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Limits to respect for autonomy principle when caring for people with dementia: Rethinking respect for people with dementia

Shingo Segawa[1] & Zümrüt Alpinar-Segawa[2]

Abstract

Dementia is an umbrella term used for a range of conditions affecting cognitive functions, such as memory, thinking, planning, understanding, and social and emotional skills. As cognitive functions decline, the abilities associated with self-determination are compromised and people with dementia become more dependent on others. As a result, family members and caregivers face the challenge of how to respect people with dementia. With demographic change and longer life expectancy, the number of people living with dementia is increasing every year. Germany, with the highest demographic change in Europe, is an aging society with an increasing number of people with dementia, putting it at the center of the debate on respect for people with dementia. The German Ethics Council, an influential moral authority in Germany, has addressed the issue of respect for people with dementia. The Council stated that the principle of respect for autonomy is effective in respecting people with moderate severe dementia who do not have a living will. Considering the lower uptake of living wills, this issue will continue to grow in importance. With this debate in mind, this paper considers what it means to respect a person with dementia. We argue that the principle of respect for autonomy is not sufficient to respect people with dementia, and that adhering to it would lead to a contradiction in the Council's position. To avoid this, we suggest focusing on personality and non-autonomous decision to overcome the problems of the autonomy principle-based approach.

Keywords: living will, non-autonomous decision, personality, principle of respect for autonomy, respect for people with dementia, the German Ethics Council

Introduction

Dementia is a syndrome which leads to a decline in cognitive function, affecting memory, thinking, orientation, judgment, planning and understanding, as well as impairing social and emotional skills (Hampel et al., 2011; WHO, 2023). There are currently more than 55 million people living with dementia worldwide, with nearly 10 million new cases each year (WHO, 2023). Among European countries, Germany has the highest demographic change (Federal Statistical Office, 2016) and is an aging society with approximately 1.8 million people with dementia as of the end of 2021 (Blotenberg, Hoffmann & Thyrian, 2023). As a result of demographic change, the number of people with dementia in Germany is expected to rise, with a current estimation of up to 2 million people aged 65 and over by 2033 (Blotenberg, Hoffmann & Thyrian, 2023) and 2.8 million by 2050 (Deutsche Alzheimer Gesellschaft, 2022).

Dementia can be caused by many conditions and mainly affects older people (WHO, 2023). As the progression of dementia impairs the ability to make decisions, professional or family caregivers are faced with the question of what the person with dementia wants and what kind of care should be provided. Specifically, if the person with dementia is no longer able to express their own wishes, a substitute decision-maker would be expected to step in and make the decisions for the person with dementia. The concern here is whether the substitute decision-makers should consider the last cogently articulated interest of the person with dementia or rather use their own judgement about what the person with dementia would decide in a given situation if they were able to (Whitehouse, 2000; Vollmann, 2001). Another way to protect the previously expressed wishes of the person is referring to a living will. Very generally, a living will is a legal document in which a person expresses their wishes about what medical treatment they want or do not want, if, due to illness or unforeseen accident, the person is unable to make

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decisions and express their wishes (Kale et al., 2024). The living will is therefore understood as "extended autonomy" (Quante, 2010). However, this does not answer the question of how to respect people with dementia who *do not have living wills*.

The focus of this paper is on the debate over respect for people with dementia in Germany, who constitute an increasing share of the population. The German Ethics Council clearly argues that the principle of respect for autonomy is effective in respecting people with *moderate severe* dementia who do not have a living will (Deutscher Ethikrat, 2012).[3] The continuing importance of this issue in Germany, where living wills are already legal, is linked to the low uptake of living wills. According to a survey conducted by the German Hospice and Palliative Association in 2017, only 43% of respondents had actually written living wills (Deutsches Ärzteblatt, 2017). Among persons with migration background living in Germany, there is a low utilization of advance directives[4] in hospice and palliative care (Henke et al., 2015). Studies also found that there are gaps for minority groups in terms of addressing the practical issues related to dementia care and life planning including advance directives (Tezcan-Güntekin & Razum, 2018; Alpinar-Sencan, 2023). Considering Germany has the highest level of immigration in Europe with almost 16 million migrants in 2020 (International Organization for Migration, 2021), this topic will continue to gain more importance. Given low prevalence of living wills, the question of how people with dementia who do not have living wills should be respected is an important one.

