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Love as a Regulative Ideal in Surrogate Decision Making

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Love as a Regulative Ideal in Surrogate Decision Making

Abstract: This discussion aims to give a normative theoretical basis for a “best judgment” model of surrogate decision making rooted in a regulative ideal of love. Currently there are two basic models of surrogate decision making for incompetent patients: the “substituted judgment” model and the “best interests” model. The former draws on the value of autonomy and responds with respect; the latter draws on the value of welfare and responds with beneficence. It can be difficult to determine which of these two models is more appropriate for a given patient, and both approaches may seem inadequate for a surrogate who loves the patient. The proposed “best judgment” model effectively draws on the values incorporated in each of the traditional standards, but does so because these values are important to someone who loves a patient, since love responds to the patient as the specific person she is.

Key words: surrogate decision making, love, identity, authenticity

There has been growing interest in models of personal identity concerned less with a person’s persistence over time than with what makes the person who she is, her “biographical” self. Such models center on a life’s narrative,¹ or the value called “authenticity,”² or a person’s ability to care about people, relationships, projects and things.³ This important development in our understanding of personhood lends itself to a new conception of personhood and full moral standing, one based on a subject’s ability to care. The way such concepts are understood, it seems to me, should in turn inform our ways of thinking about problems in which personhood status matters. One such arena is surrogate decision making for incompetent or incapacitated patients, and that is my subject.

There are currently two widely accepted models of surrogate decision making for incompetent patients: the “pure autonomy” or “substituted judgment” model⁴ and the “best interests” model. Although legal precedent arranges these standards in a hierarchy with the substituted judgment model taking priority over the best interests model, it can often be difficult to determine which of the two is more appropriate for a given patient. The former centers on the value of autonomy and responds with respect; the latter centers on the value of welfare (narrowly construed as physical welfare) and responds with beneficence. These values and attitudes, and the standards built on them, have arisen to preserve the patient-centered-ness of surrogate decision making. While these are undeniably important values and attitudes, they tend to concentrate our attention too much on just one aspect of a person (i.e. autonomy or welfare, respectively). In this
article I would like to consider a dimension of the problem that can easily be overlooked from an autonomistic or legalistic standpoint: the role that care or love can play in surrogate decision making. As a result, I will offer another framework for surrogates who love a patient. This “best judgment” alternative shifts our thinking to a more holistic view of a patient and her interests and gives a theoretical basis rooted in a regulative ideal of love or care for a model of decision making that is de facto already in use. Such a model effectively draws on the values incorporated in each of the traditional models—as many loving surrogates wish to do—but does so because these values are important to someone who loves a patient and wishes to respond to the patient as the specific person she is.

1. The two traditional models and why they present a problem

A survey of the literature on surrogate decision making quickly shows that any discussion of the subject begins by noting the two current models a surrogate ought to apply, and the court-mandated lexical order of priority between them: the autonomy-based standard of “substituted judgment” is to be applied when there is enough evidence of a patient’s wishes to do so, and if not, then the beneficence-based “best interests” standard is to be used. Both the standards and their order of priority have a clear rationale, rooted in Western medicine’s shift from the paternalistic to the patient-centered model that took place over the course of the twentieth century. As a response to manifest problems with paternalism, the value of respecting patient autonomy came to be paramount in the approach to patient care, and with it the importance of the right to refuse unwanted treatment. But this approach becomes problematic when the patient is unable to make decisions for himself. How, when a patient cannot be consulted, or cannot competently think through his options, is the patient’s autonomy to be exercised (or at least protected)? The obvious answer is that it is exercised by proxy: someone is appointed to make decisions on behalf of the patient, doing her best to reproduce the decision the patient himself would have made—hence the term “substituted judgment.”
Although it has great theoretical appeal, the limitations of this approach are well known. One limitation is the problem of standards of evidence, or how the surrogate is to show that her choice reproduces the choice the patient would have made. A living will is the gold standard for such a decision, but even these most concrete pieces of evidence of a patient’s wishes often require interpretation because few people have the ability to imagine the precise circumstances in which they will find themselves. And even if they manage to imagine the circumstances that in fact materialize, there is evidence that people are notoriously unable to predict what they can endure, so that the directive is often out of step with changing values and priorities as illness progresses, and the surrogate is left with a “siren problem”—should she obey the advance directive as binding, or the current wish of a patient who has (perhaps legitimately) changed his mind?

Another important limitation of the substituted judgment standard is the massive amount of evidence that suggests that surrogates are terrible at making decisions as their wards would have. These results appear to be robust even in the face of carefully planned interventions that include conversations about values and priorities. Thus, it proves disappointingly difficult for the substituted judgment standard to function as it was supposed to in the protection of a patient’s autonomy.

When a patient’s preferences cannot be reconstructed well enough to implement a substituted judgment, surrogates are to turn to a best interests model. Here the focus is less on the patient’s subjective judgment as it is on his objective condition: whether the benefits of proposed or continued treatment outweigh the burdens. Note that this objective assessment will take into account the best available understanding of the patient’s subjective states, such as his experience of pain. It is nonetheless understood as “objective” in that decisions are made using as much empirical evidence about a patient’s benefits and burdens (both mental and physical) as possible. Because of this, the best interests standard has the advantage that the evidence required for its implementation is available even to people who do not know the patient well.

Of course, this model has limitations as well. Aside from the obvious difficulties in determining benefits and burdens to a patient, there is a residual worry about the potential to
undervalue a patient once the patient’s ability to make his own choices has diminished significantly.

