Euthanasia and Physician Assisted Suicide in Dementia: Decision-making Capacity Revised

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Content

Abstract

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Euthanasia and physician assisted suicide (combined and referred to as "Physician Assisted Dying", and abbreviated as PAD) are legally permitted in the Netherlands provided that both a set of criteria of due care is met, and that the case is reported to the municipal pathologist. One of these criteria states that the practicing physician must be convinced that the request is both voluntary and well-considered. This requires the physician to determine that the person requesting PAD has sufficient decision-making capacity for this choice. In light of the increasing number of granted requests for PAD on people suffering from dementia in the Netherlands and the expected increase in occurrence of dementia in the years to come, the need to evaluate several approaches to the concept, criteria and standards of competence becomes a matter of great importance. Evaluating these issues is a starting-point from which we will be able to answer the question which criteria and standards of competence are justifiable in cases where people suffering from dementia request physician-assisted dying. As the dominant approach on the criteria of competence (by Appelbaum and Grisso) is unable to do justice to the reality of decision-making, the possibilities for an enriched set of criteria is investigated. Moreover, a process-related standard of competence including the outcome is proposed to account for the influence of contextual factors in the decision-making process. As a result, a set of enriched criteria and a variable standard of competence is proposed by means of a framework for "Embedded Competence".

Introduction

Euthanasia and physician-assisted suicide (hereafter combined and referred to as "Physician-Assisted Dying", and abbreviated as PAD) are still prohibited by law in the Netherlands. However, the Euthanasia Act, enacted in 2002, states that the practicing physician will not be prosecuted if a local Euthanasia Review Committee decides that certain regulatory rules, also known as criteria for due care, are abided by, and if it is reported to the municipal forensic pathologist. Although the practices involved in PAD can count on much support both within the medical professional context and within Dutch society (van Delden et al. 2011), they are still a much debated and controversial topic when it comes to granting a request from a person suffering from dementia.

The first criterion of due care states that the physician is required to be convinced that the request for PAD is both voluntary and well-considered. In order for one to be able to make a voluntary and well-considered decision, one has to at least be competent. Although there are many forms of dementia, which all present themselves differently, all of them affect cognitive functioning and decision-making capacity. This creates at least reasonable doubt about the competence of a person suffering from dementia. Therefore, when a demented person requests PAD, such reasonable doubt could motivate a physician to ensure that his patient is competent. It is of great importance that determinations of competence in general (that is, not necessarily related to requests for PAD), have a minimal margin of error. Both an erroneous determination of incompetence and an erroneous determination of competence bear significant risks in terms of the protection of important values – respectively the values of autonomy and protection against harm are at stake here. When a person is erroneously considered incompetent, his decision-making authority is wrongfully infringed upon. Conversely, an erroneous determination of competence results in an insufficient protection against the potential harms of incompetent decision-making.

Significant aspects of the domain of competence remain heavily contested. Neither on the concept of competence, nor on the criteria and standards of competence has consensus been reached. This paper will explore and critically assess current views on these issues in order to answer the following question:

> *Which criteria and standards of competence are justifiable to apply in cases where people suffering from dementia request physician-assisted dying?*

An exploration of dominant and alternative approaches to competence will be a starting-point in order to assess which of these views captures the notion of competence

most adequately without increasing the risk of improper assignment of competence to an unacceptable level.

When the question of whether or not a person is competent to decide is connected to a request for PAD, another dimension is added to the discussion. The irreversibility of death leads us to explore in some detail the ongoing discussion about risk- and outcome-related standards of competence. What role should the outcome or risk of a decision play in a determination of competence? Should a higher risk be compensated by a higher level of decision-making capacity? And more specifically, how should it be weighed in the determination of competence in a situation where a request for PAD is made by a person suffering from dementia?

In summary, the subjects mentioned here will be critically discussed in what is to follow. In the first chapter an exploration of what the Dutch Euthanasia Act consists of and how it is currently applied to people with dementia requesting PAD will be offered. In the second chapter the concept of competence will be addressed. Moreover, dominant and alternative views on the criteria of competence will be reviewed in order to evaluate their proper role in determinations of competence. The third chapter will be devoted to investigating the role of the risk and outcome of a decision and its possible influence on the requirements of competence. This will allow me to offer a proposal in which a wide array of relevant factors in decision-making are reflected, and thereby answer the central question of this paper in the final chapters.

Chapter 1 | Euthanasia and Physician Assisted Suicide in the Netherlands

1.1 The Dutch Euthanasia Act

In 2002 the Termination of Life on Request and Assisted Suicide Act, commonly abbreviated as Euthanasia Act, was enacted. This act allows physicians to perform PAD on the condition that a number of requirements of due care are complied with. These requirements of due care require the physician:

1. to be convinced that the request is voluntary and well-considered
2. to be convinced that the patient's suffering is hopeless and unbearable
3. to make sure that the patient is fully informed about his/her medical situation and prospects
4. to be convinced that there is no reasonable alternative solution for the patient
5. to consult at least one independent physician, who must have seen the patient and given his/her written assessment of the four previous requirements
6. to perform the termination of the patient's life in a careful manner.

Moreover, the Euthanasia Act provides for the possibility of replacing a verbal request by a competent person for an AED as long as the requirements of due care are complied with accordingly.The performing physician is required to report the case to the local Euthanasia Review Committee (hereafter abbreviated as ERC) after the euthanasia has been performed. The ERC assesses the report and determines whether or not the practicing physician performed the euthanasia according to the requirements of due care. If the ERC concludes that the euthanasia was performed according to these requirements, its concluding statement is considered to be final. However, if the ERC concludes that it was not performed according to these requirements, its concluding statement will be sent to the prosecutor and the Healthcare Inspectorate. The prosecutor then decides whether or not the practicing physician will be prosecuted.

1.2 Dementia and PAD in the Netherlands

Year	Total number of cases of euthanasia and PAD	Cases involving patients suffering from dementia
2009	2636	12 (0,5%)
2010	3136	25 (0,8%)
2011	3695	49 (1,3%)
2012	4188	42 (1%)

2013	4829	97 (2%)

Table 1: Cases PAD involving people suffering from dementia from 2009

Following a specific request from the Secretary of State for Public Health, the ERC's started monitoring cases PAD involving people suffering from dementia from 2009. Table 1 shows the development of these figures over the following years.

With the exception of two cases, all granted requests concerned people suffering from dementia who were assessed to be clearly competent according to the guidelines for the determination of incompetence by Royal Dutch Medical Association (KNMG, 2004).

The first case involving euthanasia on a person suffering from dementia who was deemed to have questionable competence regarding the request for euthanasia by the physicians involved was reported in 2011 (Euthanasiecommissie, 2011). Since the competence of the patient requesting PAD in this case was at the very least questionable, the request was granted partially based on the advance euthanasia directive (AED) signed by the patient. A second case involved a person who was clearly incompetent at the moment euthanasia was performed. The request was granted on the basis of an AED (Euthanasiecommissie, 2012). However, in this case the ERC concluded that the requirements of due care were not complied with accordingly. The use of AED's poses several problems (Hartogh et al., 2007; van Delden, 2004). However, since the applicability of AED's is not the topic of this paper, it will not be discussed any further.

Especially the first of these two cases is of great interest to the subject of this paper. In this case the patient was unable to give a detailed reasoning for her request for PAD. A detailed AED about the circumstances under which the patient wanted her life ended by means of PAD was present. The treating physician had conducted several conversations with the patient on the subject at the time she was still evidently competent, and the physician was convinced that the AED was signed voluntarily and well-considered. Moreover, the patient's expressions towards the subject at the time of the actual request were strongly indicative of her competence about the matter. Therefore, the treating physician concluded that he would be able to meet the requirements of due care and that the request could be granted accordingly. The first independent physician was unable to come to this conclusion due to the patient's inability to express a well-reasoned request. The second independent physician, however, was able to conclude that the patient was competent to make the request for PAD based on the expressions by the patient concerning the request. Although the patient was unable to give a detailed reasoning for her request, she was able to make clear that she wanted her life ended. Clearly, both the treating physician and the second independent physician were supported by the patient's AED and previous conversations. In the evalution by the ERC the use of this AED was of great importance for the performance of PAD in this case to be considered in line with the requirements of due

care . The apparent discrepancy between the conclusions of both independent physician is very striking. What could possibly have been the discerning factor that resulted in the different outcomes? Of course, I will not speculate about what might have caused the discrepancy in this particular case. However, the case focuses on the exact area in the domain of competence in general where great uncertainty and room for discussion occurs. It is this area that will be the focus in the chapters to come.

