

# IS HYPOTHETICAL CONSENT A SUBSTITUTE FOR ACTUAL CONSENT?

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**ABSTRACT:** The so-called *Substituted Judgment Standard* is one of several competing principles on how certain health care decisions ought to be made for patients who are not themselves capable of making decisions of the relevant kind. It says that a surrogate decision-maker, acting on behalf of the patient, ought to make the decision the patient *would* have made, had the latter been competent. The most common way of justifying the Substituted Judgment Standard is to maintain that this standard protects patients' right to autonomy, or self-determination, in the situation where they are no longer able to exercise this right on their own. In this paper we question this justification, by arguing that the most commonly suggested moral reasons for allowing and encouraging people to make their own choices seem not to apply when the patient's decision-making is merely hypothetical. We end with some brief sketches of possible alternative ways of justifying the Substituted Judgment Standard.

## Introduction

The topic we shall address in this paper is the moral justification of the so-called *Substituted Judgment Standard* (SJS), especially whether this justification really ought to involve the idea of patient autonomy, or self-determination. SJS is one of several competing principles on how certain health care decisions ought to be made for incompetent patients, that is, patients who are not capable of making their own decisions.<sup>1</sup> Although it need not be, typically the principle is meant to apply in situations where the decision is highly constrained, in that it concerns whether or not to accept a proposed treatment, for instance, rather than to make up one's mind among a more or less open-ended range of options. In its basic and most common form, SJS says that the surrogate decision-maker (who might e.g. be the physician, a relative, a friend, or a legal guardian) ought to make the decision that the patient *would* have made, *had he or she been competent*.<sup>2</sup> The contrasts most commonly made would be with the *Best Interest Standard*, according to which the surrogate simply ought to make that

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<sup>1</sup> This is rough, since in one sense many incompetent patients are able to make decisions; it's just that they are not allowed to, since they lack some other kind of ability held to be important. Exactly what conditions have to be satisfied in order for someone to be competent in the relevant sense is a complicated and controversial issue, and shall not be dealt with here.

<sup>2</sup> Some of the ways in which the formulations of this standard can differ are briefly mentioned in Broström et al. (forthcoming).

decision which best protects the interests of the patient<sup>3</sup>, or the *Advance Directive Principle*, which tells the surrogate only to see to that some prior actual decision of the patient (as for example expressed in a living will) gets executed.<sup>4</sup> It is common ground in the discussion that these standards ought to be evaluated primarily in terms of what they, or decision-making in accordance with them, do *for the patient*, and for present purposes there is no need to question this assumption, as a starting-point at least.

For reasons we shall soon mention, and then discuss at length, SJS has found wide appeal, and even among those who ultimately argue for some other decision-making standard, SJS is usually seen as an intelligible contender, worthy of serious consideration (whether as a mere complement to other standards when these do not apply or, more rarely, as a first choice even when those other principles could be used). Certainly various misgivings about SJS, or its scope, have been voiced too, ranging from the worry that this standard cannot be meaningfully applied to individuals who have never been competent, to the suspicion that SJS invites surrogates to project their own outlook onto the patient. Many of the problems identified are at root epistemic, i.e. problems grounded in the putative fact that it is often hard to *know* what the patient would have decided, and hence difficult

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<sup>3</sup> See e.g. Beauchamp & Childress (2001), p. 102f and Buchanan & Brock (1990), pp. 122ff.

<sup>4</sup> This is the label chosen by Buchanan & Brock (1990). Basically the same standard is called the *Pure Autonomy Standard* in Beauchamp & Childress (2001).

to make sure that applications of this standard meet reasonable requirements on objectivity and reliability.<sup>5</sup>

Elsewhere we have ourselves raised another problem for SJS, one that goes deeper, in that it threatens the very intelligibility of this standard as it is usually formulated.<sup>6</sup> Basically, the charge is that the traditional formulation of SJS fails to specify the conditions under which the patient is assumed to make his or her decision. It says that the surrogate should choose as the patient would have, if competent. But competence comes in degrees, and it is not clear *how* competent the patient is supposed to be in the imagined scenario, or for that matter what values and preferences we ought to ascribe to the patient in the hypothetical situation we are asked to construct. The problem isn't one which is easily rectified just by one being explicit about some minor detail that has been left out merely out of convenience or sloppiness, but concerns how to make sense of SJS at all.

Also missing from the discussion about SJS and the other decision-making standards is, on our view, proper attention to the familiar distinction between criteria of rightness, or adequacy conditions, and decision procedures, or tools, which might prove useful in trying to meet these criteria. Is SJS (or some other standard) supposed to be the measure of a good decision, whether or not we think in terms of it, or is it to be

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<sup>5</sup> See e.g. Bailey (2002), Berghmans (1997), Buchanan & Brock (1990), Collopy (1999), and Welie (2001).

<sup>6</sup> Broström et al. (forthcoming).

understood rather as a rule of thumb that we for more or less contingent reasons might be well advised to try to follow if we are to make acceptable proxy decisions (on whatever criterion of rightness)? The relevance of this distinction will be further demonstrated later in this paper.

