

# RESPECT FOR NON-AUTONOMOUS PERSONS: DEALING WITH DEMENTIA PATIENTS

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## Respeito pelas pessoas não autônomas: lidando com pacientes com demência

### ABSTRACT

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In this text, I address the question what it means to respect patients with dementia. Further, I analyze what appropriate approach to be employed while discussing dementia patients, as certain persons. I examine different approaches, such as, the autonomy approach, the best interest approach and the approach of the personality concept in the strong and weak sense. I argue that the autonomous approach which understands patients with dementia as being able to make autonomous decisions, asserts the validity of the principle of respecting autonomy. While, the best interest approach focuses on the comfort of the patient's current experience to respect the dementia patients. I point out that both the autonomous approach and the best interest approach are inappropriate for the questions which I engage in this paper. I argue and conclude that the personality concept-based approach is appropriate not in the sense that patient's personality is the only important factor (in the strong sense), but in the sense that it is an important factor for respect of the dementia patient (in the weak sense).

**Keywords:** Dementia patients; Respect for dementia patients; The principle of respect for autonomy; Self-decision; The concept of personality.

## Resumo

Neste texto, questiono o que significa respeitar pacientes com demência. Além disso, analiso qual abordagem apropriada deve ser empregada ao discutir pacientes com demência, como determinadas pessoas. Examinando abordagens diferentes, como a abordagem da autonomia, a abordagem do melhor interesse e a abordagem do conceito de personalidade no sentido forte e fraco. Argumento que a abordagem autônoma que entende os pacientes com demência como capazes de tomar decisões autônomas afirma a validade do princípio de respeitar a autonomia. Por outro lado, a abordagem do melhor interesse se concentra no conforto da experiência atual do paciente para respeitar os pacientes com demência. Assinalo que tanto a abordagem autônoma quanto a de melhor interesse são inadequadas para as questões que endereço neste artigo. Argumento e concluo que a abordagem baseada no conceito de personalidade é apropriada, não no sentido de que a personalidade do paciente é o único fator importante (no sentido forte), mas no sentido de que é um fator importante no respeito ao paciente com demência (no sentido fraco).

**Palavras-chave:** Pacientes com demência; Respeito aos pacientes com demência; Princípio do respeito à autonomia; Auto-decisão; Conceito de personalidade.

It is undisputed that the principle of respect for autonomy is one of the most relevant principles in medical ethics. Indeed, this principle has increasingly gained recognition as a guiding principle in the field. A key example is the moral acceptability of euthanasia in the sense of letting die,<sup>1</sup> which justifies itself largely on the basis of this principle.<sup>2</sup> This has proved compelling, leading to key changes. One such change was Germany's 2009 legal strengthening of the validity of a living will. This can be understood as an expression of the meaningful place that the principle of respect for autonomy receives not only in theory, but also in our practical world. Nevertheless, it seems clear to me that this principle alone is not sufficient for the explication of respect for all persons, which in my view can be classified at least in two categories: Autonomous persons who are able to make an autonomous decision, and non-autonomous persons who cannot make an autonomous decision. The principle of respect for autonomy provides an argument for respect for autonomous persons, but not for non-autonomous persons, such as those with dementia in

<sup>1</sup> In the following, the term *euthanasia* means only the form of letting die.

<sup>2</sup> Cf. BIRNBACHER 2015.

the later stage.<sup>3</sup> If we want to understand non-autonomous persons as objects of respect as well, a principle different from the principle of respect for autonomy is necessary.

The debate between Ronald Dworkin and Rebecca Dresser about the validity of Margo's living will in the 1990s, which has become something of a benchmark within this discussion, was the argument over the principle of respect for autonomy.<sup>4</sup> Since I assume that Margo's living will should be respected as an expression of her autonomy, this article basically does not address the controversy. Nevertheless, the aforementioned controversy is important for this article because Dworkin and Dresser ask the question of how to treat dementia patients not only as humans but also as a certain individual person. They agree that Margo as a dementia patient should be respected, even though, according to Dworkin, the experiential interests must be subordinated to the critical ones. Taking into account the background of my starting point, the question raised by Dworkin and Dresser can be described as follows.

How can we respect Margo *without living will* not only as a human being, but also as a certain individual person?