Chapter 2 | Competence as decision-making ability

The matter of competence is a highly debated topic, mostly in the context of informed consent. Informed consent requires that four criteria be met in order to respect the underlying value of autonomous decision-making: disclosure, understanding, voluntariness and competence (Beauchamp and Childress, 2009). Within the field of medical decision-making, competence judgements serve to establish the validity of decisions made by patients concerning their health; a decision by an incompetent person is not to be accepted as an autonomous decision. This clearly illustrates tension between the values of autonomy and protecting the vulnerable against harm when it comes to a competence-judgement. On the one hand, within the field of medical decision-making, autonomy is considered worthy of fierce protection against infringement upon the condition that the patient is considered competent. On the other hand, a patient is entitled to protection from harm on the basis of being considered incompetent. This demonstrates that what is at stake is that both improper determinations of competence and incompetence seriously infringe upon patients' rights and should be avoided if possible.

Although the importance of proper competence-judgement is usually clear, in some discussions on competence several distinctly different topics are not properly distinguished, causing confusion. As the subject of competence is of central importance to the matter at hand in this paper, I will make some preliminary remarks about the issue, distinguishing between the concept of competence and the criteria for competence; both of which remain highly debated parts of the debate.

The chapter will begin by discussing several elements important to the concept of competence. Thereafter, different views on the criteria for competence will be reviewed in order to assess their proper role in determinations of competence.

2.1 The Concept of Competence

How are we to understand the term "competence"? Competence refers to the capacity to make autonomous decisions. In order to make an autonomous decision, one needs sufficient decision-making capacity (DMC). A lack of DMC thus equals incompetence. As mentioned earlier, competence is a highly debated topic. Some properties often associated with it remain controversial, while relative consensus has been reached regarding others.

First, consensus has been reached over the fact that there should be a legal presumption in favour of competence (Berghmans, et al., 2004); all people should be considered to be competent, unless there are reasons for the opposite. As a result of this

presumption, the burden of proof lies on the side of the one taking the position that the person lacks competence.

Second, decision-making capacity is considered a relative notion (Wikler, 1979). The capability to make a particular decision is gradual in its nature (Berghmans, 2000). With the exeption of people altogether unable to communicate a decision, people usually have varying degrees of DMC in relation to particular decisions. For instance, one can posess a sufficient amount of DMC to decide what to have for dinner, but not to decide about particular medical matters. An individual's DMC regarding the same task can differ over time and between particular situations or decisions. For instance, one can be perfectly able to make a decision after a good night's sleep, but an exhausting day can cause one to be less capable of making the same decision. Furthermore, that DMC is a relative notion explains why we consider some people to be more competent at performing a certain task than others. These properties allow us to compare DMC over time and between different individuals.

Third, to be able to operationalize the concept of competence, it has to have an "all-or-nothing"-character (Berghmans, 2000). A determination of incompetence revolves around the question whether or not to leave the decision-making authority with the patient. Therefore, it requires a "yes"- or "no"-answer. So even though competence is a relative notion – one can have more or less of it regarding a particular decision – when it comes to making a decision about whether or not a person is competent, it is a notion in which the possible outcomes are mutually exclusive. When questions about a patient's competence regarding a certain decision arise, the objective of investigating that particular patient's DMC is then to determine whether or not a decision expressed by him should be adhered to. The conclusion of such an investigation thus must be uncompromising towards the patient's decision-making authority regarding that particular decision; if his DMC is above a certain threshold, the patient is deemed competent and his decision-making authority remains intact. However, if his DMC falls short of the threshold, the patient is deemed incompetent and this results in a strong reduction of his decision-making authority.

Fourth, there is general consensus about decision-making capacity being task-specific rather than general. With the exeption of people altogether unable to communicate a decision, a blanket-determination of incompetence is very likely not justified; there will be areas in which the person is able to make decisions. According to some (Buchanan & Brock, 1989; Wilks, 1997; Wilks, 1999) a particular decision can require more or less DMC of a person depending not only on individual abilities of that person but also on the complexity of the required reasoning-process or the potential risk(s) involved in the possible outcomes of the decision (Berghmans, 2000). However, as will later be discussed, if and how these factors unrelated to individual abilities are to be weighed remains a higly debated issue.

Fifth, a lively discussion continues on the topic of process-based versus outcome-based standards of competence. It is generally agreed that the quality of the process of decision-making is highly relevant for the question whether or not one possesses sufficient decision-making capacity to be considered competent to make a particular decision. However, the criteria for a thought process of sufficient quality remain controversial. What the role of the outcome of that decision-making process should be is even less clear and is the topic of ongoing discussion. According to some an outcome-based standard for DMC would harbour the danger of imposing certain "medically preferable" decisions, rendering the patient incompetent should he fail to comply with such a preferred outcome. Others claim that the outcome is an indispensible part of a decision-making process and should therefore play a role in a determination of incompetence. This issue will be addressed later on.

Finally, the concept of competence is highly normative in its nature (Berghmans et al., 2004): a determination of incompetence reflects on wheather or not the decision-making process is qualified as "good enough" to warrant decision-making authority.

In summary, despite remaining controversy regarding the exact content of the concept of competence as decision-making capacity, it is generally considered to be a normative concept both *specific* and *relative* in nature, it should illustrate the quality of the decision-making *process*, and it results in an *"all-or-nothing"*-decision about the decision-making authority of a person.

2.2 The Dominant Approach to the Criteria for Competence

Extensive debate about the assessment of competence initiated the development of a wide variety of criteria for competence, proposed by different commentators from different disciplines. Although consensus has thus far not been reached, the research by Appelbaum, and Grisso summarizes the current dominant view on the criteria for competence best. Moreover, it is this framework which served as the main source of inspiration for the guidelines towards the determination of incompetence by the Royal Dutch Medical Association (KNMG, 2004). This causes it to be of major influence on the medical standard in the Netherlands. For both of these reasons this part of the chapter will be devoted to a brief elaboration on their writings regarding the criteria for competence.

After extensive research on the requirements of informed consent, Appelbaum, Grisso et al. (Appelbaum and Grisso, 1995; Grisso et al., 1995; Grisso and Appelbaum, 1995) turned to investigate the conditions of competence to consent to treatment more closely in the 1990's. They identified four standards for determining competence to consent to treatment. These standards harbour certain decision-making capacities which need to be assessed in order to determine whether or not the standard is met.

The first and least demanding standard is described as the ability to communicate a choice. It seems very evident that a patient lacking the ability to express his desires and wishes (due to any and all illness or disorder) regarding a course of treatment cannot be considered competent. However, Appelbaum and Grisso . regard patients who are able to communicate their desires and wishes involving their treatment, but who are fickle in their expressions about the subject, as unable to communicate a choice to the same extent. This criterion on its own is very protective of an individual's right to make decisions, but does not at all take into account the process by which a decision is made.

The second standard involves the ability to understand relevant information. This standard requires comprehension of the information and concepts that apply to the decision at hand. The information that should be provided, according to Appelbaum and Grisso, is that which is necessary for an informed consent. One could, for instance, imagine that being under the influence of a sedative would have a temporary negative effect on the ability to understand relevant information. In a situation like this, this particular standard would not be met.

The third standard is the ability to appreciate the nature of the situation and its likely consequences. This standard differs from the standard revolving around comprehension in the sense that the patient must be able to apply the information abstractly in relation to his own situation. Appelbaum and Grisso illustrate this point by referring to two contrasting cases. In the first case a woman refusing the amputation of a gangrenous leg was found to be competent, because she was able to appreciate the nature and the consequences of her act. In other words, not only did she understand that one is likely to die without an amputation, she was also able to apply that knowledge to her own situation and take it into account in her decision. In the second case, a schizophrenic man was found to be incompetent, because his refusal to take medication was based on his denial that he was schizophrenic. This denial prevented him from the appreciation of the risks associated with a refusal to take medication.

