

## Considering the Welfare Impact of a Choice: Is It Always Wrong?

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### Introduction

Despite the fact that informed consent to treatment has been an accepted feature of medical practice for a long time, many questions about the ethical assessment of a patient's ability to make medical decisions remain open. In itself this is somewhat striking given that a patient's possession of decision-making capacity<sup>1</sup> is a prerequisite for obtaining valid informed consent and for honoring treatment refusals. Nor are the questions that remain open mere matters of detail. Rather it remains true that a significant number of theorists have reservations about what I call "the dominant approach" to capacity assessment (what this is, is explained below). Many people believe that the dominant approach is unable to give the right answer in an important range of cases.

Nonetheless, both the literature on these topics and relevant legislation and judicial decisions, suggest that at least one very basic ethical principle is widely agreed upon. This is the idea that capacity assessment *must* be (and must *only* be) focused on a patient's decision *processes*, on how the patient arrives at a choice. Determinations of competence must *never* be based, even in part, on the *outcome* of decision-making, i.e. on an assessment of the goodness or badness of a particular choice. I will refer to this as the "exclusive focus on process." One particular kind of

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<sup>1</sup> In the U.S. it is sometimes said that "capacity" refers to a clinical judgment whereas "competence" refers to a legal one. In the UK, insofar as a distinction is made, it is typically the opposite: "competence" is assumed to refer to a clinical judgment and "capacity" to a legal one. I use them interchangeably. I do not find distinguishing them helpful given that (1) even courts often use the terms interchangeably and (2) clinical judgments often have legal force (Kim 2010, 17-18) and (Hawkins and Charland 2020, §1.1).

consideration it rules out—a kind that often can seem highly relevant to capacity assessment—is the welfare impact of a choice, i.e. how the patient’s welfare will be affected by the choice. Because the dominant approach embraces the exclusive focus on process, it basically regards the welfare impact of a choice as *entirely irrelevant* to the question of whether someone is competent to make that choice.

The exclusive focus on process may be the most widely agreed upon ethical principle in the realm of capacity assessment. Nonetheless, I reject the idea that the *only* way to assess capacity ethically is to adopt the exclusive focus on process. Though widely taken for granted, this is far too strong. In particular, as I shall try to demonstrate, considering the welfare impact of a choice is sometimes crucial. I have come to believe that taking account of welfare in at least *some* cases is the *only way* to fix problems with the dominant approach that have been identified by numerous authors over the past decades. Without at least limited appeals to the way a choice impacts a patient’s welfare in certain kinds of cases, we simply can’t develop an approach to capacity assessment that consistently delivers acceptable verdicts. Therefore, rather than ban consideration of the welfare impact of a choice, we need instead a principled way of allowing welfare to play a carefully circumscribed role in a limited number of cases. I think this is possible. Demonstrating this is the primary aim of the chapter.

I first review the dominant approach and some common criticisms of it. I try to explain why I think addressing these criticisms will be impossible if we can’t ever appeal to the welfare impact of a patient’s choice. The main body of the paper considers *why* people are typically so convinced that *any* deviation from an exclusive focus on process must be problematic. Some of the concerns are quite general—stemming from the thought that attention to outcome must necessarily involve either inappropriate judgments about other people’s values or unacceptable restrictions on freedom, or both. I argue that this is not the case. I grant that the concerns raised are ethically important, but they do not rule out any and all consideration of outcome, as many people appear to believe. At most they

underscore the problems that would arise were we to adopt an unrestrained consideration of outcomes. Other concerns are more closely tied to the concept of welfare and arise in response to the suggestion that sometimes we ought to consider the welfare impact of choice. Again, I argue that appeal to welfare need not be problematic. It all depends on how it is done. In the final part of the paper I set out and briefly consider a proposal that builds on an existing approach to capacity assessment, but also allows limited consideration of the welfare impact of a choice. I then show how this proposal can solve the problem cases. The aim here is purely illustrative. I cannot hope in this limited space to undertake a defense of the proposal. I introduce it merely to help readers see what I mean when I say that progress is possible if we are willing to get more creative in our thinking. I aim to convince those who work on the ethics of capacity assessment that consideration of the welfare impact of a choice is not *necessarily* bad. Nor is there any reason to think that allowing some considerations of this sort will inevitably open the door to a general (but clearly unethical) policy of counting people incompetent whenever they make personally harmful choices. I am optimistic that in response to certain kinds of troubling cases we can improve assessment of decision-making capacity ethically.

