

## Chapter 5

### Substituted Decision Making

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A core principle of medical ethics states that patients should be allowed to determine whether they wish to accept or refuse treatment, if they possess the relevant decision making capacity at the time treatment decisions need to be made. In cases where patients lack capacity to make decisions regarding their own treatment, substitute decision makers must make such decisions for them. This chapter begins with explication of criteria for decision making capacity and decision making incapacity. It then outlines the main standards of substituted decision making in the legal context: the *Substituted Judgment Standard* and the *Best Interests Standard*. It then discusses the moral groundings of these standards. The moral groundings are commonly understood to be two of the cornerstones of medical ethics: the principle of respect for patients' autonomy and the principle of beneficence respectively. It then discusses how these standards apply to the formerly capacitated patient and the never-capacitated patient. It finally discusses conceptual, metaphysical, and moral challenges of substituted decision making. The chapter concludes with a summary of the most pressing issues of the contemporary debate on substitute decision making, and suggestions for fruitful future research focus.

#### Decision Making Capacity and Decision Making Incapacity

Understanding of the contemporary debate on substituted decision making requires understanding of the core concepts “decision making capacity” and “decision making incapacity.”

What sense of “decision making incapacity” motivates replacement of the patient's decision with the decision of a substitute decision maker? In England and Wales, the Mental

Capacity Act of 2005 serves as the guiding legal document for assessment of mental capacity. I will first outline the criteria for decision making capacity in British legislation on substituted decision making because the British legislation is one (although not the only) representative example of a legislation that implements what could defensibly be regarded as an interpretation of the most influential standards of decision making capacity. These standards, and their similarities with the Mental Capacity Act, are explicated below. We will focus on the sections of the Mental Capacity Act that cover capacity to consent to medical treatment. According to the Mental Capacity Act, sections 2(1) and 3(1), an individual is incapacitated if she fails to satisfy any of its criteria for mental capacity. The Mental Capacity Act's criteria for mental capacity are capacity to: (1) understand the information provided, (2) retain the information provided, (3) use the information provided, and (4) weigh and communicate the information provided.<sup>1</sup> Another major collection of guidelines for assessment of decision making capacity is the MacCAT-T standard.<sup>2</sup> The MacCAT-T standard is based on the most influential theory of decision making capacity to date, introduced by Grisso and Appelbaum.<sup>3</sup> There is rough agreement that a sound theory of decision making capacity should include certain elements, which are interpreted in the MacCAT-T standard as follows: (1) Choice: this criterion refers to the capacity to "express" or "communicate" a choice. Capacity to express or communicate one's choice is necessary because if a subject cannot express her preferences it is not possible to know her decision<sup>4</sup> (2) Understanding: In order to be capable of giving consent to treatment, an individual must understand the relevant facts related to the intervention. According to Grisso and Appelbaums interpretation, "comprehension" and "knowledge" of relevant facts are minimal requirements for understanding.<sup>5</sup> However, the requirement of "understanding" can be very complex depending on how it is being interpreted.<sup>6</sup> (3) Appreciation: The requirement of appreciation means that the patient must also have some appreciation of the decision's significance for the patient.<sup>7</sup> The facts and their

implications for the individual must *mean something* to her. A minimal interpretation of this requirement states that the patient not only comprehends the information but also believes that the information applies to her.<sup>8</sup> If a patient suffering from dementia is able to grasp that her doctors wish to amputate her feet because she faces a significant risk of dying otherwise, yet talks about what she will do once her feet are healed, she does not have “insight” in the required sense.<sup>9</sup> (4) Reasoning: Ability to reason is necessary in order for the individual to understand and appreciate in the aforementioned senses.<sup>10 11</sup> Theorists disagree regarding the extent of overlap between the Mental Capacity Act and The MacCAT-T. Some hold that the two models are, in practice, the same. They consider “using” to be similar to “appreciation” because one does not use information without fully accepting it. “Weighing” has been considered similar to “reasoning” (this is commonly understood as capacity to “weigh and compare options”). However, there is no consensus to date.<sup>12</sup>

Let us assess five commonly accepted requirements of a sound account of decision making capacity.

