Narrative Ethics and Decision-Making Capacity: An Alternate Understanding of Value in Capacity Assessments

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While informed consent is largely considered to be the most important standard in contemporary bioethics, a patient's consent to treatment is only respected when that patient is considered to possess decision-making capacity. Consequently, the model of decision-making capacity employed is integral to the proper application of the standard of informed consent. In this paper, I address several problems with the value component of the standard model of decision-making capacity in contemporary bioethics — problems that lead to a high likelihood of both false positive and false negative rulings of patient competence with regards to treatment decisions — by asking: Which personal values used to inform treatment decisions should be respected? And, what constitutes a set of articulated values? As a solution to the problems presented, I appeal to a narrative-based approach to understanding value — an approach that situates the patient within their social and personal context. Finally, as a means of both clarifying the narrative approach and demonstrating it's potential clinical application, I apply it to the contested area of treatment refusal by patient's suffering from anorexia nervosa.

1.1- Introduction

Though informed consent is largely considered to be one of the most important standards in contemporary bioethics, there has been wide debate concerning what is required for a patient's consent to be considered valid. More specifically, the debate has centered on the issue of what constitutes the minimum required capacity for decision- making. In this paper, I will demonstrate that considerations of the personal narratives of patients are necessary for determining their decision-making capacity. I will begin by outlining notions of informed consent[1] and capacity as they are generally articulated (2.1-2.2). I will then problematize the common concept of capacity by appeal to criticisms developed through a feminist relational ethic, as presented by Susan Sherwin (2.3) and offer a narrative-based approach as one solution to the problems presented (3.1-3.2). Having done this, I will demonstrate the practical application of the narrative approach

[1] I am indebted to Vida Panitch for comments and discussion on earlier drafts of this paper, and Barbara Russell for guidance concerning my research into Anorexia Nervosa. 1 'Informed consent', here, should be taken to mean 'first-person informed consent' unless otherwise indicated.

through a discussion of the contested area of refusal of treatment by people suffering from anorexia nervosa (4.1-4.2). Finally, I will address objections to the view presented (5.1-5.2).

2.1- Informed Consent

Valid informed consent, in contemporary bioethics, is used as a means of respecting patient autonomy[2] — a principle whose importance is supported by a wide consensus. Consent, by and large, is taken to have four elements: 1) Consent must relate to the treatment; 2) consent must be informed — where informed refers to the patient's knowledge of the nature of the treatment, the expected benefits and risks, the side effects, the alternatives to the treatment being offered and the consequences of not being treated; 3) consent must be voluntary — that is, free from undue coercion; and, 4) consent must not have been obtained through misrepresentation or fraud.[3] Finally, we can also add, the individual giving consent must have decision-making capacity.[4]

2.2- The Standard Model of Decision-Making Capacity

Decision-making capacity, according to the Ontario Health Care Consent Act (HCCA) is assessed through an examination of the understanding and appreciation abilities of the individual.[5] Understanding, here, refers to the patient's factual knowledge of the treatment, their ability to weigh different treatment options, and their general problem solving skills. Appreciation refers to the patient's ability to appraise different treatment outcomes rationally and in light of personal beliefs and values that are based in reality.[6] While the HCCA does not view possession of personal values as an independent component of decision-making capacity there are many who do. Dan Brock and Allen Buchanan, in their book *Deciding for Others: the Ethics of Surrogate Decision Making*, outline three, rather than two, abilities constitutive of decision-making capacity: reasoning and deliberation, understanding and communication, and possession of a consistent set of values.[7] Reasoning/deliberation and understanding/communication are equivalent to understanding and appreciation as outlined by the HCCA, respectively. However, Brock and Buchanan, require for their value component "a *set of values* or *conception of what is good* that is at least minimally consistent, stable, and affirmed as [the patient's] own".[8] [9]

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[2] Susan Sherwin, "A Relational Approach to Autonomy in Health Care," in *The Politics of Women's Health: Exploring Agency and Autonomy* ed. Susan Sherwin p. 24 (Philadelphia, Temple University Press, 1998).

[3] National Initiative for the Care of the Elderly, *Tool on Capacity and Consent*, http://www.nicenet.ca/detail.aspx?dt=635&menu=43&app=198&cat1=571&tp=9&lk=g, accessed April 2009.

