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# THE SUBSTITUTED JUDGMENT STANDARD

Studies on the Ethics of Surrogate Decision Making

Linus Broström

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# CONTENTS

ORIGINAL PAPERS	4
INTRODUCTION	5
BACKGROUND	5
The problem	5
Incompetence	6
Surrogacy	8
Normative questions about surrogate decision making	9
Two limitations	11
Standards for decision making	12
Standards as measures versus tools	17
The substituted judgment standard and its justification	19
Traditional misgivings about the substituted judgment standard	24
The substituted judgment standard in the Swedish legislative context	26
THE THESIS	28
Aims, methods, results in brief	28
The underdetermination problem (paper I)	29
The substituted judgment standard as an autonomy standard (paper II)	30
Implications for surrogate accuracy (paper III)	31
Substituted judgments as expressions of respect (paper IV)	33
Concluding discussion	35
POPULÄRVETENSKAPLIG SAMMANFATTNING	39
ACKNOWLEDGEMENTS	45
REFERENCES	47

## ORIGINAL PAPERS

This thesis is based on the following papers, which will be referred to by their Roman numerals:

- I. Broström, L., Johansson, M. and Nielsen, M.K., “‘What the Patient Would Have Decided’: A Fundamental Problem with the Substituted Judgment Standard,” *Medicine, Health Care and Philosophy*, 10 (3), 2007: 265-278
- II. Broström, L. and Johansson, M., “Extending Autonomy by Substituting Judgment: A Case of Mistaken Identity.” Submitted.
- III. Broström, L. and Johansson, M., “Surrogates Have *Not* Been Shown to Make Inaccurate Substituted Judgments.”  
Conditionally accepted for publication in *The Journal of Clinical Ethics*.
- IV. Broström, L. and Johansson, M., “A Virtue-Ethical Approach to Substituted Judgment.” Submitted.

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## INTRODUCTION

Here is a popular idea: When making health care decisions on behalf of an incompetent patient, one ought to decide as the patient *would* have decided, if only he or she had been competent. This guideline is called the *substituted judgment standard*. The present thesis will discuss what the substituted judgment standard really states, what might morally justify it, and a few related issues. The approach is not empirical, but one of conceptual clarification and normative reasoning.

Although the ultimate goal of any discussion about the merits and shortcomings of this and other standards of decision making is to have us do the right thing for those affected, the thesis will not yield a verdict on whether or not doing what the patient would have done is, all things considered, morally justified. It will, however, make suggestions about what the moral purpose of respecting such hypothetical health care choices could and could not be. But before these suggestions can be introduced, a fair amount of background is needed.

## BACKGROUND

### The problem

Every day important decisions have to be made for patients who cannot make these decisions themselves. The issues that arise are of different kinds. For various reasons, the one that has received the most attention within the field of medical ethics concerns whether or not to provide life-sustaining treatment. If a patient's survival requires antibiotics, respiratory help, dialysis, CPR, blood transfusion, or tube feeding, for example, should this treatment be provided simply on the grounds of being medically indicated? While this issue of life support has been the focus of most discussions, significant medical decisions clearly also have to be made regarding issues that are not a matter of life and death. These other issues include what treatment the patient should undergo, but also what diagnostic tests should be performed. Sometimes the matter that has to be settled is only partly related to the *care* of the patient, as when the question is whether or not the patient

should be included in a research study. And on other occasions the decision in question is not a narrow medical one, as when a choice has to be made about whether the person concerned could stay in her own home or whether it would be better if she moved to some health care facility.

The reasons why many patients are unable to make such decisions themselves also vary. Sometimes patients literally cannot make the relevant decision. Clearly this goes for patients who are unconscious at the time when the matter has to be settled, but also for patients who are simply too sedated, confused, fatigued, or in too much pain to grasp that there is a decision to be made, or to get themselves to make it. Even more frequently, however, patients are able to make decisions in some basic sense, but they are not allowed to make them, roughly because they are considered to lack sufficient understanding and rationality to be trusted with making decisions where there is something at stake. The cognitive and other mental deficiencies that are associated with advanced stages of certain degenerative diseases such as Alzheimer's disease; with certain other serious psychiatric conditions, such as psychoses and severe depression; and with serious brain damage caused by e.g. trauma, stroke or hypoxia, are such that they make it unlikely that the patients concerned will be able to make important decisions in a way that protects their own interests, or to make decisions that can be considered genuinely their own. Some patients have always been incompetent, or decisionally incapacitated, such as those who are born severely retarded. Some of those who have become incompetent later in life may regain their decision making abilities, but many of them will not.

### **Incompetence**

One's decision making abilities obviously relate to such things as one's ability to understand information, to grasp what one's options are, to assess risks and prospects, to reason logically, to weigh the possible outcomes in terms of their importance to oneself, and to act voluntarily and more or less independently of



others' views on what one ought to do. But what deficiencies exactly should be enough to declare somebody incompetent? Settling non-arbitrary and defensible criteria for incompetence is one of the biggest ethical and legal challenges that lie ahead. This is not a matter of some distinguishing psychological feature that can be detected independently of one's account of what the competence/incompetence distinction is *for*. Rather, a theory of incompetence should be an integral part of an overall account of surrogate decision making, and suggested criteria cannot be justified without reference to assumptions about what values come into play in decision making for others, and to assumptions about the proper role of the competence/incompetence distinction in protecting these values. (Cf. Buchanan & Brock, 1990).

Discussing this issue here would take us too far, however. The thesis will simply proceed on the following, largely agreed upon, assumptions: At bottom, one can be *more or less* competent, corresponding to the great variation there is in abilities for understanding, reasoning, practical rationality, independence, etc. (even though in all likelihood numerical scales will make little sense). But in addition to this graded notion of competence there is the *threshold* concept, according to which everyone is either competent or incompetent (or a borderline case, if the criteria allow for such cases), depending on whether one is sufficiently competent for the purposes at hand. In the following it should be transparent when I have the graded concept in mind, and when I refer to the threshold notion. On any threshold concept of competence remotely like the ones in play in health care today there will certainly be borderline cases, as well as cases that are simply difficult to assess. Nothing in what follows will however depend on what one ought to say about these hard cases. Finally, competence is obviously decision-relative. That is, one could be competent to make certain decisions, while not competent to make others, depending on, among other things, the complexity of the issue. (Again, cf. Buchanan & Brock, 1990.)

## Surrogacy

Wherever exactly the line between competence and incompetence is drawn, the situation where a health care decision must be made for an incompetent patient is no doubt rather common. Chances are that one day you and I will be in such a condition, facing a situation where the decision will not be up to us to make. Now, those who are incompetent need someone else to make health care decisions for them — a surrogate decision maker (or proxy). In this thesis anyone who is given the mandate and responsibility to make the relevant decision on the patient's behalf will be considered to be the patient's surrogate. Legislations differ with regard to what options they provide, but it could be the patient's spouse, a parent, an adult child, a brother or sister, or some other family member. It could also be a friend or a legal guardian. Even health care professionals could serve as surrogate decision makers, not only when they have been appointed by the patient beforehand, but in other cases too. This conflicts with common usage where a "surrogate" is often understood as some decision maker *other than* the patient's physician, for instance, but this is just a matter of terminology.

In real life, of course, decision making may often be *shared*, in important respects, even if decision making rights and responsibilities lie with one person only. And in many cases, especially if the surrogate is a significant other, the surrogacy will in practice involve much more than making decisions. It may often involve being physically and emotionally present; being supportive of and attentive to the patient; being an advocate for the patient by helping him or her to get access to the best possible care, and catering for the patient's other needs as well. It could also involve working with health care providers and family in trying to coordinate the efforts of those involved, in part by facilitating communication between all parties concerned. Surrogacy, in other words, could in many settings be a fairly complex task and give rise to fairly complex experiences. (See e.g. Meeker, 2004). It is primarily in the role of a decision maker, however, that the surrogate will be discussed in what follows.