*Inclusivity* requires that most “ordinary” adults are considered as having decision making capacity.<sup>13 14</sup> Lack of inclusiveness is commonly regarded as a feature that should lead us to reject an account of decision making capacity.<sup>15</sup> *Decision relativity* requires that the relevant incapacity is incapacity regarding the specific treatment decision at hand. Incapacities that do not affect the patient’s capacity to make decisions regarding the treatment are not relevant when the need for substituted decision making is being considered. Allen Buchanan and Dan Brock hold that “competence is competence *for some task*, competence *to do something*”<sup>16</sup> They then specify their own focus, which is “competence *to make a decision*”<sup>17</sup>

*All-or-nothing assessment* requires that the patient be judged to either have decision making capacity or not. Although capacity can occur in degrees, for practical purposes we

must be able to determine whether she is capable to decide or not. *Value neutrality* requires that patients not be judged incompetent simply because they make unorthodox or controversial choices.<sup>18</sup> *Independence from diagnosis* requires that the patient should not be regarded as incapacitated simply because she has received a certain diagnosis. Finally, some theorists have advanced an additional requirement, which is not as commonly accepted as the previous five. Theorists have argued that there might be an asymmetry between capacity to consent to treatment and capacity to refuse treatment. This could be considered as a sixth, although more controversial, desideratum. We might want to apply more demanding criteria of decision making capacity for refusal of treatment because the consequences of refusal are potentially more grave for the patient.

Although virtually all theorists agree that something like the features discussed above in relation to the Mental Capacity Act and the Mac-CAT-T are *necessary* for possession of decision making capacity, there is an ongoing debate regarding whether these features are also *sufficient*. Theorists have argued that the criteria for decision making capacity fail to acknowledge how emotions, for example, those associated with depression, affect decision making capacity. Others criticize the criteria for failing to distinguish between those of the patient's values that are sound and those that are arguably not. Examples of values that arguably are unsound is the extreme value anorexics put on being thin. Patients diagnosed with anorexia have been deemed as possessing decision capacity in the light of the criteria of the MacCAT-T standard.<sup>19 20 21</sup> Hawkins and Charland explain how the standards of decision making capacity of the Mental Capacity Act and Mac-CAT-T are supposed to relate to the desiderata just discussed. We noted that the standards of the Mental Capacity Act and Mac-CAT-T are based on the desiderata, and that the desiderata are based on the 1998 theory of Grisso and Appelbaum. The adequacy of any set of standards for assessing decision making capacity and decision making incapacity, and the theory these standards rely on, depend on

whether the standards and the theory capture paradigmatic examples of decision making capacity and incapacity. “Thus, in the initial instance, a theory is built around a selection of paradigm examples of what capacity and incapacity should be taken to be.”<sup>22</sup> Many people would regard the desire for extreme thin-ness to be a paradigmatic example of a desire that should lead us to regard the anorectic as lacking decision making capacity. Still, the anorectics in the aforementioned study did satisfy the standard criteria for decision making capacity. This is an example of possible discrepancy between the standards for decision making capacity and what could be regarded as a paradigmatic example of decision making incapacity.

Suppose we have agreed regarding the criteria for decision making incapacity. Once we have identified a case where substituted decision is needed, we must sort out what standards should guide the substituted decision makers.

#### The Substituted Judgment Standard and the Best Interests Standard

In the legal setting, two general standards are regarded as the main approaches for determining how some instance of substitute decision making ought to be conducted.

The Substituted Judgment Standard states that the substitute decision maker should strive to reconstruct the decisions the patient herself would have made in the present circumstances, had she been capable of deciding.

Let us explore the moral origins of the Substituted Judgment Standard. It is common to hold that substituted judgment is justified as a means of respecting the patient’s autonomy. If healthcare professionals are required to respect patients’ (sufficiently) autonomous, informed decisions, it might be defensible to suggest that they should aim at showing implicit respect for incapacitated patients’ autonomy by trying to reconstruct the choices of patients who are disabled by, for example, dementia, severe mental disorders or neonatal conditions. What sense of “autonomy” do defenders of the principle of respect for autonomy refer to?