The fourth and final standard refers to the ability to manipulate information rationally. It requires the patient to use logical thought-processes to weigh the risks and benefits of a treatment proposal. Even though the understanding and appreciation of information can be present, one can lack the ability to manipulate information rationally. Appelbaum and Grisso emphasize that "the 'irrationality' to which this standard properly refers pertains to illogic in the processing of information, not the choice that eventually is made" (Appelbaum and Grisso, 1995, 110).

As was previously mentioned, the ability to communicate a choice is the least demanding standard. As soon as a person expresses a choice, this standard is met. This

creates a starting point for the other three criteria. If a person is not able to express a choice, an assessment of the other standards is impossible. Subsequently, the ability to understand relevant information is presupposed in the third standard. In order for one to appreciate the nature and the likely consequences of a decision, the relevant concepts and information have to be understood first. Finally, the fourth standard operates quite independently from the second and the third. The existence of the ability to manipulate information rationally might be present even if the subject displays impaired understanding or defective appreciation. Conversely, even in the presence of understanding and appreciation, decision-making might still be impaired if the subject is unable to process information logically (Appelbaum and Grisso, 1995, 110).

With the exception of the first criterion, this framework relies rather heavily on cognitive and rational abilities. For this it has been criticised by several commentators. I will now turn to discuss some of these criticisms.

2.3 Criticism on the Dominant Approach to the Criteria for Competence

Establishing cognitive and rational abilities as the basis for determining competence has initiated the development of several measuring instruments to objectify competence. Of these measuring instruments, the “MacArthur Competence Assessment Tool – Treatment” (MacCAT-T), developed by Appelbaum, Grisso et al., is probably the most well-known (Appelbaum and Grisso, 1995; Grisso et al., 1995; Grisso and Appelbaum, 1995). It is also this instrument which serves as the basis of the guidelines by the Royal Dutch Medical Association prescribing Dutch physicians as to how decision-making capacity is to be measured. Other examples of instruments for the assessment of competence are: the Mental Competence Scale (Winograd, 1984), the Decision-Making Capacity Assessment (Fitten et al., 1990), and the Hopkins Competency Assessment Test (Janofsky et al., 1992). The strong emphasis on cognitive and rational abilities in all of these instruments, however, has raised concerns about this type of competence-measurement. The underlying assumptions in these instruments prescribe that cognitive and rational abilities serve as both necessary and sufficient requirements for competence. However, this assumption is heavily contested by critics of this view on competence who argue that several key-elements of decision-making are not or underdeveloped in the dominant approach.

First, opponents claim that these instruments are based on a conception of competence that is defined too narrowly, by not taking into account what actually motivates a patient to make a particular decision and failing to appreciate the patients’ context properly (Berghmans, 2004; Breden and Vollmann 2004). In other words, instruments based on merely cognitive and rational criteria in the decision-making process are not representative of

the way people *actually* reach decisions (Breden and Vollmann, 2004). Since a determination of incompetence purports to reflect on a person's decision-making capacity, all factors relevant for the process of decision-making should be taken into account. Neglecting to take relevant factors into account results in an incomplete image of a person's decision-making capacity. Such an incomplete determination of incompetence bears the risk of infringement upon the values of autonomy and protection against harm. One can imagine that an incomplete determination might cause the scale to tip to either competence or incompetence wrongfully. Moreover, a narrow conception of competence bears the risk of discrimination against the mentally ill, by focussing too strongly on cognition and rationality. Research by Vollmann et al. (2003) shows that psychiatrists, using their clinical judgement, classified a smaller proportion of patients as having impaired decision-making capacity than the MacCAT-T. The mere difference between psychiatrists' competence judgements and the outcome of the MacCAT-T does not necessarily mean that the mentally ill are wrongfully discriminated against. However, the discrepancy does suggest that there is difference between the criteria used by the MacCAT-T and the psychiatrists' jugdement in this research, resulting in different outcomes on an individual level. It is this difference that is of interest for the current discussion. Which factors are under- or overrated? Some argue that an emotionalist approach would do more justice to the process of determining competence (Charland, 1998; Welie, 2001; Frijda, 2002; Widdershoven and Berghmans, 2002), others emphasize the importance of including the patient's ability to value (Jaworska, 1999; Widdershoven and Berghmans, 2002). Yet others propose an approach in which *improvement* of decision-making capacity, by offering supportive environmental factors, is of pivotal importance (Widdershoven and Berghmans, 2002; Benaroyo and Widdershoven, 2004; Maeckelberghe, 2004; Welie, 2001). In the following paragraph all of these approaches will be explored in greater depth.

Second, questions have arisen about whether or not these instruments actually measure competence or other properties, such as memory and the ability to understand information (Berghmans, 2001; Berghmans, 2004). The abilities to retain and understand information are significantly related to competence but are not necessarily indispensible for it as I will argue later.

Third, although standardization by means of measuring instruments seemingly provides professionals with concrete tools to use in everyday professional reality, a negative aspect of attempting to measure competence is that, from a philosophical point of view, it detracts from autonomy as personal uniqueness (Breden and Vollmann, 2004). Competence is a highly normative notion. Attempting to measure it by means of a measuring tool suggests

that it is an empirical one. The question where to put the threshold for competence is normative in character, not empirical.

2.4 Alternative and Complementary Criteria for Competence

The criticism aimed at the cognitive and rationalist approach to competence has spurred the development of alternative and complementary approaches.

2.4.1 The Emotionalist Approach

Certain authors argue, either directly of indirectly, that the approach to competence by Appelbaum and Grisso is limited in that it does not take emotions into consideration as a necessary and constitutive part of competence. The cognitive and rationalist view on competence as presented by Appelbaum and Grisso, they claim, is not representative of the way in which people generally reach decisions. Historically speaking, emotion has a bad reputation when it comes to its influence on decision-making. Perhaps this explains why it has a limited role in Appelbaum and Grisso's approach. Emotions influence our thought-processes in both negative and positive ways: they have the potential to distort a well-considered decision-making process, but are also an important factor in the formation of preferences. Emotional and intuitive factors have to be taken into account, as people are motivated to a large degree, either consciously or unconsciously, by these factors. As Welie states: "if we want to do justice to the everyday reality of decision-making, there should be room for an 'emotionalist' concept of PDMC[1] " (Welie, 2001, 146). Moreover, Frijda (2002) argues that emotions, as a part of cognitive functioning, stand at the basis of forming personal preferences and are therefore a necessary part of decision-making capacity. According to Charland (1998), appreciation requires emotion, as one of the necessary ingredients of competence. His argument is meant not as dismissive of the account of competence proposed by Appelbaum and Grisso, but as an enrichment of this account. As earlier stated, Appelbaum and Grisso define the necessary ingredients of competence as cognitive or intellectual capacity. Charland argues that one of these components defined by Appelbaum and Grisso, namely appraisal, cannot be understood properly without adding emotion to its definition. In order for one to appreciate the nature of a treatment-decision, one has to be capable of appraising these components as personally meaningful. According to Charland, it is widely acknowledged that appraisal requires the capacity for emotion. Thus, along with the cognitive capacities normally associated with appreciation, emotional capacity is also required for appreciation. A person's goals and values are to a great extent shaped by emotion. Emotions are the source of personal preferences and without them it would even be

[1] PDMC is an abbreviation for Patient Decision Making Competence in this article by Welie.

close to impossible for a person to reach a decision at all. In addition, Charland purports that emotion is a relational concept, being the product of the interaction between the person and his environment. This emphasizes the importance of taking contextual factors into account within the decision-making process. I will return to this issue in 2.4.3. in more detail. Moreover, Charland asserts that the capacity for emotion is an important source of personal meaning-making and personal preferences, and is therefore a defining factor for an individual. The possibility of including the ability to value in a definition of competence will be the topic of 2.4.2.

