Has the Person with Dementia Lost the Right to Autonomy?

A Discussion of Ronald Dworkin’s View

on the Moral Status of the Advance Directive
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1. Introduction

1.1. Advance directive or living will – a new phenomenon

A new phenomenon, that has come to remain, is the execution of an advance directive which is the extension of the right of autonomy to a time in the future when the person may no longer be considered autonomous. An advance directive, also known as a living will, is a statement or a directive that a competent person makes in advance explicitly stating future desires in regard to the extent of medical treatment or refusal thereof. If the capacity for decision-making is lost or impaired to a degree where the person is no longer competent then the advance directive states the extent of the person’s consent in regard to medical treatment. In modern medicine, patients and medical professionals are faced with growing ethical challenges regarding medical treatment if the capacity for autonomy is lost. These challenges are particularly relevant in dealing with patients suffering from dementia. Since the nature of dementia makes it unclear to what extent the person has any right of respect for autonomy left, the question may be raised as to whether a person suffering from dementia has any rights at all. In the last decade, as a result of this, the execution of advance directives in various forms and for various motives has become widespread in many countries. This trend is in accordance with the recommendations stated in the resolution of The Parliamentary Assembly Council of Europe (Council of Europe, 2012).

The execution of an advance directive is a way to take control and responsibility over one’s own destiny in the event of becoming incompetent by exercising the right of self-determination over body and mind. The right of autonomy, which is commonly understood as a right that all persons possess by the virtue of being human, stems from this right of self-determination. Therefore, the validity and the moral authority of the advance directive is supposed to rest on the fundamental principle of autonomy.

When the advance directive is in effect it is assumed that the person is no longer competent and therefore not capable of making autonomous decisions. However, it is not always clear whether or not a person has lost this capacity. There are obvious cases where the person is no longer autonomous, such as when a patient is in a persistent vegetative state. The advance directive of such a patient could seem uncontroversial; however even in these cases there are ethical problems to be addressed. Furthermore, there are a number of medical conditions such as the progressive neurological disorder dementia, where the autonomy of the person is being limited as the disorder
progresses. It follows that in these cases we are presented with complex ethical challenges regarding the advance directive, as dementia comes in various forms and degrees.

The increasing number of cases of dementia has led to a new debate with regard to the moral authority of advance directives.¹ As the neurological disorder progresses, the person who was once fully competent will ultimately be fully dependent on caregivers. The severity of the cognitive impairment makes them unable to have any memory of self or family, or to express feelings and emotions. The prospect of severe cognitive impairment in the case of dementia motivates many to execute an advance directive giving instructions regarding future medical treatment. These instructions often express that medical treatment should be withheld, since many consider a life with dementia to be dehumanizing and devoid of dignity and meaning.

The debate regarding the moral authority of the advance directive revolves around the theme of whether or not a life with dementia is devoid of all meaning and dignity; and when the affected person has lost their capacity to express autonomous choices.

1.2. The purpose of the paper

The primary purpose of this paper is to examine whether or not, and if so to what extent, the fundamental principle of autonomy gives moral authority to the advance directive in case of dementia. Ronald Dworkin, one of the most distinguished legal and political philosophers of the modern era, ardently defends the absolute moral authority of the advance directive in the case of dementia by insisting on respecting the precedent autonomy of the person. However, I will show that his argument by analogy comparing a person with dementia to a deranged Jehovah’s witness is not cogent. Furthermore, I will show that the moral authority of the advance directive is not evident

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¹ Dworkin (1986) initiated the debate in the 80’s concerning the right of respect for autonomy in the terminal care for persons suffering from dementia. Dworkin became controversial by interpreting autonomy as precedent autonomy, which, expressed in an advance directive, is to be considered the genuine expression of the person’s autonomous self. This meant that the person with dementia no longer had a right of respect for their present autonomy. Dresser (1986) responds to Dworkin (1993) saying that in the case of dementia it is highly problematic to give moral authority to the advance directive over the patient suffering from dementia since that person is distinctly different in many ways from the person who executed the advance directive. A number of scholars interjected in the debate between Dworkin and Dresser. Among those more aligned with Dworkin’s position were: Buchanan and Brock (1986), Davis (2002, 2006, 2009), DeGrazia (1999) and Beauchamp & Childress (2001), who have influenced contemporary medical ethics emphasizing the centrality of autonomy. Among those siding with the view of Dresser, who finds it questionable that the advance directive can be given moral authority in the event of dementia, are Robertson (1991), Kuczewski (1994), Gorman (2011). Furthermore, there are a number of scholars who have discussed the various ethical dilemmas the advance directive gives rise to in the care for patients with dementia, such as Hope (1996) and Harvey (2006). A number of scholars have also discussed the problems of personal identity and personhood with respect to the moral authority of the advance directive when the person suffers from dementia; see Schechtman (1990), Buchanan (1988) and Buccafurni (2004) et al.
when considering Joel Feinberg’s more general interpretation of the principle of autonomy. I argue that neither Dworkin’s nor Feinberg’s interpretation of the principle autonomy gives moral authority to the advance directive. Further, I will discuss Dworkin’s claim that the person suffering from dementia has lost the right of autonomy. Finally, I will argue that it is debatable in the case of dementia whether the advance directive has moral authority and whether the person suffering from dementia has no right of respect for their sovereignty.

1.3. Outline

The discussion will be based on Feinberg’s interpretation of autonomy (Feinberg 1986) and Dworkin’s interpretation of autonomy as precedent autonomy (Dworkin 1986) which brings into the debate, with regard to moral authority of the advance directive, ethical dilemmas, especially in the cases of dementia. The principle of autonomy will be examined by using the case of Margo. The medical student Andrew Firlik (1991) presented in a short article the person Margo who, though she suffered from Alzheimer’s disease at an advanced stage, still had retained a life of joy and meaningfulness from her perspective.

This paper consists of two parts: The first part deals with interpretations of the principle of autonomy and its centrality in medical ethics when the individual is suffering from dementia and has executed an advance directive. Firstly, I will briefly present the case of Margo as described by Firlik. Then follows an overview of the evolvement of the principle of autonomy, specifically focusing on those aspects, that are particularly relevant for giving validity to the advance directive. Finally, the positions of two contemporary theorists Joel Feinberg and Ronald Dworkin will be presented. The positions of Feinberg and Dworkin will be applied to the case Margo where it is assumed that she has executed an advance directive while fully competent. In the advance directive she states that in the event of being incompetent and in need of any medical treatment in any form such treatment is to be withheld even if the consequence is death. I will argue, in the case of dementia, that the principle of autonomy alone does not in a convincing way give moral authority to the advance directive, which can only be enforced if the person is no longer autonomous.

The second part of the paper examines more in detail Dworkin’s argument for maintaining the moral authority of the advance directive. Firstly, I will give a presentation of Dworkin’s justification for respect of the autonomy of the person, which brings Dworkin to conclude that autonomy is lost in the event of dementia. I have reservations against Dworkin’s conclusion, and I will argue that the justification Dworkin presents for why the autonomy of the individual is to be respected unconditionally is debatable and too restrictive. Secondly, Dworkin’s conclusion requires
that there is actually a point in time when autonomy is lost. Because dementia is a progressive neurological disorder where the affected individual falls in between the two ends of the spectrum of being fully autonomous and not autonomous at all, it is necessary to discuss if at all such a point in time can be identified. I will argue that it is far from evident. Thirdly, Dworkin maintains that the person can no longer express their critical interests, which are unchanged, in the case of dementia. These critical interests are now expressed in the advance directive which must be enforced if the autonomy of the person is to be respected. He supports this position by making an argument by analogy comparing a person with dementia with a person in a persistent vegetative state. I will argue that this argument is not cogent as there are significant differences between a person with dementia and a patient in a persistent vegetative state. Finally, Dworkin’s argument for maintaining the moral authority of the advance directive based on his strict interpretation of autonomy gives rise to the question whether the person with dementia has other rights that require to be respected.