To answer this question, it is important to precisely define who Margo actually is. The various symptoms of dementia are variable depending on the individual and the progress of the disease. If a patient with dementia is understood only in a collective sense, it is inappropriate to discuss the issue of respecting a patient with dementia. Margo's assessment and guidance, as Michael Quante notes, vary depending on whether she is affected by dementia at an early stage or at an advanced stage.

First, what can be challenging is: In the face of increasing dependency, how do I relate to the attitude and the demands which the affected person, who perceives these processes in himself, takes and elevates. On the other hand, the question is: How can I preserve the dignity of a person who is no longer aware of his growing dependence? It is obvious that this perspective distinction in the different case constellations –

<sup>3</sup> In section 2, I will address the question of why dementia patients in the later stage *should* not be autonomous.

<sup>4</sup> Cf. DWORKIN 1993, pp. 201-202 and DRESSER, 1995.

think of progressive dementias, for example – will lead to very different assessments and instructions.<sup>5</sup>

Andrew Firlík describes Margo as follows:

At the apartment, Margo's Jamaican home attendant, Louise, welcomed me with giggles and smiles, [...] Before the locks were installed, Margo had, on occasion, satisfied her understandable desire to explore the city on her own. We usually found her a couple of days later [...] Margo enjoys reading, especially mysteries, she says, though I've noticed that her place in the book jumps randomly from day to day; dozens of pages are dog-eared at any given moment.<sup>6</sup>

The Swiss Academy of Medical Sciences (SAMS) divides dementia into three stages.<sup>7</sup> Dementia at an early stage is characterized by mild cognitive and/or behavioral abnormalities. Daily life is already difficult for people with dementia who find themselves in the middle stages, even if relatives or, in many cases, professionals support them. In the severe stage, dementia patients only have minimal verbal communication options, with persisting behavioral disorders and emotional disorders. According to these three courses of dementia, Margo's condition can be classified as one of middle dementia.

In a nod to Margo's dependency on others, the question is how to intervene in Margo's life. The main question in this article focuses on what kind of intervention can be considered respectful to Margo. There are four approaches available; the autonomy approach, the best interest approach and the approach of the personality concept in the strong and weak sense. On the basis of the dispute over Margo's living will by Dworkin and Dresser, the meaning of respect for Margo as a certain individual person should firstly be clarified (1). The second section shows whether the principle of respect for autonomy can be applied to the main question of this article (2). After that, I will briefly mention two types of self-decision: Non-autonomous and autonomous self-decision (3). Subsequently, the validity of the best interest approach is examined, which is used very often in the context of respect for dementia patients (4). In addition, the approach of the personality concept should be clarified, which can solve the problems of the best interest approach (5).

<sup>5</sup> Cf. QUANTE, 2019, p. 255 [transl. S.S].

<sup>6</sup> FIRLIK 1991, p. 201.

<sup>7</sup> Cf. SAMS, 2018, p. 8.

## 1. THE CONSENT OF RESPECT FOR THE DEMENTIA PATIENT

Dworkin and Dresser argue over the validity of Margo's living will. While Dworkin claims the validity of her living will, Dresser considers it invalid. Nevertheless, there is one commonality between Dworkin and Dresser in the debate over the respect of people with dementia. These two different conclusions regarding the validity of Margo's living will come from the question from which the experiential and critical interests should be prioritized.

Dworkin understands the interests of a person in two ways: Experiential and critical interests. Experiential interests concern emotive pleasures at certain times, which relate to the comforts of each experience. Every person can enjoy experiential interests. Because "nothing is more natural than any animal's desire to put itself in the way of pleasure and out of the way of pain".<sup>8</sup> On the other hand, critical interests have to do with how we, as persons, can lead a good life. For a good life the more or less coherent integrity of a person is necessary, which exists not only at a certain time, but over a period of time. Such a person leads a good life in light of his or her own values or beliefs. Dworkin is by no means trying to demonstrate that only critical interests are important to life, or life that only enjoys experiential interests is meaningless.

Nor am I saying that people who do not consciously reflect on how their lives are going as a whole, who just get on with living, taking things as they come, are defective or not living well. Lives like that can be extremely attractive, even enviable, and they are plainly preferable to lives ruined by detailed planning and constant trial-balance-sheet assessments of progress.<sup>9</sup>

But Dworkin points out at the same time that in principle, critical interests are more important than experiential interests (general priority rule).