We begin by referring to Margo, a 55-year-old woman with dementia, about whom Andrew Firlik wrote in his 1991 article. Subsequently, Dworkin and Dresser used the case of Margo to explore the validity of a living will (Dworkin, 1993; Dresser, 1995). We briefly revisit the case, paying particular attention to the specific stage of Margo's dementia (i.e., how advanced it is), since approaches to respecting people with dementia vary depending on the stage of dementia (Quante, 2019). We then use Dworkin and Dresser's arguments to explain what it means to respect a person with dementia. After examining whether the principle of autonomy is effective in respecting people with dementia, based on the debate in Germany, we propose an approach focusing on personality and non-autonomous decision to overcome the problems with the autonomy principle-based approach.

Who is Margo?

Andrew Firlik, who was a medical student at the time, wrote about Margo in his article "Margo's Logo", in which he recounted his experiences with her (Firlik, 1991). Firlik met Margo through a gerontology class and began visiting her daily. Margo was cared for by a Jamaican home health aide, named Luise, in her apartment, and a number of locks and chains were attached to the door to prevent Margo from slipping out in the middle of the night. Before the locks were installed, Margo had slipped out of the house and wandered the streets, and a few days later Firlik and Luise received a police report that a woman in a nightgown had been seen in the central park. Margo said she loved to read, especially mysteries, but the pages she read changed erratically every day. Firlik noted that although he had contact with many patients, he had a special time with Margo. They listened to music together, especially the song "Every time we say goodbye" which Margo said reminded her of her late husband. Firlik asked her if she had any recollection of the time when she was whole. Margo never called Firlik by his name, and he wondered if she did not remember him. But whenever he visited her, she was always

[3] The German Ethics Commission (2012) states that the principle of respect for autonomy cannot be applied in the case of respect for people with *severe* dementia who have significantly impaired cognitive abilities.

[4] Advance directives are legal and medical instructions about a person's future medical care if they are unable to make their own decisions. Living wills are a common form of advance directives. Advance directives include living wills and power of attorneys.

happy to see him. While Margo did not seem to remember who Firlik was, she seemed to appreciate his friendship.

Besides, Firlik noted that Margo confused him. “Despite her illness, or maybe somehow because of it, Margo is undeniably one of the happiest people I have known” (Firlik, 1991, p. 201). Firlik wondered how Margo maintained a sense of self and what would remain when old memories were rapidly lost and new ones could not be accumulated. He could not quite understand how it is possible to be friends with someone who did not even know/recognize him.

One day, Margo asked Firlik to go to school with her. The “school” was an art therapy group for Alzheimer’s patients. Alzheimer’s patients typically paint the same picture every time. Even if their memory has deteriorated and they can no longer communicate who they are, they can still express who they are through drawing. Margo bit her lower lip as she painted, “as if she were reaching back into the rudiments of her remaining brain, trying to find something” (Firlik 1991, p. 201).

The class teacher showed Firlik the large amount of artwork his class had collected over the years. Among them, Firlik spotted a single circle painted in a single pink color and immediately said, “That’s Margo’s, isn’t it?” He wrote that he saw in it the image of Margo smiling peacefully in a stage of dementia. Margo’s personality seemed circular and pastel; this was her pattern in her fragmented world. Firlik writes: “She’s been holding on to her identity. Her mind was in that drawing; she can communicate it. She knows who she is” (Firlik 1991, p. 201).

According to the Swiss Academy of Medical Sciences, the course of dementia is divided into three stages (SAMS, 2017, p. 8). Early-stage dementia is characterized by mild cognitive impairment (MCI), where the competence to perform daily activities is still preserved. For a person with moderate dementia, it is already difficult to manage daily life, even with the help of family members or, in many cases, professionals (e.g., family physician, nurse, etc.). A person in the stage of severe dementia has minimal verbal communication skills. In addition, behavioral and emotional disturbances may be persistent. According to these three stages of the course of dementia, Margo was in the state of moderate severe dementia (Baur et al., 2018; Schmidhuber, 2013b; 2014). Based on Margo’s description by Firlik, this paper refers to a person with dementia as a *person with moderate-to-severe dementia like Margo* who does not have a living will.

How is respect for a person with dementia expressed?

If Margo had a living will, Dworkin would argue that it was valid and Dresser would state that it was invalid (Dworkin, 1993; Dresser, 1989). By referring to their arguments, we will clarify what it means to respect people with dementia.