The worry is that the best interests standard can require “quality of life” judgments that allow a surrogate’s values—values which may not be in complete harmony with the patient’s values, or more importantly, his interests—to affect the assessment of benefits and burdens. In addition to belittling the patient himself by treating him as worth less than others, such quality of life judgments might lead to a slippery slope that devalues persons with all sorts of disabilities perfectly compatible with living a worthwhile, flourishing life. This would be a significant problem.

Despite limitations, of course, decisions must be made, and they must be made on some basis. Clearly the standards outlined here have their roots in important values: respect for autonomy, on the one hand, and beneficience toward the patient, on the other. And the priority of respect for autonomy over beneficience is reasonable as well, since there is no longer much question that competent patients may participate as much or as little\textsuperscript{11} as they like in directing their care, including the right to refuse treatment.

Recently it has been argued\textsuperscript{12} that in fact the line between the substituted judgment and best interests standards is rather blurry, since the implementation of each will take into account both past preferences and present condition of the patient. The way this blurring plays out on the substituted judgment side is straightforward: the standard is meant to make use of past values and preferences to extrapolate to the current situation, and always requires interpretation of both the past preferences and the current situation. From the perspective of the best interests standard things are a bit more complicated. An advantage of the best interests standard is supposed to be that it does not require detailed knowledge of the patient’s past; yet this divorces a patient from who he is and fails to take into account the fact that interests may not be confined to the physical. Some argue, for instance, that people have an interest in dignity that outlasts the ability to appreciate dignity.\textsuperscript{13} If interests are not fully confined to the physical, then (especially for a surrogate who knows the patient well, as is most often the case) a proper “best interests” judgment must take into account some of the same things employed in substituted judgment,\textsuperscript{14} with the result that the two standards are not necessarily
as distinct as the law, and surrogates themselves, would like. As I will argue later on, what a person cares about is a crucial determiner of where her interests lie; this will make space for a middle ground between substituted judgment and best interests that is able to take account of the way a significant number of patients want their surrogates to think, and the way surrogates actually think. Thus, one result of my discussion is a clarification of why we cannot fully separate the concerns of the two standards.

Further complicating the issue, there are cases in which it can be unclear which standard to use: cases in which what is in the patient’s current interests is in conflict with the dictates of substituted judgment, or cases in which it is unclear which of a patient’s interests would prevail even in her own judgment. Consider Mrs. P, a woman in her forties in the early stages of early-onset Alzheimer’s disease. Though she is still active and communicative, she is easily confused, and cannot keep track of all the details of the breast cancer she has just been diagnosed with. The complexity of diagnosis and treatment options is too much for her, and she requires someone else to make her medical decisions. How should this person go about doing so? Both past and present values must be taken into account when considering the treatment options, which in this case are lumpectomy (less disfiguring but more risky in the long run) and mastectomy (safer but obviously disfiguring). In this case, Mrs. P spent most of her adult life deriving her self-worth from her intellectual abilities and derivative professional success, and would before the onset of her dementia have chosen the safer procedure. This preference is well-known among her family, and in particular to the person serving as surrogate. Yet she has also been accustomed to being deemed beautiful; although until her Alzheimer’s this was at best a secondary source of pride, in part because she loathed treating looks as a source of self-worth, it is a major source of her self-esteem now that her intellectual powers are compromised. She is not yet so disoriented that she would not be able to appreciate the loss of her beauty. How, then, is the surrogate to decide the course of her cancer treatment?

Given her unequivocal and well-known preferences before the onset of her dementia, a substituted judgment may seem clear—as long as it is divorced from consideration of Mrs. P’s
present interests. But it is less clear what Mrs. P would have decided for herself in this situation; if she is reasonable, she might well have seen that it could be in her present self’s interest to undergo the lumpectomy rather than the mastectomy. Suppose, however, that when competent, Mrs. P had expressed a clear opinion that even when looks are one’s primary source of self-esteem, they should not be given much weight in decision making, so that it is clear that even for herself in her current situation, the competent Mrs. P would have chosen the safer procedure. Then it could well be the case that substituted judgment comes into conflict with current best interests, since a case can be made that the disoriented Mrs. P still has some claim to consideration as she is now—she is not so far gone that there is no moral loss in overriding her present interest in beauty, and perhaps the risks accompanying lumpectomy are not sufficiently great to make it clear that mastectomy is in her present best interests. So if it is the case that all in all her current best interests dictate lumpectomy, as it might well be, there is a conflict between best interests and substituted judgment. The surrogate must decide which of the standards to use.

As an extensive list of court cases involving questions of withdrawing or refusing treatment on behalf of incapacitated patients would show, such questions are not uncommon. On the surface, the conflicts appear as a clash between autonomy and present interests. As Mrs. P’s case illustrates, however, we might usefully think of conflicts like these as conflicts not between interests and autonomy, but between two (or more) different interests which are based on multiple values (e.g. autonomy, beauty, and health). The question, then, is how to determine which interests weigh the most, or which are to be given priority.

Thus, we run into a conundrum: how are we to determine whose interests take priority here? Those of a former self, or a present self?

In practice, this is a falsely dichotomous question. Several factors complicate the matter. First, there is the aforementioned blurring of the considerations relevant to each of the two standards, so that it is not clear that there are two fully distinct standards to apply. Second, there are the metaphysical quandaries latent in talk of past and present selves: which version of me is me? A
third point, related to the second, is the fact that interests and preferences continue to evolve as developments arise, and even competent patients are often working through the process of sharpening values that have not until now required clear articulation, or reprioritizing their values in light of new circumstances. The exercise of autonomy, which normally involves making decisions in accordance with one’s own values, extends to autonomy to review, reinterpret, and change one’s values.

