



# Clarifying substituted judgement: the endorsed life approach

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## ABSTRACT

A primary goal of clinical practice is to respect patient autonomy. To promote this goal for patients who have lost the ability to make their own decisions, commentators recommend that surrogates make their treatment decisions based on the substituted judgment standard. This standard is commonly interpreted as directing surrogates to make the decision the patient would have made in the circumstances, if the patient were competent. However, recent commentators have argued that this approach—attempting to make the decision the patient would have made if competent—is theoretically problematic, practically infeasible, and ignores the interests of the patient's family and loved ones. These commentators conclude that the substituted judgment standard should be revised significantly, or abandoned altogether. While this response would avoid the cited problems, it also would require substantial changes to clinical practice and would raise significant problems of its own. The present paper thus considers the possibility that the criticisms do not point to problems with the substituted judgment standard itself; instead, they point to problems with the way it is most commonly interpreted. This analysis suggests that the substituted judgment standard need not be dramatically revised or abandoned. Instead, it should be interpreted in a way that effectively promotes respect for the autonomy of incompetent patients. The 'endorsed life' interpretation described here helps clinicians and surrogates to achieve this important goal. To clarify this approach, we explain how it differs from three other recently proposed alternatives to the standard interpretation of the substituted judgment standard.

Clinical practice respects patient autonomy by allowing competent adults to decide, in consultation with their clinicians, which treatments they receive, including no treatment at all.<sup>1</sup> When adult patients lose the ability to make decisions, clinical practice relies on patient-designated or next-of-kin surrogates to make treatment decisions for them.<sup>2</sup> For example, a recent study found that 47% of adults over 65 years of age required surrogate decision making within 48 h of hospitalisation.<sup>3</sup>

In some cases, the only option available to a patient's surrogate is to maximise patient comfort to the extent possible. In many other cases, surrogates face difficult decisions regarding whether and how incapacitated patients are treated. Surrogates are instructed to make these decisions based on the patient's own directions, as specified in a formal advance directive or in earlier discussion.<sup>4</sup> When the patient did not provide any previous directives, or the patient's previous directives are not sufficient to determine which treatment option should be

pursued, many commentators argue that surrogates should make decisions based on the substituted judgment standard (SJS).

Appeal to the SJS is intended to continue to respect patients' autonomy, even after they lose the ability to make their own decisions, and even when they did not provide definitive guidance for how they should be treated. It is often assumed that the best way to achieve this goal is for surrogates to make the decision the patient would have made in the circumstances, if competent. This 'standard' interpretation of substituted judgment has been widely endorsed. Nevertheless, recent commentators have argued that this approach to surrogate decision making has serious shortcomings. Some argue that it is practically impossible to implement.<sup>5 6</sup> Some argue that it is theoretically problematic.<sup>7</sup> Still others argue that it ignores the interests of the patient's family and loved ones.<sup>8</sup> These commentators conclude that the SJS should be revised significantly, or even rejected.<sup>9</sup>

One way to address the problems with the SJS would be to abandon the attempt to respect the autonomy of patients who have lost the ability to make their own decisions and, instead, promote other patient-centred goals. For example, rather than attempt to respect autonomy, surrogates might try to protect and promote the patient's medical interests. More radically, given the difficulties frequently associated with determining what is in the best medical interests of incompetent patients, one might argue that we should abandon a patient-centred approach altogether and focus on promoting other goals that are more likely to be achieved. Surrogates, the vast majority of whom are the patient's family members and loved ones, might instead make treatment decisions based on what is best for them, without trying to determine what the patient would have wanted or what might be best for the patient. Alternatively, treatment decisions for incompetent adult patients might be based on what is best for the healthcare system, including what is best for the clinicians caring for the patient and what is best for other patients in the system.

While these approaches might address some of the concerns faced by the SJS, they would involve significant changes to common clinical practice. They also raise their own theoretical problems. Consider briefly a patient whose Alzheimer disease progresses to the point where they are no longer able to make decisions for themselves. It seems problematic to say that just before this point is reached, we should defer to their decisions, but the moment they become incapacitated, we no longer should take their preferences, interests or values into account. Although development of incapacity



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makes it significantly more difficult to determine what the patient wants and what might be in their interests, it does not seem to eliminate the moral claims the patient has on us to try to provide treatment consistent with their values and interests. Given these concerns, the present manuscript considers whether the problems with the SJS might be addressed without having to make significant changes to current practice.

Specifically, we propose to consider the possibility that the extant criticisms of the SJS apply to the way it has been commonly interpreted, not to the SJS itself. If this is right, the criticisms do not provide a reason to fundamentally alter how clinicians ordinarily treat incompetent patients. Rather, they point to the need for a new interpretation of the SJS, one with sufficient nuance and robustness to deal with the cited problems.