Dworkin states that people have two different kinds of interests: there are experiential interests and critical interests. Experiential interests refer to the pleasures or interest in feeling good by desirable experiences at a given point in time (synchronic). So, they relate to the pleasures of each experience, such as the pleasure of reading, the pleasure of listening to music, the pleasure of avoiding pain, and so on. Thus, almost everyone can have experiential interests, except those who are in an irreversible coma, for example. In contrast to experiential interest, critical interest, according to Dworkin, is concerned with the good life (Dworkin, 1993). Critical interest is not reduced to an experiential interest at a given point in time, but is an interest that is coherently considered good for one’s life as a whole from the diachronic perspective of the past, present, and future. Critical interest thus presupposes the ability to think about oneself in a diachronic dimension. Dworkin explains the difference between these two interests as follows: “[If] you are a Jew, 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” (Dworkin, 1993, p. 205).

Based on the difference between the two qualitatively different interests, Dworkin argues that experiential interests should be subordinated to critical interests essential to the good life, as long as one makes a decision in light of one's critical interests (the general priority rule). Dworkin argues that Margo's living will has validity because it expresses her critical interests. Dresser, on the other hand, argues that Margo's living will would no longer be valid. Her main criticism focuses on Dworkin's claim that critical interests should be given categorical priority in Margo's case (the general priority rule) (Dresser, 1989). For Dresser, experiential interests are at the core of respect for Margo. By relying on two qualitatively different interests, Dworkin and Dresser take opposing positions on the validity of Margo's living will.

However, Dworkin and Dresser agree on one point: if Margo does not have a living will, then experiential interests play a decisive role in respecting her. Dworkin also recognizes that experiential interests will be more important than critical interests in the case of a person with dementia (Dworkin, 1993). This is crucial when considering the question of how to respect a person with dementia, which is the focus of this paper. This is because this paper is about how to respect a person with dementia as an individual *who does not have a living will*. Based on the similarities between Dworkin and Dresser, we define respect for a person with dementia as promoting the person's experiential interests.

Respect for the autonomy of a person with dementia?

When considering the application of the principle of respect for autonomy to the debate about respect for a person with dementia, the central claim of the German debate is that a person with dementia is still capable of making autonomous choices (Deutscher Ethikrat, 2012; Kruse, 2012; Schmidhuber, 2013a, 2013c). For example, suppose a person with dementia has pneumonia with a high fever, which could lead to their death. Treatment with an antibiotic would easily return them to a state where they could, for example, enjoy reading or listening to music again. However, refusal of treatment is expressed (i.e. by facial expression, gesture, or posture). On the basis of this case, we will consider whether the principle of respect for autonomy is effective in respecting people with dementia.

The principle of respect for autonomy

The principle of respect for autonomy was proposed as a response to unethical experiments with humans in history. Against the backdrop of critical reflection on the human experiments carried out by the National Socialists, the Nuremberg Code was drawn up in 1947: "The voluntary consent of the human subjects is absolutely essential" (Nuremberg Code, 1947) Subsequently, in 1964, the Declaration of Helsinki declared the inadmissibility of performing medical procedures without the consent of the competent patient (WMA Declaration, 1964). Following the Tuskegee Syphilis Study (1932–1972), in response to failures in medical research and to protect human research subjects, the Belmont Report (1978) was written, where respect for autonomy and the importance of informed consent was identified. The question of what kind of consent should be recognized as informed consent is one of the major questions in biomedical ethics, since the normative nature of consent would be lost if the consent of patients who do not understand information about medical procedures were recognized as informed consent. The concept of autonomy plays an important role in this question (Beauchamp, 2009; Becker, 2018; Walker, 2013). It is undisputed that it is not permissible to force a patient to take medical measures that they have autonomously refused (Davis, 1995; Scoccia, 1990).

The principle of respect for patient autonomy is addressed both in cases of refusal and acceptance of medical measures. In the first case, the only question is whether the patient autonomously refuses a medical measure. The patient's decision to refuse medical measures must be respected in any case, as long as it is considered autonomous: "Autonomy as a right of

defense" (Schöne-Seifert, 2007, p. 40, authors' translation). The medical measure that is forcibly implemented against the autonomous decision is considered ethically impermissible. Respect for patient autonomy in this sense will be referred to here as negative respect for patient autonomy. Patient autonomy is *necessary and sufficient* for negative respect.

