though she still spoke about him.<sup>22</sup>

In other situations avoiding painful truths by circumvention and distraction are certainly legitimate options. Moreover, it should be kept in mind that it is not deceptive to refrain from telling people the truth or from correcting their false or mistaken beliefs when this is not called for. It can even be a case of 'truth-dumping'<sup>23</sup> or of overzealous candor<sup>24</sup> to tell patients their beliefs are false and to confront them with the painful truth when they have asked nothing. Demented patients 'living in their own world' should not be forced out of it with an appeal to truth and reality, if these have nothing to offer them but pain.<sup>25</sup>

## CONCLUSION

Assessing whether or not a certain act is to count as deceptive or whether a false statement is to count as a lie can be difficult. Assessing whether or not a specific lie or deceptive act is justified in the care for a demented patient is an even more complex and subtle matter. Assuming that lies, deception and falsehoods in the care for demented elderly are most frequently employed with the best intentions and with an eye to the patient's well-being, the central question is how to strike the balance between well-being and truth. In general one can say that methods that enhance the well-being of the patient without deception or lies should be favored above options that do use deceit, and methods of getting the truth across without hurting the patient should be favored above methods that do hurt. Even so, it still demands a lot of insight into the specific patient, his capacities, and his reactions as well as into the exact situation and possible alternatives, to judge well about individual instances of lying or deceiving. Those who know the patient well should therefore make such decisions – categorical statements about the legitimacy of deceiving or lying to demented patients are not warranted.

As a support for those who have to make such difficult decisions on a daily basis, I would like to

<sup>21</sup> Volicer, *op. cit.* note 1.

<sup>22</sup> T. Yang-Lewis & R. Moody. The Forgetful Mourner. *Hastings Cent Rep* 1995; 25(1): 32–33.

<sup>23</sup> Bok, *op. cit.* note 3, p. xxii.

<sup>24</sup> Jackson, *op. cit.* note 4.

<sup>25</sup> There may of course be cases in which the 'own reality' of the demented patient is painful, and it would be a relief for him to know the truth and connect to reality. In such cases of course one should try to get the truth across in order to avoid pain.

repeat three considerations that have been discussed above. First, that methods relying on deception or lies to enhance patients' well-being do not always succeed because there is more to well-being than just feeling good. Second, that however important truth may be in many people's lives, it can lose its function and it can become a mere burden. Finally, not only the patient but also the nursing and medical staff are

affected by the use of lies and deception. The effects of lying and deceiving on their integrity and trustworthiness should also be taken into account.

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