If you are a woman with a chance to begin a demanding career that intrigues you, but only by sacrificing time with your young children, which choice do you make? [...] Or, if you are a Jew,

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<sup>8</sup> DWORKIN, 1993, p. 203.

<sup>9</sup> DWORKIN 1993, p. 202.

should you abandon your comfortable life in Los Angeles and emigrate to Israel to identify yourself firmly with that nation's fate? People do not make momentous decisions like these by trying to predict how much pleasure each choice might bring them.<sup>10</sup>

These decisions, which are not based on experiential interests, show the importance of ethical demands on critical interests in our lives. Unlike experiential interests, critical interests that require "the ability to act out of genuine preference or character or conviction or a sense of self"<sup>11</sup> do not apply to all persons. Persons suffering from dementia who lose such abilities due to disease progression have experiential interests but not critical interests. In light of the premise of this article that Margo did not prepare a living will, there is no conflict between the two types of interests. It is clear from this assumption that the key to respect for dementia patients who do not have any critical interests must be experiential interests. In fact, Dworkin agrees that

[...] in the circumstances of dementia, critical interests become less important and experiential interests more so, so that fiduciaries may rightly ignore the former and concentrate on the latter.<sup>12</sup>

In contrast with Dworkin, Dresser considers Margo's living will invalid. Her criticism of Dworkin boils down to the argument that experiential interest should categorically take precedence.<sup>13</sup> According to Dresser, the key to respecting Margo is her experiential interest. In fact, Dresser and Dworkin disagree over Margo's living will. Despite their disagreement, they see the key to respect for Margo *without a living will* in the experiential interest. Based on this common ground between Dworkin and Dresser, I define respect for dementia patients without a living will as the promotion of their experiential interests. We can now answer the question of what interventions are considered to respect them: Interventions by others that promote experiential interests can be understood to respect Margo. The question therefore is, on what grounds others can promote her experiential interests.

<sup>10</sup> DWORKIN, 1993, p. 205.

<sup>11</sup> DWORKIN, 1993, p. 224.

<sup>12</sup> DWORKIN, 1993, p. 232.

<sup>13</sup> Cf. DRESSER, 1989, p. 158.

## 2. RESPECT FOR AUTONOMY OF DEMENTIA PATIENTS?

Some argue that Margo is still able to make decisions autonomously. It follows that the proper basis for promoting Margo's experiential interests lies in the principle of respect for autonomy (2.1). This understanding is inconsistent with my understanding of Margo at the beginning of this article, being that she is a non-autonomous person. Those who regard the principle of respect for autonomy as a valid principle in the context of respect for patients with dementia are faced with the challenge of demonstrating the systematic problem arising from the debate over the moral acceptability of euthanasia. By pointing out the systemic problem, I will discuss the appropriateness of my understanding that Margo is a non-autonomous person (2.2).

**If a person with dementia can still make autonomous decisions, the principle of respect for autonomy is the key to respect for the patient.**

### 2.1 Margo can still make autonomous decisions!

If a person with dementia can still make autonomous decisions, the principle of respect for autonomy is the key to respect for the patient. However, because a high degree of autonomous understanding, such as according to Harry G. Frankfurt, cannot be applied to patients with dementia,<sup>14</sup> the criteria for autonomy need to be lowered. Autonomy is understood as follows: Autonomy is gradual and related.<sup>15</sup> Decisions made by demented patients with the assistance of others such as "the choice of food, the clothes and the decision of which activities he/she wants to pursue"<sup>16</sup> must be understood to be autonomous. I call this autonomy concept *assisted autonomy*. Those who support the appropriateness of the principle of respect for autonomy in the context of respect for patients with dementia believe that this principle enables persons to live a good life. This raises the questions: What is a good life? Why is autonomy important for a good life? A good life of a person is generally understood in such a way that persons lead their lives in their own way.

<sup>14</sup> Cf. FRANKFURT, 1971.

<sup>15</sup> Cf. SCHMIDHUBER, 2013, p. 6 and 13ff. NYS 2013, p. 197ff and NUFFIELD COUNCIL ON BIOETHICS, 2009, pp. 26-27.

<sup>16</sup> SCHMIDHUBER, 2013, p. 6 [transl. S.S].