In light of these factors I want to argue that, rather than thinking of the matter as a question of priorities of values based on temporally separate sets of interests, we should take a holistic view of the patient, a view that attempts to appreciate the difficult details of what it means to be a human person. As a result, what we have here is ultimately a complicated version of the siren problem: how binding should commitments to values be? Which changes in circumstances warrant changes in governing values (or their priorities), and which values are so important that they should not be bent or overridden? In other words, which person should we believe: the person who binds the future self through articulate preferences, or the person who is actually experiencing the problem and (perhaps) changing his mind? This is the real question for the surrogate, just as it would be for the patient.

The problem, then, is that the hierarchy between the traditional standards encodes a linear movement of thought that may not do justice to the reality of the problem, particularly for those surrogates who have a loving relationship with the patient. With a particularly rich understanding of the patient, furthermore, a loving surrogate may find the requirements of the traditional standards inadequate, or at least, oversimplifying. It would be helpful if loving surrogates had another framework for decision making. Since the two standards that give rise to the dichotomy are grounded primarily in respect and beneficence (respectively), a holistic view must propose a way to do justice to both of these values.

In what follows I will make just such a proposal. Anyone who recognizes the competition between present interests and past wishes will likely try to seek a balance between the two. I
advocate a conception of a person’s interests that can find that balance because it is rooted in the attitude of love which, as a regulative ideal, is an attitude that focuses carefully on who a person is. Such careful attention in turn motivates a surrogate to strive for a decision that is authentic to the patient, encompassing essential components of both respect and beneficence but reducing to neither. The attempt to be authentic to the patient in turn suggests a narrative concept of personhood that can provide a theoretical basis for the way some empirical studies suggest surrogates actually make decisions. The result is a clarification of the values and attitudes underlying the process of surrogate decision making that suggests what I will call a “best judgment” model. This model provides a theoretical background for the balancing act many feel compelled to undertake.

2. Love’s normativity and a person’s interests

In order for a model based on love to be defensible, we must have in hand a basic notion of love and its normativity. Thus, in this discussion, let us understand love for someone or something as an attitude that involves concern for a particular object for its own sake (not just as an instance of a type), and that endows that particular thing with personal importance that goes beyond its impersonal value. Over the course of our lifetimes, we form attachments to some people, projects, causes and things, and not others. This process is necessary to keep us from being overwhelmed by value. Personal importance does not rule out appreciation of impersonal value. We simply cannot respond appropriately to everything that is (impersonally) valuable, so we invest emotionally and volitionally in some things and not others.

Emotional-volitional investment lies at the heart of love and makes it the distinctive attitude it is. For present purposes, love is characterized by dispositions to certain emotional episodes (joy, fear, pride, etc., which in turn are characterized by behaviors, facial expressions, thoughts, and feelings) together with the underlying attunement to and vigilance for circumstances that relate to the object of love. Love’s motivational tendency toward the protection and preservation of its object engenders dispositions to act in response to these circumstances—to exclaim in joy, laugh, cry, back
away in fear, boil over in anger, and to construct plans of action centered around the object of love. This investment has the effect of, to some extent, making the subject of love emotionally vulnerable and thus tying her welfare to the welfare of what she loves. 

It is this entangling of the lover’s welfare with that of the object of love that distinguishes love from other appreciative attitudes such as respect and admiration. Loving attachments are attitudes that endow the object with value for the lover. We might say they are valuative, as opposed to evaluative. They can grow independently of evaluative attitudes, and evaluative attitudes can form without such attachments. Attitudes like respect and admiration are evaluative responses to perceived value, but they are not as personal and do not attach a person’s welfare to their objects in the way that love does, and they do not endow the object with personal value. Of course, such attitudes usually accompany love; I not only love my spouse, but also admire and respect him.

The welfare entanglement that comes with love gives it a reflexive quality, so that loving actions are for the sake of the beloved, but also (indirectly) for one’s own sake. This is somewhat paradoxical in light of the fact that loving something involves concern for it for its own sake, and is thus an intrinsically selfless attitude. Love’s reflexivity is also important because it plays a vital role in constituting someone as the person she is. Because it takes time to come to love or to let go of love, loving engenders a fairly stable, though nonetheless constantly evolving, web of attitudes and dispositions. This web of loves in turn gives rise to the plans and intentions that constitute agency; that is, the things I love lead me to construct ongoing projects by which I organize my life into a coherent whole. Such a complex of attitudes, dispositions and projects forges my identity; the person I am is characterized by these very things.

In light of this, I want to emphasize that love plays a dual role in surrogate decision making. Most importantly, its normativity regulates the way a surrogate should deliberate for the patient, as I will illustrate. But this is the case partly because the patient’s identity is defined by what he loves. Thus, two related but different aspects of love are relevant to surrogate decision making. The self-constituting factor of love is present in that what the patient cares about makes him who he is. The
inherent attunement to another shows up in the way the surrogate’s love for the patient, with its attentiveness to who he is (and thus what he loves), is to guide her deliberation for him.