## **Normative questions about surrogate decision making**

There are many things that remain to be learned about real-world surrogate decision making. Certainly one would like to know more about how surrogates are chosen; on what grounds they make their decisions; how they feel about this responsibility; how well they succeed in following the guidelines currently in place; and so on. Crudely put, how does it actually work, and why does it work this way? In addition to the many purely empirical questions that could be asked, however, surrogate decision making raises many *normative* issues — broadly speaking, issues regarding what *ought* to be. When exactly should a patient be considered incompetent? Who should be making that incompetence determination, and what safeguards are called for in order to make the risk of arbitrariness and abuse sufficiently low? When a patient is deemed incompetent, who should then be the patient's surrogate? According to what criteria, or standard, should the surrogate's decision be judged? Roughly, that is, what characterizes an ideal surrogate decision and, if this is any different, what characterizes a good enough surrogate decision? How should the surrogate go about making up his or her mind when facing the responsibility of making a decision on behalf of the incompetent patient? What ought to be done if a surrogate fails to discharge this responsibility? And do the ethical demands on surrogate decision making coincide with the demands that one ought to impose in the law? No doubt the answers to these and related questions depend on a variety of empirical issues, and thus they cannot be conclusively settled until more is known about various matters of fact. To give just one example, in order to know what safeguards will be enough, to secure that abuse of incompetence determinations will not be a significant problem, one obviously needs to have some idea of how strongly motivated by paternalistic concern those are who are responsible for such determinations, and of what institutional framework they work within. Nonetheless, as this thesis will bear out, there is plenty of room for general normative discussions that do not depend on empirical assumptions for which we have no or little evidence.

The thesis will discuss one of the normative issues at length, and touch upon some of the others. But before going into this, I would like to say a word about their importance. A combination of factors indeed makes the matter of surrogate decision making a morally significant one. Many people are affected; often enough there is something at stake (sometimes life itself); incompetent patients are vulnerable patients; and it is not self-evident how one ought to approach the task of making decisions on their behalf. The temptation, of course, to claim that one's own favorite research topic must also be the morally most urgent topic is one that we'd do well to resist. Surely there are issues in bioethics, regarding distributive justice in the health care system for example, that are more pressing at this, or any, time, than the issue of surrogate decision making, at least in end-of-life care. Acknowledging this, however, in no way diminishes the undeniable importance of the issue of surrogate decision making.

While not the only question I will address, the main question out of which the more narrow concerns of this thesis have grown is this: Ethically speaking, what ought to be the aim of decisions made on the patient's behalf? To try to answer this question is to look for a *standard*, or principle, for decision making. Just to get a rough idea, such a standard would tell us whether a surrogate perhaps ought to do whatever she can to maximize the patient's quality of life, or whether a surrogate should perhaps instead respect the patient's previously expressed wishes, even if this will not benefit the patient to the same extent. As will shortly become clear, there are other possibilities too.

The question of what the most appropriate decision making standard is regarding incompetent patients is central among the many normative questions that surrogate decision making gives rise to. For example, one might view it as prior to questions about who should be the surrogate. After all, who could and should be a surrogate decision maker ought to at least in part depend on what one wants the surrogate to accomplish, since there might be differences in how good people are at doing what is asked of them. What criteria a surrogate ought to meet is also

arguably prior to issues about how surrogates ought to work their way towards coming up with the right decision. One needs to know what the aim of surrogate decision making ought to be before one settles on the appropriate means to achieve this aim. And this main ethical question is arguably prior to the legal question too. Appropriate legislation certainly takes into consideration more factors than a narrow ethical analysis of the issue acknowledges to be relevant, but it is equally obvious that the law should as far as possible harmonize with the conclusions of an independent ethical analysis of this issue. To say that the question of the ethically most appropriate decision making standard is central among the normative questions that can be asked is not to say that the question isn't constrained by these others. It is just to say that it seems to be the natural starting point.

## **Two limitations**

At this point two caveats might be called for. First, this thesis does not address the question of what the most appropriate decision making standard is, in general or for any given case. This question is extraordinarily complex, and depends on many issues that go well beyond what I am able to explore here. In most cases, recommending a decision making standard seems to me premature, on what we presently know, even if there is no alternative to getting by with whatever standard we find most plausible at any given point in time.

Second, the issues will be discussed in fairly abstract terms. As both health care professionals and significant others know, every real-world case involves a concrete and often enough complex medical situation, and each case also involves psychological and social particulars that make the case, if not, strictly speaking, unique, then almost so. The real world situation is not a generic one where the issue is whether or not some unnamed life-sustaining treatment ought to be given to some average "incompetent" individual, given a few easily identified facts about what is at stake. And the details that one has to confront in real-world situations

typically introduce their own challenges, and would have to be addressed when one addresses the issue of surrogate decision making in a particular case. Still, to a large extent the discussion in this thesis will abstract away from all those particulars that make a case recognizably real. While ultimately both policies of surrogate decision making and individual decisions would have to be sensitive to medical, institutional, psychological and social realities, this thesis addresses the conceptual and ethical foundations of policy, and cannot for that reason take all of this into consideration. Some readers could perceive this rather abstract discussion of the foundations of policy as uncomfortably philosophical. Still, it is not a thesis in philosophy, and those who approach the discussion expecting it to address deep philosophical problems in a fully satisfactory way will also be disappointed. The thesis addresses the issue of surrogate decision making as it has been framed in discussions that aim to contribute to actual solutions to problems within health care as we know it — discussions that by necessity are sensitive to realities that a “purely” philosophical approach could ignore.

### **Standards for decision making**

While in principle there are indefinitely many possible standards of decision making for incompetents, there are only a handful that could be taken seriously, and even fewer that have been seriously considered in the discussion about surrogate decision making. For example, settling major issues in end-of-life care by tossing a coin would be unconvincing as a general standard with broad application.

Three major standards have dominated this discussion: the *best interest standard* (BIS), what I shall call the *precedent autonomy standard* (PAS), and the *substituted judgment standard* (SJS). (PAS is otherwise known as the “advance directive principle” (Buchanan & Brock, 1990) or the “pure autonomy standard” (Beauchamp & Childress, 2001).) Very roughly, this is what they claim:

According to BIS, the surrogate ought to make the decision that best protects the patient’s (current and future) interests. According to PAS, the

surrogate ought to implement the decision that the patient has previously made, while he or she was still competent. According to SJS, the surrogate ought to make the decision that the patient now *would* have made, had he or she been competent. While these three standards will take center stage in the following discussion, portraying the ethical issue of standards of decision making as one of choosing between them would be an oversimplification, for at least three reasons. First, each standard could be explicated in different ways, so that what may seem to be one standard actually is a rough label for a family of slightly different principles. Second, the most appropriate take on surrogate decision making could involve the adoption of combinations of the relevant standards. Finally, as already mentioned, there are other possible standards too, some of which deserve to be seriously evaluated. Let me say a few words about each of these points.

Consider for example the suggestion that the most appropriate decision making standard is BIS. What standard is that? Since the notion of “best interest” could be understood in numerous ways, so could BIS. Given an extremely broad interpretation, anything we morally owe to a person will be in her best interest. Should anyone claim, e.g., that we ought to go along with what a patient prefers, out of respect for his or her autonomy, and even if this will be in conflict with what is in the patient’s best interest, a proponent of this broad notion of “best interest” will counter that this must then be a case where it *is* in the best interest of the patient to have his or her preferences satisfied. No counterexample would be possible; BIS would be the most appropriate standard by definition. However, even if one wouldn’t go this far, there is room for many different interpretations of the idea of protection of interest. The idea is to benefit the patient, but what should count as a benefit? Everyone would include the satisfaction of so-called experiential interests (cf. Dworkin, 1993: 201-204), such as the interest one has in not being in pain. But what else should count? Here opinions diverge, and with them the substance of BIS. Even if we pretend to know exactly what the outcome of a surrogate decision will be, we could still argue about what the patient’s net benefit

will be, depending on our views on the relative importance of such things as physical independence and activity, intellectual capacities, social relations, and moral dignity. Also, there could be different versions of BIS depending on the importance given to the patient's current interests in relation to his or her expected future interests. It is one thing to do what is best for the patient now or in the nearby future, and possibly another thing to act so as to protect his or her predicted interests years from now — that is, conceivably these two goals could come into conflict with one another.

Needless to say, there is no apriori reason to think that one standard could not be appropriate for certain kinds of cases, while some other standard is appropriate for other kinds of cases. On the contrary, while some standards are serious contenders in some cases, they are easily dismissed in others. For example, if a person has never expressed any views about future treatment, or views directly relevant to this issue, PAS obviously does not apply. Moreover, combinations of standards could be adopted in a single given case. For example, the most appropriate surrogate decision might be one that offers at least some minimum protection of the patient's most important experiential interests, but beyond that conforms as far as possible to the patient's previously expressed wishes. In fact, the reason why this kind of suggestion isn't made more often could be that it is already built into the framing of the surrogate's task. The patient's basic welfare interest is often already seen to in the selection of issues that surrogates are offered to address, and the options between which they are allowed to choose.

