

SUBSTITUTED DECISION MAKING AND THE DISPOSITIONAL CHOICE ACCOUNT

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1. INTRODUCTION

Medical ethicists commonly hold that patients should be allowed to decide whether to accept or refuse treatment if they possess the relevant decision-making capacity when treatment decisions are made. If patients are not sufficiently capable of making such decisions, appointed surrogates might decide on behalf of them. Clinical decisions involving patients with severe mental disorders, drug addiction, dementia, intellectual disability, or very young patients, often involve uncertainty with regards to decisional competence. Comatose patients at the intensive care units are examples of patients who entirely lack decisional competence.

According to **The Best Interests Standard**, the surrogates should base their decision on what treatment would best accommodate the patient's interests, broadly conceived. This standard is justified by the principle of beneficence. According to one influential interpretation of The Best Interests Standard, this standard assumes a generic view of interests: the interests a "reasonable" person would have under the circumstances. Examples are absence of pain and restoration and/or development of the patient's physical and mental abilities.(1) There are, however, numerous interpretations and applications of this standard. We will consider these below.

According to **The Substituted Judgment Standard**, the surrogates should attempt to reconstruct the decisions the patient herself would have made, if she were capable, in the circumstances at hand. In order for this standard to be applicable, these circumstances must be carefully specified. This standard is commonly justified by the principle of respect for autonomy.(2) It has been suggested that when patients are incapable of making the relevant

decisions, their autonomy can still be indirectly respected by reconstruction, to the greatest possible extent, of the autonomous decisions they would have made if they had been able to make decisions.(1)

It is common to hold that the Substituted Judgment Standard is only applicable to patients who have previously had the relevant decision-making capacity.(3) We will explore whether there are alternatives to the frequently applied Best Interests Standard regarding decisions involving those who never had a decision-making capacity (e.g. newborns) or where the decisional competence of the patient is entirely absent or has been low for a long time (e.g. due to coma, dementia, or severe mental disorder).(4)

Section 2 clarifies the term “autonomy.” Section 3 argues that the Best Interests Standard is difficult to apply to unconscious patients, regardless of whether they have ever been conscious. Section 4 argues that if we accept what we consider to be the *least* puzzling explanation of how unconscious patients can have interests, we are also obliged to accept that the Substituted Judgment Standard can be coherently applied to patients while they are unconscious, even if they have never been conscious. Section 5 discusses the clinical relevance of the account.

Theorists who believe that The Substituted Judgment Standard should be applied whenever it is possible to do so should welcome our proposal. It may also help substituted decision makers to systematically assess their motives for choosing a certain treatment; and it is theoretically interesting since it shows that The Substituted Judgment Standard coherently applies to cases where the subject never has been conscious.

2. THE PLACE OF AUTONOMY IN MEDICAL ETHICS

“Autonomy” is a key concept in our argument, so it is essential to be very clear about its

meaning, and its relevance for the Substituted Judgment Standard. We outline possible moral justifications for the Substituted Judgment Standard, describe our chosen justification's place on this normative map, and describe its normative appeal. By "autonomy," we here mean "second order autonomy:" the ability to make reflective choices between one's available courses of action and the ability to reflect over one's preferences.(5) This conception emphasizes the "authenticity" of one's choices. Authenticity in this sense refers to the person's "second order identification with first order desires."(6) That is, she endorses only desires that survive her own critical scrutiny. Such ability occurs in degrees, and may also vary depending on the context and what types of choices people face. Given the myriad of interesting conceptions of autonomy and their potential relevance for The Substituted Judgment Standard, we choose to focus our attention on second order autonomy. We focus entirely on so-called personal autonomy, which can be exercised regarding all areas of one's life and that does not only concern the source of moral obligation in the Kantian sense.(7) In virtue of having this capacity for second order autonomy, patients are commonly regarded as possessors of certain rights to self-governance against health care professionals. Such a right could be understood as "a barrier to unchecked paternalism."(6,8) These rights are, according to Feinberg, "a set of rights expressive of one's sovereignty over oneself."(9) These rights protect "the independence of one's deliberation and choice from manipulation by others."(6) Christman suggests: "Autonomy is the ability to decide, so for the autonomous subject of such interventions paternalism involves a lack of respect for autonomy."(6) Seana Shiffrin suggests that respect for autonomy in this sense is appealing because she takes the value of having "basic control" and "self-direction" over one's experiences to be important.(10) This principle of respect for autonomy is relevant for the question of the moral basis of the Substituted Judgment Standard. If health care 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 patients with, e.g., dementia, severe mental disorders, drug addiction or neonatal conditions would have made under the circumstances at hand, had they been competent. Beauchamp and Childress, in their influential *Principles of Biomedical Ethics*, emphasize that the value of autonomy does not override all other moral considerations involved in substituted decision making.(11) They recommend the use of reflective equilibrium in order to adequately consider the moral values at stake in clinical decisions. We do not attempt to establish that ethical principles always outplay pragmatic clinical judgement in difficult decisions. We neither attempt to say that the value of autonomy is *the only* potential moral basis for the Substituted Judgment Standard, or that the value of autonomy always trumps all other moral considerations. Rather, we suggest that the value of autonomy is *one* interesting candidate for a moral basis. Norman Cantor, for instance, emphasizes clearly that he considers substituted decision making to be a tool for respecting the previously autonomous patient's exercise of her capacity for self-determination:

“Every jurisdiction that has spoken to end-of-life surrogate decision-making has upheld a formerly competent patient's prerogative to shape post-competence care either by advance medical directive or other prior expressions. [...] All this reliance on prior expressions and previously formed values seeks to honor the previously competent patient's autonomy or self-determination.”(2)

Agnieszka Jaworska makes similar points. However, she suggests that autonomy is *the* moral basis of the Substituted Judgment Standard.(1) She suggests that the value of autonomy should be considered as trumping considerations of beneficence in the circumstances at hand.(1)

Alternatively, clinicians' obligation to collect informed consent could be justified by referring to some moral theory about a social contract. Use of The Substituted Judgment Standard could be justified on the basis of some moral theory about hypothetical contract in situations where the patient is incapacitated.⁽¹²⁾ According to this idea, using substituted judgment is justified because the patient would have consented to certain treatment under idealized conditions, i.e., had she been competent.

2.1. WHO NEEDS SUBSTITUTED DECISIONS?

Substituted decision making applies to two types of incapacitated patients.

Formerly competent patients are patients who used to have the relevant decision-making capacity but lost it. We will focus on temporarily unconscious adults who will regain consciousness if properly treated, nourished, and protected.

Never Competent patients *are* patients who have never had the relevant decision-making capacity. We will focus on patients who will develop such a capacity. Illustrative examples include very young children. Much is at stake in many of the decisions in, e.g., neonatal intensive care units. Extremely premature babies may need respiratory support and other types of advanced care. Sometimes the medical condition is so severe that the question on whether to prolong intensive care is better than withdrawing care may rise. The outcome if care is continued is uncertain, but in many cases there is a high risk that the neonate will get severe multihandicaps like cerebral palsy or blindness if the baby survives. Lack of decisional capacity of neonates does therefore leave this hard choice regarding whether to continue or withdraw intensive care to surrogate decision makers.

The Substituted Judgment Standard seems suitable for many of the “Previously Competent” patients. But is the substituted judgment supposed to reflect, the judgment the persons would make in their *current* situation, if they had full knowledge of the prognosis? We will focus on the following reasonable interpretation. The patient’s past values or patterns of decision-making could serve as a basis for reconstruction of the choices she would make regarding her treatment in the *current* situation, if she were competent, aware of her past preferences, fully informed, and fully aware of what it would be like to live with the estimated consequences of the available treatment options. Such reconstruction may be applied in clinical decision-making, e.g. in decisions where patients may suffer from dementia, severe pain, or are victims of acute injuries. However, it may be difficult or impossible to reconstruct the preferences of some “Previously Competent” patients. Such reconstruction may be especially problematic for patients with conditions like long lasting conditions that affect decisional competence. It is commonly believed that for patients who never had the relevant kind of decisional competence, *no* interpretation of the Substituted Judgment Standard is applicable.