### **§1.0 The Dominant Approach**

Insofar as there is agreement about capacity assessment, the agreed upon factors are (1) a commitment to assessing (and only assessing) core cognitive abilities and (2) a commitment to focusing exclusively on process, i.e. how someone reaches a decision as opposed to what the decision is. For simplicity, I refer to this pair of commitments as “the dominant approach” to capacity assessment. To be clear, even on the dominant approach, an assessor is sometimes allowed (indeed, required) to consider the content of the decision in a limited way. It is often important to consider the degree of rational fit between an individual’s specific choice and what she identifies as her most important value or goal, because this is a way of checking for instrumental rationality broadly construed. If a patient claims to care most about avoiding a painful ICU death, but chooses the one option most likely to result in a

painful ICU death, this is evidence of confusion, and/or inability to reason. What is ruled out by the exclusive focus on process is any assessment of the *value* of a choice independently of its relation to process.<sup>2</sup>

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<sup>2</sup> The contrast as presented in the text sufficiently captures for present purposes the contrast I wish to discuss. However, it is worth noting one additional practice that can create confusion. Many people endorse the ethicality of employing a variable threshold for capacity, which is the idea that in cases where a patient wishes to choose some particular thing which carries with it a high risk of harm, it is permissible to set the bar higher with respect to the same abilities normally required for competence (President's Commission 1982; Buchanan & Brock 1991 51-57; National Bioethics Advisory Commission 1998; Kim 2010, 34-36). So, for example, if a patient wishes to choose death when this seems in conflict with her interests, someone assessing her capacity may legitimately require that she demonstrate a higher than usual level of understanding, a greater than usual ability to reason and so on and so forth. Independently of whether such a practice is ethical, it can be unclear on which side of the process/outcome divide it falls. Although it does require an assessment of a person's choice in terms of potential harm, it doesn't allow this assessment to directly influence the determination of competence. Instead the potential harmfulness signals a need for greater precautions, which takes the form of raising the required level of cognitive ability. For this reason adopting a variable threshold is often thought to be compatible with an exclusive focus on process. Most importantly, both ideas (variable threshold and the need to focus exclusively on process) are introduced and advocated by Buchanan and Brock in their foundational work on assessment of capacity (Buchanan and Brock 1991, 50-51).

There is another distinction found in the literature between "internalism" and "externalism," where internalism is the view that capacity assessment must only consider what happens inside a patient's mind, and ignore any factors external to the patient to influence the final assessment. This seems very close to the process/outcome distinction and in some contexts they are treated as if they are the same (Pickering et al. 2022). However, those who use this terminology explicitly label the variable threshold idea as "externalist." (Buller 2001; Pickering et. al. 2022). For this chapter I stick to the process/outcome terminology, avoiding any mention of internalism/externalism. Although not strictly in line with what I say in the text, I am happy enough to accept along with Buchanan and Brock that variable thresholds are consistent with an exclusive focus on process in the relevant sense. Ultimately, I defend something that falls on the more radical side of either distinction, namely I defend (for a limited set of cases) moving beyond the exclusive focus on process *and* moving beyond internalism.