PART ONE

2. Who is Margo?

Andrew Firlik (1991) presented the patient Margo in “Margo’s Logo” in the Journal of the American Medical Association. Andrew Firlik visited Margo, who suffered from the neurological disorder Alzheimer’s disease, in her home while he was doing a course in gerontology. He realized that Margo, despite her progressed state of dementia, which had left her with little or no recollection of who Firlik was, always appeared content and happy to see him. Moreover, she was still capable of living independently with assistance from caregivers, though safety precautions were taken to make it more difficult for her to leave her home in the nights. Margo claimed she knew Firlik, though she never called him by name, and it might well be that she actually did not remember him from the last visit. However, Firlik noticed that Margo did have some sense of who he was from the way she greeted him with joy. He was puzzled but had to accept that his friend did not really know him (p. 201).

As time passed, a relationship of friendship evolved as Firlik came to know Margo, who at the same time remained a mystery to him. He noticed that Margo’s activities and her involvement in the art class were meaningful and enjoyable to her. Margo expressed that she enjoyed reading and in particular mysteries. However, Firlik noticed that she read at random in the book and he wondered if the actual reading was the “mystery” to her. Margo herself considered the activity “reading”
meaningful and enjoyable. He also noted that she enjoyed listening to records and would listen to the songs over and over again with the same enthusiasm. The song “Every Time we Say Goodbye” she said reminded her of her dead husband. Firlik wondered if Margo actually would have any recollection of her time as non-demented. Did she in fact remember her dead husband?

One day Margo invited Firlik to her workplace; an art class for patients with Alzheimer’s disease. Of particular interest to him was “a drawing of four circles, in soft rosy colors, one inside the other” (p. 201) which he immediately recognized to be painted by Margo. He noticed that Margo had painted the same picture over and over again with the same enthusiasm.

Firlik was moved by this perhaps untroubled life of Margo as she perceived it. Firlik (1991) wrote:

> Despite her illness, or maybe somehow because of it, Margo is undeniably one of the happiest people I have known. There is something graceful about the degeneration her mind is undergoing, leaving her carefree, always cheerful. Do her problems, whatever she may perceive them to be, simply fail to make it to the worry centers of her brain? How does Margo maintain her sense of self? When a person can no longer accumulate new memories as the old rapidly fade, what remains? Who is Margo? (p. 201)

The symbols of Margo’s pictures were, according Firlik, the answers to the questions. Margo’s paintings represented her mind as her “personality seem[ed] circular and pastel; her stream of consciousness, one thought within the other. This [...] was [...] her pattern in a fragmented world.” (p. 201). Firlik presents Margo, now suffering from dementia, as showing no evidence of mental suffering as a consequence of her cognitive deterioration; rather, it appeared that her condition had left her in a situation where she no longer registered the normal worries and fears of everyday life. She seemed to live in the untroubled present moment and be in a seemingly unworried and content mental state.

Given that Dworkin’s conclusion that Margo has lost the right of autonomy is true, had Margo executed an advance directive stating that in the event of incompetence all medical treatment must be withheld even if this would lead to her premature death, these instructions would then have to be carried out. Since the advance directive has moral authority over Margo in her current incompetent state, Dworkin (1993) would argue that respect has to be given to her precedent autonomy even if she now expresses that it should be overruled.
3. The principle of autonomy and the advance directive

In practical medical ethics it is the fundamental principle *autonomy* that is considered to give authority to the advance directive. In order to be autonomous it is required of the individual that they have sufficient cognitive capacity to act with competence. Hence, if the individual has the capacity to comprehend the matter in question, then they exercise their right of autonomy. In medicine, autonomy is expressed through giving valid consent to medical treatment or refusal thereof. In this section I will present the principle *autonomy* and what is required if the individual is to give a valid informed consent with respect to medical treatment.²

The principle of autonomy is a major principle that constitutes the moral and legal foundation of the advance directive, which in many countries has been given legal status. There is a common consensus in liberal societies that the individual has a right to autonomy, not only within the political and social sphere, but also within the medical sphere. The advance directive is an extension of the individual’s right to act as an autonomous being within the medical sphere. Through the advance directive, the principle of respect for autonomy of the individual is then extended into a future time if the person at that point is no longer considered to be legally competent.

When the principle of autonomy was first formulated it was used in a political and philosophical context. The term ‘autonomy’ is derived from ancient Greek meaning ‘self-determination’, ‘self-government’ or ‘independent legislative power’. Originally, the principle of autonomy referred to the right of a city or a state to rule independently without interference from foreign powers. The term soon came to describe interaction between the individual and the state, demanding that the state was to fully respect the autonomy of the individual. Under this principle the individual would enjoy the right of respect for autonomy within the political and social sphere. Immanuel Kant later extended ‘autonomy’, in his interpretation of the term, to be a right that the individual possesses by virtue of being a person. Since Kant, autonomy has come to be considered a fundamental right which all human persons enjoy. Thus, the principle of respect for autonomy entails that the individual has a right to make choices and decisions free from coercion.

Philosophers like Kant (1724-1804) and Mill (1806-1873) have provided us with theories from which contemporary interpretations of the principle autonomy have evolved. However, one should always be cautious when applying earlier theories to deal with contemporary ethical issues. This

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² This section will be based on the article “Deciding for Others” by Allen Buchanan and Dan W. Brock (1986). In this article the various components that are required for the patient to give informed consent are presented and discussed.
becomes even more evident when we evaluate the case of Margo and the moral authority of her advanced directive. As we will see, there are unacceptable implications if the principle of autonomy is considered to be the only principle that is necessary to give moral authority to the advance directive.

Various philosophers have interpreted the nature of autonomy and discussed the consequences of only taking the principle of right to autonomy into consideration when determining the rights of the patients. In recent years there has been a paradigm shift within medical ethics where the principle of autonomy has become one of the major principles. In order to respect the autonomy of the patient informed consent prior to any medical treatment or examination is an absolute necessity. Likewise, the patient always has the right to informed refusal of treatment. This paradigm shift to using a concept as autonomy that was previously mostly used within law and politics, and denotes a strict principle, has led to complex issues within medical ethics when evaluating the competence and capacity of the patient to give valid informed consent.

3.1. Competence and capacity as two fundamental components for informed consent

If an individual is considered legally competent it follows that the individual also has a fundamental right to act autonomously and make decisions even if these decisions are not in their best interest. This is an application of the principle of personal autonomy of the individual. When the person is considered legally competent it is presumed that the person can make decisions by the use of reason. Therefore, if a person is not considered legally competent, then that person cannot enter any legally binding contracts or sign papers that have a legally binding status. Accordingly, if the person, when legally competent, executes an advance directive, this cannot be changed should the person become legally incompetent at a later stage. This means that the individual can no longer make decisions that go against the advance directive. They have therefore seemingly lost their fundamental right to act autonomously.