According to Daniel W. Brock and Allen Buchanan, The Substituted Judgment Standard cannot even be coherently applied to individuals who have never formed preferences that could guide the substituted decision.^(3,13) Applying the Substituted Judgment Standard to these patients is not only an epistemological problem according to them.⁽¹³⁾ They do not, to our knowledge, develop arguments for the claim that applying this standard to the Never Competent patients is incoherent, and not merely a problem of *knowing* what the patient would have wanted had she been competent. The claim that it might be impossible to know what a patient who has never had the relevant decision making capacity would have wanted, does not imply that claims to the effect that such patients would have had some preferences had they had the relevant decision making capacity are incoherent.

3. IN WHAT SENSE DO UNCONSCIOUS ADULTS HAVE INTERESTS?

It is common to endorse two claims: (1) Unconscious patients who have never been conscious but will become conscious can have interests while they are unconscious. The Substituted Judgment Standard is regarded as not applying to them. (2) Unconscious patients who have been conscious and will become conscious can have interests while they are unconscious. The Substituted Judgment Standard is regarded as applying to them.

The question “what does the claim that an unconscious patient can have interests of *any* kind while she is unconscious really mean?” must be answered *before* we can answer the question “what type of treatment serves the unconscious patient’s “*best* interests?” The latter question has received significant attention. There is a very extensive body of literature on the topic of substituted decision making. We cannot, within the space constraints of this article, embark on a comprehensive survey of all the interpretations of The Substituted Judgment Standard and The Best Interests Standard, and their applications in different jurisdictions. Instead, we will briefly outline influential interpretations and applications, and then carefully specify what interpretations this article concerns.

There is a very extensive literature assessing how different jurisdictions interpret and apply the concept “best interests,” and how they distinguish between the Best Interests Standard and the Substituted Judgment Standard. We will outline how these issues have been treated in a British context. This is particularly interesting because the British interpretation of “best interests” *incorporates* interpretations of the Substituted Judgment Standard. Hence, the we will see that the Best Interests Standard regulates substituted decisions in the British context, *but interpreted very inclusively*.

The British *Mental Capacity Act of 2005* (MCA) holds that “an act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests.”(14) The MCA provides a non-exhaustive check-list of factors

to be considered when determining what is in the best interests of an incapacitated individual. The MCA suggests that considerations of what the patient would have wanted had she been capacitated should be integrated in the process of determining the patient's best interests. Specifically: "(a) the person's past and present wishes and feelings (and, in particular, any relevant written statement made by him when he had capacity), (b) the beliefs and values that would be likely to influence his decision if he had capacity, and (c) the other factors that he would be likely to consider if he were able to do so."(14) Antal Szerletics' report *Best interests decision-making under the Mental Capacity Act*(15) includes discussion of the application of the MCA to financial decisions on behalf on an incapacitated individual. Such applications have influenced the application of the MCA to clinical decisions and are therefore relevant to our understanding of the evolution of the best interests standard. Szerletics notes that "it might be possible that the best interests of the individual actually corresponds to what the person would have wanted if he or she had capacity to make the decision."(15, Cf. 16). Szerletics also discusses MCA's application of the Best Interests Standard to medical decisions regarding a permanently vegetative patient(17) and notes that "The Court also makes it clear that the English notion of objective best interests cannot be equated with the substituted judgment approach as adopted in the United States but the views and the personality of P will necessarily form part of the best interests assessment."(15: sect. 3) Szerletics also notes that "This view has been further elaborated in a subsequent Consultation Paper in which it is argued that the 'best interests' and 'substituted judgment' standards are not mutually exclusive and it favours 'a compromise whereby a best interests test is modified by a requirement that the substitute decision-maker first goes through an exercise in substituted judgment.'"(15, Section. 3:3) Szerletics concludes that "The integration of financial decision making into the framework of the MCA brought along the

integration of the substituted judgment standard into the best interests scheme.” (15: Section 4:1, Cf. 18)