How do we make use of love’s normativity in the present context? I propose to work out a love-based model of a patient’s interests and hence a guide to surrogate decision making that I will call the “best judgment” model. The notion of a person’s interests I wish to use defines these interests as what it makes sense to want for her insofar as one cares about her—what it makes sense to want, given that one has an attitude toward her that is concerned with the beloved for its own sake; is attentive to the details of the beloved as a particular; bestows value on the beloved beyond its objective value; entangles the welfare of the lover with that of the beloved; and in virtue of the entanglement helps to constitute the lover’s identity.

Paradigmatically (though recognizing that real life is often much more complicated), lovers have their beloved’s best interests in mind, and this is for the beloved’s own sake. What this paradigm plainly shows is that although “best interests” certainly include physical well-being, they also include a great deal more than that. With this established, we know what to look for in a new model for decision making: it must encompass a holistic conception of a person’s interests.

3. The holism of love’s normativity

Let me begin to flesh out the argument with an observation. Insofar as, out of love for the patient, it makes sense to want both that her former autonomous wishes be honored and that her remaining sense of self-worth be preserved, the patient herself has conflicting interests. Descriptively speaking, a surrogate who loves a patient typically wants to respond in a way that does justice to all of the patient’s interests, stemming from both the person as she is, and the person she used to be. In the case of Mrs. P, he will be aware that even if the lumpectomy is the right decision, there is nevertheless a residual moral cost to overriding the interest Mrs. P used to have in taking the safer, more cautious route (that is, the moral cost attending overriding the autonomous choice she would have made if competent). Yet he will also sense a moral cost to depriving Mrs. P of her beauty by
electing the less risky mastectomy. This is because he senses a vital interest stemming from something she loves, which, because it is now central to her self-conception and self-esteem, is not automatically overridden by the competing interest in health. In other words, the surrogate will be acutely aware of the competing interests of the person Mrs. P used to be and the person she is now, because those interests are not limited to health and physical well-being.

Considerations of what has been called “full moral standing” may seem to point to a present best interests view for as long as the patient can be understood to have this standing. Full moral standing is the moral status of a creature such that its interests cannot be breached in the name of any other value, including to protect the interests of others with full moral standing; it involves in the first instance a kind of inviolability. Nevertheless, particularly when different interests are in conflict, some interests must be placed above others. In light of the inviolability of any creature with full moral standing, any such violation, however unavoidable, comes with a certain moral cost. The “residue” of such moral costs signals that the person affected by one’s actions has full moral standing. And if a person has full moral standing, then her present interests should not be compromised for those of a person (her past self) who (in some sense) no longer exists.

It may seem, then, that someone who loves a patient will as a matter of fact tend to side with her present interests as long as she is capable of having interests, in the sense of loving things; or in other words, as long as she is capable of taking an interest in the interests she still has. Considerations of full moral standing are, for instance, what drive intuitions that Mrs. P should undergo a lumpectomy rather than a mastectomy, because although her intellectual powers have diminished, her capacity to care about her beauty has not, and given that it is the major source of self-esteem for her now, depriving her of it brings the kind of moral cost that signals that the present Mrs. P does have full moral standing. This kind of case suggests that any standard for decision making grounded in love will require consideration of the patient’s present best interests (which may not be limited to health).
I contend that any such standard also requires respect for past exercises of autonomy. But in light of what has just been argued, any claim that love for a patient such as Mrs. P requires respect for past wishes needs further support. Why not take a full “present-interests” view? Why think that the interests of a person who is (in some sense) no longer with us still carry any weight, on this account? What is it about love—an attitude that focuses on a person as she is—that encompasses this backward-looking view? I will be arguing that a view of surrogate decision making that grounds it in the regulative ideal of love for the patient indicates that past interests should also leave a residue, since they were part of the person the surrogate loves. This is not just a matter of the way love guides us, but why it should guide us in this way.

Examination of this question will lead to the articulation of another model for surrogate decision making. It is roughly this: the decision should be made on the basis of what the surrogate should want for the patient insofar as the surrogate loves her. It thus draws on the normative aspects of love as an attitude concerned with the beloved for her own sake, and entangling the welfare of the lover with that of the beloved. Love as a regulative ideal thus requires patient-centered decision making and is concerned to preserve the identity of the patient as far as possible.

We have seen why love should motivate a surrogate to attend to the patient’s present interests. But as I pointed out, the question is: why the past? As I will argue below, past interests still carry some weight because they arise from the values, ongoing projects, and plans for the future which served in part to make the patient a person at all, and the particular person the surrogate loves. And as a person with the full capacity for autonomy, Mrs. P projected herself into the future through those values and projects, including, in this case, the project of directing the course of any future medical treatment according to her values.

The traditional paradigm suggests that the attitude most fitting here is respect, so before I make my case fully I want to address some considerations that will further motivate my proposal. Respect for a person’s autonomy must take into account the projection of his plans into the future and the values on which they were based because respect is an attitude that seeks to honor demands
for recognition one person may place on another. It accounts for strong intuitions that deathbed promises ought to be honored, despite the fact that the “promisee” cannot call the promiser to account for breaking the promise. It also accounts for intuitions that such a promise is not absolute. The interests represented by the wishes expressed in the promises remain serious, even though they are overridable in the case of conflict with the interests of another person with full moral standing who could in principle also demand recognition—the person Mrs. P has become in light of her Alzheimer’s.

I do not, nor do I wish to, deny that respect is an appropriate attitude and an appropriate motivation in situations we have been considering. But I do want to press the point that it is not the only appropriate attitude, and concentrating solely on respect causes us to place perhaps too much emphasis on autonomy at just the point when that concept becomes murky. I want to suggest that the reasons to consider past wishes need not be based only on respect for autonomy.