However, in the case of a demand for certain medical interventions, it is not only the patient's consent that is crucial, but also the physician's consent. As noted above, it is ethically impermissible to implement a medical measure to which the patient has autonomously decided not to consent. This also applies to physicians, especially in cases such as euthanasia (Nationaler Ethikrat, 2005; Schmidhuber, 2013b). It is ethically impermissible to force the physician to implement a medical measure, to which the physician does not give autonomous consent. Thus, the physician does not have to respect the patient's autonomous decision in all cases. We call respect for patient autonomy in this sense positive respect for patient autonomy. A patient's autonomy is *necessary, but not sufficient* for this positive respect.

However, it must be emphasized that, in principle, the physician must respect the patient's autonomy in a positive sense. Otherwise, the normative nature of patient autonomy, which is already a socially important value, would be weakened (Wiesemann, 2016). If the physician does not respect the patient's autonomy in a positive sense, they must justify it. This is because the burden of justification is placed on those who violate the principle of respect for autonomy (Faden & Beauchamp, 1986). The patient's autonomy is necessary but not sufficient for positive respect. This does not mean, however, that the physician may violate it without reason.

Respect for autonomy in the context of respect for a person with dementia

Those who believe that the principle of respect for autonomy can be applied *in the context of respecting a person with dementia* (hereafter referred to as "the proponents of PRA"), assume that autonomy enables the person to live a good life.[5] However, Dworkin's concept of autonomy, which presupposes the necessary capacity for critical interest (Dworkin, 1993), is not applicable to a person with dementia whose cognitive abilities are severely impaired (Schmidhuber, 2013b; Deutsche Alzheimer Gesellschaft, 2018). To avoid the problem of such excessive demands, the proponents of PRA set low standards for autonomy and define autonomy as follows: autonomy is gradual, context-sensitive, and realized with the support of others (i.e., relational) (Deutscher Ethikrat, 2012; Klie, Vollman & Pantel, 2014; Schmidhuber, 2013a).

There are different kinds of choices, from small everyday things, like food choices, to big life choices, like medical interventions that are necessary to save a life. In most cases in medical ethics, the concept of autonomy is discussed only in the last case, from which a person with dementia is excluded, such as the autonomous decision for euthanasia. However, the proponents of PRA argue that even small everyday decisions, such as "decisions about food, choice of clothing, or what activities the person [with dementia] wants to do" (Schmidhuber, 2013a, p. 6, authors' translation), should be considered autonomous. The proponents of PRA argue that "[...] the *abilities* of people with dementia are greatly diminished in *certain areas of life*, but *in other areas* [...] they are able to make decisions for longer, especially about their preferred activities" (Schmidhuber, 2013a, p. 14, authors' translation, emphasis added). In other words, relational autonomy requires, on the one hand, a certain cognitive capacity and, on the other hand, is gradual (Deutscher Ethikrat, 2012; Schimidhuber, 2013b). To be more precise, the person must actually exercise more or less specific cognitive abilities in order to make autonomous decisions. This is because decisions that merely meet the conditions for autonomous decision-making by chance are not considered autonomous (Quante, 2002). The extent to which it is actually

[5] Please note that in this paper, we refer to the proponents of PRA as the German Ethics Council (2012), Kruse (2012) and Schimidhuber (2013a, 2013c).

appropriate to speak of autonomy in the case of people with dementia needs to be further examined.

The patient's decision is generally considered to be autonomous, if they make it intentionally, with understanding, and without external coercion (Faden & Beauchamp, 1986; Haberstroh & Müller, 2017; Klie, Vollman & Pantel, 2014). The competence required for autonomous decision making is gradual, but it has a threshold. No one would argue that a newborn, for example, has the capacity for autonomous decision making. The proponents of PRA also accept an understanding of autonomy that is gradual and has a threshold. People with dementia are no longer capable of making autonomous decisions based on complex content-related information. This includes, for example, the decision whether or not to agree to participate in a study on a dementia healthcare project (Kollek, 2005; Deutscher Ethikrat, 2012). However, people with dementia can non-verbally express their emotional states about food, mobility, and personal care through facial expressions, gestures and body language. The proponents of PRA argue that the three conditions for autonomy are included in these expressions: "Even in the late stages of dementia, reactions are possible at the level of emotional perception and differentiation that contain elements of understanding, evaluation and volition, which can also be expressed in situationally authentic participation" (Deutscher Ethikrat, 2012, p. 26, authors' translation).