Landmark documents in British legislation that have led to the MCA comprises legal documents and statutory court decisions. The use of something akin to the Best Interests Standard might be traced back to the fourteenth century legislation *Parens Patrae*, which set legal standards for the custody of mental incompetents.(18, 19, 20, 21) Subsequently, in 1959, the *Mental Health Act* occurred. Szerletics holds that the Best Interests Standard was not commonly applied in cases involving mentally disabled individuals before 1989. The *Scottish Adults With Incapacity Act (2000)*(22) adopted the concept of benefit instead of best interests(15: Section 5.3) Significant legal cases have shaped the interpretation of British legislation regulating substituted decision making. Examples include an early formulation of Substituted Judgment Standard.(23,24) There are important discussions regarding the appropriateness of the so called “Bolam Test” as a criterion of “best interests.”(25) According to this criterion, best interests means the standard of reasonable care: “a practice accepted as proper by a responsible body of medical men skilled in that particular form of treatment.”(25) Szerletics describes how the Bolam Test was replaced by a “broader, welfare based assessment of best interests.”(14: Section 3:1) Szerletics points out that although the Best Interests Standard interpreted in MCA’s inclusive sense is the standard test for substituted decision making in the UK, the best interests standard is rather a “fall back principle” in Canadian legislation, to be used when the previously expressed wishes of the patient are unknown.(14: Section 5:4) In the remainder of this article, we will treat the Best Interests Standard and the Substituted Judgment Standard as separate standards.

The debate regarding what treatment is in the *best* interests of unconscious patients assumes, however, that unconscious patients *can* have interests in some senses while unconscious. Before the questions regarding what is in an unconscious patient’s *best* interests

can be addressed, we must consider what it means to claim that an unconscious patient has interests, in *any* sense, while she is unconscious.

We will explain why we find several answers to this question puzzling, and that one answer is less puzzling than the others.

It might simply be highly intuitive to hold that an individual's interests can be affected by treatment of her while she is unconscious. Cantor and Feinberg are representative advocates of such a view.(2,26) Ascribing desires to unconscious adults might appear attractive simply because of the apparent *absence of alternative explanations* of the offensiveness of certain interventions. Michael Tooley argued that a temporarily unconscious adult has a "conceptual capability" for having desires if she had desires immediately before becoming unconscious.(27) He introduces this concept in order to explain how individuals who are incapacitated in certain ways can remain rights bearers while they are incapacitated. He does not explain or justify that claim except from suggesting that conceptual capacities are needed in order to preserve his theory's intuitive plausibility.

One of the most interesting suggestions of how unconscious humans could be described as having interests while they are unconscious has been developed by Ronald Dworkin in his 1993 book *Life's Dominion*. Dworkin distinguishes between *experiential* and *critical* interests. Having an experience or engaging in an activity is in one's experiential interest if the individual enjoys the experience or activity. Listening to poetry or music might give the individual a pleasant experience, while hearing someone sing out of tune might give the individual an unpleasant experience. Satisfaction of experiential interests does not make the individual's life go genuinely better. Something is in one's *critical* interest if it contributes to making one's life go genuinely better; it contributes to "what makes a life good."(28) According to Dworkin, one *should* want things that contribute to the genuine goodness of one's life, and people can be mistaken regarding what things make their lives go genuinely

better. Having close personal relationships, achieving valuable accomplishments, and live one's life with integrity make one's life genuinely better. He holds that if a person's critical interests are un-satisfied, her life goes worse, even if she does not understand what her critical interests are. Dworkin rejects the so-called "experience requirement," which roughly says that in order for something to be good or bad for an individual at time T1, she must actually experience it at T1. Those who reject the experience requirement claim that the satisfaction of a desire can be good for an individual even if the individual does not even know that her desire has been satisfied.(28,29) The expression "experience requirement" originates with Griffin.(29) If the experience requirement is inaccurate, rejection of it would contribute to explaining how unconscious humans can have interests while they are unconscious.

Imagine a fully competent individual: "P1." She lapses into temporary unconsciousness at some stage in her life. Call her "P2" during her unconscious period. Applying Dworkin's account, we could ascribe P2 critical interests, but not merely *qua* being P2. Dworkin's account suggests that P2 has critical interests only through her *connection* to her previous competent self P1. As temporarily unconscious, P2 will relapse back into her competent self P1. P1 before and after she became unconscious has critical interests, and P2 has critical interests only because of P2's "connection" to P1. Dworkin's discussion of *permanently* unconscious, "vegetative" patients illuminates how his views could apply to temporarily unconscious individuals as well: "When we ask what would be best for him [the vegetative patient], we are not judging only his future and ignoring his past. We worry about the effect of his life's last stage on the character of his life as a whole, as we might worry about the effect of a play's last scene or a poem's last stanza on the entire creative work."(28) The critical interests that the individual expressed while she was competent should guide our treatment of her while she is incompetent, because the preferences expressed by a competent person indicates what holistic structure, or overall character, she wishes for her life as a whole

to have. Knowing the individual's previously expressed desires helps us understand the holistic structure she wishes for her life to have, and to understand what treatment of the unconscious patient would preserve it.