[4] While there are problems with this concept, this paper will not address them. I have outlined, in brief, the elements of informed consent only for the purpose of clarifying, to some extent, what patients are required to be competent for. If informed consent was not valued, patients competence with respect to treatment decisions would, arguably, not be valued either.

[5] While I employ the Ontario-based provincial definition of decision-making capacity here it is not the case, as the following discussion illustrates, that this concept is specific to Canada— it serves merely to provide a concise illustration of the topic at hand.

[6] Ibid.

[7] Dan, Brock and Buchanan, Allen. *Deciding for Others: The Ethics of Surrogate Decision Making*. Cambridge, Cambridge University Press, 1990.

[8] Ibid., p. 25. Emphasis is from the original.

[9] While there is some debate as to whether value should be viewed as an independent component of decision making capacity— as opposed to one part of the appreciation component— I will, for the sake of clarity, present it as distinct here. It is my hope that the way of understanding value through narrative, presented below, will reinforce this distinction.

So, decision-making capacity, as it has commonly been defined, consists of the ability to understand factual components of the treatment (including knowledge of alternate options as well as potential risks), to reasonably appreciate potential outcomes of a decision, and to weigh those outcomes in light of reality-based personal beliefs and values.[10]

2.3- Problematizing the Standard Model of Decision-Making Capacity

The most pressing questions for the model of decision-making capacity, as presented above, are: which personal values used to inform treatment decisions should be respected? And, furthermore, what constitutes a set of articulated values?[11] It is important to note that both of these questions require answers that clarify our understanding of the nature of value.

While the appeal to "reality-based personal beliefs and values" in the HCCA seems to provide an answer to the first question, we can still ask to what 'reality-*based*' is meant to refer. That is, at what point do beliefs and values that are not perfectly in synchrony with reality cease to be based on reality? In seeking to answer this question, we can appeal to Freud's distinction between illusion and delusion. He says: "In the case of delusions, we emphasize *as essential their being in contradiction with reality.* Illusions *need not necessarily be false*".[12] So, perhaps an answer to the first question is: delusory values should not be respected, but illusory values can be. The second question, however, is more difficult to answer, in large part due to the fact that many people do not possess a set of values that can be articulated on demand. That is, we develop our beliefs and values through action (especially in relation to other people).[13]

The above leads to a second, more pressing problem. In discussing informed consent, Sherwin notes, "the paradigm offered...is built on a model of articulate, intelligent patients who are accustomed to making decisions about the course of their lives...[Valid] decisions are constructed as a product of objective calculation on the basis of near perfect information".[14] This, it is not difficult to see, is an ideal model that is rarely, if ever, realized. Also, the decision-relative nature of decision making does not pay enough attention to the context in which the decision is being made.[15] [16] It is assumed that an assessment of the patient's abilities can be made in isolation from the conditions in which they make the choice. This, however, is not the case. Instead, "we need to be able to look at specific decisions *as well as the context* that influences and sometimes limits such decisions".[17] Not taking the personal and social context into account can lead to both false positive and false negative rulings concerning a patient's decision-making capacity.

The potential for false positive rulings is highest when a patient makes a choice about treatment that follows the medical standard, but is not right for that person. Decision-making capacity, which is generally assumed in adults, is only questioned when the physician has some

[10] National Initiative for the Care of the Elderly, *Tool on Capacity and Consent*.
[11] All of the objections here will address the value component of decision-making capacity. This is not to say, however, that there are no potential problems for the understanding or appreciation components.
[12] Freud, Sigmund. The Standard Edition of the Complete Psychological Works of Sigmund Freud Volume 21, Translated by James Strachey. Vintage, 2001. Emphasis in the original.
[13] Frank, Arthur. *The Wounded Storyteller*. Chicago, University of Chicago Press, 1995.
[14] Sherwin, *A Relational Approach to Autonomy in Health Care*, p. 24.
[15] Ibid., p. 26.
[16] Brock, Buchanan, *Deciding for Others*, p. 18.
[17] Sherwin, *A Relational Approach to Autonomy in Health Care*, p. 32. Emphasis added.

grounds to do so[18] — the patient disagreeing with the physician is generally taken to provide such grounds.[19] So, it is possible for the patient to agree with the physician for reasons that would provide for a ruling of 'incapable' should a capacity test be administered, but, *due to the patient's agreement*, there would be no grounds for that test. This would lead to false positive rulings of decision-making capacity.