In medical ethics, the competence of the individual is evaluated before deciding whether or not the person is able to give informed consent or refusal that is valid with regard to medical treatment. However, a person may be considered legally incompetent but still be considered to be able to act with competence in certain specific matters. If the person has the capacity to comprehend what is involved in a specific matter, then, irrespective of not being legally competent, the person has sufficient capacity to act with competence and give valid informed consent.

For a person to act with competence, it is required that the person has the capacity to make autonomous choices by the use of reason. The person is required to have sufficient cognitive
capacity to comprehend the consequences of their decisions and choices. Moreover, when the
person acts autonomously they give expression to their own preferences and values. Since the
ability to make autonomous choices by the use of reason rests on the person’s capacity to
comprehend the various facets of the issue, it is very important to be able to determine “capacity”.
During a person’s lifespan their capacity to act with competence varies since their capacity can be
impaired for various reasons, temporarily or permanently. Since Alzheimer’s disease is a
progressive neurological disorder, the person’s capacity for acting with competence will decrease
with the progression of the disease.

Today, the informed consent of the patient is a cornerstone within medical treatment or
examination. The informed consent of the person is a necessary requirement for any medical
treatment and springs from the fundamental principle of respect for autonomy, which is a
fundamental and absolute right all enjoy by the virtue of being human. In order for a person to give
informed consent or refusal of medical treatment or examination it is required that the person has
the capacity to comprehend the given information, is not coerced, and has sufficient knowledge
with regard to the benefits and the risks involved, as well as of the consequences should the
treatment or the examination be refused.

The competence of the person, their capacity, and thus their ability to give informed consent or
refusal are all vital aspects to be considered when discussing autonomy as the only principle that
gives validity to the advance directive. The nature of the progressive neurological disorder
Alzheimer’s disease, which cannot be treated but only delayed in progression, poses specific
challenges to be considered when discussing the principle of respect for autonomy and the moral
authority of the advance directive.

4. The principle of autonomy as interpreted by John Feinberg and Ronald Dworkin

The primary purpose of this section is to discuss whether the principle of autonomy gives moral
authority to the advance directive in the case of a person suffering from the progressive
neurological disorder dementia. The interpretation of the term ‘autonomy’ is central to this
discussion, which is why I will now present a discussion of the interpretations of autonomy as
presented by the two contemporary philosophers Joel Feinberg (Feinberg, 1986) and Ronald
Dworkin (Dworkin, 1986). While Dworkin attempts to solve the specific problem of the demented
person’s right of autonomy where an advance directive has been executed, Feinberg on the other
hand discusses autonomy in more general terms. Feinberg’s discussion of the different meanings of autonomy is particularly interesting when scrutinizing Dworkin’s analysis.

The two contemporary philosophers Feinberg and Dworkin both emphasize the individual aspect of autonomy and refer to personal autonomy. Deeply rooted in Mill’s principle of liberty, and with a Kantian connotation, Feinberg and Dworkin, each in their own way, present a more diversified interpretation of the nature and the function of personal autonomy. Dworkin introduced the new concept ‘precedent autonomy’ as an attempt to give absolute moral authority to the advance directive in the event of Alzheimer’s disease. Feinberg, providing a more general interpretation of the principle, brings up the terms ‘capacity’ and ‘competence’ which, when applied to the case of dementia, provides a view that is contrary to Dworkin’s.

The application of these two interpretations of the term ‘autonomy’ to the case of Margo indicates that the principle of the right of autonomy does not in a convincing and satisfactory way explain why the advance directive has moral authority over the individual suffering from Alzheimer’s disease. Applying the interpretations given by Feinberg and Dworkin to the Margo case thus points to shortcomings of the principle in actual practice that need to be addressed concerning medical treatment of individuals suffering from Alzheimer’s disease who have executed an advance directive.

4.1 Joel Feinberg (1926-2004)

In Harm to Self (1986) Joel Feinberg identified four different meanings of ‘autonomy’ depending on how this multifaceted term is used. Feinberg neither offered a clear definition, nor a comprehensive discussion of the term ‘autonomy’. Rather, Feinberg claimed that in whatever way the term ‘autonomy’ is used it can always be reduced to one of these four meanings:

When applied to individuals the word ‘autonomy’ has four closely related meanings. It can refer to the capacity to govern oneself […] or to the actual condition of self […] or to an ideal of character […] or to the sovereign authority to govern oneself […]. (Feinberg, 1986, p. 28)

Of the four meanings of ‘autonomy’, as identified by Feinberg, ‘autonomy as capacity’ and the ‘sovereign authority to govern oneself’ are particularly significant when discussing the individual’s ability to give informed consent or refusal to medical treatment and their negative right to reject medical treatment or examination. These two meanings are important for the moral authority of the advance directive over an individual suffering from Alzheimer’s disease.
Feinberg (1986) uses the meaning of *autonomy as capacity* to refer to the individual’s intellectual capacity that is “determined by the ability to make rational choices” (p. 28). An individual lacking this ability is not “competent to govern themselves” (p. 28). In order to make rational choices a minimal intellectual capacity is required. Thus, the individual must have the capacity to comprehend the matter in question and have the ability to reason. They must also be able to give expression to their personal values and preferences, and act accordingly. Therefore, only these individuals “are competent to govern themselves” (p. 28). Interpreting autonomy as ‘capacity’ makes it relevant to give some consideration to the desires and choices of the person suffering from dementia, at least in the early stages.

Recognizing that the intellectual and cognitive endowments of the individual vary over time or by birth, Feinberg points out that there is a continuum of autonomy as capacity. Feinberg (1986) states that there is a “threshold […] of natural competence” which refers to the minimum capacity the individual must possess as a “necessary and sufficient condition for the sovereign right of self-government”. Therefore, since the cognitive capacity varies between individuals, as well as within a single individual’s lifespan, given that the capacity is just above “the bare threshold of competence […] the individual still has the sovereign right to self-government” (p. 30). This sovereign right to self-government makes it necessary for us to identify where the person is in the continuum of being fully autonomous and not autonomous at all. The right of sovereignty becomes particularly interesting in the argument against Dworkin when he claims that the person only has what he calls experiential interests left.³

Moreover, Feinberg (1986) argues that if the intellectual capacity of two individuals differs they are still equally “competent at performing certain tasks” given that their natural abilities, i.e. their capacity, is above a minimum threshold with regard to the specific task (p. 30). Therefore, individuals are autonomous in various degrees depending on their capacity to make rational choices with regard to a specific task or matter.

In medical ethics, when referring to the individual’s capacity to give valid informed consent or refusal, it is Feinberg’s meaning of autonomy as capacity that is used. For an individual to be autonomous there must be an inner disposition constituting the capacity of being able to reflect critically and to reason. This capacity must meet a minimum threshold in order for the required consent to medical treatment to be valid.