What alternatives are there to the three standards that dominate in the debate? The following does not amount to a complete list, but may offer some idea of what standards might be considered. One frequently mentioned standard is the so-called *reasonable person standard*, according to which the surrogate ought to make the decision that a "reasonable person" would have made. Sometimes this standard is thought of as a version, or part, of BIS (see e.g. Kopelman, 2007, cf. Harmon, 1990), and sometimes as a version of SJS (cf. Harmon, 1990). Possibly, however, it



could also be viewed as a decision making standard in its own right, even though this standard too could be explicated along different lines, depending on how one understands the idea of a reasonable person.

Another standard is what has been called the “continuer view” of surrogate decision making (Blustein, 1999; Kuczewski, 1999). This view takes as its starting point the assumption that our personal identity — who we are — is constituted by our conception of ourselves, and this self-conception is supposed to have a narrative structure. Exactly what this is supposed to mean is not entirely clear, but the idea that we construct stories about our lives, which are essentially tied to the persons we are, has demonstrably been found appealing. At any rate, on this account of surrogate decision making, our life stories are left uncompleted when we turn incompetent, and the surrogate’s task in end-of-life care, according to the continuer view, is to complete this life story, to write the last chapter in a person’s overall narrative, in such a way that it coheres with what has already been narrated.

While to my knowledge a *future-oriented* standard has never been seriously elaborated (other than in the trivial sense in which BIS is future-oriented), some such standard could well be what underlies intuitions that one may have in certain cases. An example of a future-oriented standard would be one according to which the surrogate ought to make a decision that the patient will in the future ratify, or (in the subjunctive version) *would* in the future ratify, given the possibility to do so. (Cf. the “principle of subsequent consent” in VanDeVeer, 1986: 67)

Finally, the standards introduced so far all have the patient in focus, and for the sake of the argument this normative presupposition will not be questioned in this thesis. Still, it is certainly possible to explicitly cater to other stakeholders too in a decision making standard. John Hardwig, for instance, has made a fairly compelling case for the view that the interests of significant others are often legitimate ones and that this should be reflected in the guidelines that surrogates should abide by (Hardwig, 2000).

We need to decide between competing decision making standards primarily because there is a possibility of conflicting outcomes. BIS may recommend one course of action while SJS recommends another. The continuer view may justify a certain decision, while PAS justifies another. And even if the recommendations of various standards happen to converge in a given case, we should still have an interest in making the recommended decision for the right reason.

While many different viewpoints are represented in the discussion about surrogate decision making, it is hard to escape the impression that there is a majority view. According to this view the three standards worth considering are BIS, PAS and SJS, and BIS should be the last resort, to be relied upon only when the other standards do not seem to work. As for the order of priority between PAS and SJS, opinions may diverge. Some seem to consider PAS to be the overriding standard, provided it is applicable to the case at hand (see e.g. Brock, 2004: 2485). According to this view, if there is sufficiently clear evidence of the patient's preferences before the onset of incompetence, these should be respected. Written advance directives, such as traditional living wills (where the person attempts to decide beforehand that no treatment should be given in certain scenarios) are the paradigm here. Today, however, and probably in the foreseeable future too, comparatively few people have expressed what they want done should the issue of life support arise in a situation where they are incompetent, and even when there is an advance directive, this may be difficult to interpret. (See Dresser, 2003, for an overview of these and other problems.) In those cases, according to conventional wisdom, a surrogate should turn to SJS, and proceed as he or she believes that that the patient would have done, had the patient now been able to competently address the issue.

Others seem to think that SJS ought to trump the other standards (see e.g. Ditto et al, 2001: 421), even if an advance directive may often be the most reliable evidence there is for what the patient would have decided if competent. On this view an advance directive will be seen as obsolete if it no longer reflects what the

patient would have decided now. Again, only when such hypothetical decisions, or preferences, cannot be reconstructed due to lack of convincing evidence, should the surrogate rely on BIS, and make that decision which best protects the patient's current and future welfare interests. (Here, and in the following, I presuppose a fairly narrow interpretation of "welfare interests" or "best interest", in order to make the traditional, seemingly substantial conflicts between doing good and respecting autonomy meaningful.) Shortly I shall return to this traditional way of thinking.

### **Standards as measures versus tools**

Before returning to the discussion about various decision making standards, and in particular SJS, we need to make a distinction, since there is an ambiguity in the notion of a standard, or principle. On the one hand, a decision making standard could be a standard in the sense of a condition of adequacy, or a criterion of rightness. On this understanding a standard would be something the satisfaction of which will make the decision justified. Differently put, a decision making standard could in this sense provide a measure of a good decision, without any presumption that the principle should be *used* by anyone. But a decision making standard could also be thought of precisely as a *tool* in the process of decision making, a guideline to be directed by, a rule to abide by in one's thinking, and perhaps to incorporate into the law or some explicit health care policy. The fact that the two senses can come apart in various normative contexts both helps to illustrate the distinction and explain its importance. First, a certain standard could be defended as a criterion of rightness while being unreliable as a tool in the decision making process. One scenario that would illustrate this is the one where surrogate decisions are justified to the extent that they protect the patient's "critical interests" (Dworkin 1993: 201) but where instructing surrogates to make such decisions would not be helpful since the instruction would not be understood. Another scenario is the one where surrogate decisions are justified to the extent that they promote the patient's

wellbeing but where instructing surrogates to make such decisions would generate decisions that would focus too much on physical wellbeing and too little on psychological wellbeing. Conversely, a standard could fail as a criterion of rightness, but still be useful to surrogates if it helps them make decisions that meet some other adequacy condition. For example, making the decision that the surrogate would have made for him- or herself seems wrong, considered as a criterion of rightness, but could perhaps be a reasonably reliable rule of thumb for many surrogates if the ultimate aim is make that decision which the patient would have made, if competent (SJS).

While this distinction between standards of decision making as measures vs. tools is parallel to a very familiar distinction within moral philosophy, applied in particular to the discussion about the status of utilitarianism (Bales, 1971), it is seldom made in bioethics, sometimes with unfortunate results. The growing literature on surrogates' accuracy in predicting patients' treatment preferences, which is extensively discussed in paper III, is a warning example, for instance. (For an overview, see Shalowitz, 2006.) The common starting point here is the agreed upon importance of protecting patients' continued interest in autonomy (see below), and specifically the importance of having surrogate decisions meet SJS. From this one uncritically infers that the best (or only) way to achieve this result is to instruct surrogates to predict what treatment patients would prefer. Had one carefully distinguished between standards as measures and standards as tools, it could not possibly be taken to be this evident that the best chances of satisfying SJS as an adequacy condition is to tell surrogates to try to apply it. In a few instances the inference goes in the opposite direction — SJS (as a measure of good decisions) is considered to be flawed simply because surrogates end up in the wrong place when they follow the instruction to identify what the patient would have wanted (Pruchno 2005, 2006). Again, closer attention to the distinction between standards as measures vs. tools would have made it evident that this kind of inference is fallacious.

Saying that there is an important distinction between standards as adequacy conditions and as concrete guidelines in use, is obviously not to prejudge the question whether a certain standard might work both as a measure and as a tool (or might not work as either). Somewhat less obviously, it is conceivable that the right decision could be whatever decision the application of a certain standard (considered as a tool) results in. Something along those lines will in fact be defended in this thesis (paper IV). In what follows, however, when speaking of a certain decision making standard, and of SJS in particular, I have in mind an adequacy condition, unless otherwise stated, or else revealed by the context of discussion.

### **The substituted judgment standard and its justification**

The specific concern of this thesis is SJS. By most measures, it has become a very influential principle. It plays a more or less important role in national and international health care legislation (Giesen, 1988; Sabatino, 1999), and it is virtually always treated in the bioethics literature as one of the major competing standards of decision making for the incompetent (see e.g. President's Commission, 1983; Appleton Consensus, 1989; Buchanan & Brock, 1990; Beauchamp & Childress, 2001; Sailors, 2001; Welie, 2001; Bailey, 2002). SJS has, in fact, even found its way into discussions within veterinary medicine! (Fiester, 2004.) More importantly, albeit not scientifically confirmed, considerations about what our fellow human beings would have done or wanted, had they been able to address the relevant issue, seem ubiquitous in everyday moral reflection.