According to one interpretation, autonomy should be understood as a second order capacity. This interpretation of the concept of autonomy requires understanding of the relation between “first order” and “second order” preferences. Autonomy understood as a second order capacity is the capacity to reflect over one’s “first order” preferences and the capacity to make reflective choices between the courses of action available.<sup>23</sup> An example of a “first order” preference might be a preference to smoke. A “second order” preference might be a preference not to smoke, all things considered. Autonomy understood as a second order capacity is a capacity to reflect over whether the first order preference should guide the agent’s choice whether or not to perform a certain act, for instance, smoke. This understanding of personal autonomy is subject to the challenge of regression: theorists have pointed out that even the second or third order of a preference could require further critical scrutiny. How do we know when we have exposed our preferences to a sufficient amount of critical scrutiny? Another challenge to this interpretation of “autonomy” is that reflection on our first order preferences might distort our preferences rather than reveal our most “authentic” preferences. Explaining to one’s partner that one has scrutinized one’s commitment to the relationship might damage the relationship, even in cases where the examination reveals a deeper commitment than previously assumed by the person who scrutinized it.<sup>24</sup>

Another interpretation holds that an agent is acting autonomously when her current or long-term views about which actions are worth performing guide her actions.<sup>25</sup> Other interpretations claim that in order for the agent to be acting autonomously, there must, in addition, be harmony between the agent’s actions and the agent’s long-term plans.<sup>26 27</sup> Yet others refer to a stable set of emotional states,<sup>28 29 30 31</sup> or to the agent’s character traits<sup>32</sup> or to her most thoroughly integrated states.<sup>33</sup>

All these accounts of personal autonomy agree that an action cannot be “attributed to” the agent if she “distances” herself from the action while she performs it. More precisely, according to Buss and Westlund, accounts of personal autonomy that hold autonomous agents to be “constrained by plans,” or “by well-integrated emotions,” or “traits of character” assert that an agent’s “point of view” is not “a function of whatever mental state(s) she happens to be in at some point in time.” Hence, “it is reasonable to think that her stance toward her motives is determined by her long-term values and/or her relatively stable commitments and cares.”<sup>34</sup>

The second main legal standard for substituted decision making is the Best Interests Standard, according to which the substitute decision makers should ground their decision on a prognosis of what treatment would best accommodate the patient’s interests, broadly conceived.

The Best Interests Standard can be morally justified by reference to The Principle of Beneficence, discussed by Beauchamp and Childress in their classic work *Principles of Biomedical Ethics*. Philosophers have developed numerous accounts of what “benefiting” someone amounts to.

The legal standard of best interests presumes a generic conception of interests, focusing on what a ‘reasonable’ person would prefer under these specific circumstances. Such preferences include freedom from pain, being comfortable, and having ones capacities restored. The Best Interests Standard has mostly been used when very limited or no information about the patient's idiosyncratic values and preferences are available. However, as Jaworska has pointed out, “There is no reason why, in principle, the Best Interests judgment could not be as nuanced and individual as the best theory of well-being dictates.”<sup>35</sup> According to Jaworska, retreating to considering only “generic” interests is necessary when the patient has never been capacitated. In such cases, there is no information available that

could guide the substituted decision makers towards a more idiosyncratic understanding of the patient's best interests.<sup>36</sup>

The claim that even unconscious individuals can have interests while they are unconscious, so that it makes sense to talk about what treatment would be in their best interests, has commonly been regarded as uncontroversial. However, recent contributions problematize this claim on the grounds that there is remaining un-clarity regarding what it actually means for an unconscious person to have interests while she is unconscious. Following Hawkins (2014), they argue that the most convincing interpretation of the claim is that an individual can have interests while she is temporarily unconscious if she would have certain actual interests if she were conscious, or will have certain interests once she regains consciousness. Notably, even individuals who have never been conscious satisfy these criteria, if they will be conscious in the future.<sup>37</sup>