³ Dworkin argues that the interests of the individual consist of what he calls experiential interests and critical interests. This will be discussed in part two of the paper.
Applying the meaning of autonomy as capacity to the case of Margo, it is apparent that Margo in some matters has the capacity for autonomy. For example, she does have some recollection of Firlik, she has clear preferences for certain types of food, and she takes pride in her ‘workplace’ which she invites Firlik to. However, Feinberg does not clearly define the minimal threshold of competence that is required for an individual to have the capacity for autonomy. Margo suffering from Alzheimer’s disease at an advanced stage clearly lacks the capacity to use her reason at a level that is required of her to make autonomous choices. Hence, she is incapable of understanding matters that are above a certain level of complexity. Margo seems to have some sense of who she is; she still enjoys listening to music, talking about her husband and reading books. She also enjoys “her work”, that is going to the art class for people with dementia. By applying Feinberg’s interpretation of the term ‘autonomy’ as capacity, it seems that Margo in her present condition forms her own life by making decisions that she considers to be relevant and meaningful. Therefore, she has a certain capacity for self-government and is thus autonomous. Given that Margo is above the minimal threshold for competence in some tasks she still has the capacity for autonomy in those matters. However, Margo may not have sufficient competence regarding more complex matters, such as having the necessary capacity to understand the consequences of medical treatment, and so she might not be able to give valid informed consent.

Feinberg (1986) also talks about the meaning of autonomy as ‘sovereign authority to govern oneself’. This authority to govern oneself is something that the individual has as a fundamental right. Therefore, respecting the individual entails that the right of the person to be self-governed is respected. The sovereign authority of the individual is “an authority to choose and make decisions” (p. 53) with regard to their “personal domain”, which gives the individual “the right to make choices and decisions” (p. 54). Because of this fundamental right of sovereign authority to govern oneself, the personal sovereignty must never be violated and always respected (p. 50). Even if the individual no longer has the full capacity for autonomy, then, because of this right to personal sovereignty, the individual has the right to demand that their personal sovereignty be respected. It is therefore morally wrong to violate the personal sovereignty, i.e. the self-determination, of the individual. Feinberg’s demand for respecting the individual’s sovereign authority to govern oneself is, within medical ethics, similar to the obligation to respect the personal autonomy of the patient. That is, the right of the individual to make decisions with regard to medical treatment and examinations - a right which is considered to be absolute.

With regard to Margo, her sovereign authority to govern herself must be respected. Since Margo has not lost her full capacity for autonomy she has a claim to respect for her personal sovereignty.
For the personal sovereignty of the individual to be respected it is required, according to Feinberg (1986), that the person is not totally lacking the capacity for autonomy (p. 28). In the event that Margo is in the need of medical treatment she may no longer have the capacity to give valid informed consent. However, she still has retained her right to demand respect for her personal sovereignty, meaning she has a right to refuse medical treatment or examination.

The ethical dilemma of giving absolute moral authority to the advance directive in the event of dementia becomes evident if we imagine this imaginary case: Assume that Margo executes an advance directive stating that if she is no longer competent, all forms of medical treatment, even simple antibiotics, must be withheld. Margo, now suffering from Alzheimer’s disease, contracts a mild infection and needs antibiotics. According to her advance directive, this simple treatment must be withheld from her even if she expresses the need for, or gives consent to, this treatment.

Margo, suffering from Alzheimer’s disease, still having the right of respect for her sovereignty, is not able to legally change the advance directive, as she is no longer legally competent. Following the line of Feinberg, the sovereign autonomy of Margo, who is just above the minimum threshold of capacity, must be respected since Margo is still considered autonomous. The Margo who executed the advance directive, and had full capacity for autonomy at the time, did it on the basis of her claim to respect for her sovereign authority to be self-governing with regard to future medical treatment. From Feinberg’s perspective, the Margo in the past and the Margo in the present have an equal right of respect for sovereignty. In some less complex matters they will both be equally competent, even though the Margo in the past will have a higher capacity for autonomy. Past Margo’s extra capacity would then be considered superfluous in matters where the two Margos are equally competent.

Therefore, to give moral authority to the advance directive based on respect for autonomy actually, in effect, violates the sovereignty of the present Margo. Hence, if the advance directive is to be given moral authority there must be other considerations apart from autonomy, since it is not possible to respect the autonomy of the two Margos at the same time.

4.2. Ronald Dworkin (1931-2013)

Ronald Dworkin, a highly distinguished scholar in philosophy of law and political philosophy, is considered one of the most influential philosophers of law in our time (Khan, 2013). In the article Autonomy and the Demented Self (1986) Dworkin presented a controversial interpretation of the term ‘autonomy’ which has profound implications for the person who is no longer competent and has executed an advance directive. Dworkin’s interpretation requires that the instructions in the advance directive concerning medical treatment must be followed even if the treatment or lack
thereof leads to a premature death, or if the no longer competent person requests treatment contrary to the instructions of the advance directive. Dworkin’s interpretation of autonomy, which he refers to as ‘precedent autonomy’, bears clear resemblance to that of a judicial understanding of the term ‘precedent’ and its nature. Failure to implement the instructions of the advance directive is considered by Dworkin to be a violation of the autonomy of the individual, i.e. the precedent autonomy of the individual now suffering from dementia (p. 12).

4.2.1. Legal perspective. Dworkin has contributed extensively to the discussion on the importance and the significance of the term ‘precedent’ in the justice system with regard to judicial decision-making. Fundamental to judicial decision-making is the legal principle *stare decisis*, which ensures that cases that are similar with regard to matter and facts are judged in the same way. Thus, the law is applied in a consistent way (Hughes, 1998), which ensures a consistency and a homogeneity in the justice systems and in judicial decision-making. This consistency and homogeneity in decision-making is directed by the doctrine of precedent, so that a precedent decision will reflect the practice and the decisions in similar cases in the future. Moreover, the morals of society are reflected when the doctrine of precedent is used in judicial decision-making.

When Dworkin ardently defended the moral authority of the advance directive he made an analogy to the legal and judicial systems, both with regard to the concept of precedent, and the authority of the advance directive. Dworkin attributes to the advance directive a legal status similar to that of a will, in which a testator gives instructions concerning the disposal of personal and financial assets after the testator’s death. According to Dworkin, an advance directive that is executed by a legally competent person is thus given a binding legal status at a time when the person is no longer competent. Therefore, a person who is no longer legally competent is neither able to execute any legally binding contracts, nor able to sign any legally binding statements. Consequently, a will or an advance directive cannot be altered by the person who is now legally incompetent.

Dworkin applied the doctrine of precedent to the interpretation of the concept of personal autonomy. The application of precedent to personal autonomy implies that the autonomous decisions of the legally competent person are still considered autonomous decisions at a later time when the person is no longer legally competent. This is in line with *stare decisis*, which assumes that the way the right of autonomy is exercised by a competent individual at time $t$ with regard to matter $A$ is similar to the way the right of autonomy is exercised at time $t_{\text{future}}$ by the same individual had they not been in a state of incompetence. Thus, applying *stare decisis* then requires that the autonomous decision the individual once made when competent with regard to the
instructions in the advance directive is still valid at a later time when the decision cannot be changed due to the individual’s lack of competence. Dworkin therefore assumes that the precedent autonomy of the individual reflects the autonomy of the person at a later time if the person had not been incompetent.

Therefore, Dworkin’s application of the legal term ‘precedent’ to the understanding of autonomy and his ascription of legal status to the advance directive have profound implications for the life and interests of an incompetent person that has executed an advance directive. For example, in Dworkin’s view, a situation may occur where doctors are basically forced to allow the person suffering from dementia to die, should the advance directive instruct so. In cases like these, the application of a legal term to interpret the principle of autonomy will lead to seemingly unconscionable conclusions.