Similarly, it makes sense for one who loves a patient to wish to make a decision consonant with her values—something authentic to the patient, which (as I will explain below) is not necessarily the same as deciding as she would have wished, or in accordance with her present best interests; it will likely involve reinterpreting each in light of the other. And as we have observed, respect is compatible with, perhaps even a component of, love. But respect for autonomy alone is too thin an attitude to make a judgment that does justice to the complexity of the situation under consideration and the particularity of the patient. Respect for autonomy may cause some caregivers to give less attention to current needs than is warranted. Too much emphasis on such respect may also have the effect of overlooking the process that even competent patients go through as they work through their options and set their care goals. This process quite often involves reviewing and revising their understandings of their own values, typically in consultation and dialogue with loved ones. And patients may value autonomy less, or define it differently, than the now-dominant paradigm assumes.
I have been pointing to the attitude of love as the proper guide to decision making because it seems to encompass aspects of both of the attitudes that go with the values embodied in the traditional standards for decision making. As mentioned above, love’s motivation is toward the beloved’s *authenticity*—understood roughly as “being true to oneself”—because love is responsive to the beloved’s personality and the cares that make her herself. Authenticity is a value that shares characteristics with both autonomy and beneficence, but differs from each. First, what a person autonomously chooses is not always consonant with other values, in particular with values more central (hence more authentic) to who she is. Second, what is authentic to a patient goes beyond health in part because a patient’s health is not generally something that makes him who he is. Furthermore, as circumstances change, people often revise their understandings of their values, including rearranging priorities among them. Authenticity can take this into account, however, by considering, as if in dialogue with the patient, how new information and new developments would shift priorities.

A surrogate who tries to think and act as love directs will seek to decide in a way that is consonant with his understanding of the patient’s unique set of values and characteristics, but need not be what the patient *would* have done (particularly since we can never know with certainty what she would have done)—only what she might well have done or what it would make sense for her to do. A sound decision under the regulative ideal of love is not focused on acting as the patient, but remains patient-centered. Consequently, a decision-making model grounded in love resonates well with other attempts to sharpen our understanding of the values involved in surrogate decision making (such as the narrative approach), taking into account the richness of detail and experience that go into thinking about surrogate decisions.

Advocating that a surrogate should make a decision that is authentic to the patient may still seem to run contrary to the considerations of full moral standing I brought forward earlier. This is because the perspective of authenticity views a person holistically, thus making the person’s past judgments relevant, where the considerations of full moral standing tend to view a person in time...
slices, almost as though different persons were involved. So how can a holistic perspective (rather than a choice between past or present) be justified?

In asking this question, we run directly into questions of personal identity. Surrogate decision making becomes necessary precisely when a patient has lost crucial powers relevant to making decisions. In particular, the patient has lost the ability to refine and revise the values and priorities that would normally guide her decision making. But refinement and revision of values, or at least the priorities among them, is precisely what has become necessary in light of her changing circumstances. The shifts in personality and ability attending certain kinds of illness can, as we have seen in the case of Mrs. P, make some values more important than they used to be. And so we again arrive at the question: Why should the values and priorities of someone who is (in some sense) no longer present govern the care of someone who is? What reason does a surrogate have to attempt to be authentic to “the patient,” when at least some of what made that patient the person she is has now eroded?

One suggestion put forward by what we might call narrative theorists is that what we are concerned with when we are interested in personal identity is less the metaphysical mystery of how one person can both change and remain the same than it is the concern with what makes a person who she is (and not someone else). From this perspective, personal identity is constituted (largely) by a person’s self-conception, which can be interpreted as having a narrative structure. This idea is backed well by what has been said above concerning the way loves constitute a person as the person she is: the things a person loves and the projects to which they give rise, by giving a person a sense of direction and purpose, provide the threads that weave together a narrative structure. What it makes sense for a person to do, then, is something that fits the ongoing story of a person with the projects defined by her cares. This story may display growth and change as circumstances warrant.

Thus, according to the narrative theory, a surrogate’s decision should be seen as continuing the narrative for the person who has lost her own narrative capacity—a move at least as well understood as growing out of the value of authenticity as out of autonomy. It might even be better
understood as a matter of authenticity, since when deciding for herself the subject of the narrative will likely be exercising her autonomy in order to determine, through refinement and interpretation of values, which act would be most authentic to her. There is evidence that when there is a conflict between previously stated wishes and a surrogate’s best judgment, patients prefer that the surrogate go with her best judgment. The narrative frame helps the surrogate to arrive at that judgment, and the discussion of love that I have provided gives it a theoretical grounding. The focus is not on making the decision the way the patient would have made it—there is no way to know whether she would have sharpened her values the way you do. But in aiming at authenticity, you follow a path the patient may well have taken.

Given what I have argued thus far, the continuation of a life narrative, guided by the value of authenticity, makes sense as the response of a surrogate who loves the patient for whom he must make decisions. It is not, then, a duty owed to the person out of respect for autonomy that is now gone, but rather the appreciative response of love.

This move serves not so much to require a substituted judgment view as to justify it in light of a present-interests view such as that of Dresser and Robertson, or the considerations of full moral standing I mentioned above. It need not be taken to place the interests of the fully competent past self above those of the present patient, but it shows that these concerns may—should—still carry some weight in deliberation.