Similarly, a patient could disagree with a standard treatment option and have their capacity challenged on that ground. If the belief or value that caused the refusal of standard treatment is one that does not fit with those that are medically accepted, a false negative ruling of decision-making capacity could occur. Rulings such as these are most likely to occur when the patient is a member of a group whose rationality is already socially questioned (such as women, racial minorities, indigenous peoples, and people with disabilities).[20]

3.1- Narrative Ethics

The narrative approach to ethics "differs from an assessment based on utility, duty or principle in that it gives a prime position to an account of an individual, or group of individuals".[21] This account is given by the individual, and will consequently stress the themes, events and emotions important to them. This narrative, it is important to note, is nothing like the patient history the physician has access to.[22] [23] The difference can be seen most clearly in the way that the patient's story is told. The patient history is based on answers given to a formalised set of questions. These questions provide the data relevant to treating the illness that brings the individual into the care of the physician — they isolate the information needed to solve the problem and class the rest as "mere anecdote".[24] The person's narrative, as stated above, is based on their own perception and experience of their life. In this regard, it is not necessarily expressed as clearly and formally as the patient history. It may be told "in unusual ways, through gestures, actions or word combinations hard for [an] observer to comprehend".[25] Given this, there are two questions that can be asked to help clarify the narrative being told, both of which draw on the fact that the narrative exists before the illness that prompts its telling, and continues despite that illness.[26]

The first question that can be asked is: "how did [this person] come to be here, now, like this? [A question which requires] taking the time to learn from [them], letting [their] voice be heard, and understanding [their] lived experience".[27] In receiving an answer to this question, we are able to situate the person in their social and personal context.

The second question is: who does the person see his or herself become as a result of making

[18] National Initiative for the Care of the Elderly, *Tool on Capacity and Consent.*
[19] Brock, Buchanan, *Deciding for Others*, p. 52.
[20] Sherwin, *A Relational Approach to Automony in Health Care,* p. 26.
[21] Roger Higgs, "The Contribution of Narrative Ethics to Issues of Capacity in Psychiatry", in *Health Care Analysis*, p. 308 (2004) Vol. 12, No, 4.
[22] Frank, *The Wounded Storyteller*, p. 58.
[23] Higgs, *The Contribution of Narrative Ethics to Issues of Capacity in Psychiatry*, p. 309.
[24] Ibid., p. 310.
[25] Ibid., p. 308.
[26] Frank, *The Wounded Storyteller*, p. 53.
[27] Barbara Russell, "The Crucible of Anorexia Nervosa," in *The Journal of Ethics and Mental Health* (2007, Volume 2, Issue 2) http://digitalcommons.mcmaster.ca/jemh/vol2/iss2/5/ accessed May 10, 2009.

the decision at hand? This requires the person to think about how their current choice fits with their past choices, and who they want to be; in doing so, it focuses on more than just the physiological consequences of a given decision.[28] In this respect, narrative not only situates the person in their social and personal context (a task necessarily based on that person's past actions and choices) but also provides a goal, or something to live up to in the future.[29]

Narrative approaches to ethics thus seek to situate a person in a wider context than they appear in patient histories. They do this by determining both how the person came to be who they are now and how the choices they have to make will reflect who they want to be in the future.

3.2- Narrative: a Solution to the Problems of the Standard Model of Decision-Making Capacity

Having now seen what constitutes a narrative based approach to ethics we can ask the following question: How does this solve the problems raised for the model of decision-making capacity above? I will not address the first objection (concerning values), as it will be dealt with in section 4.2. Nevertheless, it should be possible, given the description above, to see the ways in which narrative provides a solution to the problems presented. First, it rejects the picture of a perfectly rational decision maker operating under ideal conditions presented by the standard model. By accepting that we come to hold our values through action and interaction, narrative acknowledges that we do not regularly make decisions that force us to reflect heavily on past choices and future circumstances. This, in turn, shows that the values we have and can articulate come from the acts of decision-making, unlike the standard model, which requires that we already have access to our values prior to making the decision at hand. Second, due to the focus on social and personal context, narrative requires that we broaden the ambit within which we see the person being treated. In so doing, the likelihood of false positive or false negative rulings concerning a person's decision-making capacity is highly diminished. This is because, rather than only focusing on the fact that a person has a certain belief or value, narrative also takes into account why that person has it, and what caused it to develop in the way it did. This broader focus, which considers who the patient is *as well as* what they ought to do, contextualizes the decision at hand thus (potentially) giving it more weight.