The proponents of PRA emphasize that whether or not a person with dementia can make decisions autonomously, needs to be considered on a case-by-case basis (context-sensitive), and that support from others can enable the person with dementia to make autonomous decisions (relational). According to them, in this way the decisions of a person with dementia can be considered autonomous. However, such a position poses a dilemma, as we describe in the following section.

A Dilemma of respect for autonomy in the context of respect for people with dementia

In order to examine the effectiveness of referring to the principle of respect for autonomy in respecting persons with dementia who do not have living wills, two points must be noted. First, the proponents of PRA consider it as ethically impermissible to withhold life-sustaining treatment from *someone with dementia who has a condition like Margo's* (Deutscher Ethikrat, 2012; Kruse, 2012; Schmidhuber, 2013a, 2013c). Second, according to the principle of respect for autonomy, the person's autonomy should always be respected *in a negative sense*.

Let's go back to the example of the person with dementia at the beginning of Section 4, where we posit *a person with dementia in Margo-like state without a living will* has pneumonia with a potentially deadly fever, treatable with antibiotics. The person can easily return to a condition that allows them to enjoy things like reading or listening to music again. However, through her facial expressions, gestures and posture, she showed signs of refusing to take this antibiotic, despite repeated attempts by physicians, nurses, and relatives to explain its benefits. If Margo's life is to be saved, her facial expressions, gestures and postures, even her verbal expressions, must not be understood as autonomous. If they are understood as autonomous, they must be respected. Therefore, in order to defend their ethical position that it is ethically impermissible to withhold life-prolonging treatment from Margo, the PRA proponents must claim that Margo's facial expressions and gestures are not autonomous.

The PRA proponents might argue that Margo's facial expressions, gestures and postures are not considered expressions of autonomy, by pointing out that Margo may not understand the implications of not taking antibiotics. By arguing this way, it would seem that one could argue, as the PRA proponents do, that only small, everyday decisions are autonomous and that the decision not to take antibiotics is not autonomous. The problem, however, is that there is no clear criterion that only the everyday decisions of a person with dementia can be autonomous (Holm, 2001). Thus, Margo's facial expressions and gestures in refusing to take the antibiotics could also be autonomous. However, because of their ethical position, the PRA proponents

cannot respect Margo's facial expressions and gestures, even if they were autonomous. This raises the question of their interpretation of negative respect for autonomy (i.e., refusing to consent to medical treatment).

If, on the one hand, the proponents of PRA take the position that the person's autonomy in the negative sense should be respected in all cases, then they must justify why the autonomy of a person with dementia, expressed through facial expressions, should not be respected in terms of refusal of the antibiotic. If, on the other hand, they do not argue that the person's autonomy in the negative sense should be respected in all cases, then the burden of justification is placed on them to justify, why interfering with the autonomy of a person with dementia, which can be read from his or her gestures, in the sense of refusal of the antibiotic, is permissible at times. If these burdens of justification cannot be borne, the following dilemma of negative respect for patient autonomy arises: autonomy to be respected in a negative sense and autonomy not to be respected in a negative sense. The proponents of PRA cannot bear these two burdens of justification. This is because, on the one hand, they take the position that a person's autonomy should always be respected in a negative sense and, on the other hand, that it is ethically unacceptable to withhold life-sustaining treatment from a person with dementia.

Two different forms of decision: Autonomy and non-autonomous decision

The reason for the justification problem faced by the proponents of PRA is not that they consider it ethically impermissible to withhold life-sustaining treatment from a person with dementia. Considering that the physician is primarily expected to contribute to preservation or salvation of the person's life (Pellegrino, 2005), administering the antibiotic to a person with dementia should be seen as the physician's task. Rather, the justification problem stems from the proponent's understanding of people with dementia as autonomous decision-makers. To avoid this, we suggest understanding that the person with dementia is no longer able to make autonomous decisions. More specifically, a person with dementia should be understood as still capable of making a decision, but this decision is no longer an *autonomous decision*. As the proponents of PRA themselves point out, a person with dementia can still choose to read a book or to eat a meal, for example. However, this decision need not be considered autonomous. Self-decision can be divided into two categories. One is autonomous decision and the other is non-autonomous decision.