For now let us take a closer look at what effects this emotionalist position by Charland would yield for a person affected by dementia with questionable competence requesting PAD. As mentioned earlier, Charland asserts that the requirement of emotion should be thought of as an addition to the abilities required for competent decision-making put forward by Appelbaum and Grisso. Effectively, this results in an even more restrictive interpretation of competence; in addition to the cognitive requirements, a person is also required to show sufficient capacity for emotion. As Charland readily acknowledges, a consequence of his view might be that more people would be considered incompetent than would be the case if abiding only by the cognitive requirements. Although we do agree on the inclusion of an emotionalist criterion as a condition for competence, in our view, the approach proposed by Charland merely circumvents the criticism on Appelbaum and Grisso's framework, instead of addressing it directly. As Charland explains, his emotionalist approach should be considered an addition to cognitive requirements, not a replacement of them. Charland's criticism stops at addressing the lack of the inclusion of emotions in Appelbaum and Grisso's framework, leaving it intact. This might result in a higher threshold for competence. At the same time, it seems to better reflect what appreciation in the context of decision-making consists of. In light of including all factors relevant for decision-making and thereby optimalizing the full scope of criteria used to determine incompetence, the added emphasis on emotion as part of appreciation seems to be a valuable addition.

2.4.2 The Inclusion of the Ability to Value

In *Life's Dominion: An Argument About Abortion, Euthanasia, and Individual Freedom* by Ronald Dworkin (1994), a compelling argument is developed for respecting the patient's wishes prior to a state of incompetence, induced by dementia, for example. In brief, we ought to respect the person's personhood and autonomy as it was when it was still intact. This argument could be interpreted as a justification for advanced directives. Although this is not the topic of discussion in this paper, a critical response to Dworkin's work by Jaworska (1999) leads us towards a different notion of competence.

Jaworska develops an argument in favour of respecting the demented person's current wishes and preferences to the extent that the *ability to value* is still intact. She argues that as long as the patient is still able to value, respecting the expressions of the person suffering from dementia regarding his interests is appropriate for it is neither contrary to his well-being nor to the respect for his autonomy. Like Dworkin, she is primarily concerned with the interpretation of autonomy and well-being. However, she does so differently. As Jaworska states: "I associate potential for autonomy primarily with the capacity to value, and well-being with living in accordance with one's values" (Jaworska, 1999, 109).

When attempting to promote a demented person's well-being, we ought to take a closer look at what possible interests he may have. Dworkin distinguishes between two types of interests that may be of importance. First, there are what he calls *experiential interests*: we have an interest in pleasurable experiences, as well as an interest in avoiding unpleasant ones. Second, and according to Dworkin, more important are critical interests: convictions about what makes life as a whole genuinely better and/or genuinely worse, regardless of the immediate experiences brought by these convictions. He argues that people suffering from dementia are unable to originate critical interests, because they are unable to reflect on the entirety of their life with regards to what makes their life genuinely better. Therefore, they cannot be regarded as autonomous agents. Although Jaworska agrees with the distinction between experiential and critical interests to some extent, she rejects Dworkin's contention that one needs the ability to reflect on his life as a whole in order to express genuine critical interests. Critical interests, she argues, are "simply convictions about what is good to have, which do not require the ability to grasp or review one's whole life" (Jaworska, 1999, 113), and this goes hand in hand with the ability to value. According to Jaworska a value can be distinguished from a mere desire by looking at the result from taking away the object of a value or a desire; so long as one does not genuinely mind lacking it, it is a desire. Taking away the object of a value cannot result in indifference.

According to Jaworska, there are three features that are strongly indicative of valuing. First, the person thinks that he is correct in wanting what he wants. Loosing one's current values would be considered a mistake – one holds one's values to be correct. Of course, consistency requirements apply here, meaning that one cannot value something and also its opposite at the same time. Second, achieving what one wants is closely linked to one's sense of self-worth: a person often values himself in terms of how well he succeeds in living up to his values. Finally, the importance of achieving what one wants is independent of one's own experience. Values usually do not aim to achieve a positive experience for the holder of the value. Regarding this final point, Jaworska readily admits that values are not necessarily entirely independent of one's experience. In this sense it may be difficult to discern values

from mere desires. However, when something matters to a person regardless of how it would affect their immediate experience, it is more likely a value than a desire. For instance, the wish to be able to experience good wine might be considered a mere desire. However, if upon closer consideration the wish to experience good wine is closely tied up with the wine-lover's sense of self-worth, this wish changes from a mere desire into a value. It is not the inability to enjoy a particular wine at a particular time (the immediate experience) that is bothersome, but the inability to enjoy wine altogether. Taking away the object of this wish – the ability to enjoy good wine – does, in this case, not result in indifference. On the contrary, because this person identifies with the ability to enjoy good wine, it detracts from his sense of self-worth.

From this analysis Jaworska argues that the ability to value consists of the ability to establish principles governing one's actions. Having an interest in doing or having the things we consider to be good in our lives and avoiding the things we consider to be bad, are what these principles are made of. Moreover, Jaworska argues, contrary to Dworkin, that critical interests do not necessarily override experiential interests as long as they are established in terms of values by the valuer.

The above-mentioned features indicating the presence of the ability to value, do not suggest that valuing requires grasping the narrative of one's entire life. An indication of the ability to express a value is that the person seems to have some normative conception of himself as a person, a set of ideals in terms of which his sense of self-worth is shaped. This does not necessarily need to be connected to his past or his future. A value can be relevant for one's sense of self-worth without adding to the entire narrative of one's life. The fact that a demented person is unable to grasp the narrative of his entire life is therefore insufficient ground to deny him all decision-making authority.

According to Jaworska many people suffering from dementia will hold on to the ability to value long after other abilities to bring these values into practice, such as means-ends reasoning and planning, have left them. She contends that the mere ability to shape one's principles as values renders the person capable of at least a basic level of autonomy, and that a lack of skills to bring these values into action is insufficient reason to consider him unable to be autonomous altogether. Dementia often causes people to lose understanding of the world around them, making it difficult or even impossible for them to translate their values into appropriate actions. Imagine a situation in which a person suffering from dementia would be unable to live his life according to his values all on his own, but who would be able to do just that with some help in translating ends into means. Would there be any moral grounds on which to deny him to hold on to this part of his autonomy? Of course, if his set of values were to change by the day due to dementia, it would be impossible to grant him this level of

autonomy. This, however, is not different from how capriciousness in non-demented people poses problems for autonomy.

The features suggesting the existence of the ability to value as well as the claim that valuing is closely connected with the capacity for autonomy, and the contention that means-ends reasoning and planning are mere tools for implementing values are grounds for Jaworska to dispute a solely cognitive framework in general, and Dworkin's approach to this matter in particular.

Jaworska also makes an explicit connection between the ability to value and emotion, claiming that emotional engagement is a constituent part of valuing. Certain convictions regarding what one should value are needed in order to shape one's values. Having such convictions in the first place requires one to attach emotional significance to the object of value. Although this all sounds very familiar to Charland's emotionalist approach, it bears an important difference: while Charland's emotionalist approach merely added something to the cognitive framework, Jaworska's approach is a more critical response to the cognitive framework. The ability to value is quite clearly an enrichment of Appelbaum and Grisso's requirement for the ability to appreciate the nature of the situation and its likely consequences. A little less obvious is its attempt to weaken the requirement for the ability to process information rationally. Whereas Appelbaum and Grisso require that information is processed logically, Jaworska argues that although complicated thought-processes to plan and act autonomously might no longer be within a person's grasp, the ability to value might still be. And to the extent that this ability is still present, one ought not deny a person all decision-making authority.

Despite Jaworska's efforts to describe what 'valuing' consists of, it remains somewhat unclear what kind of expressions would qualify as sufficient to determine that one has the ability to value. And what level of (verbal) communication is necessary to construct one's expressions as constituting a value without too much room for interpretation? If a person is unable to express himself explicitly or without much detail about the decision at hand, what is allowed in terms of interpretation? What level of interpretation is justified and when do we cross a line?

This brings us to a second concern about the level of autonomy that remains in this type of evaluation. As Jaworska readily acknowledges the ability to value cannot be considered sufficient to equal full-blown autonomy, it merely "makes possible the most minimal and basic level of autonomy" (Jaworska, 1999, 130). However, it remains rather unclear how to interpret this minimal and basic level of autonomy, and how it relates to decision-making authority. Imagine a patient suffering from dementia who is still able to show his ability to value his independence related to a dissent regarding a nursing-home

admittance. Despite his difficulties describing a complete account of his reasoning for his dissent, he is still able to express himself about the subject in a manner consistent with what Jaworska calls valuing. Would this be sufficient to leave full decisional authority for this decision with him? If not, what level would be appropriate?