**The received view: hypothetical consent as autonomy ‘light’**

Whether conceived of as an adequacy condition or a tool, SJS needs to be morally justified, just like the other suggested principles for decision-making for the incompetent. One way of justifying SJS would be to argue that this standard protects incompetent patients’ right to *autonomy*, or self-determination, when they are no longer capable of exercising this right on their own.<sup>7</sup> The assumption that SJS is in this particular sense an *autonomy standard* is, in fact, the received view. Here are just a few quotes from the literature, reflecting this assumption:

Given a commitment to autonomy, substituted judgment is an ethically better basis for proxy decision making than the *reasonable-person* or *best-interest* standard. [---] Patient autonomy is, after all, the main reason we embrace substituted judgment [...]<sup>8</sup>

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<sup>7</sup> “Right” should here be understood in the rather noncommittal way presupposed in much of the relevant discussion. We make no assumption here about the status of rights.

<sup>8</sup> Hardwig (2000), pp. 46, 53.

In the case of proxy advance directives, the same respect for self-determination that justifies the recognition of the authority of an advance directive in the first place suggests that the proxy ought [...] to attempt to make decisions according to the substituted judgment standard [...] <sup>9</sup>

Even if the patient has not extended her autonomy by authoring a living will, some degree of authorship can be retained. A person other than the patient [...] can try to reach a 'substituted (non-)consent [---] [I]n [SJS] the authority of the decision reached ultimately is derived from the patient's autonomy.<sup>10</sup>

There are ways to interpret the idea of autonomy on which it is not a matter of self-determination in the sense of the person being allowed and encouraged to make his or her own choices.<sup>11</sup> It might be about such (rather elusive) things as letting the individual's own "deepest values" inform decision-making, or about implementing the "life plan" that may somehow be thought to be inherent in a person's pattern of choices and psychological make-up. However, it is clear that in the context of health care and the bioethics literature on standards of decision-making what one almost always has in mind is precisely this idea of giving patients the opportunity to make their own choices (when this is appropriate), to support them in their decision-making, and then extend this idea about self-governance so

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<sup>9</sup> Buchanan & Brock (1990), p. 112.

<sup>10</sup> Welie (2001), pp. 170f. Not all of these writers, it should be said, *defend* SJS.

<sup>11</sup> For an alternative approach, and a general discussion about the notion of autonomy, see e.g. Agich (1993).

that at least much of it can be applied also to those who are not capable of making actual decisions. One might say that the mainstream thought is that incompetent patients need not have to, and ought not be made to, *lose* certain privileges just because they are no longer competent.

Few, if any, of those who seem to think of SJS as an autonomy standard would want to make use of this standard when more regular autonomy principles apply, such as when a competent patient is able to give, or refuse, informed consent to a proposed treatment. In other words, the voluntary and informed choice of a competent patient should, on this view, trump any considerations concerning what he or she would have decided under other circumstances. In line with the view that the satisfaction of actual wishes ought to be the first choice, it has also been suggested that the autonomy protected by SJS is a compromised kind of autonomy, autonomy *light*, as it were:

[SJS] is, at best, a weak autonomy standard.<sup>12</sup>

[...] substituted judgment is a much softer replication of a patient's autonomy [than when proxies are guided by the patient's instructions].<sup>13</sup>

[...] the self-determination of the incompetent individual is potentially much compromised compared with what is possible for someone who is competent.<sup>14</sup>

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<sup>12</sup> Beauchamp & Childress (2001), p. 171.

<sup>13</sup> Collopy (1999).

Some commentators flesh out these caveats better than others, but none of them go to the heart of the problem, as we see it, and they all remain committed to the view that if there is some justification for SJS it has to do with incompetent patients' right to self-determination.

It is noteworthy that we have yet to see an explicit and convincing argument for the view that it's appropriate to interpret SJS as an autonomy standard. That SJS protects the autonomy of incompetent patients, albeit a compromised form of autonomy, has very much been taken for granted, and the skeptical questions that have been raised concerning this standard have, as we have already mentioned, mainly dealt with the possibility of ensuring sufficient reliability and objectivity in actual use. This absence of arguments certainly should be a cause for concern, since the appropriateness of grounding SJS in autonomy considerations isn't self-evident. On a stronger note, in this paper we wish to suggest that there may not in fact *be* any good arguments to this effect. We make this case not by offering a knock-down argument, but by providing enough circumstantial evidence to securely place the burden of proof with those who believe that on a proper understanding of SJS, this standard is about the preservation of patients' right to self-determination, even after they have become incompetent.

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<sup>14</sup> Bailey (2002), p. 485f.



**“But is it *autonomy*?”**

How could one go about questioning the autonomy justification for SJS? There are different routes that one might want to take. One approach to questioning SJS as an autonomy standard would make it into a conflict about the proper use of words. It might be tempting to argue that when we are dealing with merely hypothetical decisions we have strayed too far away from the ordinary concepts of autonomy or self-determination. The actual and the hypothetical are so dissimilar, the argument would go, that thinking of SJS as having to do with autonomy would certainly stretch, if not strictly violate, the rules of language. After all, to emphasize the obvious, hypothetical decisions are merely hypothetical, and not real, so how could there be self-determination of any kind in executing these decisions that no one has?