Notice that one effect of centering the decision on authenticity and the response of love is that, because of love’s reflexivity, the decision is in a broad sense based on the needs of the lover—in particular the need to construct a response that expresses the characteristic appreciation of the lover for who the beloved is. The move in effect shifts the outlook from that of the patient to that of the surrogate while nevertheless remaining patient-centered in virtue of the fact that love motivates the lover to act for the sake of the beloved. As a result, there is less need to worry about whether the past interests of the patient are, as such, fulfilled. It is not only a question of the patient’s interests, but also the surrogate-as-lover’s, since the latter will encompass the former.
There is some evidence that such an approach would be welcomed by a significant number of patients (though not all). First, it has increasingly been noted that the traditional Western definition of and emphasis on autonomy is not consonant with the traditions of other cultures, for instance those in which decisions are traditionally made for a patient by his family. Second, even in the United States studies suggest that patients themselves often define autonomy in different ways, place less emphasis on it, or wish other factors to be considered (e.g. stress on the family). Moore et al. conducted a study with this idea in mind, taking seriously the fact that surrogates cannot realistically live up to the standards of impartiality demanded by the substituted judgment and best interests standards. Why not, if possible, make partiality an ally by bringing it into the open and examining what it requires of a responsible surrogate? Surrogates are typically loving family members who are trying to balance their intimate knowledge of the patient’s (former) preferences with his current interests. Moore and her colleagues crafted what they also term a “best judgment” model, aimed to cut a middle path between substituted judgment and best interests, focused on balancing out factors important in each of the other two. In their study, one third of their sample of elderly adults living in senior housing communities preferred that their surrogates employ the researchers’ “best judgment” standard, rather than substituted judgment or best interests. (Half chose substituted judgment, and the rest best interests.) Concerns of patients choosing this model included the complexity of the decision making process, the need for holistic judgments on quality and quantity of life, and considerations of the family’s interests—all factors that are well accounted for on the view of surrogate decision making I am proposing for those who love a patient.

Obviously, any study has its limitations, and in any case Moore et al.’s best judgment model came in second to the substituted judgment standard. Nevertheless, a best judgment model grounded in love as its regulative ideal, as I’m suggesting, should be able to take the patient’s emphasis on autonomy into account. It is clear that some middle path matches important intuitions—including those of a significant number of patients—about how surrogate decisions ought to be made. Furthermore, it is no worse off than the other standards with regard to danger of
pollution by the surrogate’s self-interests. It is possible that using the language of love will invite misunderstanding, since it is easy to assume that we all know what love demands. But I think this is not necessarily a bad assumption; the account given captures love’s core well enough to fit the understanding of most who stop to reflect on what love demands.

Moreover, the best judgment model has some advantages over the others. First, there is the advantage of acknowledging that people cannot make such decisions wholly by putting themselves in another’s shoes; it is impossible to be free from some emotional and personal interest. My proposal recognizes and legitimates this by making use of the reflexive qualities of love. By avoiding the pretension that they are deciding as the patient would, a best judgment model may set some surrogates’ minds at ease as they work through a cognitively and emotionally difficult decision making process because they need not attempt to divorce themselves fully from that process. Additionally, it gives some legitimacy to the inclusion of the surrogate’s or family’s interests, in cases where the patient loves the surrogate as the surrogate loves the patient. In such a case, a natural part of what is in the patient’s interests is the welfare of the surrogate and other family members (as the surrogate is typically a family member). Third, the best judgment model still draws on the values that make each of the other two standards attractive (considerations of autonomy and beneficence), a balancing act which many surrogates in fact undertake anyway (thus adhering to neither of the other models strictly).

Finally, the “best judgment” model rooted in love seems closest to the process that loving surrogates actually go through in making their decisions. One study found that surrogates go through a process that can be described as “pre-grief,” a process of coming to terms with not only a barrage of complicated medical information, but with “who the person had been in the past and who the person was expected to be now,” as well as with their own changed identities once the loss finally occurred. A best judgment model, with its emphasis on love and the requisite reflexive recognition that the surrogate’s world is changing at the same time as the patient’s, does justice to this process.
Another study emphasizes the balancing act that surrogates undertake as they strive to “see them through with care and respect.” This recognition of both the need for independence and autonomy and the need for care and comfort is a hallmark of love, which recognizes that a person’s interests are not only physical, but emotional and social. Worth noting, too, is the fact that surrogates tended to put the patient’s needs before their own, another hallmark of love.

Matching the experience and preferences of surrogates and patients is not in itself a normative reason supporting the use of a best judgment model; just because it matches the preferences of a significant population does not mean it is correct. But good models are ones that capture the values those affected believe to be most important for the situation. This is what the traditional models attempt to do, and if the best judgment model does better (for loving surrogates), that should count in its favor. The best judgment model helps to codify, and hence perhaps govern, a process that takes place whether we like it or not. Furthermore, having theoretical support for what happens in practice can give surrogates some confidence in their own judgments and ease psychological burdens.