The question is, of course, to what extent these concerns pose a threat for Jaworska's proposal. Looking back at the accusations facing the dominant approach to competence we remember that they, on the one hand, are unable to capture the full extent of competence and, on the other hand, try to measure a profoundly normative notion as if it were an empirical matter. Perhaps letting go of measuring tools based on the dominant approach to competence comes with exactly this trade-off: a richer conception of competence taking into account all relevant elements for decision-making capacity, but leaving some of what is under scrutiny up for interpretation and discussion.

2.4.3 Improvement of Decision-Making Capacity

Yet another alternative view draws attention to the moral knowledge and skills on the one hand and communicative aspects on the other hand involved in competence. According to proponents of this view the main question should not be: "how competent is this person?" but "how can we enable this person in attaining autonomy?" and "how can we advance or develop this persons' competence in exercising autonomy?" (Welie, 2001; Widdershoven and Berghmans, 2002; Benaroyo and Widdershoven, 2004; Maeckelberghe, 2004). According to the proponents of this view competence is not a static property, but a dynamic part of the relationship between the patient and both the people personally close to him and the professional caregivers. In order to assist the patient in maintaining (part of) his autonomy, the focus should be on restoring or developing his ability to make decisions by making him feel more 'at home' in the situation. According to the hermeneutic approach by Benaroyo and Widdershoven, competence is primarily a matter of being able to interpret the world and respond to it: "if a person has the capacity to understand the world and give meaning to the situation, he or she is able to make decision [sic], and is thus competent" (Benaroyo and Widdershoven, 2004, 298). This is what they refer to as "meaning making ability".

Similar to the relational aspect of Benaroyo and Widdershoven's view on competence, Maeckelberghe (2004) asserts, by means of a feminist approach, that the ability to make a decision is not merely the ability of the person making the decision, but it is an ability promoted or reduced by the context in which it is exercised. The ability to exercise "autonomy competency" is not some ability we own, but it is something we develop "over and over again, in dialogue with others" (Maeckelberghe, 2004, 322).

What is of key importance in this alternative take on competence is that it assigns at least a part of the responsibility for promoting competence of the person involved on the people around him. The promotion of meaning-making ability, and through that decision-making capacity, as opposed to determining competence as a matter of fact is the objective of this view.

A possible objection against this approach is that it becomes difficult to distinguish between competent en incompetent people. Isn't almost every person able to "make meaning" to at least some extent, and therefore competent? As with other approaches, due to the normative nature of the concept of competence it is very hard to determine a clear, non-arbitrary distinction between competence and incompetence. That being said, Benaroyo and Widdershoven concur that it is not only possible to determine what is adequate and what is inadequate behaviour in a given situation, it is a vital part of a judgement of competence. According to them the source of knowledge as to what is adequate or inadequate is experience. Following Aristotle, this approach stresses that only experienced people are able to determine what is right and what is wrong in practical matters, explicitly acknowledging that a determination of competence "requires that the evaluator is competent (in the sense of practical rationality) herself" (Benaroyo and Widdershoven, 2004, 300). At first glance, this line of reasoning might seem vulnerable to the objection of inviting unjustified paternalism into determinations of competence. However, the role of the evaluator is later specified as "an *articulator* of perspectives, a *facilitator* of dialogue and a *recaller* of contexts and meaning which are usually obscured and hidden", (Leder, as cited by Benaroyo and Widdershoven, 2004, 301) and explicitly not as someone pointing in the direction of a particular course of action or a particular outcome. The subject of paternalism will be discussed at greater length in Chapter 3.

What this approach achieves is that it forces us to look further than competence as a trait of a person. It draws attention to the process and conditions that surround a determination of competence and integrate this in the requirements of such a determination. Rational and cognitive abilities, as put forward by the dominant approach, are to some extent important, but fail to offer a comprehensive structure for competence. The extent to which a person can be considered competent at least in part depends on factors external to him, notably the context in which a decision is to be made and the capacity of the caregivers around him. As these factors play a significant role in the decision-making process, they should also be part of a determination of competence.

2.4.4 Conclusion

The dominant approach to the criteria of competence appears to suffer from several points of critique. Although the four elements in this approach seem to grasp important parts of decision-making ability, they are unable to offer a comprehensive image of the entire scope surrounding it.

An enrichment of especially the ability to appreciate the nature of the situation and its likely consequences was offered by means of an emotionalist approach and the inclusion of the ability to value. Moreover, the requirement for the ability to manipulate information rationally was slightly weakened by Jaworska's account of the ability to value. Finally, the promotion of decision-making capacity by means of creating a context supportive of this capacity was added. The next chapter will focus on other factors external to the person making a decision that might influence competence.

Chapter 3 | Variable standards of competence

As mentioned in Chapter 2.1, one of the properties of the notion of competence is that it is specific. There is an ongoing debate about whether or not competence is only dependent on abilities or characteristics of the person making a decision or that risk should be added to the equation in one form or another. This chapter is dedicated to an analysis of this debate, an investigation of its concerns, and its applicability in requests for PAD by people suffering from dementia.

3.1 Risk-related standards of competence

Several authors (notably Buchanan and Brock, 1989; Wilks, 1999) have defended the idea that standards for decision-making capacity ought to vary with the risk involved in the choice in question; the higher the risk, the higher the requirements for decision-making capacity and vice versa. Buchanan and Brock for instance argue that a higher level of communication, understanding, and reasoning skills is required to be considered competent if the risk relative to alternatives is greater. Their conception of risk in this assertion is that it is "a function of the severity of the expected harm and the probability of its occurrence" (Buchanan and Brock, 1989, 55). On the same side of the spectrum Wilks (1999) propounds a related but distinctly different view, arguing that higher negative consequences of a decision require a higher level of reliability in performing the task of decision-making, implying a higher level of competence. Buchanan & Brock assume that death is not only invariably harmful, it is considered the most severe harm imaginable (1989, 51). If a person is to make a treatment-decision in which one of the options bears a relatively high risk of death, he will, according to this line of reasoning, be expected to meet a higher standard of competence in order to hold on to his decision-making authority. However, Wilks remains somewhat more implicit about how "negative consequences" should be defined. He argues that the more negative the outcome if one fails to perform particular task, the more important it is to minimize the chances of failure. To increase the reliability at a task, one must demand a higher level of competence. So: the more negative the consequences of failure at a task are, the higher the demands on the required level of reliability, and therefore, the higher the demands on the required level of competence. Wilks adds that negative consequences of failure in his view equal risk. This line of reasoning results in the following principle: "the higher the risk in a task, the higher the standard of competence desirable in the doer of the task" (Wilks, 1999, 156). What "negative consequences of failure" consist of, however, remains unclear.

What these writers have in common is that they claim that the more complex the decisional task at hand, the higher the requirements for the level of decision-making capacity. Unfortunately, it remains rather unclear how this complexity is to be determined and

weighed in considerations about competence. In order to get a better understanding of this strategy, let us take a closer look at the interpretation of risk and harm as described here applied to a person suffering from dementia with a request for PAD.

For the person suffering from dementia with a request for PAD the considerations as put forward by Wilks on the one hand, and Buchanan and Brock on the other hand would raise the bar of competence significantly. The objective of a request for PAD is the termination of one's life, which would be considered the greatest harm imaginable by these proponents of a risk-related standard of competence. The probability of the occurrence of this harm in the case of a granted request for PAD is one hundred percent. Or, if we translate it to the definition of risk as proposed by Buchanan and Brock (risk being a function of the severity of the expected harm and the probability of its occurrence): death (the outcome of the decision) x 100% (the probability of death's occurrence) = highest risk imaginable. Applying this risk-related standard of competence in this type of case would amount to requiring the highest possible level of competence. If risk-related standards of competence of this kind would prove to be the most plausible way of incorporating risk into the equation, this would leave the person suffering from dementia with a request for PAD behind with a very slim chance at having his request taken seriously, let alone granted. But aren't we setting the bar too high? And is such a risk-related standard of competence a plausible one? I will argue that it is not.