There is some merit, we think, to this “semantic” objection, but at the same time we would rather not make this issue a quibble over terminology, if it could be avoided.<sup>15</sup> The mechanisms of concept formation in natural languages are remarkably allowing, and we are in no way committed to denying that there are sufficiently intelligible connections between paradigmatic cases of self-determination and the hypothetical case to warrant subsumption under the same concept. And warrant aside, anyone is of course free to use the relevant expressions as they please. On our view, it would for these reasons be more promising to make the argument a *moral*

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<sup>15</sup> The same would go, *mutatis mutandis*, for an analogous metaphysical claim that whatever SJS may protect, it isn’t the natural kind *autonomy*.

one, for example in terms of values. The point would then be that, however one chooses to use words like “autonomy” or “self-determination”, the values, or moral reasons, underlying our respect for people’s actual choices (as implemented in the principle of informed consent, for instance), do not carry over into the merely hypothetical realm, and that any marketing of SJS that suggests otherwise is clearly misleading.<sup>16</sup>

**Possible values in actual self-determination. Do they really justify SJS?**

In this main section we offer a catalogue of familiar values that can be associated with people making their own decisions in some given area of life, and briefly explain why they are not promising as values to appeal to in a defense of SJS. Precisely because the autonomy justification of SJS has been sloppy at best, we believe that a more systematic examination would do the debate good. The list makes no claim to completeness, but we think, and take to be important, that we have the main contenders covered.

*Positive feelings associated with autonomy*

There are certainly many reasons why having the opportunity to make one’s own choices, and to actually make them, might be valuable. One such reason is that there may be a direct *hedonistic* gain in people making their

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<sup>16</sup> To make it more manageable we here focus on values associated with *respect* for autonomy, in the sense of people being given the opportunity to make their own decisions. However, a corresponding argument could easily be provided if we took *strengthening* of people’s autonomy (as implemented in the idea of “empowerment”, for instance) as the object of comparison.

own decisions. To put it bluntly, often it may simply feel good to be allowed to make one's own choices, and to make them. Inversely, it may well feel bad when we are forced by circumstances, or coerced by other people, to do things against our will. This is putting it bluntly indeed, because it fails to recognize many distinctions that are there to be made, and fails to recognize many nuances in the range of our emotional responses to making our own choices, or not being allowed to make them. For instance, we may attach a certain hedonistic value to *having the opportunity* to make certain choices, and a different value to *actually make* a decision. Also, the notions of feeling good or bad are obviously just shorthand for a great variety of distinct states of mind, with their own phenomenological flavor and functional role.

For present purposes, however, we need not aim for completeness and absolute accuracy in describing these hedonistic reasons for attaching a value to people making their own choices. Such details are immaterial, because the hedonistic argument for actual self-determination cannot be used to support the idea that we ought to respect the patient's *hypothetical* choice. For one thing, the patient may not be able to feel *anything* anymore — as would be the case if he or she is in a permanent vegetative state — and then we have no hedonistic reason whatsoever to act in accordance with SJS (or with any other decision-making standard, for that matter). And if the patient *is* able to feel good or bad about things (as when incompetence is due to dementia, for instance, confusion otherwise caused, pain or fatigue) there would normally be no reason to think that what his or her current feelings are has anything directly to do with whether or not his or her *hypothetical* wishes are satisfied. To the extent that we are concerned

with autonomy related hedonistic values we ought as a rule rather to try to meet the patient's current *actual incompetent* wishes, in those cases, since those are plausibly the only wishes that are relevant to the patient's current experiences regarding locus of control, positive and negative. To sum up, in the large majority of cases the surrogate has no obvious hedonistic reason to make a decision in accordance with SJS (if the purpose is to do something for the patient).

There is another point too. Even if SJS could be justified on hedonistic grounds when the patient on the rare occasion is able to have the relevant experiences, obviously it would still not be *because* it feels good to be actually self-governing that he or she would enjoy having her hypothetical decisions respected. The hedonistic justification for SJS would in this sense be independent of whatever hedonistic benefits there may be to making one's own actual choices. The same goes for those cases where the patient will eventually regain sufficient mental capacities. In that scenario, he or she may well come to appreciate that the surrogate has made decisions in accordance with SJS, and to that extent there may be a hedonistic argument in favor of this standard (although ultimately the standard would be a future oriented one, assessing the surrogate's decision in terms of what the patient will later appreciate). However, that would again be an independent argument for SJS, not based on the putative fact that it feels good to make one's own decisions.

*The value of facilitating the development of autonomy*

Sometimes there is reason to let people make their own decisions not because they are autonomous individuals but because allowing them to

influence their own life helps them *develop* autonomy. Our attitude towards children is the most salient example of this. Small children start out life with virtually no autonomy, but slowly develop their capacity for self-determination as they grow up. One aspect of parenting consists in giving children choices and concomitant responsibility, as if they were autonomous, in order to facilitate the development of autonomy. This might seem to be of special importance for the present discussion, since SJS is intended to be an autonomy related standard applicable precisely to those who, strictly speaking, have no autonomy to exercise. It is easily seen, however, that the reasoning underlying our providing children with possibilities for making decisions of their own doesn't apply to the typical case of SJS governed decision-making for the incompetent. In some of the situations where we are inclined to decide in accordance with SJS — when the patient suffers from dementia, or is in a permanent vegetative state, for example —, there are no prospects of reinstalling autonomy, and in those situations where advances can be made in that regard — for instance, when the patient's incompetence is due to heavy medication —, these advances will as a rule not be the result of applying SJS. Thus, SJS cannot be justified by reference to the sometime autonomy promoting value of allowing people to make their own choices.