In the United States, the most widely adopted approach to assessing decision-making capacity is a version of the dominant approach. This is the four-abilities model developed by Thomas Grisso, Paul Appelbaum, and colleagues (Appelbaum & Grisso 1988, 1995; Grisso & Appelbaum 1995, 1998a; Grisso, Appelbaum, Mulvey & Fletcher 1995). Their model requires, first, that a patient be able to “evidence a choice,” i.e. *communicate a choice* somehow, though not necessarily verbally. It requires, second, that a patient *understand* the facts relevant to her decision (she must grasp and comprehend what she is told about her medical condition and the options open to her including the option of no treatment). It requires, third, that a patient *appreciate* the facts of her situation, which is usually interpreted to mean that she must accept that the information given to her is true and really applies to her. Finally, she must have the *ability to reason*, namely, the ability to compare her options and relate them to her own values (Grisso & Appelbaum 1998a, 31-60; Kim 2010, 19-26).

The four-abilities model remains the most widely used approach to capacity assessment in large part because it has been so carefully worked out at various theoretical levels (Berg et. al. 1996). In addition, Grisso, Appelbaum and colleagues have developed a guide for clinicians that interprets each ability concretely and an empirical instrument (the McCAT-T) to make it easier to assess capacity in terms of the four abilities (Grisso & Appelbaum 1998a; 1998b).

In the UK, capacity assessment is governed by the Mental Capacity Act of 2005. This document, like the four-abilities model, identifies four key abilities, namely (1) the ability to understand the information relevant to a decision, (2) the ability to retain that information, (3) the ability to use or weigh that information as part of the process of making the decision and (4) the ability to communicate the final decision (whether by talking, using sign language, or any other means) (MCA, Part I, section 3). Some theorists assume that despite slight differences in language, the criteria of the UK act and the four-abilities model are basically equivalent (Zhong et. al.). However, others think they are *not* equivalent (Ryan 2019). Thankfully, there is no

need to settle the question here. Both models are versions of the dominant approach, and in particular, they both embrace as morally foundational the focus on process.<sup>3</sup>

Other models have been developed, and others are used, but most are versions of the dominant approach.<sup>4</sup> Therefore, problems with the dominant approach are problems for these as well. For simplicity when necessary, I use the four abilities model for illustrative purposes, but readers should remember that the arguments discussed have a much broader application.

## **§2 Problems with the Dominant Approach**

The dominant approach reliably produces false positives in certain kinds of cases, i.e. it indicates that a person has decision-making capacity when this is not plausibly the case. Although there are various examples one could appeal to,<sup>5</sup> I focus here on patients with anorexia nervosa, for the simple reason that such cases have been widely discussed and there is interesting data supporting the claim about false positives (Tan, Hope & Stewart 2003; Tan et. al. 2006a, 2006b). The problem cases are ones in which a patient reaches a point of extremely low-weight, the patient's health and life are seriously endangered, and yet the patient refuses any form of treatment involving weight gain. The dominant approach deems some (though not all) such patients as having capacity. However, it seems a failure of the model that it says *any* patient fitting that description is competent.

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<sup>3</sup> The Mental Capacity Act of 2005 opens with a set of five principles that govern the act, one of which is "A person is not to be treated as unable to make a decision merely because he makes an unwise decision." (Part I, section 1).

<sup>4</sup> Kim (2010, 61-65) lists and compares a number of different tools developed for assessing capacity.

<sup>5</sup> There is another set of criticisms of the dominant approach that is similar in its focus on false positives. This literature focuses on the role of emotion (as opposed to values) in decision-making, arguing that in some cases people who are emotionally disturbed and ought not to be deemed competent are nonetheless treated as competent by the dominant approach. See in this regard: Bursztajn et al. 1991; White 1994; Elliot 1997; Charland 1998a, 1998b, Rudnick 2002; Breden & Vollmann 2004; Berghmans 2011; Halpern 2011, 2012; Holroyd 2012; Hermann 2016.

Often, patients with anorexia nervosa who are found to lack capacity fail the (four-abilities model) requirement of appreciation (Tan et. al. 2006a; Grisso & Appelbaum 2006). Although they understand what people are telling them, they refuse to accept it as true. They may deny that they have a disorder at all or deny that the disorder is endangering their lives.