In support of Dworkin's argument, critical interests are reflected in autonomous decisions, while experiential interests, associated with the pleasures of momentary experience, such as the pleasure of reading a book, are expressed in non-autonomous decisions. Autonomous decision, as was made clear in the section above, is the object of respect for autonomy. The non-autonomous decision of a person with dementia, such as the choice of food or clothing, may not be the object of respect for autonomy, but it should still be respected insofar as it may contribute to an increase in the person's quality of life. Many empirical reports show that such choices improve the quality of life of people with dementia (Moyle et al., 2015; Daly et al., 2018).

If a person with dementia does not have the capacity to make autonomous decisions, then that person cannot make an autonomous decision not to take antibiotics. Accordingly, there is no conflict between saving the life of a person with dementia and the principle of negative respect for autonomy. Therefore, the key to respect for a person with dementia should not be found in the autonomous decision, but in the non-autonomous decision. However, the person's non-autonomous decision does not necessarily promote their experiential interests. For example, if the person decides to go outside when it is raining heavily, this does not promote his or her experiential interest. Thus, the caregiver of a person with dementia needs to interpret which non-autonomous decisions will best serve their experiential interests. As we will see in the next section, the personality approach can be helpful in this process.

The personality approach to respect for people with dementia

Personality is understood as a bundle of personal characteristics that distinguishes an individual from other individuals (Quante, 2002; Friedrich & Zichy, 2014). Therefore, personality also requires some consistency (Allport, 1937; Cervone & Shoda, 1999; Lieblich & Josselson, 2013), and personality cannot be understood on the basis of inconsistent characteristics. As many have already pointed out, a person-centered care is recommended when respecting people with dementia (McCormack, 2006; Fazio et al., 2018; Rose & Dening, 2023). By reflecting on how the person with dementia has lived, or what they liked, it is possible to provide appropriate care (Deutscher Ethikrat, 2012; Dichter & Schmidhuber, 2016; Haberstroh & Oswald, 2014; Klie, 2005). "Without considering life history backgrounds, the needs of people with dementia often remain unrecognized or are misinterpreted, which means a threat to or reduction in their subjective well-being" (Berendonk et al., 2011, p. 13, authors' translation).

As can be seen from this quote, the concept of personality plays a critical role in promoting the experiential interests of a person with dementia. By considering the person with dementia's personality, professional caregivers can appropriately interpret which of their non-autonomous decisions promote their experiential interests. It must be emphasized, however, that the personality approach does not require that non-autonomous decisions necessarily correspond to one's personality. The correspondence between personality and non-autonomous decisions does not necessarily imply the promotion of experiential interests: "If the well-known polar explorer and adventurer Sir Ranulph Fienness [...] 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 we not be equally justified in discounting this wish [...]?" (Holm, 2001, p. 156).

At first glance, these two quotes seem to contradict each other. On the one hand, there is an emphasis on the importance of personality ; on the other hand, there is criticism of over-emphasis of personality. However, these two quotes make it clear that personality should not be seen as an absolute indicator, rather an important one. As the second quote indicates, people with dementia can be greatly disadvantaged by taking personality into account in care in certain situations. However, this does not mean that personality is generally unnecessary in the context of respecting people with dementia, but rather that personality should not be considered at all times. This understanding of personality is appropriate for respecting people with dementia. There is no such thing as a one-size-fits-all approach to respecting people with dementia in the first place (Klie, Vollman & Pantel, 2014). One-size-fits-all approach would respect the person with dementia as a person in general, but not as an individual. Therefore, using personality as a key indicator, respect for people with dementia requires a situation-specific response. In many cases, it is essential to work with family members who know the person with dementia best (Edvardsson et al., 2010).

Conclusion

This paper addresses the issue of how a person with moderate severe dementia like Margo, who does not have a living will, can be respected. We referred to Dworkin and Dresser's discussion on the validity of living wills for people with dementia and defined respect for people with dementia as promoting their experiential interests. We then argued that the principle of respect for autonomy does not apply in this context. If we want to reconcile the position that autonomy should be respected in all cases *in a negative sense* with the position that withholding medical intervention to protect the life of a person with dementia is ethically unacceptable, then we cannot consider the decisions of a person with dementia to be autonomous. There is no doubt that autonomy is an important value in our society. However, autonomy is a concept, not an absolute, for a good life (Beauchamp & Childress, 2013). By taking into account the personality

and the non-autonomous decision of the person with dementia, the person is respected in an appropriate way.

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