#### *Epistemic values of autonomy*

One possible moral reason for respecting actual decisions is based on the idea that people are in an epistemically privileged position that should be utilized in the promotion of their own interests. On one construal of this idea people are generally the best judges of what is in their own best interest. On another construal, people may not be the best judges of what is

in their own interests, as traditionally understood, but still they have epistemic access to information (experiences, preferences, facts about themselves) such that letting them make their own decisions will in general de facto promote their own interests. The latter would cover the cases where people's decisions are due to psychological processes that are largely unconscious, but still utilize personal experiences in generating decisions — decisions that are “rational” in a way they may not have been if they had been the outcome of an intellectual assessment of one's interests and what promotes them. An example might be the case where we succeed in avoiding some danger by acting upon discomfort rather than a more fallible intellectual assessment of the extent to which the risk is a threat to our interests. Either way, according to this line of thought, what has final prudential value, i.e. value *by itself* for a person, is whatever is in the person's best interest (broadly understood); respecting her actual choices has instrumental value in promoting this aim, but no value by itself.

If this instrumental value gives us reason, albeit a defeasible one, to respect these choices, the assumption has to be that there is often enough no other better way to realize whatever has final value. Here “no other better way” has to be understood as no other better *available* way, as otherwise one could for instance have appealed to the judgment or epistemic credentials of some omniscient being, as (trivially) being even more reliable. Such a procedure would, by definition, have an even greater instrumental value, but ordinary people are the ones who are singled out as instruments in the promotion of final value, because their verdict seems to be the best one among those that we can reliably lean on in actual practice. As a corollary, in assuming people to be the best available judges of what is in their own

interest, or to have special access to information that de facto leads them to make decisions that typically promote their own interests, one assumes, in effect, that other people's assumptions about what those concerned *would* have chosen (under suitable circumstances) are generally inferior. Now, what does this imply for the value of deciding as the patient him- or herself would have?

From the putative fact that there is a superior instrumental value in people making their own choices it does not simply follow, without certain auxiliary assumptions, that if we decided as the patient would have, a decision would be made that would be more reliably instrumental in protecting the patient's interests than any other available means. To see this, we only have to remind ourselves that SJS, as traditionally formulated, is underdetermined, in that it fails to fully specify the conditions under which the patient ought to be imagined to make his or her decision. If, for instance, one were to assume that the surrogate ought to make the decision that the patient would have made under *epistemically disastrous* conditions, it is fairly obvious that there would be no justification in assuming that such a procedure would promote the interests of the patient. In any case, such justification cannot be immediately derived from the alleged fact that competent individuals are epistemically privileged in a way that suggests that they ought to be allowed to make their own decisions. For the argument from the epistemic value of actual self-determination to go through the chosen conditions would have to be at least as favorable, epistemically speaking, as those warranting respect for actual choices. Otherwise there could, for all that has been said, be some way of protecting

the patient's interests that would in general be more instrumental to that aim.

Of course, deciding as the patient would have, even under somewhat less favorable conditions, might still prove to be epistemically superior to other available means as long as those hypothetical circumstances are *sufficiently* favorable, and as long as we could determine with enough reliability what the patient would have decided under those circumstances. The problem, however, with stipulating such favorable conditions, in order for there to be an epistemic value in making a decision based on SJS, is that the epistemic value of respecting these hypothetical choices may not be of much use to us, precisely because we cannot in general know what those choices would be. Hence, our motivation for attaching an instrumental value to actual self-determination does not carry over to decision-making in accordance with SJS. The *point* of respecting actual choices, on the present story, would be to *utilize* an epistemic privilege had by competent individuals in the promotion of their own interests. We cannot, however, in the same way utilize the epistemically privileged position of the idealized (now incompetent) patient, because we need to identify this position and determine the verdict it would yield, something that we may not be in any better position to do than figure out on our own what would best promote the patient's interests. This difficulty is indeed practical rather than theoretical, but it's not as if it is *merely* practical. In attaching a sufficient instrumental value to people making their own choices, we are inherently sensitive to what is within the realm of possibility and likelihood. This focus on *available* means for protecting people's interests does reflect a practical concern, and this practical concern is the *only* concern (on this



story) justifying the weight we give to self-determination. If taken seriously, this practical concern would then dictate that we ought not to disregard the epistemic difficulties associated with successfully applying SJS. Certainly this procedure of substituted judgment might still be the best one available, if the ultimate goal is to protect the patient's interests — one proposal to that effect will be mentioned below, under the heading “Alternative approaches”. It cannot, however, be deduced that it is, just from the assumption that competent individuals are the best judges of their own good, but the procedure would have to be evaluated on its own terms.

#### *The value of responsibility*

When people are allowed to make actual choices, they are typically held *responsible* for these choices. There are exceptions to this, well known in their general outline, albeit controversial when it comes down to details. Basically, the more a given choice is the outcome of either ignorance or force, the less the person who made this choice could reasonably be held responsible for it. Being responsible is a complex notion, tied to a series of conditions still under debate. Holding someone responsible for a decision, and taking responsibility for it, are also complex notions, tied to a broad range of possible repercussions and credits — the “reactive attitudes”, as they are sometimes put. Whatever views one might have on the niceties concerning these conditions and attitudes, however, it is a commonplace that someone who is taken to be morally responsible for something has to be an autonomous (enough) individual, and conversely, if someone can be assumed to be an autonomous (enough) individual, this individual will typically be held responsible for the choices she makes.

Now, in addition to these connections between responsibility and autonomy, one could also view responsibility as part of the *point* of self-determination. Being responsible for one's decisions is on this story a *privilege* had by the individual, a prudential value among others, in addition to whatever value it may have for society that its members could be held accountable for what they do. Just why it would be good for you or me to be responsible for our choices is obviously difficult to say, and one might try to work out this idea in a number of different ways. Again however, for present purposes we need not elaborate on this.