4.2.2. Precedent autonomy. If, as Dworkin (1986) argues, the autonomy of the incompetent person is synonymous to precedent autonomy, then respecting the precedent autonomy of the person requires that the instructions of the advance directive is implemented. Furthermore, Dworkin argues that the desires expressed by the individual now suffering from dementia are inconsistent with the preferences and values of the individual not suffering from dementia. The person suffering from dementia has lost the capacity to create and direct a life that is continuous and fundamentally their own based on rational decisions and personal beliefs and convictions.

Essential for the validity of Dworkin’s argument is that the life of the individual is perceived as ‘one’ entire life in which dementia is an ending stage. This ending stage is considered one of several stages which together constitute the uniqueness of the individual’s life. The personal identity is expressed through autonomous choices whereby the competent person forms his own life according to values and preferences he has chosen freely (p. 9). The assumption that the person prior to the onset of dementia and the person now with dementia are not two distinct persons but one and the same is fundamental to Dworkin’s defense of his argument, and is something he reiterates throughout his work.

The presumption that “the personal identity survives even the most serious dementia” (p. 6) is a necessary premise for the argument that the autonomy of the individual is violated if the instructions of the advance directive are not respected, even if these instructions have serious implications for the individual now suffering from dementia. Dworkin writes “If my claims about personal identity are wrong, and identity does not survive dementia, many of my arguments and conclusions about the rights of the demented would have to be abandoned” (p. 6). This necessary
premise is something that some of Dworkin’s opponents dismiss. For example, David DeGrazia (1999) argues that the person with dementia is distinctly different from the person who executed the advance directive; Dresser (1995; 2003) argues that the necessary psychological continuity over time is lost, and therefore we are dealing with two different persons. However, for the sake of the discussion of Dworkin’s argument, let us assume that Dworkin is right regarding the survival of the personal identity.

Dworkin asserts that the genuine expression of the demented person’s autonomy is to be found in an advance directive, assuming that such a directive exists. With the emphasis on precedent autonomy, Dworkin stresses that the individual has a right to respect for autonomy - a right that is preserved even when the person is suffering from dementia. The disorder of dementia masks the underlying personal identity of the individual, which is expressed through autonomous choices. Therefore, the autonomy that must be respected is the autonomy that is expressed by the individual behind the mask of dementia. Dworkin (1986) claims that “dementia has occurred in the course of a larger life whose length must be considered in any decision about what rights [the individual suffering from dementia] has” (p. 4), and that “it is necessary to show respect of his life as a whole” (p. 5).

Therefore, the individual has a right to respect for autonomy; an autonomy that is not to be violated even in the state of dementia when the individual no longer has the capacity for autonomy. This means that the individual cannot request that present expressed desires and wishes are respected, since these do not reflect autonomous choices made by an autonomous individual. Dworkin therefore concludes that there is no longer any reason to respect the autonomy of the individual suffering from dementia since his “choices and demands, no matter how firmly expressed one by one, systematically contradict one another, or reflect no coherent character whatever […] [and] he has presumably lost the capacity that it is the point of autonomy to protect” (p. 9). Moreover, the person with dementia has actually lost a right, i.e. the right to respect for their present desires and wishes. This is a position that Dworkin later defends in *Life’s Dominion: An Argument about Abortion, Euthanasia, and Individual Freedom* (1993).

Dworkin’s interpretation of autonomy reveals his background in legal philosophy. He insists that the precedent autonomy of the competent individual be respected. Dworkin (1986) states that:

A competent person’s right to autonomy requires that his past decisions about how he is to be treated if he becomes demented, be respected even if they do not represent, and even if they contradict, the desires he has when we respect them, provided he did not change his mind while still in charge of his own life. (p. 13)
Therefore, the autonomy to be respected is the precedent autonomy expressed in the advance directive, as the individual no longer has the capacity for autonomy.

To support his view on precedent autonomy Dworkin makes a comparison between a deranged Jehovah’s Witness who out of respect for his autonomy is denied a requested blood transfusion and an individual suffering from dementia who requests that the instructions of the advance directive are overruled (p. 13). This comparison is flawed because in the case of the Jehovah’s Witness, who temporarily is not considered competent, that person will eventually regain full capacity for autonomy and have the capacity to change his previous autonomous decision. He is denied his request for a blood transfusion out of respect for his personal autonomy since it is assumed that “he will have a different opinion when he recovers his senses” (p. 13) and will have to live with the fact that his autonomy has been violated. There is an asymmetry between these two cases since the individual suffering from dementia, in contrast, will not regain full capacity for autonomy and will not have the capacity to change their previous autonomous decision, which was expressed in the advance directive. The person suffering from dementia would never even be conscious of the violation. Because of the asymmetry between the cases I find the analogy unconvincing.

Given that Dworkin’s perception of autonomy is reasonable, the idea of precedent autonomy requires that the individual, when competent, has actually made an autonomous decision with regard to the future, expressed through an advance directive. Thus, Dworkin uses the concept of precedent autonomy to give moral authority to the advance directive.

Applying the meaning of autonomy as precedent autonomy to Margo, who has executed an advance directive stating that any medical treatment be withheld, will make evident the serious consequences of Dworkin’s conclusion that an advance directive must always be followed. Margo, suffering from Alzheimer’s disease, lives a life that is, from her perspective, meaningful and without suffering. She needs antibiotic treatment for a mild infection which potentially could become life-threatening. Margo does not refuse treatment - in fact she expresses a desire to be treated. It seems that Margo has a capacity to comprehend her present situation, which could be sufficient to consider Margo competent enough to make an appropriate decision concerning her need for treatment. According to Dworkin, Margo should be denied treatment irrespective of the fact that she has some degree of capacity for autonomy. This seems unreasonable, since Margo still has a right to be respected as a human being with dignity.

Dworkin himself recognized the profound consequences of his argument. He said that “many would be outraged by the prospect of denying an incompetent patient life-prolonging care he pleads for, of
allowing someone to die who very much wants to live, just because, years earlier, he signed a
document requiring this.” (p. 13). However, Dworkin would say that the patient’s right to
autonomy, as expressed in the advance directive, supersedes any moral outrage or objections we
might have, since the competent patient’s right cannot be trumped by anything that is not another
conflicting right (Dworkin, 1977, p. 191-192).4

4 Dworkin is known for his ‘Right Thesis’ which he gives an elaborate account of in Taking Rights Seriously (1977). The
legally competent individual is the legal holder of a right, e.g. the right to respect for their autonomy. Dworkin
describes rights as ‘trumps’, meaning that the person cannot be denied his rights out of principle. If a person’s right is
in conflict with other ethical considerations such as the person’s well-being, Dworkin holds that the person’s right
trumps any other ethical considerations that do not pertain to rights themselves. Since the person with dementia has
lost their right of respect for their autonomy, Dworkin would argue that the right the person had when competent
must prevail and be respected (p. 191-192). As I interpret Dworkin, he regards rights as absolute

4.3. Feinberg’s and Dworkin’s interpretation of autonomy in relation to the advance directive

It is evident from the presentation of Feinberg and Dworkin that if nothing else but autonomy is to
give moral authority to the advance directive, it does not do so in a convincing way, which is
highlighted in the case of Margo. Dworkin’s understanding of autonomy as precedent autonomy has
not managed to provide a full and satisfactory account for why the advanced directive of Margo
should be implemented. Feinberg’s understanding of autonomy as capacity or as the sovereign
authority to govern oneself does not give moral authority to the advance directive since Margo,
suffering from dementia, still has some capacity for autonomy left. Applying Feinberg’s
interpretation, it is not possible to conclude that the advance directive should have moral authority
in the case of dementia based solely on the principle of autonomy.