Harmon (1990) offers an overview of the *legal* history of SJS, and according to this the origins of SJS can be found in 19th century "lunacy" law. Basically, what happened was that sometimes a relative of a so-called lunatic — someone who had lost his or her decision making capacities — made an appeal to receive a (greater) share of the lunatic's "surplus income". This was income that supposedly went beyond what was needed in order to provide for the lunatic's

basic welfare. When this was felt to be reasonable, but existing law would not allow for simply giving the lunatic's money away, there was a need for a legal fiction that would legitimize these kinds of exceptions. SJS appeared to fit the bill — if the lunatic would have given this property away to the one who made the appeal, had he or she been of sound mind, then the appeal should be granted. Apparently courts alternated between interpreting SJS as a reasonable person standard, addressing what “any reasonable lunatic” would have done, and interpreting it in the more appropriate subjective manner, where the issue would be what *this particular* lunatic would have done, if reasonable. On the former interpretation, as long as the appeal seemed reasonable, not much further evidence was perceived to be needed to establish that SJS was satisfied. On the latter interpretation, on the other hand, there were substantive evidential standards that needed to be met, before one could grant the appeal, and thus less risk of abuse (cf. Baron, 1990).

Subsequently SJS was applied also in cases where the one whose property might be given away was not a lunatic, but what was called an “idiot”, that is, someone who had never in his or her life been competent. In those cases, of course, there could be no meaningful evidence of what the idiot would have decided, had he or she not been an idiot, over and above whatever general evidence there might be of what a reasonable person would have done. Another noteworthy development, which takes this closer to current practice and our current concerns, was that this legal fiction was later used not only in cases where the issue was one of money, but of such things as the legitimacy of organ donation, sterilization and medical treatment.

I will not try to trace the certainly complex history of SJS in medical ethics. Its statutory role may well have contributed to the widespread acceptance and discussion of this standard; at any rate the many controversial legal cases that have been decided during the last decades, such as the *Quinlan*, *Cruzan* and *Saikewicz* cases (Olick, 2001, provides an overview) have no doubt spurred some of the discussion about SJS in the field of medical ethics. Conversely, current

legislation might have been influenced by developments within medical ethics too. Most discussions of SJS have taken place within a broader discussion about standards for surrogate decision-making, but some treatments focus on SJS alone. Commentaries that deserve special notice, in view of their ambitions or insight, include VanDeVeer (1986), Buchanan & Brock (1990), Welie (2001), Bailey (2002), and Kuczewski (2004). In terms of apparent impact, especially on the empirical literature related to SJS, President's Commission (1983) stands out (see e.g. Sulmasy et al, 1988; Seckler et al, 1991; Fagerlin et al, 2001; Pruchno et al, 2006).

Probably the best way to understand what SJS is about, and how it has been perceived, is to look at the problem it has been expected to address. This problem has to do with the widely agreed upon value of patient autonomy. When it comes to rules, policies and ideology, there has been an undeniable trend during the last decades towards allowing for and encouraging patient participation in health care decision making. The most salient example of this is presumably the doctrine of informed consent, according to which patients must be informed about their diagnosis, prognosis, treatment options and more, and according to which the patient then has to consent to treatment (research, etc.) before the relevant measures can be taken. This is not the place to discuss the niceties and implications of this doctrine (for this, see e.g. Post, 2004: 1271-1313), but it is certainly an important background assumption to consider when thinking about substituted judgments. While patient self-determination has been promoted in many different contexts, competent patients' right to refuse a certain treatment, or to be treated at all, has for obvious reasons become a major issue regarding patient autonomy. And since a common worry seems to be that of receiving life-sustaining treatment in situations where the prolongation of life might come at too high a price, the right to refuse such treatment is the focus of many discussions.

Now, the doctrine of informed consent is straightforwardly applicable only in situations where the patient is competent. This, however, is far from always the case. In intensive care, geriatric care, or other end-of-life care patients are often

unable to give or refuse consent, at least not sufficiently informed, voluntary and rational consent. Certainly it would be possible in such situations to abandon the idea of patient autonomy, and recommend that a surrogate relies on BIS instead, making a treatment decision that promises to maximize the net benefit for the patient, on some suitable understanding of what amounts to a benefit. This is typically not what has happened, however. Assessing the net benefit of the available options is subject to both epistemic difficulties and difficulties that run deeper — difficulties that concern necessarily shaky assumptions about what is ultimately good for a person. And there is a widespread belief that these difficulties, and the unwelcome paternalism of BIS, can be avoided, since there appears to be ways in which the patient's autonomy can still be respected, even if he or she is currently incompetent.

The instrument that most clearly promises to protect the value of, or right to, self-determination in this context is the *advance directive*, broadly conceived. If a person while still competent makes a decision about what future treatment she accepts and what future treatment she rejects, a surrogate who respects these choices, and acts in accordance with them, will certainly thereby allow the patient to be self-determining, in an obvious sense of this notion. Such a surrogate will comply with PAS. The most well-known kind of advance directive is the so-called living will — a document in which choices regarding life-support in hypothetical future scenarios are registered — but there are other instructional directives too (as opposed to directives that merely appoint a surrogate). (Olick, 2001, argues for the moral importance of advance directives.)

For all its appeal, PAS is generally thought to be plagued by a number of problems, ranging from practical problems regarding the implementation of a system of valid advance directives to deep philosophical problems about personal identity and the notion of precedent autonomy (see e.g. Dresser, 2003, and Davis, 2002). Still only a small minority has completed advance directives, so for most situations where surrogate decision making is called for one could not know how



to apply PAS. Moreover, advance directives cannot realistically be made to cover every possible combination of health status and treatment, and thus there will be many situations in which the directive has nothing explicit to say. And even when the directive may cover the situation at hand, the exact intentions of the person who issued it may remain unclear. Such interpretation problems should normally be easy to deal with when patients are competent, because then they can be asked for clarification. That is no longer possible when the patient is incompetent, and thus there could be significant interpretation problems that are an obstacle to reliably satisfying PAS.

The more fundamental ethical misgivings with PAS concern the moral legitimacy of allowing what happens to the incompetent patient to be governed by commitments of the past. According to one objection, there are cases in which the transformation of a competent individual into an incompetent one is so radical, that they should not be considered to be the same person, as in the advanced stages of dementia. But if they are not the same person, it could no longer be a case of self-determination; or so the objection goes (Dresser & Robertson, 1989). And even if one rejects criteria of personal identity that have this result, one could question the value and moral justification of allowing the patient's past decisions to outweigh his or her current interests, especially when the considerations that made the person make the commitment in the first place may no longer be relevant.

One way of looking at SJS, reflected in much of the literature, is as a second best solution, given a commitment to patient autonomy, and given the many problems that PAS faces. There may not be a valid advance directive to respect, and hence no possibility to responsibly rely on PAS. However, if the surrogate could make that decision which the patient would have made, had he or she been competent, this would also, according to common wisdom, protect the patient's right to self-determination (even if the person has not appointed a surrogate with the explicit instruction to rely on this standard). The following quotes illustrate this line of thought:

“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...” (Hardwig, 2000: 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...” (Buchanan & Brock, 1990: 112)

“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’ on behalf of the now incompetent patient. [---] [I]n [SJS] the authority of the decision reached ultimately is derived from the patient’s autonomy [...]” (Welie, 2001: 170, 171)

Not everyone makes the connection as neatly explicit as this, and not everyone who associates SJS with this justification should be seen as defending the standard under this interpretation. Nonetheless it is safe to say that it is the received view that SJS is in this sense an autonomy standard, a contention reinforced by the fact that no other justification of it is typically proposed or addressed. The view is not only that SJS could be made sense of in terms of autonomy, or self-determination, but also that the standard serves to *extend* patients’ opportunities for autonomy. In other words, SJS does not on this view allow for the protection of a *new* value, one that is not protected when patients are competent. Rather, SJS is considered to be a prosthesis of sorts — something the satisfaction of which guarantees continued self-governance even if the patient has lost his or her capacity to exercise it on his or her own.

### **Traditional misgivings about the substituted judgment standard**

SJS has by no means escaped criticism, and even those who support this standard often have misgivings about it. Occasionally the objection raised is that SJS fails to yield the right results on grounds of logic, as it were, or more precisely on grounds

of the semantics of so-called counterfactual conditionals. For instance, is it not the case that if the patient had been competent, in most instances he or she would not consent to the withdrawal of life support, because if the patient had been competent, he or she must have been in such a state where life sustaining treatment either would not have been given in the first place, or where life support would make sense since the life that the patient would not find worth living is just a life where he or she would be incompetent? This kind of objection (raised in Wierenga, 1983, for example) is rare, however, and it should be possible to dismantle it with a few clarifications and, if needed, technical maneuvers (see e.g. Barnbaum, 1999).