The critical issue is whether one could justify SJS by appealing to the would-be prudential value of people having responsibility for their decisions, and even in the absence of a convincing theory as to why having responsibility would be good for people, it seems to us obvious that one could not. The reason is simple: No reasonable account of what responsibility amounts to would make us responsible for an *actual* decision just because this is a decision we *would* have made under certain counterfactual conditions. The only one with significant responsibility for this decision would be the surrogate. Any responsibility for this decision that the patient would have merely in virtue of having contributed to the surrogate's substituted judgment — by being the person he or she has been, say — would surely be minor, and in any case wouldn't favor decision-making in accordance with SJS rather than some other decision-making standard (the application of which could be traced back to facts about the patient). And if we aren't responsible for decisions made if we haven't in fact made them ourselves, neither can we enjoy any benefit that having such responsibility would bring.

*Could* people be responsible for their merely hypothetical decisions, and enjoy the privilege, if any, of having such responsibility? This is not the occasion to discuss this controversial idea. It would not lend support to SJS anyway, since such responsibility would be in place even without an actual decision being made, as recommended by this standard.<sup>17</sup> Neither would it make much difference if one were to maintain that the responsibility related point of autonomy isn't only that responsibility makes life better for those who are responsible, but that there is a benefit for those who get off the hook. In the context of SJS the idea would then be that one virtue of this standard is that when surrogates choose as the patient would have, they themselves are *less* accountable for the decision than they would otherwise be. It's not clear why this would amount to a virtue, of course, but it seems reasonable that it would somewhat take the pressure off the surrogate, who might feel that he or she is facing a difficult task. Just how the surrogate would become less accountable by conforming to SJS is something of a mystery, however. It may certainly be true that if the surrogate decides as the patient would have, the latter would typically have no or little ground for blaming the former for making this decision. But that's just saying that the *patient* may not belong to those who are (would be) in a position to charge the surrogate with failing to discharge his or her responsibility.

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<sup>17</sup> One example of a view according to which the patient could be responsible in virtue of the fact that he or she would have made a certain decision, but where the surrogate deciding in accordance with SJS would not make the patient more responsible, is the one defended in Zimmerman (2002).

Surely the surrogate could still be accountable for making this decision, and since it seems clear that the patient could not be held accountable for the actual decision made, it's intriguing, to say the least, how responsibility for that decision could be made to disappear by SJS.<sup>18</sup>

*Autonomy as a final prudential value*

We have listed several possible reasons why actual self-determination might be valuable, but it could be argued that we have omitted the most obvious reason. The values listed so far have been *derivative* values — self-determination being causally *instrumental*, perhaps, in securing some other valuable state of affairs, or an otherwise *necessary condition* for something good to obtain. Fairly often, however, it would seem that we treat deciding for oneself as a *final* prudential value — part of the good life not because it can be associated with something else that is of value, but simply good in itself.

Unless one wishes to avoid all serious talk about values, or is willing to acknowledge that each derivative value generates an infinite regress of derivative values, there is no denying that something has to have final value. Neither is there anything obviously objectionable in the suggestion

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<sup>18</sup> If the issue is heavily regulated, in that the surrogate would violate the law, e.g., if he or she did not rely on SJS, this could certainly be thought to lessen the surrogate's responsibility. But responsibility for the decision would presumably not vanish altogether. Rather, some of this responsibility would be transferred to the legislator.

that self-determination is such a thing, a final prudential value, although one might be legitimately suspicious of any *quick* claim to that effect. Granting that autonomous decision-making may have final prudential value is one thing, however. It also needs to be established, if SJS is to be viewed as an autonomy standard on this ground, that the *same* final value is instantiated when someone's hypothetical decisions are respected as when his or her actual decisions are. Certainly it could be the case that SJS protects a final prudential value, but so could the Best Interest Standard, and that by itself would not make the latter an autonomy standard. And surface similarities, such as the fact the two cases both involve talk about the patient's decisions, are obviously not sufficient to settle that the same values are at stake. Anyone who proposes to justify SJS in this way thus has a burden of argument, one that, in our view, is yet to be discharged. The final prudential value of deciding as the patient would have doesn't simply follow from the final prudential value of actual self-determination — an argument is called for, that establishes that acting in accordance with SJS *achieves the same good thing* as respect for (or promotion of) actual self-determination does.

It is true that for this view to be sustained, one need not go so far as to show that it would be immaterial, value wise, whether actual decisions or merely hypothetical decisions were respected. Consider just about any case where a patient is *competent*. Here the issue can always be raised whether the patient ought to be able to make his or her own decision, or whether one ought to make that decision *for* the patient that he or she would have made, under the same or some other circumstances. One might argue that since SJS protects an *impoverished* form of autonomy — cf. the remarks to that

effect quoted above —, in such cases it is indeed usually more important to uphold the right to actual decision-making than the right to make hypothetical choices. But hypothetical decision-making would only be of *lesser* value, according to this line of thought; it would not instantiate a different *kind* of final value.

This piece of reasoning is problematic for at least two reasons. First, there are many examples of valuable states of affairs such that seemingly minor alterations result in states of affairs with possibly no value at all. Singing in tune may have a great value, while singing *almost* in tune is often unbearable; loving your children may have great value, while loving your merely *hypothetical* children seems odd at best. For all that has been argued, the same could go for the present case, where those who defend SJS on the basis of the alleged final prudential value of making one's own actual choices owe us some reason to believe that the features of hypothetical decision-making that make this a "compromised" or "softer replication" of autonomy are not the features that are absolutely crucial to the value of autonomy.