To understand why *some* non-minor patients with anorexia nervosa who are refusing life saving treatment are deemed to *have* capacity, consider Terence for whom appreciation is *not* an issue. Terence was diagnosed a little over a year ago, and although he has been underweight all along, he was fairly stable until recently when his weight began to drop precipitously.<sup>6</sup> He now has such a low body-mass index that he is in serious danger of dying, yet he refuses treatment for weight gain. However, he appears to fully *understand* his situation and the likely outcomes of different choices. He not only grasps these facts abstractly, but apparently accepts them as the facts of *his situation*. He acknowledges that he might die without weight gain. Nonetheless, he insists that he *cares more* about being thin than about anything else. He states emphatically that he would rather die than put on weight.<sup>7</sup> The dominant approach deems Terence competent. He is merely someone with unusual values that need to be respected.

It is extremely difficult to identify what has gone wrong in such a case when we restrict our focus to processes of decision-making. Tan et al. (2006) suggest we

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<sup>6</sup> Although anorexia nervosa is more common among females, males make up approximately 10% of patients (Weltzen 2016). I use a male character to emphasize that anorexia is not merely a disorder of women.

<sup>7</sup> The case of Terence is based loosely on cases described by Tan et. al. (2006a) in a small study of capacity among anorexia patients. All were deemed competent on the basis of assessment with the MacCAT-T. Although two patients clearly lacked appreciation, the rest seemed to have insight into their illness but, like Terence, were simply not willing to gain weight. One of the patients in this study is quoted as saying that death is preferable to gaining weight (2006a, 274-5).

distinguish between merely unusual values and “pathological values,” that are the product of anorexia nervosa itself. The thought is that it may be permissible to judge a patient to be lacking capacity to make certain decisions *if* the values informing those decisions are pathological. In short, considering values directly is okay if the values themselves are produced through a flawed process, and anorexia is such a process. However, it is at this point that we encounter problems.

First, it is not always possible to consistently distinguish new values arising in the context of illness and values *caused* by the illness. For example, many people learn new things and come to think differently as a result of experiencing illness. Their new values reflect experiential learning, not pathology, but it can be hard to clearly distinguish cases of one sort from cases of the other.

However, much more problematically, we cannot assume *that values caused by illness or disorder are bad for decision-making*. An illness or disorder may have many effects on a person, some bad, some good. Plausibly, we label something an illness or disorder because the bad effects on people generally outweigh any good effects. But this is compatible with there being *some* good or neutral effects. Not everything caused by an illness or disorder must be *bad*. Moreover, we need a particular kind of badness. In Terence’s case, we need confidence both that the way he values thinness is caused by anorexia nervosa and that *by producing such values anorexia undermines his ability to make certain kinds of decisions*. In other words, we need a link between pathological values and *bad decisions*. Such a link does not automatically follow from establishing that certain values are caused by anorexia nervosa.<sup>8</sup>

Notice, however, there is a very simple way to state what’s wrong in Terence’s case, it is just that we have trained ourselves not to say it. If we temporarily drop the ban

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<sup>8</sup> For other responses to the proposal about “pathological values” see Charland 2006; Grisso & Appelbaum 2006; Vollman 2006; Tan et. al. 2009; Whiting 2009.



on considering more than just decision-making processes and consider directly whether Terence's choice is consistent with his overall best interests, it is plausible to think it is not. Now we can easily say what is wrong with his decision *and* explain why his anorexia nervosa is relevant to the problem. His decision is a poor decision because it is disastrous in terms of his own welfare. It turns out that anorexia is, in fact, relevant *because* of its connection to his values. Only now we say it is the particular way Terence values thinness that is leading him to make this poor choice, and his anorexia nervosa is the cause of this value. Thus we can say, his anorexia nervosa is undermining *his ability to make choices in accordance with his own interests*. Finally, it is now easy to see why it initially seemed bizarre to say that Terence merely has *unusual* values. His values are not at all unusual for someone with anorexia nervosa.<sup>9</sup>