Contrary to Feinberg, Dworkin’s attempt to solve the problem by introducing precedent autonomy
leads to chilling and serious implications for the person suffering from mild dementia, who still
may have capacity left for competence to an extent of still being able to make autonomous decisions
in certain matters. Therefore, though autonomy in a legal sense is a necessary and sufficient
condition to give informed consent or refusal of treatment, and to execute an advance directive,
there are other considerations to be taken into account in the cases of the progressive neurological
disorder dementia, such as the degree of dementia, the individual’s ability to give expression to
desires, and preferences that were there prior to the onset of the disorder. It seems reasonable to
give some degree of respect to the autonomy of the person suffering from dementia. Therefore, it is
difficult to establish reasons why the desires of the person with dementia should not be respected in
any form when these conflict with the instructions in the advance directive.
PART TWO

5. Discussion of Dworkin

In part one, I presented an overview of the principle of autonomy as interpreted by Feinberg and Dworkin. I concluded that these interpretations did not convincingly show that appeal to autonomy alone gives moral authority to the advance directive in the case of dementia. Dworkin argues that the right of autonomy that should be respected in the event of dementia is in fact the right of precedent autonomy, which is expressed in the instructions of the advance directive. In Dworkin’s view, autonomy is a right that the legally competent individual holds by the virtue of being a person; a right that requires to be protected, but is actually completely lost in a person suffering from dementia (1986, p. 10; 1993, p. 225). Dworkin uses an analogy with a deranged Jehovah's Witness to establish the conclusion that, in the case of dementia, the advance directive has moral authority and cannot be overruled without violating the person’s autonomy, i.e. the precedent autonomy. I argued that Dworkin’s argument from analogy failed to justify why the advance directive should be given moral authority.

Dworkin attempts to overcome the challenges that the progressive neurological disorder dementia presents when it comes to considering the individual’s right to respect for their autonomy and the moral authority of the advance directive. Dementia specifically poses a number of problems within medical ethics, since autonomy is a requirement for the patient to give valid consent to medical treatment or refusal thereof, and it is unclear whether or not the person suffering from dementia has sufficient capacity for autonomy. Dworkin’s solution is to say that in the case of dementia the person has simply lost the right of autonomy. However, that person’s right still exists and is preserved in the instructions of the advance directive. Therefore, the right to be invoked is the right of respect for their precedent autonomy.

Dworkin justifies his conclusion by appealing to what he calls the evidentiary view and the integrity view (1986, p. 7; 1993, p. 222). With these two views, Dworkin presents an argument giving justification to why the autonomy of the individual should be respected; a respect that is not extended to the person suffering from dementia since they do not have what Dworkin calls critical interests, i.e. they are no longer able to create a life that is distinctly their own, reflecting their personal values and convictions (1993, p.199-208). In part two I will analyze and discuss these two views, and contest Dworkin’s conclusion that the person with dementia has simply lost the right of
autonomy. In contesting Dworkin’s conclusion I will focus on three major objections against his argument:

(1) Even if Dworkin is right in his conclusion, he has to show that there is a point in time where autonomy is completely lost, which I claim he has not managed to do.

(2) If we assume that there is such a cut-off point, Dworkin has to be able to show that the person suffering from dementia (e.g. Margo) has actually passed that point. I maintain that the argument Dworkin uses to show this is flawed.

(3) Assuming that Dworkin’s strict criteria for having autonomy are accurate, it makes it too easy to neglect other ethical considerations; the person now suffering from dementia may have other rights or interests that require respect.

5.1. The integrity view and the evidentiary view

When the individual exercises their right of autonomy they take responsibility for living a life that is formed and created according to their own personal character. Before the onset of dementia, the individual lived a life that was based on the values and convictions which they considered essential in creating a good life. Dworkin considers it essential for creating a good life that the individual can express their critical interests, which reflect their personal beliefs and convictions (2011, p. 195). By living according to their personal beliefs and convictions the person lives a life that is worth living; a life that is dignified (1993, p. 201). Moreover, respecting the dignity of the individual is fundamental to Dworkin; he argues that a life is only worth living if it has dignity (2011, p. 423). The individual has a right to respect for their dignity, which is a right that requires that they take responsibility for their decisions. The reason we should respect these decisions, i.e. the autonomy of the individual, is because it promotes the wellbeing of the individual.

Dworkin presents two views on autonomy to give reasons for why the autonomy of the individual should be respected. According to these two views, the evidentiary view and the integrity view, the person suffering from dementia has lost the capacity to make decisions by the use of reason. The person does not know what is in their best interest, nor do they have the necessary ability to take responsibility for their choices. Dworkin (1993) concludes that “we would not extend the right of autonomy to decisions made by seriously demented” (p. 223) since the capacity for autonomy is lost. Therefore, the person with dementia has lost the right of autonomy. Dworkin reaches this conclusion by appealing to the evidentiary view and the integrity view.
According to the evidentiary view, the right of autonomy is based on the premise that the individual is the best judge of what is in their own best interest. Dworkin holds that when a person exercises their right of autonomy, i.e. is allowed to make decisions free from coercion, they show evidence of greater well-being. Dworkin does not explain the nature of what constitutes ‘well-being’ or ‘interests’, he merely states that what is in our own best interests is what promotes our well-being. Therefore, decisions made by the person according to their best interests should be respected if we are to respect the individual’s right of autonomy. However, Dworkin acknowledges even decisions that are contrary to the best interests of the individual, either due to altruistic reasons, or due to lack of will, are in general respected by others even though it does not seem to lead to greater well-being of the individual. Following this it would be hard to argue for why the decisions of the person with dementia, who does not know what is in their best interest, should not be respected, yet this is exactly what Dworkin does. In order to get around this problem Dworkin complements his argument by appealing to what he calls the integrity view.

The integrity view offers a description of autonomy based on the integrity of the individual in order to give justification for respecting the autonomy of the person. Dworkin uses this view to show that the moral authority of the advance directive is absolute in the case of dementia, even if the person suffering from dementia emphatically insists that the advance directive should be overruled. Fundamental to this view is the respect for the integrity of the individual, which the individual expresses through their choices and decisions, forming a life that is distinctly their own and reflects their unique personality. Dworkin (1993) states that “recognizing an individual right of autonomy makes self-creation possible” and that “people often make choices that reflect weakness, indecisions, caprice, or plain irrationality” (p. 224). Therefore we should respect those decisions of the individual that contribute to creating a life that is truly their own according to their critical interests.

When talking about the best interests of the person, Dworkin distinguishes between critical interests and experiential interests. Dworkin defines ‘critical interests’ as those interests that are reflected in the decisions made by the use of reason. This is contrary to the decisions reflecting the experiential interests of the person, which are made with regard to things that the person finds pleasurable and satisfy their senses. Dworkin regards experiential interests as associated with a specific time and place, and therefore they are not reflective of the individual’s life project, which the individual strives to fulfill throughout life. A life that is lived primarily satisfying the experiential interests of the individual is therefore, according to Dworkin, a life that is empty and devoid of meaning. An individual who has lived a life informed by their critical interests, even though their life may have
seemed unstructured and the decisions made were not in their own best interest, has nevertheless lived a good life since they have adhered to their life project, even though it may not have been achievable (2011, p. 191-218).