Rather, the overwhelmingly most common objection is *epistemic*, that is, having to do with the possibility of knowing, or of having evidence for, what the patient would have decided. In order for there to be a point in having a standard asking surrogates to decide as patients would have, if competent, more often than not there has to be reasonably reliable evidence on the grounds of which surrogates can make the relevant judgments. As already mentioned, the risk of arbitrariness and abuse that might come with SJS if one does not demand there to be solid grounds for making a certain substituted judgment is precisely what has made courts in the U.S. require “clear and convincing evidence”. (Cf. Baron, 1990. For a critical discussion, see Kuczewski, 2004.) And the worry is that such evidence can be scant. If the patient has in the past expressed any specific treatment preferences, general values, or thoughts about how he or she then viewed the prospect of getting ill, of becoming incompetent, and so on, these could presumably serve as a basis for an educated guess about what the patient would now have decided if competent. But how could one responsibly apply SJS in the absence of such evidence? And even if there is some evidence pointing in one direction, to extrapolate from this information may often be highly speculative, or so the objection suggests. (Sailors, 2001: 187-188 and Welie, 2001: 179 are good examples of this skeptical stance.) Again this is merely anecdotal, but the almost universal spontaneous reaction to hearing about SJS, from people who have not seriously

reflected about these issues, is to ask: “But how could one know what the patient would have decided?” And this skepticism seems also to be confirmed by empirical studies on surrogates’ accuracy about patients’ treatment preferences, where the conclusion typically drawn is that surrogates should not be expected to be able to make decisions that reliably satisfy SJS (more about this below).

Other difficulties that have been brought up in connection with SJS are often rooted in this basic epistemic worry. For example, sometimes words of caution about the merits of SJS are based on the hypothesis that surrogates may not always be empathic enough to reliably meet this standard, as they may instead inadvertently project their own preferences or interests onto the patient (cf. Schneiderman et al, 1993, 1997; Fagerlin et al, 2001). Whether or not there is something to this objection, this is of course only a problem if the evidential basis of substituted judgments is weak from the start. And sometimes the problem that SJS seems impossible to apply in cases where the patient has never once been competent (as with those who are retarded) is characterized as a problem of (totally) absent evidence (Welie, 2001: 179).

To sum up, commentators often view SJS as sufficiently clear in what it says, as a standard that promises to extend the patient’s autonomy to situations of incompetence, but as difficult to apply with sufficient objectivity since knowing what the patient really would have decided may be difficult.

### **The substituted judgment standard in the Swedish legislative context**

The concerns of this thesis are not specific to the situation in any one part of the world. For obvious reasons, the status of SJS in the Swedish context nonetheless deserves special mention, albeit brief. While the Swedish health care legislation does not explicitly afford patients with a *right* to self-determination, there is a solid protection of this interest, manifested in various provisions (Rynning, 1994). Central among these are the provisions in the Health and Medical Personnel Obligations Act and the Health and Medical Services Act, where it is required that

medical care shall, as far as possible, “be designed and conducted in consultation with the patient and that the patient must be shown consideration and respect” (op cit: 499). For most cases this translates as a requirement of informed consent, in order for it to be legitimate to give treatment or other medical care to a patient. As expected, however, this applies only to patients who are competent. While there is an ongoing legislative process concerned with these issues — of which the committee report 2004:112 is a part — the conditions under which treatment or care can be given to those who due to incompetence cannot themselves participate in the relevant decision making is still not regulated in a full and satisfactory way. Part of the aim of this regulatory work is to find solutions which give due weight to patient autonomy. The role of advance directives is discussed in this context, and so is the idea of hypothetical consent, i.e. SJS. The explicit idea of respecting the patient’s merely hypothetical decisions has not been the subject of public debate, but is mostly mentioned in various contributions to the legislative process. This is, of course, compatible with SJS-based thinking actually being central to everyday moral thought — as witnessed, for example, by the fact that the perhaps most common objection against the use advance directives is that they would become obsolete when they no longer represent what the patient would have wanted.

The general role of hypothetical consent in Swedish health care law and health care guidelines is a topic that deserves to be treated far more ambitiously than a thesis with the present focus could manage, and so I suffice with bringing to the reader’s attention two things that are relevant to the role of SJS in the Swedish health care system. First, Rynning (1994) discusses the conditions under which SJS-based decision making could be seen to harmonize with the requirement in the law that the patient’s self-determination and personal integrity be respected (385-395), and she contends that there are such conditions. Second, and in line with this, SJS appears to be assigned a very important role in a current legislative proposal about surrogate decision making for incompetent adults in health care. In the latest committee report on this topic, SOU 2004:112, statutes about health care surrogacy

are suggested, including statutes about what standards ought to govern surrogate decision making. According to 22§ in the proposed health care surrogacy act (*Förslag till lag om ställföreträdare för vuxna inom hälso- och sjukvården m.m.*) a surrogate ought to imagine what the patient's position on the relevant health care issue would be, if he or she had been competent. And this hypothetical preference, according to this central clause, should ("in principle") be the basis for the surrogate's decision. The justification given, while open to interpretation, seems to be in line with the received view.

## **THE THESIS**

### **Aims, methods, results in brief**

The kinds of investigation that form the major part of this thesis do not easily lend themselves to a familiar classification in terms of aims, methods, results. It explores SJS as a conceptual construct, and explores the ethical foundations of this standard, in ways that do not fit standard methodological paradigms in either the natural or the behavioral sciences. The thesis aims to critically evaluate various aspects of SJS that are relevant to its credentials as an adequacy condition on surrogate decisions. It does so by addressing what exactly SJS states (paper I), and by scrutinizing and constructing arguments about the moral justification of SJS (papers II and IV). The ostensible purpose of the study resulting in paper III is somewhat different, viz. to assess whether or not the empirical evidence supports certain conclusions about surrogates' chances of making accurate substituted judgments. This too, however, is just as much part of the endeavor to critically evaluate, and display possible confusion about, the substance of SJS. Those are not empirical investigations, and the methods used can all be said to be instances of what is simply "critical thinking", of the kind that forms the core of analytical philosophy. The results of this critical thinking, as they were reported in each paper, are summarized below.

## **The underdetermination problem (paper I)**

Paper I argues that the traditional formulation of SJS is seriously incomplete, and it discusses different ways to fill in what is missing from it. SJS states, on this formulation, that the surrogate ought to make that decision which the patient would have made, had he or she been competent. The paper argues that most discussions make little sense unless one assumes that this should be interpreted literally — stating that surrogates ought to do what patients actually would have done, had circumstances been other than they are in certain specific ways. So understood, the vanilla version of SJS is incomplete or, as the paper puts it, “underdetermined”, in the sense that it does not sufficiently well specify the hypothetical scenario that the surrogate is asked to imagine. All it assumes about it is that the patient is “competent”. But, first, it does not clarify *how* competent the patient should be imagined to be. And second, neither does it clarify any other aspect of the patient’s hypothesized condition, such as the patient’s (hypothetical) beliefs, values, commitments, emotions, mood, or the external circumstances surrounding the decision. Depending on how the scenario is described in these regards, this could presumably have consequences for what the patient would have decided. With the help of a fictitious case the paper illustrates and discusses a few different ways of specifying these missing “decision conditions”. For instance, one might suggest that SJS should ask the surrogate to make that decision which the patient would have made the last time he or she was competent. Or one might suggest that SJS, in an effort to be more charitable, rather should ask the surrogate to make that decision which the patient would have made when he or she was “at the height of his or her powers”. Those would both be examples of *prior* decision conditions, i.e. conditions obtaining sometime in the patient’s past. One might also suggest that SJS, on the preferred understanding, tells the surrogate to do what the patient “characteristically” would have done, given his or her general personality. Or one might urge that SJS should *idealize* the patient’s decision conditions (to some suitable degree), asking the surrogate to decide as the patient would have

decided under more or less favorable conditions. Other possibilities are mentioned too. The claim is made that a theory of SJS would have to address this issue, either by arguing for some specific completion of that which is left open, or by making a case for the claim that no such completion is needed. On either story, the preferred way of morally justifying SJS would presumably dictate one's stance towards the problems of underdetermined decision conditions.