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<sup>9</sup> In a recent article, Pickering et al. (2022) make a point somewhat analogous to the one I make here. They note that there are some patterns of thinking that are not obviously irrational (they do not run afoul of formal rules of reasoning), and so not already built into the four-abilities framework, but which are nonetheless potentially problematic from the standpoint of decision-making and often recognized as such. Moreover, they believe the only way to capture what is problematic with such thinking (when it is problematic) is to show in a particular case that it led to a harmful choice. The example they discuss involves a woman refusing dialysis (the example comes from a UK case adjudicated under the Mental Capacity Act of 2005). Her clinicians claimed she lacked capacity to make the decision because her thinking was "rigid, black and white, and catastrophic." Pickering et al. acknowledge that thinking like this can indeed be problematic from the standpoint of decision-making, but not in the sense that it *invariably* leads a person to make a poor choice. They think we should want to be able to appeal to such factors (e.g. catastrophic thinking) in capacity assessment, but in order to explain why this form of thinking—a form we admit is only *sometimes* problematic—is problematic in this woman's case, it is necessary to point to the fact that catastrophic thinking has led her *to make a seriously harmful choice*.

Their point is interesting, and related in some ways to the point I make here in the text, namely that in order to explain what is problematic with the values that originate in anorexia nervosa, we have to show that *such values lead to self-destructive choices*. However, I have other concerns with their article, articulated in footnotes 9 and -.

I fully grant we would never want to say *without qualification* that a person is incompetent to make a choice because the choice conflicts with his welfare. However, we should remain open to the thought that we could make progress ethically by introducing a limited consideration of welfare. Before sketching a way to do so, however, I want to consider the worries that lead people to embrace a process only approach. Some of these are very general worries about considering the content of a particular choice. Others are more specifically focused on a particular way we might want to evaluate a choice, namely in terms of its welfare impact. I shall consider each type of worry in turn.

### **§3 Why focus exclusively on processes?**

What then explains the sense many people have that the only ethical way to approach the assessment of decision-making capacity is to exclusively consider processes of decision-making? Here I will consider one common reason that doesn't make sense in this context, and two that make sense as concerns, but that, in themselves, do not establish that any deviation from a process focus *must* be unethical.

#### **§3.1 Paternalism**

Sometimes people say that the exclusive focus on process is necessary if we are to avoid paternalism. However, that response doesn't really work. Paternalism is interference with another person's decision and/or action for the sake of that person's own good. However, only a certain kind of paternalism is morally objectionable, namely, paternalistic interference with the choice of a *competent adult* (Feinberg 1986, 3-8). Therefore, if one wanted to claim that allowing certain kinds of considerations to play a role in capacity assessment is bad *because* such a practice is objectionably paternalistic, one would have to know already who is and isn't competent. For we could only know the practice to be objectionably paternalistic if (among other things) it was known to unfairly limit the freedom of competent people, for example, if it were known to declare competent adults

incompetent and then limit their choices. However, the question of what exactly counts as having decision-making capacity is what we are trying to determine. We can't therefore start with the assumption that such a practice is objectionably paternalistic without begging central questions.

### **§3.2 Judging Values**

There are, however, other reasons for adhering to a process focus that can be, and have been, raised. Some of these appeal to the idea that we should not be in the business of *judging another person's values*. However, what this means is not transparent. I am aware of several concerns often expressed this way. Sometimes, fully decoded, the message is "Don't assume your values apply here" or "Don't impose your sense of what would be good for you on someone else." In other cases, the message is "Don't judge another person's values because you can't possibly know what really makes sense for them." And finally, in still other contexts, the full message is "Don't judge another person's values because their values are their business, not yours."