Dworkin's and Tooley's accounts seem equally puzzling. A mere claim that an unconscious patient "has" interests *while she is unconscious*, in virtue of her previous interests, does not explain why she has interests while she is unconscious.

Hawkins recently(30) defended the claim that some incapacitated¹ individuals, *qua* incapacitated individuals, can have critical interests. We will argue that her account is the least puzzling explanation of how unconscious patients can have interests, and, if we accept her account, then we should accept that the Substituted Judgment Standard coherently applies to unconscious patients, even if they have never been conscious. She aims at establishing the "Nonalieness Principle (NA):

"It is a necessary condition of X's being intrinsically good for A at T1 that either (1) A respond positively to X at T1 if she is aware of X at T1 or (2) A be such that she *would respond positively to X at T1 if she were aware of X at T1.*" (30, p. 527, italics added)

3.1 INTERPRETION AND DEFENCE OF NA

Hawkins holds that NA could be read as indicating either that X is *intrinsically* good for A *now* because she *would* respond positively if she were aware of X, or that X is *instrumentally* good for A now because she *will* respond positively to X once she becomes aware of X. But Hawkins holds that in order for X to be good for A in either of these senses, X must actually be experienced by A at some point.(30. p. 530) We believe that the assertion "X is good for A

¹ Hawkins focuses on demented humans and does not apply her account to foetuses and premature babies; we will suggest that her account is relevant for these beings, but not take a stand on whether Hawkins would want to apply her account to these beings.

if she would respond positively to X if she were aware of X, and will respond positively to X at some point,” provides a less puzzling explanation of how A can have interests while she is unconscious than Dworkin’s suggestion that her interests while unconscious can be determined by the interests of her previous competent self, or Tooley’s stipulation of conceptual capacities for having interests. We cannot argue conclusively for this claim, and merely suggest that NA is attractive because the claims that A would respond to X in some way were she conscious, and that she will respond to X in some way once she regains consciousness, are not metaphysically curious, and are fully comprehensible. NA also avoids all of the challenges involved with explaining how P2, while unconscious, can have critical interests *because* her competent self P1 had critical interests. It would be fully comprehensible to claim merely that the critical interests of P1 should be honored once P1 turns into her unconscious self P2. But the claim that P1's critical interests should be *honored* by treating P2 in certain ways does not imply that P2 has any critical interests. The critical interests of P1 cannot be assumed to be the critical interests of P2 simply because P1 and P2 are the same organism.

We will suggest that examples advanced by Hawkins could be considered as providing intuitive support for NA, but note that opponents of NA could advance these, or other, examples in favor of their view. We conclude that both positions have intuitive support that cannot be conclusively quantified and compared.

Hawkins describes an individual who has cancer in his pancreas, who is asymptomatic, and unaware of his cancer. Applying NA, we could say that something intrinsically bad has happened to him already, because he *would* be devastated if he knew about the tumour, and he will learn about it and be devastated at some point. Alternatively, NA would allow us to say that something instrumentally bad has happened to him already as the tumour will cause something intrinsically bad, and that something intrinsically bad will happen to him once he responds negatively. Also, being loved by one’s relatives although one

is incapable of ever knowing of it is not, according to Hawkins, a “good” in any sense. But proponents and opponents of un-sensed goods could use the same examples to support their view, which suggests a methodological challenge.

Any of the following claims is coherent: If a patient is being mistreated while unconscious (i) something instrumentally bad happened to the individual while she was unconscious and something intrinsically bad will happen to her once she learns about the incident. (ii) something intrinsically bad happened to the individual while she was unconscious because she would have responded negatively had she known about the incident and she will respond negatively once she learns about it. (iii) something intrinsically bad *would* have happened to her had she been conscious when the molestation took place, and that something intrinsically bad *will* happen to her once she learns about the molestation. An interest in physical integrity could arguably be classified as a critical interest.