We argue that surrogates can help to respect patient autonomy by choosing the option that best promotes the course of life that the patient valued. On this analysis, the standard interpretation of the SJS—make the decision the patient would have made in the circumstances, if competent—offers a useful rule of thumb or heuristic for implementing the SJS in many contexts. In particular, patients frequently make decisions based on the type of life they value for themselves. Hence, considering what decision the patient would make often yields the decision that promotes that type of life. At the same time, this is not always the case. For example, some patients make what they themselves regard as systematic mistakes and poor decisions in certain settings. In these cases, appeal to the endorsed life approach allows surrogates to avoid the same mistakes and promote the life the patient valued for themselves. This analysis suggests that the ‘endorsed life’ interpretation of the SJS may avoid the practical and theoretical shortcomings faced by the standard interpretation, while still promoting respect for the autonomy of patients who have lost the ability to make their own decisions and did not provide definitive guidance for how they want to be treated.

We begin with two points of clarification before proceeding. Many incompetent adults can express preferences for how they wish to be treated based on their (typically limited) understanding of the circumstances. They can indicate that they do not want to go to the hospital or they do not want to receive a particular treatment. These cases raise difficult and important issues regarding how best to balance the present expressed wishes of incompetent individuals with the competent preferences of the same individual. For present purposes, we will bracket this issue by focusing on incompetent patients who are unable to offer input regarding their treatment (e.g., patients in a coma) and incompetent patients who do not object to the course of treatment selected by their surrogate. Second, the standard interpretation’s appeal to what the patient would choose, if competent, makes sense for incompetent adults who were once competent. We will maintain this focus and limit our analysis to adults who were once competent and thus had the opportunity to competently formulate their own values. The question of how to treat children and adults who were never competent raises distinct issues that merit their own analysis.

### THE STANDARD INTERPRETATION OF THE SJS

The SJS was originally described in several 19th century English court decisions, including *Ex Parte Whitbread* (1815), *In Re Blair* (1836) and *In Re Earl of Carysfort* (1840). At the time, English courts were permitted to distribute the property of incompetent adults only in ways that benefitted the individuals themselves. This principle prevented courts from distributing the property of incompetent adults in ways that did not benefit

the individual, but that the individual themselves would have endorsed. For example, in *Whitbread*, the principle that the property of incompetent adults should be used for the individual’s benefit only prevented the courts from distributing money to close relatives in need, even when it was clear that the individual would have wanted the money to go to their relatives. To address this concern, the courts endorsed the SJS, which allowed them to take into consideration how the incompetent individuals would have wanted their money to be used.

In the 1960s and 1970s, US courts faced difficult cases involving the medical treatment of adults who had lost the ability to make their own decisions, including *In Re Quinlan* (1976) and *In Re Guardianship of Pescinski* (1975). The courts recognised that, as in the earlier English property cases, their decisions should be based on the patient’s wishes, not based on how the courts or others wanted the patient to be treated. To promote this goal, the courts adopted the SJS. Some courts, including the court in *Mtr of Eichner* (1980), described the SJS in terms of promoting the patient’s best interests. Others, such as the court in *Superintendent of Belchertown State School v. Saikewicz* (1977), described the SJS in terms of making the decision the patient would have made if competent. Over time, this latter characterisation became the standard interpretation. As a result, the SJS is now widely understood as instructing surrogates to ‘make the decision the incompetent person would have made’<sup>2</sup> or to choose ‘as the incompetent individual would choose in the circumstances were he or she competent.’<sup>4</sup>

It is not surprising that this interpretation of the SJS has gained wide acceptance in medical contexts. It is consistent with the description of the SJS favoured by some courts and it is easily explained and, at least ostensibly, easily understood. In a complicated medical scenario involving an incompetent adult patient, it is relatively straightforward to instruct the surrogate to choose the option that they believe the patient would choose for themselves, if competent. Further support for this approach comes from the fact that respecting the autonomy of competent adults involves treating them based on the option they choose for themselves. Hence, it initially seems plausible to assume that respecting the autonomy of now-incompetent adults involves treating them based on the option they would choose for themselves, if competent. Despite the plausibility of this line of reasoning, recent commentators have argued that the SJS is problematic in several important ways.