3.2 Criticism on risk-related standards of competence

The most frequently pursued line of attack against risk-related standards of competence is the argument that these standards undermine the "principle of symmetrical competence" – the idea that to be competent, one must be competent to decide on a matter either way (Checkland, 2001). This principle finds its origin in the way in which decisional questions are usually framed: the possibilities are to either accept of refuse a specific option, where these possibilities are presented in symmetrical terms (Charland, 2014). For example, in the case of appendicitis, the possibilities are usually to either get an operation or not. The principle of symmetrical competence holds that there is one threshold of competence to be met for the different options. The risk-related standard would in this case apply a higher threshold for refusing the operation (the option bearing a high risk of serious complications and possibly even death) than to complying with the proposal of surgically removing the appendix (the option bearing significantly less risk), creating an asymmetry.

The problem with this asymmetry, as Cale (1999) claims, is that it invites an unjustified imposition of normative values into the assessment of competence in to play. As she claims, this asymmetry seems to suggest that where a patient's values differ from that of

the medical, institutional or societal norms and where the negative risks associated with the patient's preferences are high, these differences possibly render the patient incompetent, *regardless* of the patient's abilities and capacities to decide. It is thus both some property external to the person under assessment (risk), combined with the result of the patient's preferences (outcome) that determines whether or not the person under scrutiny is competent. When the patient conforms to the medical, institutional and/or societal norms he is not nearly as thoroughly scrutinized as when he decides differently from these norms. This type of paternalism is unwarranted according to opponents of risk-related standards of competence.

Another objection to risk-related standards of competence is that the issues of decision-making capacity and decision-making authority are conflated. According to this criticism the question whether or not a person has decision-making capacity should be determined first. The question whether or not the decision should be overruled on paternalistic grounds is a separate issue and should be treated as such (Wicclair, 1999). Proponents of risk-related standards of competence do not adopt this distinction and refute it on that basis. The focus of a risk-related standard lies not merely on capabilities, but incorporates the question of whether or not a person is able to make a particular decision under particular circumstances, thereby including the issue of decisional authority (Berghmans, 2004).

3.3 Responses to the problem of asymmetrical competence

In response to the problem of asymmetrical competence Wilks argues that it need not be as problematic as it appears at first sight. Sound medical decision-making should on the one hand reflect a person's well-entrenched personal values. On the other hand, according to Wilks, it would be reckless to not take irreversibility into account when determining competence. Taking irreversibility into account would reflect the reality of human situations and human choices much more accurately. Asymmetrical competence need not represent the total loss of the autonomy to choose. As Wilks states: "It is rather as if someone says, 'You can either say yes or no. If you say yes we will immediately comply. If you say no we will have to discuss the matter further, and we may comply, or we may not'" (Wilks, 1999, 158). The problem with this defence is that, other than it being reckless not to take risk into account, Wilks does not provide a grounded counter-argument for the problem of asymmetrical competence. He does however make a shift from claiming that risk is the defining element to introducing the outcome as an outset in a determination of incompetence. Perhaps it would shed more light on the issue if we would consider the outset

to be the *outcome* of a decision-making process, rather than the *risk* involved in that decision.

Buchanan and Brock, when addressing the proper role of the evaluator of competence, offer both the start of a counter-argument for the problem of asymmetrical competence as well as a shift in perspective from risk to outcome. They characterize the aim of the evaluator as attempting to detect a sense of *reasonableness* in the decision of the person with questionable competence. Reasonableness in this context means, according to Buchanan and Brock, that the outcome should make sense to the evaluator not in terms of what he or a majority would find reasonable, but in terms of it originating from that particular person's underlying and enduring aims and values. Buchanan and Brock (1989) claim that this is the proper focus of a process-related standard of competence. Note how they imply that adopting an outcome-related standard does not exclude the possibility of a process-related standard. Wijsbek (2000) states it more clearly, arguing that the discussion about process-related versus outcome-related standards of competence is in it self slightly confused. The assumed dichotomy between these standards is, according to him, absent. If there is no decision, the decision-making process seems futile. Or as Wijsbek states: "The outcome of the process is not an independent criterion from that process, but an indispensible part of it: the outcome is the last phase of the process" (Wijsbek, 2000, 84). The distinction commonly propounded between process and outcome in this discussion is therefore unhelpful. Note how this view incorporates the outcome in a process-related standard of competence. Upon further thought, it only makes sense to include the actual decision as part of the process of decision-making, and with that, as part of a process-related standard of competence. According to Wijsbek, making a decision consists of cognitive, affective and volitional elements. Making a reasonable decision consists of a balanced relationship between these elements. Although Wijsbek does not refer to it explicitly, including the outcome of the decision-making process almost inevitably entails including some account of risk. For is the risk of an outcome not necessarily a discerning feature of that outcome? The conception of reasonableness that Wijsbek propounds here is slightly different from Buchanan and Brock's. I will return to the issue of what reasonableness in this context means in greater detail in 3.4. First, I would like to address how these considerations might influence the problem of asymmetrical competence.

Let us return to the example of the patient diagnosed with an appendicitis. There are essentially two options for him in this situation: either to get surgery or not. Outcome one consists of undergoing surgery; the harm consists of moderate inconvenience due to the surgery, and a relatively low chance to die during or after surgery. Outcome two is deciding to not undergo surgery; there is a reasonable chance of severe complications, including

death. According to a process-related standard of competence incorporating the outcome, as mentioned above, either option possibly reflects a competent decision to the extent that it is deemed reasonable. If one's decision-making process and resulting decision are considered reasonable, a determination of competence would be warranted. Both the options of undergoing surgery and of refusing surgery have the potential to be reasonable, depending on the process for reaching that decision. This condition, however, does not result in the disappearance of the asymmetry in a risk-related standard of competence. A judgement of unreasonableness would, under these conditions, lead to a determination of incompetence. While both the options of undergoing surgery and refusing surgery have the potential for reasonability, they both also harbour the potential for a lack of it. This could result in a situation were one would be considered competent to choose one option, and incompetent to choose the other. The question is, of course, how problematic this asymmetry is. As we saw earlier, according to Cale the problem with asymmetrical competence is that it invites an unjustified imposition of normative values into the equation. However, I argue that there are justifiable ways of incorporating normative values into a determination of competence.

3.4 A proposal for a Variable Standard of Competence

In the previous paragraphs both an analysis of risk-related standards of competence, and its objections have been offered. Shifting the focus from the risk to the outcome of a decision-making process in a process-related standard for competence seems a promising way to at least partly counter the objection of asymmetrical competence. As we saw in 3.1, the purpose of adding risk to the equation in determinations of incompetence was to minimize the margin of error in these determinations: the higher the risk in making a decision, the higher the demand on the reliability of the decision-maker to make the decision properly. Could it be possible that the margin of error in determinations of incompetence would be minimized more adequately if the focus would lie on the outcome rather than on the risk? In order to investigate this further, we need to have a better understanding of what "reasonableness" related to the outcome consists of and how it should be operationalized. How are we to define reasonableness? What makes a decision reasonable? And to whom should the decision be reasonable?

Earlier, we saw that according to Buchanan and Brock, for an outcome to be reasonable, it should make sense to the evaluator not in terms of what he or a majority would find reasonable, but in terms of it originating from that particular person's underlying and enduring aims and values. Wijsbek, on the other hand, purported that making a decision consists of cognitive, affective and volitional elements. A balanced relationship between these elements is what makes a decision reasonable. It could be argued that the formation of

enduring aims and values requires cognitive, affective and volitional elements. From that perspective these two views are very similar. But is this all that there is to it? Or do the aims and values themselves have to contain a sense of reasonableness? I believe they do. Reasonableness is not merely built from a reasonable connection between one's aims and values on the one hand and the outcome of one's decision on the other. If the aims and values themselves are entirely foolish, it is hard to detect any sense of reasonableness.