3.2 OBJECTIONS AND RESPONSES

Here, we need to carefully consider the following objections to the claim that, in order for X to be intrinsically good for a person, she must be aware of X at some point. Aristotle suggested⁽³¹⁾ that the flourishing human life is not reducible to what one experiences: one can be dishonoured without ever knowing it, and one’s children can suffer misfortune without one ever knowing it. We pity people whose desires and feelings are so foolish that they don’t see that they are being humiliated—i.e., who don’t feel humiliation although in fact they are being humiliated. These examples are supposed to show that is misguided to see the contents of one’s consciousness as all that there is to a person’s interests, to her good. They carry intuitive force, but so do examples intended to show that one’s well being can only be affected by things we experience at some point. It is defensible to claim that the intuitive appeal of these competing traditions cannot be measured and compared in any

uncontroversial way. Grant for the sake of the argument that both of these competing traditions have intuitive appeal according to their respective advocates. Hawkins' theory goes some significant distance when it comes to systematizing and explaining the intuitions in support of the claim that something must enter a person's conscious experiences at some point in order for it to be intrinsically good for her. We have at least shown that the view that a person must respond positively to an alleged intrinsic good at some point in order for it to actually be intrinsically good for her should be taken very seriously.

But our argument might be vulnerable to the following objection. Suppose someone murders the agent while she is being unconscious. Our view seems to imply that her interests have not been adversely affected because the murder will never enter her conscious experience. It seems that, according to our view, her interests are not adversely affected at the time she is being killed. We suggest two responses to this objection. First, we saw that the eagerness to describe such a murder as adversely affecting the victim's interests has been motivated by the claim that such a description is needed in order to explain why such a murder is a violation of the victim's rights. But the moral *wrongness* of killing temporarily unconscious individuals can be explained while denying that such wronging affects her interests in any sense. One of the authors has argued in other places that neither a capacity for exercising autonomous choices nor a capacity of having interests in any sense is necessary in order to be a rights bearer.²

Secondly, the issue of if and how death affects our interests adversely is subject to ongoing dispute. Even the badness of deaths that occur while the individual is conscious has been disputed. Because of the lack of consensus regarding these issues, we cannot simply

² This argument has been developed in detail in (omitted for review purposes.) This argument also provides a response to Tooley's claim that we must stipulate a conceptual capacity for having interests in order to explain how temporarily unconscious humans can have rights while they are unconscious.

assume that it is intuitively plausible to hold that *any* death that occurs while one is asleep necessarily affects one's interests negatively. The objection above claims that the death is the result of *murder*. We indicated that the wrongness of such acts can be explained in terms of rights violations without assuming that the victim's interests are being adversely affected. If the victim dies in her sleep without any foul play being involved, the issue of if and why her interests are adversely affected remains unsettled.

3.3 ACCEPTING NA IMPLIES THAT THE SUBSTITUTED JUDGMENT STANDARD COHERENTLY APPLIES TO UNCONSCIOUS PATIENTS WHO HAVE NEVER BEEN CONSCIOUS

A capacity for having critical interests implies a capacity for reflecting over one's life as a whole. Hence, an unconscious person would also un-controversially be capable of making the *choice* not to be intrusively intervened with while she is unconscious, and once awake, she may hold that she would have made this *choice* had she been conscious. Everything NA claims about under what circumstances an unconscious adult can have critical *interests* while she is unconscious also establishes that the individual can have a *dispositional capacity for exercising choices* under the circumstances NA mentions. If the individual would be capable of having some critical interests were she conscious, she would also be capable of exercising some choices were she conscious. If this is accurate, we may claim that the Substituted Judgment Standard coherently applies to unconscious adults who have never been conscious.