### CRITIQUES OF THE SJS

#### Practical difficulties

Most incompetent patients who are in need of treatment never faced the same, or even similar circumstances, while they were competent. As a result, in many cases, it is extremely difficult or even impossible to determine what decision someone who is now incompetent would make in the circumstances, if she were competent.<sup>10 11</sup> Surrogates can attempt to draw on other information, such as past conversations with the patient, to determine what the patient would have decided in the present circumstances. Yet, empirical studies find that patient-designated and next-of-kin surrogates frequently are unable to correctly identify what choice their charges make while capacitated.<sup>12</sup> These data suggest that surrogates are unlikely to be able to accurately identify what choice an incompetent patient would have made if competent.

These studies posed a range of treatment scenarios separately to competent patients and to their surrogates, asking patients to indicate what treatment they would want, and the surrogates to predict what treatment the patient chose. When the scenario

involves significant changes to the patient's health status, surrogates are only slightly better than chance at predicting what choice the patient makes.<sup>12</sup> The stress, anxiety, uncertainty and complexity that is associated with actually making decisions for a loved one who has become incapacitated and needs medical treatment likely further reduce surrogates' ability to make accurate substituted judgments. Critics conclude that reliance on the SJS 'amounts to complicated guesswork,' and puts surrogates in an almost impossible situation.<sup>6</sup>

### Theoretical problems

We respect competent patients' autonomy by treating them based on the decisions they actually make.<sup>13</sup> By contrast, respect for autonomy does not provide a reason to treat competent patients based on decisions they would have, but never in fact, made. This line of reasoning suggests to some commentators that the standard interpretation of the SJS—make the decisions the patient would have made, if competent—has 'nothing to do with respecting the patient's capacity for self-determination.'<sup>14</sup> The problem, on this view, is that it is not possible to respect the autonomy of incompetent patients who did not provide any directives for how they should be treated. These commentators conclude that the SJS should be replaced.<sup>15</sup>

Other commentators argue that 'considering what an incompetent person would do if competent' ignores the most important aspect of the case in question, namely, the fact that the patient is not competent.<sup>16</sup> Consider a surrogate who has to make treatment decisions for a relative who has had a stroke. The standard interpretation of the SJS, taken literally, seems to instruct the surrogate to imagine that her relative is now competent. However, if the relative were competent, she presumably would not have had the stroke, in which case there would be no need to make a treatment decision. The fact that a healthy person would not choose to take medications for a stroke obviously does not provide reason to avoid treatment now that she has had a stroke. These commentators conclude that the SJS ignores the most important aspect of the cases to which it applies, and should be abandoned.

Next, how incompetent patients are treated can have profound consequences for their family and loved ones.<sup>17</sup> For instance, whether a ventilator is continued for an incompetent patient, or withdrawn, can have profound emotional and financial consequences for the family. Additionally, the process of making treatment decisions itself can place significant stress on surrogates. Deciding for a loved one whether they remain on a ventilator or are withdrawn and then die can lead to significant anxiety and guilt.<sup>18 19</sup> It can leave surrogates feeling that they killed their loved one and wondering if they were right to do so.

Critics argue that instructing surrogates to make treatment decisions based on the decision the patient would make seems to disregard the interests of the surrogate and loved ones. For example, making the decision the patient would make for themselves if competent seems to eliminate from the decision-making process the fact that someone else is making the decision for them. The patient, if competent, may have chosen to remove their own ventilator. However, in cases where making this decision would place enormous burden and guilt on the surrogate, the patient may prefer that the surrogate elect to keep them on the ventilator. In this way, the SJS's emphasis on respect for patient autonomy seems to ignore 'the interests of my family members'.<sup>8</sup> These critics conclude that the SJS should be replaced with a standard that better takes into account the interests of the patient's family and loved ones.<sup>8 15 20</sup>

These criticisms point to legitimate concerns with how the SJS has been interpreted and applied. At the same time, the SJS provides a way to make decisions that can help surrogates and clinicians, and has become a standard part of clinical practice. Hence, we should be reluctant to abandon the SJS altogether, as critics advocate, unless it is not possible to identify a better interpretation that addresses the critics' concerns. Ideally, such an interpretation would be compatible with current clinical practice in contexts where the SJS is already working well, but will clarify the application of the SJS in cases where its use is problematic.

### THE ENDORSED LIFE APPROACH

The early English courts recognised that the assets of incompetent individuals should not be distributed based on the judge's personal preferences. Similarly, surrogates should not make treatment decisions based simply on their own preferences, without regard for the patient's wishes. The SJS was introduced in the medical context as a way to allow patients' course of treatment to be guided by their own wishes, even after they lose the ability to make their own decisions. Imagining what decision the patient would make in the circumstances provides a useful rule of thumb for helping to further this goal. Simply put, patients typically make decisions based on what best promotes their values. At the same time, the criticisms reveal that there are cases for which this rule of thumb is not appropriate. In such cases, the central goal of the SJS—to promote autonomy by taking into account the wishes of incompetent patients—remains essential.