The requirement to obtain a capacitated patient's informed consent to treatment has commonly been regarded as supported by the principle of respect for autonomy. We saw that substituted decision making has been regarded as a way of indirectly respecting the incapacitated patient's autonomy. It is, however, important to note that recent contributions to the legal and philosophical literature on substituted decision making argue that the standards of decision making capacity and the standards of autonomy have been run together in the Mental Capacity Act and that these standards should be regarded as separate. Obtaining the patient's informed and un-coerced consent does not in itself guarantee that the patient has reflected on the decision at hand. English and Welsh law include requirements that could partly avoid this problem: they require that the capacitated patient not only give her un-coerced consent after receiving the relevant medical information, but that she has also understood and reflected on the information. Lewis<sup>38</sup> argues that an individual may possess mental capacity, which is necessary but insufficient to possess autonomy, and possess full



medical information while being un-coerced by medical staff. Nevertheless, she might be vulnerable due to coercion or dependency for care from individuals other than medical staff. She is then capable of making decisions regarding her treatment, yet she is not autonomous. These individuals have been classified as capacitated vulnerable patients. In such cases, courts have authorized substitute decision makers to make decisions on these individuals' behalf, attempting to eliminate the vulnerability. According to Lewis, the current use of substituted decision making to alleviate the vulnerability of such patients is objectionable because depriving a capacitated yet vulnerable patient of decision making authority arguably conflicts with the requirement to respect her freedom to exercise her capacity for autonomous choice. To avoid such conflicts, Lewis recommends that the capacitated vulnerable patient be given decision making authority, with support, whenever possible.

“Clinicians offering treatment options and describing probable benefits and potential harms. On the other hand, patients are required to communicate their values and preferences.”<sup>39</sup>

Having a clear map of the available standards that might guide substituted decision making, we are equipped to discuss what method of substituted decision making is most suitable for different categories of patients.

#### To Whom do the Standards Apply?

Substituted decision making applies to formerly capacitated patients and never capacitated patients.

Formerly capacitated patients are patients who were previously capacitated but have lost their relevant decision making capacities. Examples include patients suffering from dementia and patients who have suffered serious strokes. The substituted judgment standard is commonly regarded as suitable for this category of patients. Formerly capacitated patients

may have formulated explicit, written preferences regarding their treatment in the event they become incapacitated. Written instructions regarding the patient's treatment preferences in case of future incapacitation are called advance directives.

Never capacitated patients are patients who have never possessed the relevant decision making capacity. Examples include infants and patients who are born with severe cognitive disability. As these patients have never expressed any preferences regarding their treatment, the best interest standard is commonly regarded as the only option for this category of patients. However, if we accept the previously mentioned suggestion that temporarily unconscious patients can have interests in the sense that they would have some actual interests if they would be conscious, we are equally entitled to say that they would be capable of making certain choices if they were capacitated. If this claim is accurate, unconscious patients could be viewed as possessing "dispositional" capacity for making choices. The substituted judgment standard could then be applied even to patients who have never been conscious: the substituted decision maker could attempt to reconstruct what choices the patient would make if she were capacitated. The challenges of this view are epistemological challenges, but the view is coherent.<sup>40</sup>

The Substituted Judgment Standard and the Best Interests Standard, as well as the moral groundings of these standards, support a major account of how these standards apply to the previously capacitated patient and the never-capacitated patient. The "orthodox view," defended by Brock<sup>41</sup> states:

1. Respect a written instruction ("advance directive") regarding the patient's preferences regarding her treatment, should she become incapacitated, whenever a directive is available.

2. If the patient never wrote an advance directive, apply the Substituted Judgment Standard, relying on available information about the patient's past decisions and expressed values.
3. If medical staff are unable to apply the Substituted Judgment Standard because the patient has never been capacitated or because information about the patient's former decisions and values is unavailable, they should use the Best Interests Standard.

While the “orthodox view” appears to picture the patient and the medical staff as the only parties involved in the substituted decision, recent contributions to the literature emphasize the importance of acknowledging the views of other individuals affected by the decision. Feminist critiques of standard conceptions of autonomy also emphasize the importance of sound relations to maintain a capacity for autonomy. “Relational” conceptions of autonomy analyze how “internalized oppression” and “oppressive social conditions” adversely affect autonomy.<sup>42</sup>

The claim to the effect that the standard of substituted judgment is preferable whenever a patient previously expressed views regarding her treatment in case she becomes incapacitated is challengeable in numerous ways.