Moreover, and just as importantly, making the case that hypothetical decision-making instantiates the same *kind* of final prudential value also seems to be an uphill struggle. What seems to be particularly hard to reconcile with this view is the fact that in the situation where the patient is competent the final value of autonomy would seem to be protected only when we respect the individual's *actual* choice, since deciding on the person's behalf as he or she would have (whether under the same or some other circumstances) typically seems *paternalistic*, not only of lesser value.

That this should be alarming is evident considering that paternalism, according to common wisdom, is the very opposite of respect for autonomy.

Of course, none of this goes to *show* that SJS cannot possibly protect the same kind of final value as respect for actual decisions does. The problems just mentioned, however, highlight how utterly unfounded this position is. Why believe in the first place that hypothetical consent serves the same final purpose (albeit to a slightly lesser degree) as actual consent does, when hypothetical consent is seen as an inferior, paternalistic alternative to actual consent from a competent individual? How could you tell that we are dealing with the same value? Until this issue is seriously addressed, the idea that hypothetical decision-making mirrors the final value of actual decision-making is simply strikingly ad-hoc.

*Autonomy as demand: Darwall*

To round up this discussion, let us finally mention a recent suggestion by Stephen Darwall.<sup>19</sup> When self-determination is thought of as a final prudential value, the reason we have to respect others' decisions, or promote their decision-making, is still an "agent-neutral" reason; a reason that anyone has, who has the capacity and opportunity to bring about this beneficial state of affairs for those concerned. Maybe, however, the physician (or whoever the decision-maker happens out to be) has a defeasible obligation to respect the choice of the competent patient not

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<sup>19</sup> Darwall (2006).

because the physician has a reason to give the patient a *benefit*, as someone who is in particularly good position to do so, but because the choices that competent people make are worthy of respect *simply because they make them and claim, with specific or general address, their right to have these choices respected?* Darwall elaborates in broadly Kantian terms this idea of autonomy as *demand* (rather than benefit), by maintaining that the right to autonomy is intimately connected to the capacity and authority “to address a claim or demand to someone as a free and rational agent.”<sup>20</sup> “It is a presupposition of this [second-personal] standpoint”, he continues, “that addresser and addressee alike can accept and act on reasons that are grounded, not in the value of anything that might be an object of their desire or volition [...] but in an authority they have to make claims to each other simply as free and rational wills.”<sup>21</sup> Basically, in other words, the need for getting consent from the patient to a certain treatment would, on this view, be intrinsic to the physician taking the patient to be a full-fledged person, as it were, regardless of whether or not this person is benefited in some way (either by the outcome of the decision or by the very fact that the patient is allowed to make his or her own choice).

Needless to say, a fair amount of clarifying would have to be done before we could assess this view. Darwall’s paper obviously says considerably more about the issue, even though many of the ideas introduced await further elaboration. The outlines of this account should nonetheless be clear

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<sup>20</sup> Op cit., p. 264.

<sup>21</sup> Ibid.



enough for us to be able to see that the importance of merely hypothetical consent could not be given the same justification. In essence the proposal seems to be that the respectworthiness of people's choices are inherent in their being *competent* in a certain way, that they have a capacity to "act on reasons that our grounded [...] in an authority they have to make claims to each other simply as free and rational wills." For instance, small children are for that reason excluded from this kind of right to autonomy, on Darwall's account, even though there may well be other reasons, related to their welfare and development, for allowing them to make their own decisions. But competent in this sense is precisely what those to which SJS is primarily applicable are not. Some of them no longer make any claims, and none of them act on reasons grounded in an authority they have as free and rational wills, since they have no free and rational wills, as understood by Darwall. This is not to say that whatever respect hypothetical decisions deserve cannot somehow be derived from the justification for the right to actual self-determination suggested by Darwall. He himself just might hint in that direction, when he points out that "we certainly think we owe respect, including of their wishes, to beings who lack the full capacities necessary for autonomy of the will"<sup>22</sup>, and he promises to say more about it in his forthcoming book.<sup>23</sup> But however this derivation would go, the main point stands, viz. that it cannot be *automatically* assumed, as typically seems to be done, that SJS is justified just because there is justification for

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<sup>22</sup> Op. cit., p. 271, footnote 20.

<sup>23</sup> At the time of writing, the book isn't out yet. It should be by the time you read this.

principles of respect for actual self-determination. A special story would have to be told, on why one ought to proceed in just the way one would have reason to if there was an actual demand for autonomy. Which is just another way of saying that the justification for SJS, if there is one, goes beyond the justification for respecting actual self-determination.

### **Alternative approaches**

That SJS may not have any justification as an autonomy standard obviously does not imply that SJS cannot be justified in any way. As far as we can tell, whether or not there is some justification for SJS is still an open question. In this final section we shall briefly sketch three alternative views, among what probably are many alternatives, on the moral foundation of this standard. We offer these sketches fully aware of the fact that what we provide won't suffice for a serious evaluation, and that certainly it may turn out when all has been said and done that none of these alternative accounts could be sustained. The point of outlining alternative approaches, even in this impressionistic fashion, is merely to help those who view the autonomy foundation for SJS as almost platitudinous see and take seriously the *possibility* that the real justification for satisfying patients' hypothetical wishes lies elsewhere.