To address the difficulties highlighted by the critics, consider an alternative interpretation of the SJS, the 'endorsed life' interpretation. This interpretation understands the SJS as directing surrogates to make decisions based on which option best promotes the life the patient valued for themselves, including the influence the patient wanted to have on the lives of others. This interpretation has the virtue of basing treatment for incompetent patients on the patient's own values, without appeal to the fiction that the patient currently is able to make decisions.

Even patients who never indicated how they wanted to be treated in the event of incapacity likely offered indications of the sort of life they valued for themselves, or the kind of treatment that they regarded as good or bad for them. For instance, an individual may have placed great value on living independently, or on the interests of her loved ones, or she may have consistently valued quality of experience over quantity. Another patient may have valued fighting on, even when the costs are high and the chances of success are low. Respecting these patients' autonomy is not a matter of appeal to counterfactuals. It is not a matter of guessing what they would choose now if they were competent. Instead, it involves basing treatment decisions on the type of life that the patient, in fact, endorsed for themselves. This approach respects patient autonomy by allowing the course of life that the patient endorsed while competent, their values and dreams, to continue to determine the course of their lives, even after they are no longer competent.

The endorsed life interpretation regards 'the decision the patient would make for herself, if competent' as one way to try to determine what treatment option is most consistent with the life the patient valued for themselves. Since individuals typically make decisions based on the life they value for themselves, imagining what decision the patient would make in the circumstances often provides a way to promote this goal. Hence, this approach can be a useful rule of thumb, and should not be

discarded. However, in other cases, this approach will lead to choices that are inconsistent with the patient's endorsed life.

Consider an unconscious patient who, while competent, often made mistakes in assessing probabilities, or frequently fell prey to a particular cognitive bias, such as choosing the option that is framed in terms of avoiding harms rather than the one framed in terms of gaining benefits. The fact that the individual, if competent, would make decisions on this basis, does not provide a good reason to make decisions in that way now that they are incompetent. It does not respect the patient's autonomy to say: 'he would have misunderstood the risks, therefore I should make my decision based on the same (mis)understanding.'

To consider a more complicated case, imagine that the patient avoided needles and injections while competent, and is now in need of intravenous antibiotics. Given that the patient would decline the antibiotics if competent, the standard interpretation, understood literally, suggests that the surrogate should decline the antibiotics as well. On the endorsed life interpretation, the fact that the patient would decline the intravenous antibiotics, if competent, is relevant to, but not determinative of, what decision the surrogate should now make. It depends on *why* the patient avoided needles. Does this trace to the fact that the individual valued a life free of needles, or to something else? One possibility is that the patient avoided needles because injections are inconsistent with her fundamental values. Perhaps she endorsed a religious view which held that invasive procedures are inappropriate incursions into a sacred sphere. This view would provide a strong moral reason for the surrogate to decline the antibiotics on the grounds that the patient endorsed for herself a life free of injections. By contrast, if the avoidance of needles was the result of a fear that the patient regretted and viewed as baseless, but was never able to overcome, the fact that the patient refused injections while competent does not provide a reason to avoid intravenous antibiotics now that she is incompetent. There is no respect for the patient in saying: 'she was unable to bring herself to accept injections so we should reject them on her behalf.' In this way, the endorsed life interpretation does not ask simply what decision patients would make for themselves, if competent. Similarly, it does not ask simply what preferences the patient happened to have while competent. Instead, it considers their attitudes towards those preferences and the decisions that resulted from them.

When competent patients are faced with a decision, they make a particular choice. Thus, the standard interpretation of the SJS seems to imply that there is a single correct choice in every case, and the surrogate has the burden of identifying it based on limited information. By contrast, the endorsed life approach recognises that depending on the circumstances, several options may be equally consistent with the life the patients endorsed for themselves, and allows the surrogate to draw on a wider range of information about the patient to determine which options those are. Of course, this approach does not render the job of surrogate an easy one, but it may, nonetheless, reduce surrogate burden to recognise that there is not always just one correct decision that the surrogate is charged with identifying.

## THEORETICAL FOUNDATIONS

To understand the endorsed life approach, and how it differs from the standard interpretation of the SJS, it is helpful to distinguish at least two different aspects or senses of respect for individual autonomy. Perhaps the most basic aspect of respect for individual autonomy involves a negative sense of not interfering with the choices or decisions of competent adults. This

sense implies that competent adults should be allowed to make their own decisions independent of the interference, manipulation or coercion of others, based on whatever considerations the individual happens to rely on. This sense of respect for individual autonomy is sometimes referred to as respect for individual self-determination. However, this term can refer to the negative aspect of others not determining the course of one's life or to the positive aspect of one actively determining the course of one's life. To emphasise the fact that this aspect of respect for autonomy is based on the value of non-interference, we will refer to it as respect for individual liberty.