### **The substituted judgment standard as an autonomy standard (paper II)**

Paper II presents the traditional moral justification of SJS, according to which this standard extends the patient's opportunity for self-determination, to the situation where the patient is incompetent. It goes on to challenge this justification, not by arguing about the proper use of words like "autonomy" and "self-determination", but by suggesting that the moral reasons we have for respecting the actual choices of a competent patient seem not to be serviceable as reasons for respecting a patient's purely hypothetical choices. The paper lists common or conceivable reasons, and argues either that the alleged value of respect for actual self-determination does not obtain when the patient's decision is merely hypothetical, or that an independent argument would be needed to establish that SJS protects the relevant value.

Specifically, it is argued that SJS cannot be justified by reference to: (a) the facilitation of the development of capacities for autonomy; (b) positive feelings associated with self-determination; (c) people being the best judges of what is in their own interest; (d) the (possibly intrinsic) value of choosing freely; (e) the value of being accountable; (f) so-called second-personal reasons for the right to self-determination.

According to the paper, these failures to show that reasons for respecting the decisions of competent individuals are also reasons for respecting patients' hypothetical decisions imply at the very least that the burden of proof lies with those who support the received view. The paper also sketches, in impressionistic



fashion, three different accounts on which the moral justification of SJS would not have to do with patient autonomy. The purpose of these sketches is not to show the relevant accounts to be plausible, but to help the reader imagine what a non-traditional justification of SJS might look like, and how one such account could conceivably be preferable to approaching SJS as a standard that protects autonomy.

### **Implications for surrogate accuracy (paper III)**

Paper III does not discuss SJS per se, but the issue of whether or not surrogates could be expected to be able to comply with this standard. In a number of empirical studies surrogates have been shown not to be particularly good at predicting patients' treatment preferences, and frequently one has concluded that this puts into question surrogates' chances of making decisions that meet SJS. The paper critically evaluates this inference and the research paradigm on which it is built.

Common to the empirical studies assessed is a certain research design. Actual or potential patients are asked to express their "preferences" regarding various life-sustaining treatments in one or several hypothetical future scenarios where they themselves would not be able to make decisions due to incompetence. The questions they are asked typically have the following form: If you were in condition C, would you or would you not want treatment T? Potential surrogates for these individuals are asked to "predict" what the latter would want under the relevant circumstances. Surrogates' accuracy, as measured by the concordance between patients' expressed preferences and surrogates' predictions, is then taken to reveal surrogates' ability to make decisions in accordance with SJS.

The paper maintains that the relevant studies have failed to show that surrogates have made inaccurate substituted judgments (as these should be understood in SJS), and that in fact no empirical study *of this kind* could ever demonstrate that surrogates should not be expected to be able to comply with SJS. It offers a four-step argument for this claim. First, the decisions that SJS refers to

are merely hypothetical and hence not susceptible to the kind of observational confirmation that the relevant studies on surrogate accuracy are built upon. Second, since the traditional formulation of SJS underdescribes this standard, it is quite possible that when appropriately completed SJS tells the surrogate to decide as the patient would have done under circumstances that are significantly different from the ones research participants (the patients) have been in. Third, and even stronger, the paper argues that patients and their circumstances should in fact be somewhat idealized in comparison to what may often be the case when they elicit their preferences in a research setting or, for that matter, when they make actual decisions. Roughly, that is, the question should not be what the patient would have decided under conditions that mimic the ones under which he or she have made an actual conjecture about future preferences, or made an actual decision. The question should be what the patient would have decided under *favorable* conditions, i.e. ones where the patient is fully informed about relevant facts, has thoroughly thought about the issue, isn't unduly influenced by the opinions of others, and so on. Fourth, the paper contends that it is conceivable, for all that has been shown, that surrogates are better equipped to identify these more or less idealized decisions than they are at predicting patients' actual choices. It is by no means ruled out that empirical studies of some kind could illuminate the issue of surrogate accuracy — and the paper mentions data that could have a bearing on this — but the kind of correlation test that researchers have hitherto largely relied upon is argued to be flawed by design. The paper also offers a few suggestions as to why the relevant methodological mistakes have been made. Briefly, there might be a conflation of preferences for hypothetical situations with hypothetical preferences; an unwarranted commitment to the view that there could be no better evidence of what the patient would have preferred than what the patient actually has preferred at some point in time; and a commitment to SJS as a prosthetic device for extending self-determination, something which might also blur the distinction between what the patient would have preferred and what he or she actually has preferred.

### **Substituted judgments as expressions of respect (paper IV)**

Paper IV returns to the issue of the moral justification of SJS, and offers a way of thinking about this that is significantly different from the one criticized in paper II. It outlines a virtue-ethical approach, according to which the moral point of substituted judgments is not to further any interests that the patient might have. Rather, such judgments are suggested to be natural manifestations of certain virtuous sentiments and attitudes towards the patient. The paper suggests that *respect* (for person) could serve as a crude approximation of the relevant mindset, where this amounts to something over and above non-violation of a person's rights or interests. Basic respect for another human being is tentatively claimed to involve the recognition of a perspective other than one's own, and a concomitant willingness to inform oneself about this perspective, and to interpret it charitably. Part of such respect is an acknowledgment that one's own outlook has no special standing among all the perspectives that there are or could be. Depending on the nature of the relationship between the surrogate and the patient, manifestations of such respect could have somewhat different sources and come in somewhat different clothing. Two kinds of relationship are mentioned, even though many real-world cases may not fit these categories in a straightforward way. If the surrogate does not have a personal relationship with the patient, the substituted judgment is suggested to be a *symbolic gesture*, which conveys respect for person, or manifests the surrogate's solidarity with the patient's vulnerable predicament. But if the surrogate has a personal relationship with the patient, especially a close one, a substituted judgment may not so much be a conventional, and in that sense optional, symbolic gesture as a psychologically more or less compelled response. Personal relationships seem to be characterized by what has been called second-personal address, that is, giving one another reasons (for doing things) that are tied to have been given by a Me to a You. Normal people — in both the statistical and the normative sense — may simply be unable to end such relationships and its

characteristic second-personal address when and just because one person can no longer relate in the same way due to incompetence; or so the paper suggests.

The paper ends with mentioning a few implications of this virtue-ethical approach. The first implication concerns the importance of surrogate accuracy. A surrogate who does not care about whether or not the patient actually would have made the relevant decision clearly would not be respectful or virtuous, since aiming for accuracy is obviously part of complying with SJS. Still, in the ultimate analysis, no harm will have been done just because a surrogate makes a substituted judgment that happens to be inaccurate, since on the account offered in this paper what matters is whether the surrogate has demonstrated the appropriate attitude towards the patient. Traditional concerns about surrogate accuracy and the difficulties associated with finding out what the patient truly would have decided thus appear to be exaggerated, on this view. The paper also points out that this virtue-ethical approach calls into question the seemingly common assumption that a decision making standard will govern the conduct of all surrogates alike. Since respect could come in different shapes, depending on the nature of the relationship between the surrogate and the patient, different surrogates could be obligated by SJS to a different extent and in different ways. This approach also makes progress on the underdetermination problem (paper I), in that it explains why some ways of specifying the patient's decision conditions are unacceptable (disrespectful), while simultaneously explaining why no detailed, particular specification is needed for SJS to make moral sense.

## **Concluding discussion**

How do the claims made in these papers hang together? Some connections are evident, such as the one between the case against the traditional justification of SJS and the positive virtue-ethical alternative just outlined. Other connections may not be quite as transparent, however, even if some of them have been mentioned.

A few commentators have noticed before that the traditional formulation of SJS underdescribes the counterfactual decision making scenario. For example, VanDeVeer (1986: 392-393), Dworkin (1994: 191), and Baergen (1995) show themselves in various ways (and to different degrees) to be aware of this conceptual lacuna. But in addition to providing a more serious elaboration of the issue, the thesis suggests in effect that the widespread neglect of this problem is a significant cause of mistakes made in both empirical research and normative reasoning about SJS. Differently put, one of the things that the thesis tries to convey is that the basic point made in paper I is not just a pedantic point about conceptual precision, but a point directly relevant to issues that we should all agree are important. First, it is directly relevant to our assessment of the success of surrogates (paper I), given that that SJS is the preferred decision making standard. One reason why the empirical literature on surrogate accuracy is confused is precisely that one has not paid sufficient attention to what SJS really states, and had the underdetermination problem been better understood, one would presumably have been less at risk of relying on the flawed study designs that characterize this research. This research is, in fact, plagued by other methodological problems too (see Johansson & Broström, submitted), so proper attention to the underdetermination problem would not alone make for impeccable empirical research. That the failure to notice and address that the traditional definition of SJS underdescribes the relevant counterfactual situation is a significant source of detrimental methodological confusion is beyond doubt, however. The general lesson, of course — even if this should have been known already — is that conceptual discipline and clarification ought to be prerequisites also for research that seems straightforwardly empirical.