My life [...], from a fundamental point of view, cannot be a good life through paternalistic effort. My life can be a good life only if I can live my life from the inside according to my beliefs and values.<sup>17</sup>

In order to live a good life, a person makes decisions based on his or her values and beliefs. Advocates of the concept of assisted autonomy acknowledge that in this sense, dementia patients cannot live their own lives because of disease progression. According to the advocates of the concept of assisted autonomy, dementia patients do have their own beliefs and values, such as preferences for food and clothing; they simply cannot make decisions based on their own values and beliefs. With the assistance of others, they can make decisions based on their values and live their lives in their own way; an autonomous decision; a good life. A good life of a person, which is understood as living according to his or her own values, is inseparable from autonomy.

However, the model of assisted autonomy faces the question of whether this model can really be included in the category of autonomy. This is because autonomy originally means self-legislation.<sup>18</sup> Proponents of the model of assisted autonomy address this question by emphasizing the relational aspect of autonomy. There are many related autonomous concepts, but the proponents of those concepts at least agree that

[...] people grow up and live in social relationships, and their preferences, attitudes and values are acquired in relationships with other people and are therefore subject to social influence.<sup>19</sup>

Given that a person lives only in relationships with others, the autonomy of a person exists also only in relationships with others. By emphasizing the essential element of autonomy, dependence on others, the model of assisted autonomy considers decisions *carried out by others* to be autonomous. Importantly, others must carry out decisions that are consistent with the personality of the person with dementia. Caregivers must therefore read which decisions are consistent with the patients' personality. The decisions of

<sup>17</sup> RÖSSLER, 2017, p. 394.395 [transl. S.S].

<sup>18</sup> Cf. BOBBERT; WERNER, 2014, p. 105.

<sup>19</sup> ACH; SCHÖNE-SEIFERT, 2013, p. 43 [transl. S.S].



patients with dementia which are not consistently integrated into the value system are not always understandable, so that caregivers need to interpret their decisions expressed in various forms, such as gestures and facial expressions. The proponents of the model of assisted autonomy recognize the importance of the concept of personality.<sup>20</sup> Thus, the autonomy of dementia patients is assured through the caregiver finding a decision that is consistent with the personality of the dementia patient and executing the decision. The following shows that the model of assisted autonomy faces systematic problems.

## 2.2 Systematic problems of the assisted autonomy concept

A central problem with the model of assisted autonomy is illustrated by the discussion of respect for autonomy in the context of the moral acceptability of euthanasia, which is divided into letting die and killing. Patients' decisions in letting die, in which patients refuse medical treatment, must always be respected, if it is autonomous. The reason being, it is not acceptable to enforce medical treatment when the patient refuses it autonomously.<sup>21</sup> Applying this analysis of the relationship between autonomy and respect to a model of assisted autonomy raises systematic problems; according to this model, caregivers must let patients with dementia under certain conditions die. For example, if a demented patient refuses to take a medicine, the caregiver must follow that decision, although it may have been necessary to survive. The decision to refuse taking medicine may be consistent with the patient's personality, because he or she may have rejected modern medicine before getting dementia. As proponents of the assisted autonomy model consider it morally problematic to let a patient with dementia under these conditions die, they have the burden of proof to explain what it means to respect such a patient. *On the one hand*, if they consider it correct that the patient's autonomy to letting die must be always respected, they must explain why the autonomy of the dementia patient to refuse to take a medicine is not respected. The autonomy in the sense that the patient does

<sup>20</sup> Cf. MCCORMACK, 2002, p. 117 and NYS, 2013, p. 197.

<sup>21</sup> Cf. World Medical Association, Declaration of Lisbon on the Right of the Patient. Online: [http://dl.med.or.jp/dl-med/wma/lisbon\\_e.pdf](http://dl.med.or.jp/dl-med/wma/lisbon_e.pdf) [27.07.2019].