#### Challenging the “Orthodox” View

The view that advance directives and the Substituted Judgment Standard should be applied whenever the patient has previously been capacitated does not take into consideration that the ‘earlier capacitated self’s’ interests and ‘the current incapacitated self’s’ interests might conflict. A patient’s loss of decision making capacity can be permanent but less radical, and ‘the current incapacitated patient’ might now have new interests that differ from the interests she had while she possessed decision making capacity. While capacitated, she might have valued her intellect highly and expressed wishes not to be treated for life-threatening conditions should she become cognitively disabled. However, once her cognitive impairment

progresses, new interests emerge. For example, she now clearly enjoys gardening and music and clearly expresses a will to live. How ought the interests of the earlier and current self be balanced in substituted decision making? According to one interpretation of this conflict, “the conflict is between the autonomy of the earlier self and the well-being of the current self. Alternatively, “the interests of the earlier self are well-being interests” The conflict, then, is between the well-being of the earlier self and the well-being of the current self. The discussion below applies to any of these interpretations.<sup>43</sup>

We could defend prioritizing the views of ‘the former self’ by pointing to some kind of *authority* that the former self might have over ‘the current self.’ The reasons for this authority are spelled out differently by different theoretical accounts. The basic idea is that the ‘former self’s’ superior abilities give her authority to control ‘the current self.’ Once ‘the current self’ drops below a certain threshold of capacity, her interests are so marginal that the ‘former self’s’ interests should be given priority.<sup>44</sup>

The most imposing challenge to this view is that the surrogate must make the best decision for the patient *as the patient currently is* about how to manage the patient's life from now on. How are the patient’s previous interest relevant for the current decision regarding her treatment?<sup>45</sup>

A defender of the aforementioned “threshold view” would respond as follows: First, one can satisfy past interests in the present. Ronald Dworkin makes a distinction between “experiential” and “critical” interests.<sup>46</sup> (Experiential interests are interests in experiences of enjoyment and interests in avoiding undesired experiences such as irritation. Such interests are clearly grounded in the present. Critical interests do not depend on the experience of their satisfaction. Critical interests are interests in having what one values or cares about being realized. According to Dworkin, it is justified to satisfy a previously capacitated individual’s critical interests.

Second, the past critical interests are still her interests in the present, even if she can no longer take an interest in them. Dworkin offers a convincing argument to the effect that satisfying “past” interests can still matter in the present.

Other challenges to the “orthodox view” refer to assumptions about criteria for personal identity. Drastic alterations of one’s psychology due to for instance Alzheimer’s disease implies that the individual does not survive. Hence, any interests “one’s predecessor in one’s body” might have had are not a proper ground for decisions on behalf of “the new individual” who subsequently emerged.<sup>47</sup> The lack of identity between “the earlier and current self” undermines the authority of the earlier self.

Other objections to the orthodox view refer to criteria for prudential concern for one’s future self. One can claim that because the psychological connections between “the two selves” is so weak, this fact undercuts any authority the former self might have over the current self. We can accept this while also accepting that the changes occur in one individual who persists over time: the former and present selves are not numerically different.<sup>48</sup> Jaworska (2009), referring to McMahan<sup>49</sup> points out that we are still able to challenge “the continuity of interest between the earlier and current self” by scrutinizing the “concern the earlier and current self would appropriately have for one another.”

This chapter outlined major themes and issues in the contemporary debate on substituted decision making. The most influential demarcation of subjects deemed “incapacitated” in legal terms is subject to challenge. The assumption that informed consent should be justified by reference to the principle of respect for autonomy is a major topic of debate. Relatedly, patients who are capacitated according to the legal standards, yet vulnerable to coercion and manipulation may be subject to either excessive coercion or left unsupported by the current legal framework. A growing body of literature, inspired by so-

called “relational” conceptions of autonomy, emphasizes the importance of relations for the maintenance of the capacity for autonomy.

Arguably, these are the issues that scholars have identified as the core areas of focus within the interdisciplinary field of research on substituted decision making.

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<sup>15</sup> Hawkins, Jennifer and Louis C. Charland

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