Spot checks of empirical studies on this and neighboring topics unfortunately suggest that the need for this kind of conceptual dissection and care is vast.

Just as important, the indeterminacy addressed in paper I is directly relevant to how one should understand the moral foundation of SJS, that is, why one should care about “what the patient would have decided” (papers II and IV). Once this indeterminacy is pointed out, it becomes obvious that those who view SJS as an autonomy prosthesis would have to address this issue in either of two ways. Either the response would have to be that it does not matter that much how one chooses to specify the counterfactual decision making scenario, or perhaps that one does not have to specify it at all. This seems hard to reconcile with the view that SJS protects some specific value, or values, associated with self-determination. Or else the response would have to be a substantive suggestion as to how the incomplete characterization ought to be completed, which accords both with our most solid moral intuitions about substituted judgments and with the autonomy justification. And, at a minimum, the prospects of meeting this challenge do not look promising either. The upshot is that problems that surface when we try to be a little more precise about the content of SJS actually have a significant bearing also on the moral issue of what good decisions based on this standard accomplish.

Now, the argument against the received view remains non-demonstrative. In part this is because the received view is an indistinct, and possibly moving, target. After all, what *exactly* is being claimed when substituted judgments are said to extend the patient’s autonomy? And in part the argument is non-demonstrative simply because it is an inductive and (to some extent) abductive one. To simplify somewhat, paper II lists reasons for respecting the choices of a competent patient, and argues that *those* reasons do not apply when the patient’s decision is merely hypothetical. Certainly, however, it is conceivable that one could come up with additional reasons that do apply in the hypothetical realm. Likewise, the received view is charged with having a hard time solving the underdetermination problem, whereas the virtue-ethical approach is claimed to do better, in virtue of partially

*dissolving* this problem. Still, inferring from this that SJS cannot be justified as an autonomy standard is, at most, an inference to the best explanation, and as such non-conclusive. The bottom line, however, is that any attempt to save the truth of the claim that SJS protects the patient's autonomy is likely to come at a significant price, and ultimately may not be of much interest. The price that one probably would have to pay is that the autonomy protected by SJS would be nothing like the autonomy protected by competent decision making, but a new kid on the block, or else the same autonomy as the one we know only in such a diluted sense that little is gained by having them subsumed under the same label. In either case, SJS would no longer be able to immediately earn its justification from the fact that we already agree to give great weight to actual patient self-determination in health care.

Although I think there are significant gains in shifting to a virtue-ethical approach to SJS, along the lines of what is suggested in paper IV, there are many issues that are still insufficiently understood and that deserve further attention. Some of these are specific to SJS and the particular approach championed here. For example, the niceties of the idea of respect for person remain to be elaborated. Making this idea something more than a catchword is an important first step, but this specific approach to SJS would obviously be strengthened if it could be backed up by a more comprehensive theory of the nature and moral role of respect. Admittedly, the intuitive plausibility of the virtue-ethical approach also seems greater when applied to certain kinds of cases than when applied to others. For instance, it seems to me to ring more true for substituted judgments made in situations where the issue to be decided concerns life support for patients in a persistent vegetative state than it does when applied to SJS-based decision making in cases where the patient is expected to regain competence, and future research should among other things further explore this possibility of SJS being justified in different ways depending on what kind of situation it is applied to.

Other issues that require continued and deepened attention are more general. Virtue ethics itself, for instance, faces some general theoretical challenges,

such as the fundamental challenge of justifying, or at least explaining, why some traits qualify as virtues while others do not. And while I do consider it to be one of the merits of a virtue-ethical approach that it does not have to avail itself of the contentious idea of *surviving interests* (including interests of those who dead), just how much of an advantage this is evidently depends on whether or not one could ultimately make sense of such interests. This is one of the issues that remain to be settled.

Unanswered questions aside, this thesis strongly argues for a re-evaluation of SJS. The thesis questions the traditional picture of SJS as a standard whose moral point is to extend patients' opportunities for self-determination, and whose biggest problem is that surrogates often cannot know what the patient really would have decided. It replaces this picture with one according to which no moral harm is being done just because the surrogate makes an inaccurate judgment about what the patient would have decided. The reason for this, according to this alternative approach, is that SJS should rather be seen as a codification of a virtuous way of being, or of what the appropriate attitude towards the patient ought to be, in connection with surrogate decision making.



## POPULÄRVETENSKAPLIG SAMMANFATTNING (SUMMARY IN SWEDISH)

Patienters rätt till inflytande över sin egen vård har länge betonats i bland annat sjukvårdens styrdokument. I synnerhet gäller detta rätten att neka till föreslagen behandling. Många patienter är dock av olika anledningar oförmögna att själva ta ställning i de frågor som aktualiseras. Till dessa så kallade *beslutsinkompetenta* patienter hör de som vid tidpunkten för beslutet är medvetslösa, svårt dementa, psykiskt störda, eller av andra orsaker alltför förvirrade, trötta eller smärtpåverkade för att vara i stånd att göra ett meningsfullt val. En beslutsinkompetent patient behöver någon som fattar det aktuella vårdbeslutet för dennes räkning — en *ställföreträdande* beslutsfattare. Den som ges rätten och ansvaret att fatta detta beslut för patienten kan exempelvis vara en partner, en annan familjemedlem, eller en nära vän. Man kan också tänka sig att en så kallad god man skulle kunna fungera som patientens ställföreträdare i vårdfrågor, liksom läkare och annan personal som har ett vårdansvar för patienten. Den problematik som denna avhandling tar sin utgångspunkt i handlar om vilka *riktlinjer* som bör gälla för ställföreträdande beslutsfattande.

I den medicinetiska diskussionen har olika förslag framförts om hur vårdbeslut för inkompetenta patienters räkning bör fattas. Ett förslag är att en ställföreträdare bör fatta det beslut som bäst tillvaratar patientens nuvarande intressen (principen om patientens bästa). Om frågan gäller behandling, kan tanken till exempel vara att åstadkomma den för patienten bästa avvägningen mellan livslängd och livskvalitet, så långt detta kan bedömas. Precis vad som är i patientens intresse är naturligtvis svårbedömt, och principen om patientens bästa uppfattas ofta som otillfredsställande också på grund av att den inte alls tycks kunna tillgodose patientens rätt till självbestämmande. Ett annat förslag utgår just från att alla personer bör ha rätt att själva fatta viktiga vårdbeslut och att denna rätt faktiskt kan tillgodoses också då patienten är inkompetent, förutsatt att patienten har givit

uttryck för sin vilja innan denne förlorade sin förmåga att ta ställning i den aktuella frågan. En ställföreträdarens uppgift blir då att se till att den inställning som patienten tidigare har framfört respekteras (principen om förhandsautonomi). Principen om förhandsautonomi är emellertid också förenad med svårigheter. Den mest uppenbara är kanske att principen bara är tillämplig då ett beslut redan har fattats av patienten, eller när han eller hon faktiskt har gjort sina önskemål kända. För närvarande utgör dessa fall en klar minoritet. Därutöver tillkommer andra svårigheter, såsom svårigheten att tolka den av patienten avsedda innebörden i dessa så kallade förhandsdirektiv, och det moraliskt problematiska faktum att principen om förhandsautonomi fäster vikt vid människors förgångna inställning, medan deras aktuella perspektiv inte tillgodoses.

Enligt ett tredje förslag bör en ställföreträdare fatta det beslut som patienten själv nu *hade* fattat, om denne *hade* varit beslutskompetent. Denna princip om att respektera patientens *hypotetiska* inställning kallas på engelska “the substituted judgment standard” (SJS). Något namn på svenska har ännu inte etablerats, även om den ibland omnämnts som principen om vikarierat samtycke, eller principen om hypotetisk vilja. Avhandlingen handlar om just denna princip. Avhandlingens huvudsakliga syfte är att granska SJS, ur framför allt en etisk synvinkel. Metoden är i vid mening analytisk-filosofisk, i betydelsen att principens ställning belyses genom begreppsanalys, argumentationsanalys och moralfilosofisk argumentation.