**The essential problem with the model of assisted autonomy is that it considers self-decision of patients with dementia to be autonomous. To avoid the problem of the assisted autonomy model, self-decision should be distinguished from autonomy.**

not give consent in the interference is understood in two senses; autonomy that must be respected (refusal of medical treatment: letting die) and autonomy of patients with dementia that must not be respected (refusal of taking a medicine: letting die). As long as advocates of the assisted autonomy model support the above thesis that autonomy is a necessary and sufficient condition for respecting the decision of euthanasia (letting die), they cannot fulfil the required burden of proof. *On the other hand*, if proponents of the assisted autonomy model do not accept the thesis that the patient's decision to euthanize (letting die) must be respected as long as it is autonomous, then they bear the burden of proof as to why it is allowed to intervene in a patients' autonomy as a denial of consent. It seems to me that it is impossible to fulfill this burden of proof. Given this problem, it is not appropriate to consider Margo's decisions autonomous. We should then regard Margo as a person who cannot make autonomous decisions.

### **3. TWO DIFFERENT FORMS OF SELF-DECISION: AUTONOMOUS AND NON-AUTONOMOUS SELF-DECISION**

The fundamental question of this article emerges again from previous discussions; on what basis can others promote the experiential interests of dementia persons. In other words: How can we respect Margo? The essential problem with the model of assisted autonomy is that it considers self-decision of patients with dementia to be autonomous. To avoid the problem of the assisted autonomy model, self-decision should be distinguished from autonomy.

In fact, many bioethicists understand autonomy and self-decision as synonyms.<sup>22</sup> But the concepts of autonomy and self-decision can be distinguished. To make this clear, one can ask whether a demented person can still decide to eat meat or fish or to drink a glass of water or a cup of coffee. The patient can definitely make such decisions. Although these decisions are a form of self-decision, they must not be considered autonomous. In other words, self-decision can be divided into two forms.

<sup>22</sup> Cf. BROCK, 2013, p. 264, HOLM, 2001, p. 154 and ELLIOT 2012, p. 543.

1. Self-decision associated with autonomy (autonomous self-decision)
2. Self-decision not associated with autonomy (non-autonomous self-decision)

The patient's autonomous decision, on the one hand, is thematic in the context of withholding medical treatment. As long as the patient's self-decision from the physician's point of view is autonomous, physician intervention in the patient's autonomous self-decision is not permitted. The practice of medical treatment that patients autonomously refuse is morally unacceptable. I call respect for autonomous self-decision in this sense *a negative respect for autonomous self-decision*. Autonomous self-decision of the patients is necessary and sufficient to respect it in a negative sense. Unlike autonomous self-decision, physician intervention in a patient's non-autonomous self-decision is morally acceptable under certain conditions. For example, if a patient with dementia refuses the necessary care without understanding, caregivers may be allowed to intervene in the patient's self-decision.

A patient's non-autonomous self-decision is neither sufficient nor necessary in a negative respect for autonomous self-decision. It is therefore not subject to the argument of respecting autonomous self-decision. However, as long as non-autonomous self-decision is a form of self-decision, it does not mean that non-autonomous self-decision is not respected in any case. Self-decision itself is normative, so even non-autonomous self-decision is subject to respect. Given the systematic problem of the assisted autonomy model, the key to respecting patients with dementia should be found in non-autonomous self-decision rather than in autonomous self-decision. Caregivers should rely on the patient's non-autonomous self-decision to promote their own experiential interests. This avoids contradictory situations in which the assisted autonomy model fails.

At the same time, however, it is clear that not all non-autonomous self-decisions can promote the experiential interests of patients with dementia, namely respect for them. Caregivers must therefore interpret which non-autonomous self-decision of dementia patients promotes their experiential interests. The question then is, which

approach is appropriate for that purpose. There are three possible approaches: The approach oriented to the best interests of patients with dementia and the approaches oriented to the personality of patients with dementia in the strong and weak sense. According to the best approach, as shown below, patients with dementia are respected when the caregivers promote their experiential interests based on the patient's point of view and the synchronic perspective. According to the personality approach in the strong sense, patients with dementia are respected when the caregivers promote their experiential interests based on the patient's and others' point of view and the diachronic perspective. This approach assumes that care that aims to match personality and non-autonomous self-decision promotes experiential interests. Finally, according to the personality approach in the weak sense, patients with dementia are respected when the caregivers uphold their experiential interests based on the patient's and others' point of view and the synchronic, diachronic perspective. Unlike the personality approach in the strong sense, this approach does not make the assumption that only care that aims to match personality and non-autonomous self-decision promotes experiential interests. In the case of the personality approach in the weak sense, it is an open question whether care seeks to match personality and non-autonomous self-decision.