4. DISPOSITIONAL CHOICES

Never-Competent patients such as premature infants and Formerly-Competent patients whose preferences are not easily identified are relevantly similar to temporarily unconscious adults, and, therefore, The Substituted Judgment Standard applies to them as well. The claim that an

individual would have certain interests or a capacity to exercise choices if she were conscious, and that she will have certain interests and capacities once she becomes conscious, does not presuppose previous consciousness. Even an individual who has not previously been conscious *would* have some interests, and be capable of making choices *if* she were conscious. A premature infant would be capable of making the choice not to expose herself to certain kinds of degrading touching if she were capable of autonomous agency, and will, once she becomes aware of it, hold that she would have chosen not to be exposed to such touching. If this claim is adequate, the never-competent and hard cases of former-competent can also have capacity for exercising autonomous choices in a dispositional sense. Previous interests and choices have merely epistemological relevance: they can indicate, as a validity check, *what* interests or choices should be ascribed to the temporarily unconscious adult in a dispositional sense.

Does this argument imply the implausible claim that we can coherently talk about what a mouse or a fork would autonomously choose were it to become conscious? And if what any entity E would choose were it to become conscious determines how we may treat E, then we are committed to moral restrictions on how we may treat any entity E whatsoever. One might claim that premature human babies have, as a biological matter, the potential for autonomous choice while mice and forks do not. So restrictions on treatment would not apply to mice and forks. But (i) not every premature baby has this biological potential and (ii) the conceptual weight would then be put on the moral relevance of the potential for autonomous choice. The moral relevance of such potential remains controversial. It cannot simply be assumed. Our response to this prominently discussed challenge is the following. We focus solely on *temporarily* unconscious humans. We defend what we consider to be the least puzzling explanation of how such humans can have interest while they are unconscious. We saw that the least puzzling explanation of how such beings can have interests is that they have

interests in NA's sense. We argued that if they can have such interests, it follows that they can also have a capacity for making choices in this sense: a capacity for having critical interests implies a capacity for exercising choices. Now, "Never-Competents" that will become conscious if they survive and remain healthy are also temporarily unconscious. One of the authors has provided a defence of the moral relevance of such potentiality, and a complete account of criteria for inclusion in the class of rights bearers, in other places.³ Since such "Never-Competents" are relevantly similar to "Previously-Competents" in the sense of being temporarily unconscious, Never-Competents also have dispositional interests and dispositional capacities for exercising agency. Beings who used to be conscious but are now permanently unconscious might be similar to spoons; those who will regain consciousness are not.

5. THE IMPORTANCE OF EXPRESSING A RESPECTFUL ATTITUDE

Our defence for the practical relevance of our account comes in four related parts. First, our account can provide a new type of justification for choosing a treatment option. Referring to a patient's dispositional choices as justification for a substituted decision expresses at least implicit respect for patient autonomy. People who share the defensible view that it is morally desirable to show implicit respect for the patient's autonomy should welcome this justification. Implicit respect for autonomy is not the only, or necessarily trumping, moral value at stake in substituted decisions. But the concept of dispositional choices allows us to incorporate expression of implicit respect for autonomy into substituted decisions, without loss with regard to other morally relevant considerations. Providing conceptual space for justifying one's decision by reference to respect for the patient's dispositional capacity to make choices does not prevent advocates of the Best Interests Standard to interpret the decision by reference to the patient's best interests.

³ Cf. (Omitted for review purposes.)

Suppose that a substituted decision maker recommends the health care team to withdraw life-prolonging treatment from a pre-mature infant with Downs Syndrome, and justifies this decision by referring to the infant's dispositional interests: if the infant would be capable of responding positively or negatively in NA's sense, she would not want to live her life with Downs Syndrome, and also in chronic pain and a complex set of severe disabilities. Alternatively, she might justify her recommendation by referring to the infant's dispositional choice not to live such a life.

We should acknowledge the distinction between being unable to *know* the content of the patient's dispositional choices, and holding that the claim that the patient can have a capacity for dispositional choices is *incoherent*. The former is an epistemological difficulty. The latter claim points out an alleged logical difficulty. By making this distinction, we have begun understanding the benefits of giving clinicians the conceptual *opportunity* of expressing the attitude of implicit and indirect respect for patients' autonomy.