The first concern is a simple reminder that welfare is highly individual, and that to understand what is good for someone else requires considering what *they* value, what *they* enjoy, what *their* life is like, and trying to understand how *they* will see or experience changes in their life. It is a reminder that welfare must be understood from the perspective of the person whose welfare it is.

The second emphasizes lack of sufficient knowledge and/or understanding to judge. There is a very important truth behind this thought. Human beings value an unbelievable range of things, and prioritize their values in countless ways. Moreover, something that appears at first to make no sense can often be seen to make sense in the context of a particular life with all its complexity. Thus something you don't value and can't imagine valuing, might nonetheless make sense for someone else. Unfortunately, even if we try to adopt the perspective of the other, we often can't appreciate these differences unless we know a great deal about the

person and the situation. Since we usually lack such detailed knowledge, we should not judge.

This kind of view doesn't have to deny (and shouldn't deny) that problems can arise for a person because of her values. Most people value many things. Most people also attach great value to (among other things) leading a life that is fulfilling *from their own perspective*. But it is not uncommon for people to fail to recognize conflicts among their values. And sometimes people unknowingly embrace an aim or goal the pursuit of which will undermine their chances of leading a fulfilling life.

The view in question counsels *humility* in the face of complexity and I agree that humility is extremely important. However it is also important to see that *by itself and without more detail* these concerns do *not* force us to conclude that the only way to avoid problems is to stick to assessment of processes. Acknowledging the need for caution, even extreme caution, is not the same as establishing that a certain kind of judgment can't be made, or if made, made well. It all depends on the details.

The final way of understanding the claim about judging values is as a reminder that in general people are supposed to be free (within the domain of self-regarding action) to do as they please. They have, and it is *good* that they have, the right to make both good and bad choices. Any attempt to judge another person's choice (the thought goes) seems to presuppose that when/if we discover bad choices we may intervene. But we may not.

This point is extremely important and comes as close as anything to explaining persistent worries about sticking to processes and not considering outcomes. People are supposed to be free to make mistakes. If we routinely consider the welfare impact of a person's choice and *always* declare individuals incompetent to make choices that negatively impact their welfare, we do away with the freedom to make mistakes. In effect we force people to live well. But freedom is meaningless when it is only the freedom to choose among good options.

However, this concern about judging welfare is a concern about *always* considering the welfare impact of a choice and *always* declaring individuals incompetent to make choices that negatively impact their welfare.<sup>10</sup> Such a broad policy would, indeed, undermine an important freedom and label far too many people incompetent. However, acknowledging the importance of the freedom to make mistakes, and therefore accepting the need to avoid *that* kind of unrestricted policy, does not in itself show us that we must embrace an exclusive process approach. We would first need to understand the relationship between alternative approaches and freedom. Recognizing the importance of this kind of freedom does not rule out the possibility that limited consideration of a patient's choice in a limited number of cases might not undermine this form of freedom and might therefore be justified.

The last point may be clearer when presented from a slightly different angle. We can agree that we need a fair and principled way of dividing people into two categories: those who have a good enough ability to look out for themselves and should be left alone to do it, and those who don't. Even assuming we do not yet have a precise understanding of how to draw that line, we can see that the capacity/non-capacity line *is not the same as* a second line dividing those who sometimes make poor choices and those who make only wise ones. Therefore, we know that *any approach that sorts people using the second line* is unjustified. We know that it will wrongly limit the freedom of some people whose freedom we can all agree should *not* be limited. However knowing that it would be ethically problematic to adopt any approach that sorts people along the second line, is not the same as knowing that

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<sup>10</sup> Recall from earlier the article by Pickering et. al. (2022) that argued that certain kinds of unusual thinking patterns can't be identified as problematic unless or until we show how they lead to choices that undermine welfare. A major problem of their article is that having suggested we need to sometimes consider the welfare impact of a choice, they stop. They do nothing to assure their readers that were we to accept their point, we would be able to use this insight in a constrained, ethical way. We do not want to simply be in the habit of deeming people incompetent whenever and because they make harmful choices, but Pickering et. al. give us no indication of how we are to avoid that.

any approach that considers a patient's choice will sort people along the second line or some other inappropriate line. It remains to be seen. We do not yet have a solid reason for thinking the only ethical approach is to focus exclusively on process.