Perhaps it would be helpful to consider another perspective in order to learn more about reasonableness. In an article exploring the "taboo on killing" in relation to performing euthanasia, Den Hartogh (2009) argues that joint decision-making is an important part of dealing with this taboo. Den Hartogh claims that the taboo on killing partially explains the reluctance to perform euthanasia. For a physician to be able to cross the line of terminating one's life there needs to be something which could be described as a "medical friendship" (Den Hartogh, 2009, 166): a close relationship between the patient and the physician which transcends a normal medical relationship. This special relationship allows the physician to surpass the stage where he is a mere means to an end, by playing an active role in confirming the patient's decision to request PAD. At least part of the purpose of this active role is to find reasonableness in the request from the patient. For a physician to be able to perform euthanasia, the request has to be put in terms of reasons intelligible to him. In the case that the aims and values amounting to the request are unintelligible to him, the taboo of killing will be impossible to overcome no matter how logically well-connected these aims and values are to the request. This example related to a request for euthanasia shows how the mechanism of determining reasonableness works. Let us go back to the example of the patient with an appendicitis to see if it is applicable there. What if the patient were to refuse surgery based on the claim that his enduring aims and values entail that life is not worth living without any bodypart that he was born with. His aims and values seem well-connected to his refusal, making it reasonable under some conceptions of reasonableness. However, it would be very hard to call this a reasonable decision, because its underlying aims and values are unintelligible to most. Therefore, reasonableness in the context of a variable standard of competence requires not only that the outcome of the decision-making process is reasonable (in the sense that the outcome is grounded in aims and values), but also that the aims and values on which the outcome is based are reasonable (in the sense that they are intelligible to others) (Bolt and van Summeren, 2014).

In light of this, the notion of "harm" might also deserve some reconsideration. As was mentioned in 3.1, according to Buchanan and Brock, death is invariably harmful. Wilks uses the term "negative consequences" instead. In his writings he appears to assume that the meaning of "negative" in this context is uncontroversial; that we would all agree on what a

negative consequence would be if we would see one. I claim that this is a very arguable assumption. For what would be a negative consequence of failure for one, would not necessarily be a negative consequence for another. Based on Wilks' line of reasoning, however, it would not be contentious to claim that he would consider death a highly negative consequence of failure at a decisional task. In that sense, his views on what a high risk consists of can be considered similar to those upheld by Buchanan and Brock. However, especially when we take reasonableness into account, what is or is not harmful might suddenly change.

When we take a closer look at the Euthanasia Act in the Netherlands, it becomes apparent that at least part of its justification rests on the possibility of having an interest in the termination of one's life. One of the requirements of due care states that the physician needs to ensure that the patient suffers hopelessly and unbearably. Hopeless and unbearable suffering, for the patient, is the basis on which he desires to have his life terminated. The patient considers the prolongation of his life as contrary to his enduring aims and values due to the hopelessness and unbearableness of his suffering. Therefore, if the physician is convinced that the patient desiring euthanasia does so on the grounds that he suffers hopelessly and unbearably in light of his reasonable aims and values, the validity of the request for euthanasia would hence be justified (it goes without saying that all of the other requirements for due care would have to be met as well). More broadly, this line of reasoning allows for the possibility that it can be in one's interest to die. It follows that when the outcome of a decision is (possibly) death, it does not necessarily follow that that is the more harmful outcome for that particular person. Therefore, the conception of harm argued for by proponents of the risk-related standards of competence earlier in this chapter does not warrant a higher threshold for competence on the grounds that the outcome of death invariably consists of the greatest harm imaginable. To the extent that one is able to express a decision that is reasonable both in terms of being grounded in aims and values, and intelligible to an evaluator, the outcome of death does not necessarily equal the highest risk possible. The irreversibility of death, however, does warrant the safeguards (being the intelligibility of the values on which the patient bases his decision) included in the conception of reasonableness offered here.

These considerations would be equally applicable to a situation in which a person suffering from dementia would request for PAD. If the person affected by dementia would be able to express his wish to die and the hopelessness and unbearableness of his suffering in terms of his aims and values, he ought to be taken seriously. An evaluator is to determine both whether or not the content of his aims and values is reasonable, and whether or not the request is reasonable in terms of being grounded in these aims and values.

One might say that this proposal for a process-related standard of competence incorporating the outcome allows for paternalism to come into play again after all of our efforts to eliminate the unjustified paternalism correlated to a risk-related standard of competence. However, I assert that this proposal suggests a suitable way to include a limited amount of paternalism in the highly normative matter of competence determinations. It is simply impossible to exclude all normative content from a determination of competence. Let us not forget that the question of competence comes into play when tension arises between the values of autonomy and of protecting the vulnerable against harm. The question is not: "should we allow paternalism in determinations of competence?", but "how should we balance paternalism and autonomy in determinations of competence in such a way that it does justice to a person's decision-making ability?". This proposal is at the very least a start of the answer to that question.

Chapter 4 | “Embedded Competence”

Despite the obvious differences, all of the alternative takes on competence mentioned in Chapter 2 share an important similarity as well. Contrary to the dominant view on competence, these approaches in a way personalize decision-making capacity. Whereas Appelbaum and Grisso’s approach provides us with a way in which to objectify decision-making capacity (and therefore making it a measurable quality) it does so in a relatively impersonal manner. By contrast, the alternative approaches to competence (by incorporating emotions, the ability to value and the influence of our surroundings) personalize decision-making capacity profoundly. In Chapter 3 it was pointed out that not only properties of the person under scrutiny should be taken into account into determinations of competence, but that the outcome of a decision should also play a particular role. All of these considerations will now be put together in order to create proposal for an “embedded” type of competence; a comprehensive framework for the evaluation of competence including all factors relevant to decision-making.

So what would “embedded competence” (EC) look like? And how would it relate to a request for PAD by a person affected by dementia with questionable competence? These are the questions I will now address.

Since a determination of incompetence attempts to reflect on the ability of a person to make a particular decision, all factors relevant to the process of decision-making should be taken into account. Neglecting to take relevant factors into account results in an incomplete evaluation of decision-making capacity, bearing the risk of infringement upon the values of autonomy and protection against harm. As earlier established, the reality of decision-making is better reflected better by certain alternative and complementary takes on competence, as well as a particular inclusion of the outcome of a decision. My proposal for EC therefore consists of the following elements:

- Enriched criteria for competence. As the mainstream approach to the criteria for competence was unable to include all relevant factors in the process of decision-making, an enriched account seems necessary. Especially the criteria concerning the ability to appreciate the likely consequences of one’s decision, as wel as the ability to manipulate information rationally are to be deepened. As long as one is able to express one’s principles as values, a basic level of autonomy is still within grasp. This ability does not require a grasp of one’s life as a whole or means-ends reasoning. To be able to have principles to begin with, one has to be able to attach emotional significance to different convictions. Emotion, therefore, is a constituent part of the ability to

value. Furthermore, promoting one's decision-making capacity by optimalizing the circumstances under which an evaluation is to take place should be part of an evaluation of competence.

- A variable standard of competence. Including the irreversibility and reasonableness of the outcome of one's decision-making process into an evaluation of incompetence seems both necessary and justified. Since competence is an inescapably normative notion, a regulated inclusion of norms in the evaluation of competence is simply required. Reasonableness in the context of a variable standard of competence requires not only that the outcome of a decision-making process is reasonable (in the sense that the outcome is grounded in aims and values), but also that the aims and values on which the outcome is based are reasonable (in the sense that they are intelligible to others).

This conception of EC immediately points out one very obvious objection, namely that the inclusion of factors in a definition of competence which are hard to objectify causes problems for measurability. How is one to objectify competence if the criteria for it are distinctly subjective and personal? Proponents of these personalized views readily acknowledge that there is no clear cut-off point for the end of competence and the beginning of incompetence. The outcome of a determination of incompetence is therefore never a factual outcome, regardless of whether it was established by means of a more cognitive framework or by this proposal for EC. Related to this observation is the emphasis proponents of personalized views to competence placed on their standpoint that the impersonal and cognitive view on competence fails to measure competence, for it fails to do justice to the every-day reality of decision-making. Therefore, it seems that it is not this conception of EC that causes difficulties for measurability, but that the slippery notion of competence in and of itself is a quality that is impossible to objectify, mostly because of the fact that it is a profoundly normative notion. What the dominant approach to competence creates is a false sense of security about whether or not competence is present.