Given these two justifications for why autonomy should be respected, Dworkin concludes that the person with dementia has no autonomy to be respected since the capacity for it no longer is present. Rather than being coherent and consistent, the choices and decisions expressed by the person with dementia are often contradictory and incoherent with no reflection of the characteristics of the decisions by person without dementia. Therefore Dworkin concludes that “we would not extend the right of autonomy to decisions made by seriously demented” (1993, p. 223), since the capacity for autonomy is lost.

5.2. Objections to Dworkin

5.2.1. First objection. In Autonomy and the Demented Self (1986) and Life’s Dominion (1993) Dworkin reaches the conclusion that the person suffering from dementia has lost their right of respect for autonomy. I object to this since he has not yet in a satisfactory way shown that it is possible to identify a specific point at which autonomy is actually lost. Dworkin presents three cases from which it seems he draws the conclusion that such a point exists, without considering whether or not it is actually possible to identify it.

In the case of the patient in a persistent vegetative state I agree with Dworkin (1993) that the patient has “no sense of their own critical interest” (p. 232). Therefore, Dworkin concludes that the advance directive must be followed in order not to violate the autonomy of the once competent person, since it is obvious that the person does not have the capacity to act according to their critical interests. According to Dworkin’s view, when the person is no longer capable of creating their own life based on their critical interests, that person has lost their capacity for autonomy and therefore also their legal right of respect for autonomy. In the case of the patient in a persistent vegetative state it is possible to identify a specific point (unconsciousness) at which autonomy is completely lost.

In the cases of the progressive neurological disorder dementia there is no statutory criteria for determining when the capacity for autonomy is lost; autonomy is lost gradually. Giving moral

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5 My position is that in order for Dworkin to succeed in his argument there must be a specific point in time T at which the person no longer meets the statutory criteria for being considered legally competent, as well as having completely lost their capacity for autonomy (from Dworkin’s perspective). Since it is possible to identify a time when the person meets Dworkin’s criteria for having a right of respect for their autonomy, and a later time when the person does not meet these criteria, the conclusion is that there must be a transition point T where the before-state changes to the after-state.
authority to the advance directive in these cases may have absurd consequences. Dworkin presents an imaginary case where the individual expresses significant mental suffering and discomfort (p. 220). The instruction of the advance directive states that no medication whatsoever may be administered. According to Dworkin these instructions must be adhered to out of respect for the individual’s autonomous decisions, even if the individual now expresses a desire for medical relief. Dworkin assumes that at some point this individual has completely lost their autonomy. The difference between considering an individual autonomous or not could in some instances be the difference between letting that individual suffer or not.

Finally, Dworkin (1993) presents an imaginary case ‘Margo’ (p. 226) in which Margo, while competent, had executed an advance directive instructing that her life be terminated in the event of dementia. Dworkin presumes that Margo now has lost her autonomy and therefore her advance directive takes precedence. Even though Margo still seems to have the capacity to express desires and wishes that are coherent to a certain degree and is, as Firlik describes, “undeniably one of the happiest people I have ever known” (Firlik, 1991, p. 201), Dworkin insists that “Margo’s past wishes must be respected” (p. 226) and her life must be terminated. Dworkin does recognize that “this conclusion is troubling, however, shocking“ (p. 226) and “we might have other good reasons for treating Margo as she now wishes, rather than as in my imaginary case, she once asked. But still, that violates rather than respects her autonomy” (p. 229). If Margo were to express a desire that the instructions of the advance directive should be overruled, Dworkin would conclude that the instructions be followed since she has passed the transition point and completely lost the capacity for autonomy.

In the two cases involving dementia Dworkin has not at any point managed to show that it is possible to identify the transition point that separates having the right of respect for autonomy and not having it, as is possible in the case of the patient in a persistent vegetative state. I find it doubtful that it is possible to identify a transition point after which, in the case of dementia, the person has lost capacity for autonomy. It is problematic to base important medical decisions on the arbitrary distinction of being autonomous or having lost autonomy.

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6 This is the same Margo that Andrew Firlik presented in the article “Margo’s Logo” in the *Journal of the American Medical Association* (1991).

7 When Dworkin discusses the moral authority of the advance directive he is not considering the ethical contents of the instructions, nor the ethical consequences of carrying them out. His ethics are deontological with a clear Kantian connotation.

8 The ‘other good reasons’ we might have for not treating Margo according to her past wishes is that we may find it morally wrong to actually terminate the life of a person. Even if we grant a person the right to die, it does not follow that we are morally obliged to carry out the termination of that person.
5.2.2. Second objection. Let us grant for the sake of argument that there is a transition point at which the autonomy of the person suffering from dementia is completely lost. Dworkin, then, has to convincingly argue that the person suffering from dementia (e.g. Margo) has actually passed that point, i.e. that the person suffering from dementia has lost autonomy completely. However, Dworkin’s argument is not convincing. For instance, his analogy with the person in a persistent vegetative state is flawed.

The person in a persistent vegetative state, due to being unconscious, no longer has the capacity to express their experiential interests nor their critical interests, the latter of which Dworkin regards as a necessary condition for autonomy. Therefore, not respecting the advance directive of the person would be a violation of their autonomy, according to Dworkin. When the person suffering from dementia has passed the transition point their capacity to express their critical interests is lost. In this case, the advance directive must be adhered to even if the person suffering from dementia expresses experiential interests that are contrary to it. In both cases, Dworkin assumes that the critical interests survive.\(^9\) Since neither of the two patients is capable of expressing their critical interests Dworkin considers the two cases to be equal with regard to the authority of the advance directive (1993, p. 230).

I consider this analogy to be flawed, as there are significant differences between the two cases. Firstly, the person in a persistent vegetative state is not capable of responding to any stimulus, whereas the person suffering from dementia, even in the last stages, can still express emotions and be sensitive to external stimulus. Secondly, the person suffering from dementia will often have some capacity left to make decisions that they consider relevant and meaningful to them. Because of this it can be argued that the person suffering from dementia still has some capacity for autonomy left, and therefore has not passed the transition point where autonomy is completely lost.

Dworkin claims that Margo (1993, p. 201-226) in her advanced state of dementia should be considered equal to the patient in the persistent vegetative state, since she can only express her experiential interests and not her critical interests.\(^10\) Dworkin bases this on the description that Firlik (1991) gives of Margo, who now only has the capacity to express what Dworkin calls experiential interests, such as her interest for reading, listening to music, her preference for

\(^9\) As I see it, a consequence of Dworkin’s arguments is that if it were possible to make the unconscious conscious, and lift the disorder of dementia, the individuals would have the same critical interests as the ones expressed in the instructions of their respective advance directive.

\(^10\) Dworkin would argue that Margo, who can no longer make autonomous decisions by the use of reason, lives a life that is guided only by her experiential interests; a life that is empty, devoid of meaning, and has no life project. Therefore, Margo no longer has the opportunity to fulfill her responsibility to live well, which is the goal of the good life.
sandwiches, or her passion for painting the same picture over and over again. Margo’s capacity to express her critical interests is diminished, or no longer present, and she no longer knows what is in her best interest. Moreover, Margo’s present life is fragmented and her actions do not reflect a coherent self-identity. Her life now is disconnected from the life lived prior to the onset of dementia; her character is no longer apparent (Firlik, 1991, p. 201).