Secondly, our proposal serves as a structured mental checklist that might be a practical tool. The question "what would this particular patient have reason to choose if she were capacitated" (let us label this question Q1) views the patient as a possessor of dispositional choices. Suppose a previously competent patient is conscious, but has not had the relevant decisional competence for a long time, and has not, while competent, expressed any explicit preferences regarding her treatment should she lose decisional capacity. Examples include patients suffering from long term drug addictions. One proposed strategy for substituted decision making for such patients is attempted reconstruction of the patient's "authentic" preferences by identifying the patient's life as a coherent "narrative." This disputed concept has been interpreted in numerous ways. Here, we merely assume that the substituted decision makers consider previous choices and statements by the patient that might guide a reconstruction of what treatment she "would want" in the current situation, if she were

capacitated. Scholars have pointed out that this method is respectful because it recognizes the patient's individuality, but also recognizes the profound difficulties of knowing what the patient "would have wanted." Scholars have also noticed the risk of substituted decision makers' imposition of their own views regarding what characterizes "a good life" in this reconstruction process. We suggest that viewing the patient as a dispositional "chooser" throughout this reconstruction process helps us preserve a patient centred perspective when creating such a narrative. This is because viewing her as a dispositional chooser reminds us to view her as a dispositional *initiator* of actions; as the source of whatever actions she might have engaged in had she been capacitated. Viewing her in this way reminds us to attempt to assume her individual perspective at all times. Viewing her as a holder of interests might fill the same function as long as we focus on her as a "holder," without slipping into subjective evaluations of what interests such "holders" should have. We may view her either as a dispositional initiator of actions, or as a dispositional holder of interests. Both descriptions are fine as long as they serve the purpose of helping us view her as an "initiator" or as a "holder," and remind us not to impose our own views regarding what interests are weightier or what choices would be preferable according to the substituted decision makers. These descriptions could help us focus on what treatment option is most consistent with the patient's previous preferences and choices. If substituted decision makers may choose how to view the patient (as a "holder" or an "initiator,") this might help them remind themselves to focus on the patient's own perspective rather than imposing her own preferences on the patient.

Thirdly, if substituted decision makers may choose their preferred "mental tool" for assessing their own attitudes, the "tool" might be more efficient. A substituted decision maker who endorses the view that it is imperative to show implicit respect for autonomy might be more motivated to remain patient centred in her decision if she pictures the patient as a dispositional chooser. A substituted decision maker who endorses the view that protecting

interests is imperative might be more motivated to remain patient centred in her decision if she pictures the patient as a holder of interests in NA's sense. The substituted decision maker is then given some discretion regarding what description of the patient she considers morally relevant. But allowing her to be subjective in this sense is consistent with a respectful approach because *she may only choose amongst descriptions of the patient that are patient centred*. Scholarshave suggested that applying the Substituted Judgment Standard to these patients might take the focus from the substituted decision makers' own preferences and help them focus on the perspective of the patient. We need empirical evidence to see how these two standards come into play in clinical decision making.

Robin Dillon suggests what all understandings of "respect" have in common: "respect is a particular mode of apprehending the object: the person who respects something pays attention to it and perceives it differently from someone who does not and responds to it in light of that perception [...] The idea of paying heed or giving proper attention to the object which is central to respect often means trying to see the object clearly, as it really is in its own right, and not seeing it solely through the filter of one's own desires and fears or likes and dislikes."(32) Integrating (Q1) with clinical decision-making may increase awareness of how one's own personal and professional values come into play in the interaction with patients in shared decision making. Pragmatic aspects of the decision-making process, such as the need to make decisions quickly and the technical intricacy involved in many of these clinical decisions, might add further complexity to the suggested normative framework. Decisions in the neonatal intensive care unit, especially clinical decision-making for the smallest babies with serious conditions, where the prognosis of survival and/or future life quality is very uncertain is one example where shortage of time and technical complexity are involved. Pragmatic aspects of the decision making process challenges any theory on substituted decision-making, not just ours.

Fourthly, if we are sceptical to the usefulness of the dispositional choice account, then we should be equally sceptical to Hawkins' explanation of how unconscious people can have interests in NA's sense. The two accounts are equally coherent and both have intuitive appeal. But many people do find Hawkins' type of explanation useful. If we are reluctant to jettison Hawkins' proposal, then we should be equally reluctant to jettison the dispositional choice account.

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