Failing to provide us with this false sense of security, EC leads us to a second objection; it will most likely demand considerably more effort of the professionals involved in determining incompetence. Compared to relatively straightforward measuring tools like the MacCAT-T, it will probably take more time and possibly more experience to perform a determination of incompetence by means of EC. Repeated conversations with the person suffering from are required to establish their ability to value. Moreover, during both the preparation for the conversation and the conversation itself, a comfortable and safe environment needs to be created in order to optimize the demented person's ability to value.

This requires an effort from both the person's loved ones and the professionals involved in his day-to-day care. With this in mind, I acknowledge that EC is likely to result in a considerably larger effort on the part of the professionals involved. The question that should be answered at this point is whether this increase in effort is justifiable in light of the likely results yielded. The proposal for EC, by not feeding a false sense of security as to whether competence is present or not, provides us with a more accurate way of determining whether or not someone is competent, resulting in a more adequate protection of the highly appreciated value of autonomy. Because EC does much more justice to the way in which people actually reach decisions, it protects autonomy and with that decision-making authority on the one hand, and safeguards against wrongful determination of competence, thereby protecting the incompetent against harm inflicted through their incompetent decisions. In other words, by broadening the conception of competence, the margin of error is significantly diminished. Both the value of autonomy and the value of protection against harm are more adequately protected.

The next question in need of an answer is: How does this conclusion relate to the requirement of competence in a request for PAD? In other words: is the proposed framework of EC of any use in cases of people suffering from dementia requesting PAD?

One of the reasons to oppose PAD in general is that it is thought that there is always a risk of wrongful termination of life (Den Hartogh, 2000). This is an even more poignant worry in PAD in cases involving people suffering from dementia. How is one to be sure that PAD does not take place against a person's will? We claim that this proposal for EC supplies sufficient safeguards to prevent this from happening. Imagine a person suffering from dementia displaying the ability to value by repeatedly and somewhat consistently expressing his wish to die by means of PAD. The irreversibility of the outcome of PAD provides safeguards in that it requires the evaluator to investigate if there is a sense of reasonableness in both the connection between the request and the person's aims and values, and in the content of the aims and values on which the request is based. If this is the case, there appears to be little reason not to take the request for PAD seriously. Obviously, this does not necessarily mean that the request meets the other requirements of due care; those need to be addressed separately and sufficiently as well. It is only when all requirements of due care are met, that the request for PAD is warranted. Note that this means that at this point there is no difference between those affected by dementia, and those who are not; if a person cannot be regarded as incompetent by means of EC, the request for PAD cannot be deemed invalid on the basis of a lack of competence. EC merely broadens the scope of competence.

What happens however in case of “false-positives” and “false-negatives”[2]? The development of the proposal for EC was mainly motivated by the wish to decrease the number of false-positives (erroneous establishments of incompetence) so that the number of people whose autonomy is infringed upon (in relation to a request for PAD) will be minimized. Certainly, EC cannot guarantee a perfect outcome in this respect. However, I do think that by broadening the scope of competence by means of EC, the result will be that people will less often be wrongfully releaved of their decision-making authority in relation to a request for PAD. All the elements important in the decision-making process are reviewed within this framework. This results in a more adequate understanding of a specific person’s abilities in decision-making. Although this method is both more adequate and precise, it does not guarantee a perfect outcome. The group of people erroneously found to be incompetent, however, does not affect the possibility of wrongful termination of life, as they are (wrongfully) excluded from their request for PAD being taken seriously. In other words, in this group of false-positives no lives are wrongfully terminated by performing PAD.

At first glance, wrongful termination of life could pose a problem in the group with false-negatives (erroneous lack of establishment of incompetence). An incompetent person erroneously determined not to be incompetent could be the victim of wrongful termination of his life, for he is in fact unable to make autonomous decisions and should therefore have been protected against this harm. Upon closer reflection however, this sequence of events seems very unlikely. In order for a request for PAD to be taken seriously, regardless of the question of competence, the request needs to be made repeatedly and somewhat consistently by the person requesting it. Repeatedly, as both the first and the second physician will frequently ask whether or not the patients’ request for PAD in adequetly reflects his true wish. Consistently, because capriciousness, whether present in a person afflicted by dementia or any other person, is hard to tolerate when the outcome is death. People lacking the ability to value, despite efforts to make them feel more ‘at home’ in the situation, will not repeatedly and somewhat consistently request PAD. The mere fact that one repeatedly and consistently requests PAD at the very least suggests the presence of the ability to value one’s life as no longer worth living; it requires one to attach emotional significance to the value of one’s life. Therefore, a person falsely determined to be competent

[2] EC attempts to determine a patient’s incompetence. Therefore a positive outcome is an outcome of incompetence and a negative outcome is an outcome of competence. Consequently, a “false positive” is an erroneous establishment of incompetence and a “false negative” is an erroneous establishment of competence.

does not run the risk of his life being terminated wrongfully, for he will not be able to request PAD in the manner required both morally and by Dutch law.

Conclusion

In the previous chapters I have identified several problems with the dominant approach to competence, in particular the approach developed by Appelbaum and Grisso. This framework is not only the current dominant framework in general when it comes to determinations of incompetence, it also forms the basis of the Dutch guidelines for physicians to evaluate decision-making ability. Therefore, these problems apply to the Dutch professional standards regarding the subject as well.

Summarizing, the identified problems with Appelbaum and Grisso's framework are the following. Firstly, this framework fails to do justice to the process of decision-making as it occurs in reality by using a conception of competence that is defined too narrowly; the framework highly emphasizes a cognitive approach in decision-making. Moreover, because of this emphasis discrimination against the mentally ill poses a danger. The framework by Appelbaum and Grisso neglects three key components which are of vital importance to the process of decision-making: the inclusion of emotion, the ability to value and the importance of supporting factors in the environment of the person making a decision. Secondly, opponents claim that measuring-tools, like the one developed by Appelbaum and Grisso, fail to measure competence altogether. What they measure instead are properties such as memory and the ability to reproduce information. Finally, the use of measuring-tools, although at first sight very convenient for professionals, suggests that it is possible to objectify the deeply moral notion of competence.

After an exploration of alternative and complementary takes on competence, several elements of these alternative views were combined in a framework of Embedded Competence in order to address the problems encountered by the dominant approach. Personalizing and individualizing the concept of competence by emphasizing the ability to value (of which the ability to have an emotional attachment to particular aspects of life is an inherent part) and the role of a person's surroundings in the course of a determination of competence more adequately reflect the elements contributing to the process of decision-making. Although this framework clearly represents a process-related standard of competence, I argued that it would be justified to also take into account the outcome of the decision-making process in the determination of competence. As long as the outcome of a decision-making process is logically related to the aims and values that a person professes, and the aims and values themselves are intelligible to others, it confirms a person's competence without leaving too much room for unjustified paternalism. Demanding a relation between the outcome on the one hand, and aims and values on the other leaves little room for interpretation, and with that paternalism exhibited by the evaluator of competence. Consequently, EC is more likely to protect one's autonomy, diminishing the chances to a

false positive outcome of a determination of incompetence. Addressing the cognitive abilities relevant for competence (i.e. the abilities necessary for valuing) might lower the bar for reaching the threshold for competence. This might create a window of opportunity for those who fall short of the more narrow conception of competence offered by Appelbaum and Grisso, for instance in cases comparable to the one described in 1.2. As we saw there the expressions by the person requesting PAD were of such a level that different physicians drew different conclusions about the competence of that person about the request for PAD. Applying EC in such a case would possibly yield a conclusion contrary to a conclusion based on a less comprehensive framework, while at the same time serving to protect both the values of autonomy and pretection against harm more adequately. Whilst exploring the applicability of EC to requests for PAD by people suffering from dementia, I argued that it contains sufficient safeguards to prevent both false positives and false negatives. People in need of protection against harm possibly inflicted by their decisions (on the grounds that they are incompetent to make these decisions) are extremely unlikely to become the victims of a wrongful life termination. A request for PAD involves at least a repeated and somewhat consistent wish to have one's life terminated. This requires one to attach personal meaning to one's life, to value one's life as no longer worth living. A lack of this ability to value would invariably amount to being unable to express any such wish at all. The mere expression of a request for PAD at the very least suggests an ability to attribute personal meaning to the wish to die. As long as this wish is expressed in terms of personal aims and values that are intelligible to others, one is entitled to at least being taken seriously in this request.

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