Respect for individual liberty promotes the goal of ensuring that our lives are not controlled or determined by the preferences, values, decisions or choices of others. If our liberty is respected, then the course of our lives is determined by the choices that we make for ourselves. Respect for individual liberty is based on recognition of the fact that much of the value of individual autonomy is negative, it lies in others not determining how our lives go. The value of non-interference implies that the mere fact a competent adult makes a decision for how their lives should go provides an important reason to respect that choice, independent of the extent to which the choice is wise or promotes the individuals' interests or even is consistent with the individual's own values.

One way to understand the standard interpretation of the SJS is in terms of the recognition of the central importance of respect for individual liberty. We respect competent adults by treating them based on the decisions they make. Hence, the way to respect incompetent adults is to treat them based on the decisions they would make if competent. The fundamental problem with this approach is that the value of being in control, *per se*, depends on one being able to make one's own decisions. It is essentially impossible to realise this value with respect to individuals who are no longer able to make their own decisions and did not leave any directives for how they want to be treated. While one could abide by the principle in these cases, the value of doing so is lost.

Imagine an individual who suffers a closed head injury as the result of a car accident and is now unconscious without having left any directives for how they want to be treated in the circumstances. It is possible, in this case, to act in accordance with respect for individual liberty by not interfering in the course of the individual's life. Emergency personnel could do this by declining to touch or move the individual at the scene of the accident. Clinicians at the hospital could do this by leaving the individual on the gurney in the hallway and not doing anything to or for the patient. In short, the clinicians could decline to treat the individual as a patient. While this (non-)treatment would not interfere with any exercise of control by the patient, it would not involve the clinicians respecting the individual's liberty. In the circumstances, the clinicians cannot respect the individual's liberty. They cannot allow the individual to control the course of his treatment because the patient is not able to now make decisions and did not prospectively indicate how he should be treated.

Given that it is impossible to respect the liberty of unconscious adults who left no directives for how they should be treated, one might conclude that there is no sense in trying to respect their autonomy, full stop. This line of reasoning suggests that we ought to abandon the SJS. However, the fact that we cannot respect the liberty of incompetent adults leaves open the possibility that we can respect their autonomy in other senses. In particular, the value of respect for autonomy goes beyond simply allowing individuals to be in active control and

recognises the value in allowing individuals to form and carry out plans for how their lives should go. While it is not possible to respect the liberty of individuals who are now unconscious (and who did not specify in advance how they should be treated), we can still respect their autonomy by helping to bring it about that the course of their lives going forward is based on their own values and views regarding how their lives should go.

The decisions individuals make and the decisions that promote the life they value for themselves can diverge when individuals make mistakes. For example, a competent patient may fail to recognise their own values, or they may be unable to make the decision that best promotes their values for other reasons, such as an irrational fear. It is also important to note that the life individuals value for themselves frequently underdetermines the choices they should make. In many, likely most choice decisions, the life that we want to lead does not uniquely privilege one option over all the others. The decision of which of 5 favourite restaurants to go to or which outfit to wear on a given day, frequently cannot be resolved by appeal to the type of life that one wants to lead. In many cases, one simply makes a choice and follows where the choice leads. Again, respect for individual liberty provides an important reason to respect the individual's choice in these cases, even though the option they choose does not better promote their interests, and is not more consistent with their values than the other options available to them. This reveals that, on the endorsed life approach, there may not in some, perhaps many cases, be a correct choice that the surrogate is challenged with identifying. Once the patient loses the ability to make these decisions, there is no value (for them) in trying to predict which pair of socks they would arbitrarily have chosen to wear.

For many individuals, how they want their lives to go depends in deep and complicated ways on the impact that their life has on the lives of others. The endorsed life interpretation is based on the life the patient valued for themselves. For at least most people, the life we value is broader than just the experiences we have. It also includes the impact our lives have on others. In this way, it takes into account the interests of the patient's loved ones to the extent that the patient valued their interests. Many parents base their views of the good life for themselves on having a positive impact on the lives of their children. Being in love frequently involves an inability to disentangle what constitutes a good life for oneself from what constitutes a good life for one's loved ones.