I contest the assumption that Margo has passed the transition point and can no longer express critical interests. According to Firlik (1991) Margo seems to be content, is capable of expressing joy, as well as capable of establishing a relationship with Firlik that is meaningful to her. Although she may not have a grand life project Margo may still have a life she considers to be good, as her life without her friendship with Firlik and her ‘art classes’ would be less good. It could be argued that Margo’s critical interests are still present to some extent despite her advanced state of dementia.

Even though Dworkin (1993) would argue that Margo does not have any critical interests, Margo is significantly different from the patient in a persistent vegetative state since the mere fact that she is conscious means that she has a right of respect for her sovereignty. It is difficult to uphold the conclusion that Margo’s desires should be overruled by her advance directive on the same basis as the patient in a persistent vegetative state, since it could be claimed that she still has some capacity left for autonomy. From Dworkin’s analogy, you could not conclude that Margo has actually passed the transition point, since she still seems to give expression, although diminished, to critical interests.

5.2.3. Third objection. I have contested Dworkin’s conclusion by questioning whether there is a transition point after which autonomy is completely lost, and whether it is possible to show that the person suffering from dementia has actually passed that point. Dworkin’s conclusion is founded on his strict criteria for having autonomy, i.e. the person being able to express critical interests by the full use of reason, and thus forming and creating a life according to their life project reflecting their unique personality (1986, p. 25). If the right of respect for autonomy is based on these strict criteria it becomes too easy to neglect other ethical considerations that need to be taken into account in the event of dementia. Therefore, giving moral authority to the advance directive dismisses other rights that the person may hold. That is, ‘rights’ not understood in accordance with Dworkin’s strict definition of the term, but rather rights that we feel that every person has.

Fundamental to Dworkin’s argument is that “the competent and demented self are the same person” (1986, p. 4), and that critical interests do not change over time. The life of the person is seen as one

11 As discussed in chapter 3.
entire life where dementia is just the end stage. If we for the sake of argument accept Dworkin’s high threshold for what constitutes critical interests, then the following considerations will show that Dworkin’s conclusion is problematic:

1. The person suffering from dementia has changed radically in the sense that the interests they express now are significantly different from those prior to the onset of dementia. The person without dementia and the person with dementia can be considered one and the same since the person is part of a specific family in a specific social setting. However, the person before and after the onset of dementia exhibits different personal characters. Therefore, if there arises a conflict between the desires and choices the person expresses and those expressed in the advance directive before the onset of dementia, I find it highly debatable that the present views of the person suffering from dementia should be dismissed in favor of the instructions in the advance directive.

2. The person suffering from dementia makes decisions that neither necessarily reflect a coherent self-identity, nor a structured belief system. Nevertheless, it can be claimed that these decisions originate from the core of the person, i.e. that the critical interests are showing through the mask of dementia to some extent. Therefore, if there is a conflict between present desires and those expressed in the advanced directive, the present desires ought to be given some weight.

3. In the event of becoming incompetent, i.e. suffering from dementia, the person executes an advance directive reflecting their critical interests at that point in time. However, it is commonly observed that individuals without dementia for various reasons change their belief system in radical ways, and others still accept it out of respect for the individual’s autonomy. Therefore it is possible that if the person had had first-hand experience of dementia, they would have executed a different advance directive. In other words, if we could lift the dementia from the person it is possible we would find that their belief system has changed radically.

4. Dworkin will argue that the person is not capable of expressing their critical interests, i.e. those interests that contribute to a life project. While the critical interests of the person are masked by dementia, the person suffering from dementia may still have the capacity to express some of their critical interests. For example, Margo enjoys the visits of Firlik and invites him to her ‘workplace’. It can be argued that maintaining social connections is part of what constituted her critical interests when she did not suffer from dementia, and is part of what Dworkin considers to contribute to her life project.
5. Finally, Dworkin does not seem to attach any significance to the fact that a person’s life is fundamentally their own. We all have a desire to be in charge of our own life, giving expression to our own decisions. Often, a person suffering from dementia is compared to a child, who has not yet reached the age of being legally competent, and thus does not enjoy the right of respect for autonomy. We give consideration to the child’s desires concerning life and death in medical treatment out of respect for their sovereignty, i.e. the respect they enjoy by virtue of being human. It could be argued that children have a diminished use of reason compared to adults. Nevertheless, the decisions of a child are respected. Therefore, denying the person suffering from dementia any rights that would overrule the advance directive seems to be violating their right of respect for sovereignty.

I find that Dworkin limits the understanding of a good life by reducing it to be dependent on rational choices that are based on an idealistic picture of what constitutes worthwhile ambitions. Towards the end of life, our critical interests may be more associated with what makes our life coherent and meaningful in the near future, and are not necessarily dependent on rational choices.

6. Conclusion

The execution of advance directives has become increasingly more prevalent as a sign of a desire to have control over one’s life. In addition, there is a strong emphasis on the respect for the autonomy of the individual. However, although autonomy in the legal sense is a necessary condition for executing an advance directive, I have argued that it is not sufficient to give moral authority to the advance directive in the event of dementia. Neither Feinberg nor Dworkin has convincingly been able to show that the advance directive, in the case of dementia, should be given moral authority. According to Feinberg, respect for autonomy does not give moral authority to the advance directive; the advance directive can be overruled if the personal sovereignty of the individual is violated, even if they no longer have full capacity for autonomy. Dworkin, on the other hand, maintained that the respect for personal autonomy requires respect for the person’s precedent autonomy. However, this position leads to consequences that have serious implications for the person suffering from dementia, and does not provide a reason for why the advance directive should not be able to be overruled.

In Life’s Dominion (1993) Dworkin offered an argument as to why the advance directive always had to be respected in the case of dementia, irrespective of the expressed desire of the patient that
the instructions should be overruled. He addressed it as a legal issue, claiming that the person suffering from dementia had actually lost the right to autonomy and therefore had seemingly lost the capacity to give informed consent or refusal to medical treatment or examination. I have argued that Dworkin’s strictly legal approach is not convincing when it comes to giving moral authority to the advance directive in the case of dementia. Since dementia is progressive neurological disorder it is not possible to identify a specific point in time where the person has lost their right to respect for autonomy. There is no univocal correlation between being legally competent and having the capacity to give valid informed consent regarding medical treatment or refusal thereof.

In order to fully examine whether or not an advance directive ought to have moral authority in the case of dementia there are other aspects that need to be considered, such as the nature of a person and personal identity, the dignity of the person suffering from dementia, as well as the nature of the advance directive itself, e.g. whether it needs to be more precise. Advance directives are often formulated in a general way and there is often need for interpretation, especially in the cases of dementia where competence and autonomy is lost in stages.

Due to scientific progress the human lifespan has increased, and since it seems that the occurrence of dementia is related to advanced age, there will in the near future be an increased population of people suffering from various forms of dementia. Therefore there is an immediate need to discuss relevance and authority of the advanced directive. The increasing number of diagnosed cases of dementia forces us to confront important issues, specifically what it means to live a good life and what it means to be respected as a unique human being.

“Those with dementia are still people and they still have stories and they still have character and they are all individuals and they are all unique. And they just need to be interacted with on a human level.”

Carey Mulligan

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References