#### **4. THE MEANING OF RESPECT FOR THE DEMENTIA PATIENT: THE BEST INTEREST APPROACH OF THE DEMENTIA PATIENT**

##### **4.1 The best interest approach**

The best approach is aimed exclusively at the well-being of patients with dementia, where the personality of the patient should not be considered. This approach relies on the thesis that there is numerical identity before and after dementia but no personal identity: »demented patients are not, in some sense, the same persons they were before«. <sup>23</sup> Personal identity, which generally goes back to John Locke, is one of the fundamental philosophical questions. The thesis of the

<sup>23</sup> ELLIOTT, 2012, p. 544.

best approach that there is no personal identity is actually based on his argument. Personal identity, according to Locke, extends into the continuing past of first-person memory. According to it, there is no personal identity between me in the present and me when I was three years old. The required condition for personal identity – the continuity of first-person memory at two different times and points – is not satisfied here. Based on Locke’s personal identity theory, advocates of the best-interest approach point out that the personality before dementia cannot be attributed to the dementia patient.

**The best interest approach that the personality before dementia has nothing to do with the demented person has two consequences; it eliminates the perspective of others and focuses only on the synchronic perspective.**

The neurological damage associated with their condition destroys memory and the associated sense of oneself as persisting through time, as well as affecting intellectual capacity, personality and values.<sup>24</sup>

The best interest approach that the personality before dementia has nothing to do with the demented person has two consequences; it eliminates the perspective of others and focuses only on the synchronic perspective. We think generally that relatives are very important for dementia patients and their opinions are also important for care planning. Relatives are regarded as the people who know best how the person *lived* and what he or she *liked* before becoming demented. But the best interest approach does not recognize relatives’ advantage in the context of care. According to the best interest approach, relatives know the person before dementia, not the demented patient who has nothing to do with that person. Their opinions are not helpful in caring for people with dementia. In addition, the best interest approach not only considers it impossible to bring the personality of the previous personality into the care debate, but also considers it morally inappropriate. Care aimed at matching personality and non-autonomous self-decisions can be problematic for dementia persons themselves.

If the well-known polar explorer and adventurer Sir Ranulph Fiennes [...] became demented and wanted to go out into a blizzard, there would be an excellent connection between this desire and his previous stable personality; but would not be equally justified in discounting this wish [...].<sup>25</sup>

<sup>24</sup> MCDUGALL, 2005, p. 39.

<sup>25</sup> HOLM, 2001, p. 156.

Dementia patients are not interested in whether non-autonomous self-decision is consistent with their personality, but only in whether their every experience is comfortable. Their interests are not directed to the future, but are limited to the present. Unlike a person who can make autonomous decisions, the past and the future have no role in respecting people with dementia. According to the best interest approach, respect for patients with dementia lies not in the coincidence of non-autonomous self-decision and personality, but in the aim of comfort with current experiences. The fundamental problem with the best interest approach, as we see below, is that it is based on Locke's personal identity theory, which relies on first-person memory.

#### **4.2 The fundamental problem of the best interest approach**

In this section, I would like to examine whether personal identity can be derived only from first-person memory. Locke's theory of personal identity has had a profound impact on us to this day.<sup>26</sup> He posited that one's personal identity could be extracted from first-person memory. According to Locke, there is no personal identity between individuals who fail to conceive of themselves as themselves at different times and places based on first-person memory. But one's personal identity cannot be derived solely from first-person memory, which is fallible and also cannot correct memory errors. For example, we cannot merely determine from a first-person memory whether a mental episode, such as eating sushi a week ago, really happened or was a *déjà vu* moment. Therefore, it is insufficient to extract personal identity from first-person memory alone.<sup>27</sup>

#### **4.3 Two problems regarding the two consequences of the best interest approach**

The two consequences of the best interest approach – removing the perspective of others and focusing only on the present – can be ethically problematic, especially in respect to patients with dementia. It is clear that understanding from the patient's current point

<sup>26</sup> Cf. LOCKE, 1975.