While respect for liberty does not apply to incompetent adults (reminder: we are bracketing the question of the extent to which the care of incompetent patients should be guided by their currently expressed wishes), respect for their autonomy in this sense does. Even when a patient loses the ability to make their own decisions, we can make treatment decisions for them that promote the life they endorsed for themselves. This approach is justified on at least two grounds. First, making decisions based on which treatment option is most consistent with the course of life the patient endorsed for themselves shows respect for the things that the patient themselves valued, such as the fulfilment of plans they cared about. This approach also provides patients with a kind of indirect control over their lives once they become incapacitated. Through advance directives, competent individuals can exert a type of direct control over the future course of their lives. They can specify, e.g., that they do not receive mechanical ventilation. For patients who did not provide any advance directives, whether formal or otherwise, the endorsed life interpretation provides some indirect control in the sense that the treatment they receive when they are no

longer competent is based on the life that they endorsed for themselves while competent. It is not simply based on the decisions they made, whatever the reasons for those decisions. Instead, it is based on the values they promoted and the life they wanted to lead.

Individuals often change the kind of life that they endorse for themselves over time. This raises the question of which endorsed life should be the goal of surrogate decision making. The fundamental principle in this regard is that respect for individuals' views on how their lives go includes respect for changes that competent adults make in how they want their lives to go. We do not respect a competent 60-year-old patient by basing treatment decisions on the values they endorsed when 30 years old. We respect them by treating them based on the values they presently endorse. Similarly, if a now-incompetent patient completed several conflicting advance directives while competent, we follow the one they most recently completed. In practice, individuals will endorse different aspects of a life at different times; we cannot perfectly capture a person's wishes about all the aspects of the life that they endorsed for themselves by appeal to their last competent moment. However, values that we know a patient abandoned while competent should not be taken into account by their surrogate.

The claim that we respect the autonomy of the present incapacitated patient by making treatment decisions based on the life they endorsed when last they were competent assumes that the incapacitated patient and the previously competent individual are the same person. This assumption will not hold when the processes that led to decisional incapacity (e.g., stroke) cause such drastic changes to the patient's brain that the person who exists after these changes is literally a different person than before. Although cases involving a change in personal identity are of theoretical interest, they are of limited practical relevance. It is exceptionally rare that an incapacitating injury or disease damages the brain enough to destroy one person but leaves sufficient cognitive function for a literally different person to emerge.

Like respect for liberty, basing decisions on the life the individual endorsed for themselves has both individual and societal value. It allows the life the individual endorsed to continue to be realised even after they have lost the ability to actively pursue it. It, thereby, provides reassurance for other patients that their care in the event of incapacity will be based on their own choices and values. It also, like respect for liberty, provides some break on abusive practices that might result if we reject a patient-centred approach entirely. It helps to prevent individuals and institutions from pursuing whatever course of treatment is best for them independent of the impact it has on the patient and the patient's interests and values. To clarify the endorsed life approach further, the next section evaluates how it compares to three other proposed alternatives to the standard interpretation of the SJS (table 1).

## OTHER VIEWS

### The authentic life approach

Daniel Brudney emphasises the aforementioned point that respect for individual liberty, what he refers to as self-determination, is not relevant for adults who have lost the ability to make their own decisions. He writes:

The will is not in the picture. The reason to find a surrogate for Bill is that here and now, at this very moment, Bill is not capable of the competent exercise of his will. He is no longer self-determining. By hypothesis, there can be no present competent exercise of Bill's will; otherwise, he wouldn't need a surrogate.<sup>14</sup>

**Table 1** Approaches to surrogate decision making

	Standard interpretation of SJS	Authentic life (Brudney)	Substituted Interests (Sulmasy and Snyder)	Family interests (Chan)	Endorsed life
Goal	Do as the patient would do	Continue the life the patient led	Promote the patient's best interests	Promote the family's interests	Promote the life the patient valued
Implementation	Choose the option that the patient would choose, if competent	Choose the option that best balances the authenticity of the patient's life with competing considerations	Choose the option that promotes the patient's interests, as informed by their preferences and values	Family makes decision collectively	Choose the option that best realises the life the patient valued for themselves
Is the life the patient lived relevant?	Yes, as evidence of what the patient would have done	Yes; try to continue the same life.	Yes, as evidence of what's in the patient's interests	Only to the extent it is relevant to the family	Yes, as evidence of what the patient valued
Are family preferences relevant?	No	Possibly, because family preferences may outweigh the importance of promoting an authentic life	Only if satisfying family preferences is in patient's best interests	Yes, family preferences matter regardless of what the patient wanted	Yes, to the extent the life the patient endorsed for themselves includes concern for their family's welfare.
Role of advance directives	Take priority over SJS	Take priority over SJS	Provide evidence of what is in the patient's best interests	Generally not used	Take priority over SJS

SJS, substituted judgment standard.