Avhandlingen bygger på fyra artiklar. Artikel I argumenterar för att den traditionella formuleringen av SJS är oklar i vissa väsentliga avseenden. Enligt SJS bör, som nämnts, ställföreträdaren fatta det beslut som patienten själv hade fattat om denne hade varit beslutskompetent. Men inget sägs om *hur* kompetent patienten bör antas vara, eller hur man för övrigt bör föreställa sig den kontrafaktiska situation i vilken patienten är förmögen att fatta det aktuella vårdbeslutet. Bör man fatta det beslut som patienten hade fattat då han eller hon *senast* var kompetent? Bör man kanske fatta det beslut patienten hade fattat “i sin

krafts dagar”, vad nu det kan tänkas innebära? Eller bör man fatta det beslut som patienten “typiskt” hade fattat, givet dennes grundläggande personlighet? Artikeln beskriver och kommenterar dessa och andra möjligheter. Det är förvisso inte självklart att det är olyckligt att inte fullt ut beskriva den hypotetiska beslutssituationen (se artikel IV), men den gängse synen på SJS och hur denna standard rättfärdigas moraliskt förefaller inte kunna övertygande förklara varför detta skulle vara oproblemiskt.

Artikel II diskuterar det traditionella sättet att moraliskt rättfärdiga SJS. Den vedertagna synen på denna princip är att den i likhet med principen om förhandsautonomi tillgodoser människors rätt till självbestämmande. En beslutsinkompetent patient kan förvisso inte längre på egen hand utöva något självbestämmande, men enligt gängse synsätt kan en ställföreträdare som lyckas fatta det beslut som patienten hade fattat tillgodose den rätt till autonomi som den inkompetenta patienten inte är i stånd att skydda själv. SJS uppfattas här, bildligt, som en *protes* — en mekanism för att möjliggöra det värdefulla patientinflytande som annars skulle ha gått förlorat. Artikeln driver tesen att detta traditionella sätt att rättfärdiga SJS inte är hållbart. Många olika skäl kan anföras för varför beslutskompetenta personer bör ges möjlighet till självbestämmande. Exempelvis kan det ha att göra med instrumentella värden, såsom att vi “mår bra” när vi tillåts styra vårt eget liv, eller att vi kan antas vara de som bäst kan bedöma vad som är i vårt eget intresse. Det skulle också kunna ha att göra med att frihet att välja, och att ta ansvar för de val som görs, har ett egenvärde. Artikel II listar de huvudsakliga skälen, och argumenterar för att dessa inte är tillämpliga när patientens beslut, eller önskemål, är blott hypotetiska. De värden som respekten för faktiskt självbestämmande skyddar kan alltså inte skyddas enbart genom att patientens hypotetiska inställning respekteras.

När invändningar riktas mot SJS har de oftast att göra med att principen möjligen är svår att tillämpa. Kan man verkligen veta med tillräcklig säkerhet vad patienten själv hade beslutat? Sådan skepsis har underblåsts av empirisk forskning

enligt vilken ställföreträdare är förhållandevis dåliga på att förutsäga patienters behandlingspreferenser. I dessa studier har patienter ombetts att uttrycka sin inställning till olika behandlingsalternativ i hypotetiska sjukdomsscenarier. Presumptiva ställföreträdare till dessa personer har i sin tur ombetts att förutsäga vilken inställning patienterna har, och träffsäkerheten har visat sig påfallande låg. En vanlig slutsats är att ställföreträdande beslutsfattare har relativt dåliga förutsättningar att följa SJS. I artikel III ifrågasätts denna slutledning. Artikeln konstaterar att de beslut som SJS handlar om inte är faktiska, utan blott hypotetiska — beslut patienten *skulle ha* fattat om denne hade varit kompetent. Som sådana kan de inte *observeras* på det sätt som skulle krävas för att i en empirisk korrelationsstudie fastställa graden av träffsäkerhet i ställföreträdarens bedömningar. Den innehållsliga oklarhet som diskuterades i artikel I innebär vidare att de rent hypotetiska beslutsomständigheter som patienten bör föreställas vara i kan vara annorlunda än de omständigheter som undersökningsdeltagarna faktiskt befunnit sig i när de meddelat sina behandlingspreferenser. Artikeln argumenterar för att patienter och deras beslutsomständigheter i själva verket ofta bör idealiseras i förhållande till de som normalt råder. Den fråga ställföreträdaren många gånger bör ställa sig är alltså, ungefär: Vilket beslut hade patienten fattat under *gynnsamma* omständigheter, dvs. om denne varit välinformerad, genomtänkt, inte under otillbörlig påverkan av andras åsikter, osv. Det konstateras att ställföreträdarens förutsättningar att identifiera denna mer eller mindre idealiserade inställning möjligen kan vara bättre än deras förutsättningar att förutsäga patientens faktiska behandlingspreferenser. Artikeln nämner också några omständigheter som skulle kunna förklara varför man utifrån dessa träffsäkerhetsstudier felaktigt dragit slutsatser om ställföreträdarens förutsättningar att följa SJS.

Kan det vara moraliskt försvarbart att försöka fatta det beslut som patienten själv hade fattat av något annat skäl än att det möjliggör självbestämmande? Artikel IV argumenterar för det, och skisserar en så kallad dygdetisk ansats. Enligt en sådan är ett visst ställföreträdarbeslut moraliskt önskvärt

inte på grund av att det lyckas tillgodose patientens intressen (av välfärd, självbestämmande, etc.). Snarare föreslås SJS-baserat beslutsfattande vara uttryck för en viss inställning, eller hållning, som utmärker en moraliskt välfungerande människa. Den hållning som artikeln lyfter fram är vad man grovt kan beskriva som *respekt för person*. Exakt vari sådan respekt består förtjänar en närmare analys, men föreslås i artikeln åtminstone bestå i ett erkännande av att till den människa för vars räkning man har att fatta ett beslut hör ett *perspektiv*, och ett erkännande av att ens eget perspektiv saknar moralisk särställning. Annorlunda uttryckt innebär respekt för person ett erkännande av ett slags fundamental jämlikhet. Respekt för också med sig en beredskap att informera sig om den andres perspektiv och att tolka det välvilligt. Två renodlade typer av fall skisseras. I det fall ställföreträdaren inte har en nära personlig relation med patienten föreslår artikeln att beslutsfattande i enlighet med SJS utgör en sorts symbolisk gest. Genom att fästa vikt vid det perspektiv man associerar med patienten signalerar denna gest respekt för dennes person, eller uttrycker solidaritet med patientens utsatta position. I det fall ställföreträdaren och patienten har en nära personlig relation, föreslås beslut baserade på vad patienten själv hade gjort vara psykologiskt än mer naturliga, ibland närmast tvingande. Moraliskt välfungerande individer föreslås försöka upprätthålla nära relationer även efter det att ena parten blivit inkompetent, och respekt för dennes person kan innebära att man fortsätter att förhålla sig till denne som om personen ännu “talade till” en. Artikel IV beskriver också några av den dygdetiska ansatsens implikationer. Ställföreträdares träffsäkerhet blir till exempel mindre betydelsefull om SJS i grunden handlar om att inta ett lämpligt förhållningssätt. Det är vidare tänkbart att olika ställföreträdare — beroende på vad slags relation de har till patienten — kan vara förpliktigade av SJS i olika utsträckning och på delvis olika sätt. Ansatsen konsekvenser för problemet att den traditionella formuleringen av SJS underbeskriver den hypotetiska situation man ska föreställa sig berörs också. Den föreslagna ansatsen kan förklara varför somliga sätt att mer exakt beskriva de omständigheter under vilka patienten skulle fatta sitt beslut är moraliskt

oförsvarliga, samtidigt som den kan förklara varför inga detaljerade omständigheter som regel behöver specificeras.

Sammanfattningsvis problematiserar avhandlingen den gängse bilden av SJS som en princip vars moraliska syfte är att utvidga patienters möjligheter till självbestämmande, och vars största problem är att ställföreträdare ofta saknar tillförlitlig information om vad patienten verkligen skulle ha beslutat, eller önskat. I dess ställe tecknar avhandlingen en alternativ bild, enligt vilken ingen egentlig moralisk skada uppkommer bara på grund av att ställföreträdaren råkar göra en felaktig bedömning av vad patienten hade valt, eftersom SJS kanske snarare handlar om vilket *förhållningssätt* till patienten en moraliskt välfungerande människa uppvisar i samband med ställföreträdande beslutsfattande.

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\*\*\*

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