### *The Best Interest Standard properly individualized*

While the *Best Interest Standard* certainly is going through a rough period, in terms of support in the bioethics community and among legislators, there is still something obviously plausible about the thought that the ultimate aim in health care decision-making ought to be the promotion of health, quality of life, and whatever interests the patient might have in addition to

these, interests that health care could reasonably be asked to be concerned about. One of the major risks in acting in the patient's best interests, and what one may often have in mind when there is a charge of paternalism, is that there is too much emphasis on allegedly objective or allegedly shared values, and too little sensitivity to interests that are more particular to the patient, grounded in his or her own life or way of living. There is room for erring in all kinds of way here, ranging from the cursory life-at-any-price assumption to the unimaginative judgment that the quality of life for the severely disabled individual has to be meager. This neglect of the subjective, however, is not intrinsic to the idea itself, that the main requirement on decision-making for others is that they are benefited. It may just be that when this idea is put to work by health care personnel and others, i.e. when surrogate decision-makers explicitly attempt to do what they think is best for the patient, they almost can't help but end up with a judgment that reflects too much of society's values, or their own likings, and fails to give due consideration to facts about the patient that would point to utility assumptions tailor-made for this particular person.

This raises the possibility that one might stick to the *Best Interest Standard*, as the measure of good decisions, and have SJS serve as a practical antidote, in that we might perhaps maximize the chances of protecting the patient's real interests, if we *think* more in terms of SJS than in terms of promoting the patients "interests". We can here see the importance of distinguishing between SJS as a criterion of rightness, or adequacy condition, and SJS as a rule of thumb, or tool, to be employed by decision-makers or those who give decision-makers instructions on how to carry out their task. The suggestion, in other words, is that the *Best Interest Standard*,

and not SJS, is our criterion of rightness, that against which we should measure the adequacy of the proxy's decision, but that SJS, and not the *Best Interest Standard*, is what we should tell the surrogate to try to apply. The underlying assumption isn't that acting in accordance with SJS (i.e. actually choosing as the patient would have) will necessarily maximize the benefit to the patient, as some idealized preferentialist account of prudential value would suggest. Neither is there a commitment to the view that people have some epistemic privilege when it comes to the promotion of their own interests, as in the previously discussed epistemic argument for SJS as an autonomy standard. The assumption is merely that *trying* to apply SJS will probably counteract any tendency to disregard all those personal circumstances and features that help determine the patient's interests. SJS would on this story simply be a decent enough tool to ensure that sufficient attention is paid to things subjective, when one tries to benefit the patient. Whether this is plausible, of course, will depend on a number of empirical assumptions that we cannot discuss here. The point is just that, depending on how the empirical facts turn out, this story would offer a possible justification of SJS, which doesn't make SJS into an autonomy standard.

#### *Honoring a person*

Sometimes the main purpose for doing something is to *honor* somebody or something, to *show recognition*. Some of us write a paper for a Festschrift to a colleague we highly respect. The paper may not be particularly good, its topic might be quite far away from the main professional concerns of the honoree, and if against all odds many people will come to read it, there are little prospects of it making a positive difference to anything anyway. Still it would as intended manage to express appreciation, as long as certain

other conditions obtain. Such acts of recognition are often part of the moral life, and can presumably be given some kind of normative foundation. Another case: Many of us sooner or later have to deal with the death of a loved one. Some of the things we do when this has happened, surrounding a funeral for instance, serve to honor the person who has passed away. There are flower arrangements; candles are lit; we make the funeral a Christian one, if that's what the deceased would have wanted, and sing some particular hymn, if that's what he or she would have liked.

Two things are worth noting about this last example. The first is that it's not clear who, if anyone, is the beneficiary of such acts of honoring. One might hold the view that the person to whom tribute is paid still has interests, even if he or she is now dead, one of which is precisely to receive recognition of the relevant kind. One might also, however, deny that it makes any sense to think that there are such surviving interests. In that case, our expressions of respect would perhaps have to be understood as ultimately justified by what they do to those who are still alive instead, including perhaps by what they do to us. Or one might adopt a deontological approach, according to which it is an intelligible suggestion that acts of honoring of the relevant kind are called for whether or not they actually have any valuable effects on anyone.

The second, and for present purposes more important, point is that we here have an example involving SJS based thinking without there really being an issue about protecting the deceased's right to self-determination. When people are allowed to choose the music for their own wedding, the obvious reason for this is that others shouldn't interfere with their right to make

their own decisions regarding issues that concern primarily them, and won't harm others to any significant extent. It's simply a small implication of the right to lead one's own life. But when a certain piece of music is chosen for a funeral, with the justification that this is what we think that the deceased would have picked, this surely has nothing to do with dead people having some right to being self-governing. It's just a way of commemorating someone who we have appreciated.

Maybe, then, SJS could and should be understood in a similar way in the context of health care decision-making. In deciding as the incompetent patient would have, if competent, perhaps we primarily make a symbolic gesture, the purpose of which is precisely to honor this person, to show him or her respect, or recognition, as a person. Again, we might think that the incompetent patient benefits from this, or we may think that there are no such interests to protect, in which case the real beneficiaries, if there are any, are the significant others, those working with the patient, or even something more vague or general, like "society".