<sup>27</sup> Cf. QUANTE, 2007, p. 50 ff.

of view which non-autonomous self-decision promotes the experiential interests of demented patients is essential for respecting them. As mentioned in section 2, it is widely accepted that the implementation of medical practices that a patient has autonomously rejected is considered unacceptable paternalism, even if necessary for life-saving. However, this approach cannot be applied to patients with dementia who cannot make an autonomous decision. Thus, paternalism, such as forced feeding or restraint, may be morally justified in such patients.<sup>28</sup> Even if paternalism can be morally justified under certain circumstances, it cannot be understood as a respect for patients with dementia as defined in section 1 as the promotion of experiential interests. It is relevant to determine which non-autonomous self-decision promote experiential interests based on the patient's current perspective.

Nevertheless, the view of others cannot be ignored from two standpoints. The exclusion of the perspective of others, *on the one hand*, makes it impossible to properly understand the meaning of respecting patients with dementia. As long as the support of others plays an essential role in respecting them, we cannot exclude the perspective of others.<sup>29</sup> Respect for patients with dementia which excludes the perspective of others is insufficient in itself. The exclusion of the perspective of others, *on the other hand*, leads to problematic consequences. This is especially noticeable if the caregiver is not convinced of the care plan. Being forced to provide unsatisfactory care increases the risk of caregiver burnout, which is problematic not only for the caregivers, but also for the dementia patients themselves. For these two reasons, the perspective of others should not and cannot be overlooked in the discussion of respect for patients with dementia.

In order to solve these two problems – the exclusion of the perspective of others and focusing only on the synchronic perspective – it is necessary to consider the viewpoint of others and the diachronic perspective. As will be seen below, the concept of personality plays an important role in solving these two problems.

<sup>28</sup> Cf. KNELL, 2018, p. 63.

<sup>29</sup> Cf. MCCORMACK, 2002, p. 117.



## 5. THE MEANING OF RESPECT FOR THE PERSON WITH DEMENTIA: THE CONCEPT OF PERSONALITY

First, this section will clarify why the concept of personality can contribute in solving the two problems in the best interest approach. At this point, it is important to understand the content of the personality concept (5.1). Finally, the validity of the personality concept approach in respecting people with dementia is verified (5.2).

**If the concept of personality in a strong or weak sense is the key to respecting a patient with dementia, two problems of best interest approach – the exclusion of the perspective of others and focusing only on the synchronic perspective – can be eliminated.**

### 5.1 The concept of personality

*Personhood* is the condition for being a person. When a human being fulfils the conditions for being a person, they are regarded as a person and as a bearer of the moral status attributed equally to all persons. If action A is morally unacceptable for person A, it should be also morally unacceptable for person B. For example, if the act of killing is understood as a morally unacceptable act for one person, it is also deemed to be unacceptable for another. In the dimension of personhood, it is not possible to elicit the difference in moral status between persons. However, the ethical requirements of a person are highly variable, depending on the individual and the circumstances of the individual. Referring to the euthanasia discussion, it is easy to see that a person suffering from an incurable disease may wish to die, while others do not. This makes it clear that the dimension of personhood does not adequately capture the ethical requirements of persons.

Unlike personhood, the concept of personality is generally characterized by the individual characteristic of the person. Persons build their own personalities over time in their interactions with others.<sup>30</sup> Relationships with others and diachronic perspective are, therefore, components of ones' personality. If the concept of personality in a strong or weak sense is the key to respecting a patient with dementia, two problems of best interest approach – the exclusion of the perspective of others and focusing only on the synchronic perspective – can be eliminated.

<sup>30</sup> Cf. QUANTE, 2007.

## 5.2 The concept of personality in a strong and weak sense for respect of the dementia patient

However, if the application of the personality concept regarding the question of respect for patients with dementia brings new problems, then the approach of the personality concept as a whole is not suitable. According to the best interest approach, the concept of personality is in this context *in principle* not suitable. The question here is whether the concept of personality is *in principle* inappropriate for the argument about respect for patients with dementia. The approach of the personality concept responds to this question in both a strong and weak sense.

Proponents of the personality concept approach understand this position only in a strong sense. The respect for dementia patients occurs in the caregiver caring for a demented patient according to his or her non-autonomous self-decision, which is consistent with his or her personality. The personality approach in a strong sense argues that the correspondence of non-autonomous self-decision and personality promotes the experiential interests of dementia patients.<sup>31</sup> The concept of personality is in this sense the key to respect for them. The best interest approach objects to the claim that non-autonomous self-decision, which does not match the personality but its promotion of experiential interests, is not considered.