The proposed best judgment model has the limitation that it requires detailed knowledge of the patient, knowledge that is not likely to be accessible to caregivers who do not actually love the patient. Caregivers can and do (and should!) take a loving approach, which attempts to see the patient for who she is and not just as a patient, but there may be no substitute for intimate knowledge of a person before her illness. This is a limitation shared with the substituted judgment model, but not with the best interests model. In a sense, of course, the best judgment model is simply a more expansive version of the best interests standard, resting on a broader conception of a person’s interests than the typical benefits/burdens approach. But we cannot do away with the “narrow” version of the best interests model altogether, because some people may not have surrogates with such a close relationship. Still, in the majority of cases in which surrogates are needed, it is a loving family member who must decide, and again, understanding that love is a sound basis for a decision will likely prove to be some comfort.
Is the model too hard to operationalize? From the loving surrogate’s perspective, it is no harder to implement than the substituted judgment standard, and again, the best judgment model has the advantage of being truer to life by being responsive to specific patients’ weighting of relevant values. This model, like the others, can offer no clean formula. But it provides a more subtle understanding of how a decision that does not adhere strictly to either of the traditional standards can still be legitimate. For specific patients, it may “collapse” into one of the other standards—for a patient who valued his independence highly, a loving surrogate would do best to decide as he would; for patients who valued health goals, or for patients whose surrogates are unfortunately not close enough to them to love them and know their values, a surrogate may only be able to act on the considerations of a best interests standard. In any case, one thing the best judgment model offers is a theoretical footing for the de facto process that loving surrogates employ.

It is unfortunately unlikely that the best judgment model’s criteria can be made clear enough for the model to be implemented in law. Still, part of the point I’m making is that love has a normativity that can be put to use in the decision making context; there is a more personal framework available for those surrogates who love the patients for whom they must make difficult, emotional decisions. In addition, given that the best judgment model attempts to balance the values embodied in the currently articulated legal standards, evidence relevant to those standards will be relevant to the best judgment.

For many, thinking about the problem in the familiar terms of love may make the process less intimidating, and it allows a central motivation of a loving surrogate an acknowledged place in the decision making process. In this sense, what I offer here is meant less as a replacement of the other two standards than it is a way of thinking about the same problem through a different frame, one that may be more comfortable for many. The model is even more patient-centered than the traditional models, because it offers patients—and, incidentally, surrogates—recognition for who they are.
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Notes

1 Velleman (2003); Blustein (1999); Kuczewski (1999).
2 Taylor (1991); Bradney (2009).
4 This model is sometimes split into two. In the first, a patient’s wishes have been made explicit, usually formally, as in a living will or other document. In the second, there are no explicit wishes to draw on, and a surrogate must reconstruct what the patient would have wanted from other knowledge of the patient. For the purposes of this paper, I lump these together under the label “substituted judgment” because both are rooted in the value of autonomy.
5 A note about terminology is in order. Different authors (and sometimes the same author at different times, e.g. Harry Frankfurt) label the attitude I have in mind in different ways; it is sometimes called love, sometimes care. Below in section 2 I will elaborate what I take to be the core volitional features of this attitude, which I think several major accounts of the attitude have in common. (I have in mind here the accounts of Harry Frankfurt, Irving Singer, and Nel Noddings.)

The choice of the word “love” rather than “care” does, it seems to me, strain the normal use of the word in English; we don’t normally talk about “loving” a cause or project in a serious way, as I will want to do. (We instead talk about dedication, commitment, etc.) Nevertheless, as Irving Singer emphasizes, love is multifaceted and can be for objects and ideas as well as people; even if we don’t use the language of love with regard to inanimate objects or abstractions, the volitional core of the attitude is the same. Thus, in order to reserve the possibility of using “caring about” for things that matter to us but which we don’t truly love, I follow Frankfurt (in The Reasons of Love), Singer, and others in the use of “love.” This also avoids confusion in a context in which “care” can mean medical treatment.
7 For discussion, see Welie (2001) and Torke (2008).
8 See Sulmasy et al. (1998); Shalowitz, Garrett-Mayer, and Wendler (2006); Stephen C. Hines et al. (2001); Peter H. Ditto et al. (2001); Teno et al. (1997); Marks and Arkes (2008).
9 Some even argue that best interests ought always to be invoked; see Dresser and Robertson (1989).
10 See Rhoden (1990) for an extended discussion; see also Cantor (2005).
11 Given the emphasis on autonomy, participating little in medical care decisions is (a) not that common, but (b) sometimes controversial when it does arise. It is beyond the scope of this paper, however, to discuss whether or not competent patients ought to participate in their own medical decisions.
12 Moore et al. (2003), following Rhoden; Berger, DeRenzo, and Schwartz (2008).
13 See, for instance, Koppelman (2002).
14 As Fan (2002) points out, even the beneficence-based Hippocratic tradition doesn’t exclude consideration of a patient’s wishes; you can’t ensure successful treatment without the patient’s cooperation, which will be harder to secure when the patient feels that he is not being heard.
15 Case borrowed from Jaworska (2007a).
16 See below for a further argument on this point.
17 Again, language is somewhat awkward here; we ordinarily distinguish between “people” and (mere) “objects.” For ease of exposition, however, I will usually write “object” rather than “object or person,” since a person can be the object of love.
18 For extensive discussions of this attitude, see Jaworska (2007b); Helm (2010); Anderson (1993); and Frankfurt (2004) and (1999). With the exception of the later Frankfurt, these sources employ the word “care” for what I am calling “love.” The account I give here, which encompasses the core volitional features I take these accounts to have in common, is also indebted to Velleman (2008) and the work of Irving Singer.
Since I am interested in its core features, I am glossing over possible differences in the kinds of love one might have for spouses or friends or siblings or children. Love of spouses or friends, for instance, may have an evaluative element that is not present in love of children or siblings. I contend, however, that any evaluative element that may be present is not part of love’s core characteristics.