Why would honoring take the form of an application of SJS, rather than some other form or expression? The full answer to this will surely be a long story. But here is one possibility: In the situation where a decision has to be made, one natural way of manifesting that we *see* (or *saw*) the patient for who he or she is (or was), or at the very least *aimed* to see him or her, is perhaps by making a judgment about what this person would have decided, had he or she been able to. Such recognition, in turn, may more than anything else honor the incompetent patient, by acknowledging the individuality, or distinctiveness, of this person, as it were. And if *some*

account roughly along those lines could be made to stick, it is evident that the moral foundation of SJS has little to do with some claim to self-determination (on behalf of the incompetent patient), in the sense underlying the traditional principle of informed consent, for example. SJS would be given a justification here, but it would be an independent justification, divorced from standard reasoning about rights to autonomy.

*Human nature and the lastingness of personal relationships*

While no doubt paying tribute is part of life, be it frequent or more sporadic, one might have the view that our tendency to be concerned about what incompetent patients, or the dead, would have wanted or decided is not so “cerebral”, or considered, as this idea about honoring would seem to imply. Instead, it might be suggested, it is simply part of the normal functioning of people to go on treating incompetent others *as if* they were still competent decision-makers, to some degree and for a while at least. An individual with whom you have had a personal relationship will typically not be approached as a mere object, say, the minute those capacities that we take to be central to personhood disappear. This is simply how normal people *work*. But this may not only be descriptive of our psychology, there is perhaps also a *virtue* to be made of this necessity of sorts.

It’s not clear how this would go, of course. A consequentialist account might look for something like the world being a better place if individuals stick to the rule that others should be treated as full-fledged persons even after they have ceased to, strictly speaking, have that status. Anyone who has let herself become such that she could switch only with great difficulty, from seeing someone as a person to seeing him or her as a non-person,

might for instance be better equipped to exhibit the kind of stability and willingness to make various kinds of commitments that many human relationships profit from? Or maybe the moral issue is more one of keeping an implicit promise of sorts, consequences aside? One could, for instance, argue that personal relationships between individuals are simply in part built upon a tacit understanding that as a rule one doesn't completely stop treating one another in the autonomy recognizing way, just because competence and prototypical personhood are no longer there.<sup>24</sup> This unspoken convention that personal relationships have certain longevity should presumably be understood more as part of the culture within which humans interact, than as an individual contract, an implicit agreement between the specific individuals who have a personal relationship with one another. It pervades our activities and the way society is organized, is part of the game we play, as it were, and is not so much an optional settlement between particular individuals. In any case, this proposal would not amount to saying that the incompetent have a right to self-determination for the same reason as competent people should be allowed to be, within limits, self-governing. At most, it would amount to saying that it's intrinsic to personal relationships, as these are understood in the cultural framework that gives sense to our way of living, that one normally proceeds *as if* there was still autonomous decision-making worthy of respect, even when there isn't.

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<sup>24</sup> Stephen Darwall's ideas about the "second-person standpoint" seem very much to the point in this context.



*Some possible implications*

We have suggested the mere outlines of three different views on the justification of SJS, on which this decision-making standard is not an autonomy standard. Now, if any of these kinds of alternative account is on the right track, we'd perhaps do well to rethink certain aspects of the standard. As SJS is normally formulated, it appears rather *demanding*: the surrogate is supposed to identify that one decision which the patient would have made, and no other decision would do. But it's not obvious, on either of those stories, that one would have to be that strict. For one thing, at least on the latter two ways of justifying SJS, shouldn't *aiming* for correctness, with good-enough internal evidence, suffice? The symbolic utility of the act would presumably remain the same, and neither would it affect the soundness of continuing a relationship with the patient as if he or she would have been competent, that the decision made may not be exactly the decision the patient would have made, had he or she been competent. And not only do these approaches suggest a move from the importance of accuracy (although this may still be important from the perspective of the surrogate) to the importance of having sufficiently good subjective reasons for believing that this is what the patient would have decided. They also suggest that even more important than trying to get it right, might be to *avoid getting it way wrong*. It may be, for instance, that surrogates are to be applauded if they (try to) figure out exactly what the patient would have decided, but that their morally important task is merely (to try) not to make a decision that the patient would *never* have done. Sometimes this might be all that is needed for the surrogate to pay sufficient attention to this very individual's well-being, for example, as suggested by the view according to which SJS should be seen as a tool for satisfying the *Best Interest*

*Standard.* In fact, such a loosening of the SJS requirement seems to fit well with all of these alternative moral foundations for SJS. And the less demanding standard may furthermore often be the one we put to work in real health care decision-making, which would lend some independent support to these alternative ways of defending SJS.

### **Concluding words**

We have argued that there is little support for the orthodox view that SJS is an *autonomy* standard. We wish to reemphasize that what we mean by this is just that however one wants to define “autonomy” and related terms, the normative reasons for deciding as the patient would have, if there are any, appear not to be the same as the reasons we have for not interfering with the choices of competent patients. Certainly, under some sufficiently general description, the right to have one’s hypothetical decisions respected, and the right to have one’s actual decisions respected, may come to the same right; the right perhaps, to get respect for one’s person, or one’s dignity. But those are broad and somewhat elusive notions, ones that in the present context more serve to mask the many striking normative differences between the two cases than to say anything particularly informative about their similarities. We wrote this paper against the background of a common temptation to buy into clearly simplistic view on SJS, according to which SJS is obviously the standard to turn to when one wants to protect incompetent patients’ right to self-determination, in just the way regular autonomy principles protect this right when it comes to competent patients. Whatever interesting connections between the two there may be, this just cannot be right. SJS embodies an interesting thought about what surrogate decision-makers ought to do, and deserves a more conscientious defense

than the reflex like appeals to patients' right to self-determination typically on offer.

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