If the patient is not in a position to exercise his will, one might conclude that surrogates should then attempt to promote the patient's best interests. Brudney argues that there is another option. We should use the SJS, not to make the decision the patient would have made, but instead to promote the authenticity of the patient's life in the sense of continuing the life that the individual lived. In effect, the goal of the SJS on this view is to minimise the break between the life the patient lived and the way the patient's life goes now that they can no longer make their own decisions: 'On this view, deferring to the answer to the "What would the patient choose?" question, maintains the coherence of the patient's life.'<sup>14</sup>

Brudney points out that the life the individual lived, and maintaining its authenticity, does not have as much normative weight as the decisions a competent adult makes for their own lives. One reason for this is that sometimes: 'authenticity will involve false beliefs, poor reasoning, and so forth. Then the right thing to do might be to accede to best interest considerations.'<sup>14</sup> Thus, on Brudney's view, the option that would best continue the life the individual led is one, among several important considerations. The others include at least the patient's best interests and the interests of others, especially the patient's family and loved ones:

If the family's interests are relevant then sometimes those interests might tip the scale. Understanding the moral underpinning of the 'what would the patient choose?' question as authenticity not self-determination makes such outcomes more likely since authenticity seems easier to override than self-determination.<sup>14</sup>

The present analysis agrees with Brudney's fundamental point that respect for individual liberty (self-determination) is not relevant with respect to patients who have lost the ability to make their own decisions (and failed to leave directives for how they should be treated in the circumstances). We also support Brudney's goal of finding an alternative basis for the SJS rather than simply appealing to the patient's best interests. Brudney finds this basis in the life that the individual lived, whereas the endorsed life approach finds it in the life that the individual valued for themselves, whether or not they, in fact, lived that life. Brudney hopes to minimise the break in the narrative before and after the patient loses the ability to make their own decisions. The endorsed life approach, by contrast, may countenance a significant break, depending on the extent to which

the life the individual lived is consistent with the life they valued for themselves.

To see this difference, consider a patient who loved his family. However, when under the stress of making medical decisions, he frequently found himself becoming angry at his family over minor issues and making decisions without regard to their interests. Continuing the life that the patient lived would suggest that we should make decisions that do not take into account the interests of the patient's family (note: the standard interpretation of the SJS would yield the same result). This is the decision that continues the life the patient in fact led. However, imagine that the patient also consistently regretted making these decisions afterwards and would apologise to his family, stating that their interests were very important to him and wishing that his anger did not 'get the best of him'. There seems to be very little value, if any, in continuing this pattern of decision making after the patient loses the ability to make his own decisions, despite the fact that it would continue the life that the patient lived.

By contrast, there is significant moral value in making decisions based on the life the patient valued for themselves. The endorsed life approach recognises this value by directing surrogates to make decisions based not on the choices he, in fact, made—ones that did not take into account his family's interests—but on the life he wanted to lead. The life that the individual valued for themselves has greater normative weight than the life they simply happened to live. Thus, the endorsed life approach, as contrasted with the authentic life approach, yields decisions that we should morally be very reluctant to over-ride.

Finally, there is little data on how surrogates think about substituted judgment. However, one study suggests that surrogates think of substituted judgment along the lines of the endorsed life approach, that is, as a means, not for making whatever decision the patient would have made for themselves or promoting the life the patient happened to lead, but in terms of honouring the patient's values.<sup>21</sup>

### The Substituted Interests model

To consider a second alternative, the Substituted Interests approach emphasises the goal of making the decision that 'advances the good of each patient as a unique individual'.<sup>15</sup> The standard interpretation of the SJS argues that decisions should be based first on what decisions the individual made,

including preferences indicated in an advance directive. When the patient did not leave any instructions, surrogates should make decisions based on which option the patient would have chosen if competent. And, when that is unknown, surrogates should attempt to promote the patient's best interests. On this approach, the earlier steps take precedence over the later steps.

The Substituted Interests approach proposes to integrate these steps into one model. Under the Substituted Interests approach, surrogates should make decisions based not on what the patient would choose, but on what they think is best for the patient. Described in this way, the Substituted Interests approach may sound like another way of characterising the best interests standard. However, the point of this approach is to emphasise that what is best for an adult who has lost the ability to make their own decisions is not independent of how they lived their lives. Instead, in deciding what is best for the patient, the surrogate should take into account the type of person they are, where this includes taking into account their 'authentic values, wishes, and real interests'.<sup>15</sup> This approach thereby recognises that what is best for an individual depends, to some extent, on their own values. The Substituted Interests approach also has the advantage over the authentic life approach of focusing on the patient's values rather than more broadly on the life the patient lived, independent of the extent to which it was consistent with the patient's values.