In addition to the personality approach in a strong sense, there is in my opinion the personality approach in a weak sense, which does not assume that the correspondence between non-autonomous self-decision and personality is the only important factor in respecting people with dementia. The concept of personality can sometimes be very helpful for caregivers to interpret which non-autonomous self-decision is in the patient's experiential interests. Regardless of theoretical differences – the best interest approach or the personality approach in a strong and weak sense – all bioethicists who deal with the question about respect for persons with dementia agree, that the way dementia patients express their own decisions is not always understandable. It remains unclear in most cases which non-autonomous-self-decision promotes their experi-

<sup>31</sup> Cf. FORD; MCCORMACK, 2000, p. 42 and Heliker 1999, p. 514.

ential interests. Under this assumption, which is shared by all approaches, all available sources should be used to get to know the dementia patients. By knowing the patient with dementia, caregivers can sometimes better interpret which non-autonomous self-decisions promote their experiential interests.

Without taking into account biographical backgrounds, the needs of people with dementia often go unrecognized or misinterpreted, which is a threat or reduction in their subjective well-being.<sup>32</sup>

**The concept of personality approach in a weak sense is a time-consuming task, when it is deemed important for this approach to know the personality of the dementia patients. This usually requires time and, in addition, co-operation with relevant people (relatives and caregivers and so on) is necessary.**

The concept of personality approach in a weak sense is a time-consuming task, when it is deemed important for this approach to know the personality of the dementia patients. This usually requires time and, in addition, co-operation with relevant people (relatives and caregivers and so on) is necessary. It should be emphasized at this point that the concept of personality approach in a weak sense does not reject *in principle* the position of the personality approach in the strong sense as inappropriate. Because the correspondence of non-autonomous self-decision and personality can be important for respect towards the person suffering from dementia. The personality approach in a weak sense recognizes this correspondence of non-autonomous self-decision as possibly adequate in respect for it, but not as sufficient. The non-autonomous self-decision, which does not correspond to personality, but promotes the experiential interest, can also be considered within the framework of the approach of the concept of personality in a weak sense.

The approach of the concept of personality in a weak sense can contribute to the promotion of the experiential interests of the person with dementia, so that the concept of the personality is therefore not considered *in principle* unsuitable for the respect of the patient. If someone wants to persist in the opposite position, the dispensability of the perspective of others and the diachronic perspective must be justified. But this burden of proof, as we saw, cannot be fulfilled. Approaches that ignore these two perspectives are furthermore inadequate from an empirical point of view. Shimada expressly points out the importance of others.

<sup>32</sup> BERENDONK; STANEK; SCHÖNIT; KASPAR; BÄR; KRUSE 2011, S. 13 [transl. S.S].

It is not uncommon for care managers to make offers to family caregivers to keep the person with dementia longer in the facility if caregivers have the impression that the relatives are overwhelmed by the care.<sup>33</sup>

The relatives are immediately important for the person suffering from dementia in the sense that they take over the care work. The care facility is important for the relatives who take care of the person with dementia in the sense that it can reduce their burden of nursing care in a variety of ways, such as counseling, day care, ambulatory care, and so on.

## CONCLUSION

Thus, it is not autonomous self-decision, but non-autonomous self-decision that is the key to promoting the experiential interests of persons with dementia. However, as not every non-autonomous self-decision promotes their experiential interests, caregivers must interpret which non-autonomous self-decision contributes to it. In view of the differentiated symptoms of dementia, it seems to me neither possible nor appropriate to seek the criterion of universal validity. It should be verified on a case-by-case basis with regard to the individual personality of the dementia patient. It cannot be overlooked that the relation of non-autonomous self-decision with the promotion of experiential interests can only be answered inadequately, either from the synchronous perspective or from the diachronic perspective. Moreover, this is not the pure problem of either the dementia sufferer or the other. The cooperation between all concerned (dementia patient, caregivers, relatives and care facility, and so on), from both the synchronous and the diachronic perspectives, enable us to find out which non-autonomous self-decision of the person with dementia would best further their experiential interests. As a result, patients with dementia are respected as particular individual persons.

<sup>33</sup> KUROKI; LEWERICH; SHIMADA, 2018, S. 88 [transl. S.S].

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