Now that we have briefly seen how the use of narrative solves the problems raised for the standard model of decision-making capacity, I will seek to show the advantages of this approach through a discussion of treatment refusal by patients suffering from anorexia nervosa.

4.1- Anorexia Nervosa

Anorexia Nervosa (AN), which is characterized by severe restriction of food intake, even to the point of starvation, has one of the highest death rates of all psychiatric illnesses.[30] [31] People suffering from AN, in the vast majority of cases women, usually have a distorted body

[28] Ibid.
[29] Frank, *The Wounded Storyteller*, p. 61.
[30] Russell, *The Crucible of Anorexia Nervosa*
[31] Gans, Margery and Gunn Jr., William, B. "End Stage Anorexia: Criteria for Competence to Refuse Treatment" in *The International Journal of Law and Psychiatry*, 677-695. Permagon, 2003.

experience, viewing themselves as 'fat' even when they are severely emaciated.[32] [33] Body experience, here, is preferred to body image as it includes "cognitive responses (what we think we look like), affective responses (what we feel we look like), and optative responses (what we want to look like)".[34] While there is no definitive cause of AN, it has been hypothesized to develop due to one or more of the following: a psychiatric illness or delusion; a desire to protest society's expectations of women; a need to regain power; a wish to master something difficult; or a reliance on distorted values.[35] AN has also been strongly associated with a need for constant control.[36]

Due to the fact that, if untreated, people suffering from chronic AN can die as a result of the secondary effects of starving themselves — amenorrhoea (which has been linked to severe osteoporosis), heart disorders (including low heart rate, and low blood pressure), electrolyte imbalances, and severe gastrointestinal complications — the permissibility or impermissibility of treatment via force feeding has been widely debated.[37] [38] This issue is especially important because a common feature of "the disorder is that patients have difficulty cooperating with attempts to help them regain weight, even when their health is endangered".[39] That is, they refuse treatment even when death is likely to occur as a result of that refusal.

4.2- Refusal of Treatment for Anorexia: Standard and Narrative Approaches

Due to the fact that informed consent is meant to protect the rights of capable (autonomous) patients, and that capability is determined through an assessment of the understanding, appreciation, and value based abilities of the patient, the standard model of decision-making need only ascertain whether the patient with AN does in fact satisfy these requirements. Regarding the first two, it has been noted that people with AN generally have "a good understanding of their illness, its consequences, and the treatment...being offered".[40] In this regard, they satisfy the understanding and (at least minimally) the appreciation components of decision-making capacity.

The difficulty, however, concerns not the understanding or appreciation but the value component. As mentioned above, the value component of the standard model of decision-making capacity requires that the patient have possession of a consistent set of values and beliefs based in reality by appeal to which they can justify their treatment decisions. The question, when discussing treatment refusal by patients who suffer from AN is: are the patient's values to be respected? If not, then that patient would be deemed incapable to make the decision at hand. If they were, the patient would be deemed capable. It is here that problems arise for the standard

[32] Ibid.
[33] Giordano, Simona. *Understanding Eating Disorders: Conceptual and Ethical Issues in the Treatment of Anorexia and Bulimia Nervosa*. Clarendon Press, Oxford, 2005.
[34] Ibid.
[35] Russell, *The Crucible of Anorexia Nervosa*.
[36] Giordano, *Understanding Eating Disorders*, p. 214
[37] Ibid., pp. 27-29.
[38] Russell, *The Crucible of Anorexia Nervosa*.
[39] Jacinta Tan, Tony Hope, Anne Stewart, "Competence to Refuse Treatment in Anorexia Nervosa", in *The International Journal of Law and Psychiatry*, p. 697 (Pergamon, 2003)
[40] Tan et al, *Competence to Refuse Treatment in Anorexia Nervosa*, p. 701.

model. Due to the fact that the standard model only addresses what the person's values are, and not how they came to have them, the values of the patient with AN seem irreconcilably contradictory. The patient may state that they do not want to die, while simultaneously refusing the only treatment that offers a chance of saving their life.[41] Furthermore, people with AN may understand that treatment is what is best for them, while still feeling that it is not a choice they wish to make.[42] The narrow scope of the standard model of decision-making capacity, which focuses only on what the patient ought to do and not who they ought to be, is unable to reconcile these conflicting values; they most often manifest themselves in the incompatibility of not wanting to die and refusing life-saving treatment.