The bases for the substituted interests approach and the endorsed life approach are very different. The Substituted Interests model moves away from 'the autonomy the patient cannot exercise'.<sup>15</sup> The endorsed life approach agrees that it does not make sense to attempt to respect the liberty of adults who have lost the ability to make their own decisions. However, it is based on the assumption that it makes sense in theory, and is, to some extent, possible in practice to continue to respect the autonomy of adults who have become incapacitated. It does this, as noted, by making decisions based on the life the individual endorsed for themselves while competent. Of course, the life the individual endorsed depends crucially on their values. Thus, both the substituted interests approach and the endorsed life approach will make similar decisions in many cases.

The extent to which the two approaches will endorse the same treatment choices depends on the extent to which our interests are determined by our values. To the extent that our interests are determined by objective factors beyond just what we happen to value, the two will come apart—our best interests will not depend solely on the life we value. The approaches also will come apart to the extent that one endorses a preference satisfaction view of interests such that an individual's interests are determined by what the individual in fact wants or prefers, independent of the extent to which the individual values or endorses those preferences.

To see this difference, consider how the two views would handle the example of an adult Jehovah's Witness who very much wanted to live a life that never involved blood products. On the endorsed life approach, the patient should not receive blood products because that is the life he endorsed for himself. On the Substituted Interests approach, one needs to first ask whether receiving blood products would promote the patient's interests more than not. On this approach, the fact that the patient opposed receiving blood products is relevant to, but not determinative of how they should be treated. The surrogate needs to ask whether the extent to which the patient's interests are set back by receiving blood products might be outweighed by other considerations, including the extent to which their interests are promoted by extending the length of their life. Hence, the Substituted Interests approach might recommend

that surrogates make one choice if the patient is young and potentially has a long life ahead of them, and a different choice if the patient is older, such that saving their life does not provide a sufficient number of extra years to compensate for the harm of receiving the transfusion.

### Family interests

Some critics point out that the standard interpretation of the SJS runs the risk of ignoring the interests of the patient's family and loved ones, and ignores the fact that someone else must make decisions for the patient.<sup>22 23</sup> Moreover, they point out that it is not possible to respect 'the patient's capacity for self-determination, either past or present'.<sup>12</sup> One option then is to argue that incompetent patients should be treated according to the preferences of the family and loved ones, even when their preferences conflict with the preferences of the patient.<sup>8</sup>

While this view makes sense, we argue that it is problematic both in terms of how it treats specific individuals and as a matter of policy. Consider the prior example of patients with Alzheimer disease who slowly lose cognitive capacity over time. Initially, while they are losing some capacity they retain competence and are able to make their own decisions. However, at some point, they lose either a critical capacity, or their abilities with respect to one of the critical capacities drops below the threshold that is necessary for competence. Consider an individual just before and just after this transition. Just before the transition, we respect the decisions they make even when their family strongly objects. However, the family interests view endorses a completely different approach now that the person has had further degradation in a critical capacity. Imagine, e.g., that they are no longer able to evaluate probabilities sufficiently to be competent. It seems odd at best to say that while the patient retained this capacity their values should determine how they are treated, but after they have lost this capacity, the family's preferences either are now controlling or at least can trump the patient's values in some cases. This is problematic on an individual level. It also seems problematic as a matter of public policy to say that once this transition occurs we will not respect patient considerations in the way that we did previously. This certainly does not seem an ideal way to engender public trust in their medical care. In contrast, on the endorsed life approach, the interests of the family are relevant and should be taken into account to the extent that the life that the patient endorsed for themselves included consideration of the impact on their family.

### CONCLUSION

Early courts endorsed the SJS as a way to respect the autonomy of individuals who have lost the ability to make their own decisions. On the standard interpretation, clinicians and surrogates implement the SJS by considering what decision the patient would have made in the circumstances, if competent. This approach succeeds in promoting patient autonomy in some but not all cases. Critics point out that problems arise if this rule of thumb is understood as defining the SJS. They conclude that the SJS should be dramatically modified, or abandoned. The endorsed life interpretation avoids the concerns highlighted by the critics by directing clinicians and surrogates to make treatment decisions that promote the life patients valued for themselves. This approach respects patient autonomy by allowing patients to determine the course of their own lives, even during periods of incompetence. This approach also provides surrogates and clinicians greater flexibility in helping to promote this important goal, while maintaining significant continuity in clinical contexts where the SJS is already successful.

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