19 Although not material to my present purpose, it is worth noting that although love is at its core an emotion, it does have a rational structure. Loving certain things can make more and less sense; reactions stemming from love can also make more or less sense. (It does not, for instance, make much sense to love a saucer of mud intrinsically, at least not without a very interesting supplemental story; it also makes no sense to react with chagrin when someone praises your prized pickle recipe.) See Helm (2010) and Anderson (1993).

20 In the case of things and projects, which do not technically have welfare, the term “welfare” is used as a shorthand for being in good condition (for things) or being furthered (for projects).

21 In this paper, I use “respect” to mean respect for autonomy, as in the basic Kantian attitude that is owed to anyone with a certain kind of dignity. I thus set aside the question of whether there is a more robust kind of respect that attaches to specific others with whom we have particular relationships.

22 See Jaworska (2007b) and Bratman (2000).

23 I borrow this move, and the notion of a person’s interests that follows from it, from Darwall (2002).

Defining interests in this way gets around the fact that human relationships and motives are complex and possibly polluted or eclipsed by self-interest.

24 See Jaworska (2007a) for a fuller discussion; my description of full moral standing relies directly on hers.

25 When the patient is no longer capable of this sort of love, then it seems plausible that past wishes would then return to dominance. This is not obvious, but it follows from considerations put forward in the discussion below.

26 This claim may seem surprising, given that standard accounts of full moral standing ground it in the feature that is usually considered to separate humans from other creatures: intelligence or rationality. Yet the difficulties with such an account are well known, and appeals to common sense regarding which creatures have or lack the requisite mental powers cannot resolve it. The account of love and a person’s interests I gave in section 2 suggests a different grounding for full moral standing: the capacity to love. Jaworska (2007a) presents a more detailed account than I have given here.

27 As Dresser and Robertson (1989) do.


29 As Dresser and Robertson argue (1989).

30 Kuczewski (1999); Berger, DeRenzo and Schwartz (2008); Moore et al. (2003).

31 See Winzelberg, Hanson, and Tulsky (2005); Berger, DeRenzo and Schwartz, (2008); Torke (2008).

32 Though see Taylor (1991) for an intricate discussion of the concept.

33 This is an overgeneralization; there are a considerable number of people whose medical conditions have shaped their lives and personalities in such a way that they would not be themselves without them. Nevertheless, in the context of surrogate decision making, the conditions that make a surrogate necessary are probably not the ones that have shaped the patient’s character, and so I let the generalization pass.

34 See Brudney (2009) for a discussion of authenticity as the proper value to focus on; much of what I go on to say relies on his account. Also, see Blustein (1999) and Kuczewski (1999) for discussions that make narrative the central focus. These ideas are not new; what is new here is the theoretical background that makes these ideas normatively relevant.

35 Here I draw especially on Blustein (1999) and Kuczewski (1999). See also Velleman (2003); Torke (2008). Koppelman (2002), although she is not what I would term a narrative theorist, points out that if autonomy amounts to balancing reason and desire, then the decision of the surrogate should be made in this spirit, using the current likes and desires seen as part of the character of the former self. This holistic picture has much the same spirit as the narrative theorists, though I would argue that her emphasis on dignity is ultimately off target.


37 This conclusion finds further support in a persuasive argument by Whiting (1986) that part of what makes a future self yours is your concern for that person, even if all she has in common with you is psychological continuity. If this is the case, then a lover (or a surrogate) is justified in being concerned for the patient in her current state to the same extent and in the same way a person herself would be, thus projecting interests that are now past into the future.

38 This move might seem to encourage conflicts of interest. However, given love’s normativity as explained in section 2, it should not; love is at its core an attitude that centers on the beloved. The repercussions for the lover are secondary, and in any case they are centered on what the surrogate wants in his capacity as a lover—and not along any other dimension. If the surrogate serves his own interests rather than those of the patient...
when these conflict, then he will not be acting according to the best judgment model put forward here. Of course, I cannot claim that in practice everyone who attempts to guide his decision making by the normativity of love will succeed in being as selfless as the situation may theoretically demand; but this problem is no worse for the best judgment model than it would be for either of the other two. See Marks and Arkes (2008) for related discussion.

39 Fan (2002); see also Freedman (1993).
42 There is growing recognition that surrogates need support through the decision making process. See Lipman (2008), as well as Vig et al. (2006) and Vig et al. (2007).
43 Chambers-Evens and Carnevale (2005); Berger, DeRenzo, and Schwartz (2008); Vig et al. (2006); Meeker (2004).
45 Meeker (2004).
46 In this particular study, most of the patients were still communicative and able to participate in their care decisions, even though family members were the ultimate decision makers. I don’t necessarily think this is a limitation on the study’s relevance to my argument, since there is no reason that surrogates cannot have the same intentions or go through similar processes for less communicative patients by consulting other family members or their memories of the patients when they were more communicative. This is borne out in the study during the process of “acting for” the patient, in which advocacy for the patient’s needs was expressed by concerted attempts to have the patients’ choices honored. Honoring choices in turn included not only acting on the patient’s known wishes, but also honoring known goals and wishes in contradiction to written directives. This suggests the perspective of the best judgment model, grounded in love, rather than a substituted judgment model, grounded in respect for autonomy.
See also a discussion of family support by Alexandre Lautrette et al. (2006).

References


Dresser, Rebecca and John A. Robertson. 1989. “Quality of life and non-treatment decisions for incompetent patients: a critique of the orthodox approach.” *Law, Medicine, and Health Care* 17: 234-44