The narrative approach, as described above, can be employed to solve this problem. By contextualizing the values the person holds, it is possible to develop an understanding of why they were caused to develop in the way they did.[43] Given the complex aggregate of factors that can lead to the development of AN, understanding the context in which the patient makes their decision could change the way that decision is viewed. "A refusal of treatment that, in another patient, might look 'suicidal' may, for the patient diagnosed with anorexia nervosa, be an affirmation of the only life she can conceive of living".[44] This is not to say, however, that every case will be the same. Just as not every instance of severe AN should be treated with force-feeding, not every instance should stop treatment just because that is what the patient demands. The importance of narrative involvement in determinations of decision-making capacity is seen in its ability to discern with greater accuracy what should be done in a given case. This does not mean that use of narrative ensures that the right decision has been made; it only seeks to assure that the best decision was made for that person at that time.

Thus, the narrative approach to decision-making capacity offers a higher likelihood of the right determination being made, as it contextualizes the patient's choice in light of their past, and who they want to be. In the case of patients refusing treatment for anorexia, narrative is essential to discerning capacity because it offers a method of reconciling values and beliefs that, under the standard model, would be considered hopelessly contradictory. It is important to note here that this does not mean that the values that get supported in the end are fully rational — recall that illusions (values or beliefs that do not contradict reality, but are highly improbable) can be accepted as reasons for action. There is a difference between capacity and rationality as demonstrated by the objections above (originally raised by Susan Sherwin).

I have now demonstrated the problems with the standard model of decision- making capacity, and the ways in which a narrative approach can solve these problems. I will now address two possible objections to the view I have presented.

5.1- An Objection to Narrative as part of the Value Component of Decision-Making

While this paper has presented narrative as a way of understanding value, objections could be made on the grounds that narrative should be distinct from value — that is, that it should be viewed as a required fourth component of decision-making capacity. While this may seem

[41] Ibid., p. 702.
[42] Ibid., p. 704.
[43] Russell, *The Crucible of Anorexia Nervosa*.
[44] Gans, Gunn Jr., *End Stage Anorexia: Criteria for Competence to Refuse Treatment*, p. 680.

plausible, as the patient's narrative is not the same as the patient's values, there is a problem that comes from positing narrative as a component of decision-making capacity and that is much like the problem faced by the standard model of decision-making capacity: if we view narrative as a component in and of itself, it would require that a patient be able to articulate their narrative as a part of the capacity assessment. However, as Sherwin demonstrated with respect to values, it is not necessarily the case that we would have access to our narrative in the way required. It is for this reason that narrative is best seen as a way of understanding, or giving weight, to the value component of decision-making capacity.

5.2- An Objection to the Narrative Approach based on Applicability

A second objection that could be raised is as follows: while it is possible that attempting to understand the experience of the patient, thus situating them within their narrative, will help us to understand what to do in the situation, it also brings with it the risk of our distorting the patient's experience in a potentially harmful way.[45]

This risk, however, is diminished by the simple admission that we cannot identify fully with the patient. While there is a possibility for misrepresentation of values in the process of learning about the narrative of the patient, there is also a possibility for greater understanding of the individual case — an understanding that would not be possible without the use of narrative. That is to say, the potential risk is far outweighed by the potential understanding that could be gained. Finally, an almost systematic perversion by the physician of what patient says would have to occur for the risk associated with the narrative approach to equal the misrepresentation that the standard model risks by occluding narrative involvement.

6.1- Conclusion

I have shown that a narrative approach is necessary to determinations of patient's decision-making capacity through an analysis of the problems with the standard model of capacity and how narrative involvement can solve those problems. While this paper has not provided a way of implementing narrative approaches to ethics in a clinical setting, it is my hope that it has elucidated some of the theoretical groundwork that would be required for such an implementation.

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