#### **§4 Why is considering the *welfare* impact of a choice problematic?**

##### **§4.1 Medical Welfarism**

As soon as one proposes that it might be good to assess the welfare impact of a choice, a different set of concerns arise in relation to welfare itself. To begin with, many people might worry about what “welfare” means, and fear that it means something they couldn't possibly agree with or endorse for broad use. One particularly potent version of this worry is the fear that *medical values* would be promoted as if they are ultimate welfare values.

Medicine has a number of values that inform its practice. It is sometimes said that it has just one value—health—that it promotes, but this is misleading because there is no one thing—“health”—people agree about. When we stop and consider we see that, depending on context, clinicians aim to promote a variety of values, including (1) preserving life, (2) reducing pain, (3) preventing illness, (4) preventing loss of function, (5) restoring function that was lost, (6) managing the symptoms of chronic illness, and many others. Not only are there multiple values at work, there is often an implicitly accepted way of prioritizing among these values. In the past, there was much more explicit recognition that medical values were prioritized and much greater agreement among clinicians generally on what those priorities were. Although there is much less of that now, implicit assumptions about the importance of particular medical values still continue to shape medical thinking.

Particular treatment decisions are justified in terms of one or more medical values they promote. However, the really important point is that medical values are themselves only instrumentally important insofar as they align with and/or promote the patient's overall welfare. In the past, many doctors lost sight of this,

treating medical values as ultimate welfare values and assuming that certain ways of prioritizing values were beyond dispute. For example, some doctors placed such a high priority on preserving life that they were willing to risk disfiguring their patients and/or causing their patients significant suffering for only a slightly better chance at prolonged life (Natanson v. Kline; Ubel 2012, 38-41). Equating medical values with welfare actually led to decisions destructive of welfare. Although this happens much less now, this mode of thinking is still a very easy one to fall into. Elsewhere, I have labeled the simple equation of medical values with welfare “Medical Welfarism” (Hawkins 2021).

Many people legitimately fear the return of Medical Welfarism. They recognize that the choices dictated by Medical Welfarism can sometimes be disastrous for individuals. They may worry that reference to welfare is code for Medical Welfarism. Or they may worry that whatever is intended by someone proposing to assess welfare, any policy that opens the door to (even limited) consideration of welfare will open the door to Medical Welfarism. If one thinks this way, then one will fear that allowing clinicians to consider the welfare impact of a choice when assessing capacity will mean that they often deem a choice contrary to welfare when it is really just contrary to medical values. If they count such individuals as incompetent, they may end up forcing inappropriate medical values on some patients.<sup>11</sup>

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<sup>11</sup> My second concern with the argument of Pickering et. al. (2022) is that they want to take account of the harmfulness of a choice, but not only do they give no indication of *how* to do this, they also give no account of welfare or of what makes a choice harmful. But without some pre-agreed parameters for thinking about welfare, adopting their recommendation and leaving it up to individuals to decide what counts as welfare is an invitation for a bad sort of reliance on medical values. Indeed, their own discussion has hints of medical welfarist thinking in it. They discuss the case of a woman, C. She was in need of and refusing dialysis because her kidney function had been damaged by an overdose of paracetamol (acetaminophen) and it was not fully clear (she had been given mixed statements about) whether her dependence on dialysis would be temporary or not. Though one would want to hear more details, nothing in the article begins to explain why we should think she is making a *harmful choice*. Perhaps she is, but no case is made for it. She is choosing death, but death in itself is not

That would, I agree, be deeply problematic. I am no fan of Medical Welfarism. However, there is no requirement that welfare be understood this way. Nor is it obvious that it is impossible to avoid Medical Welfarism. It might be possible to introduce a specific conceptual framework for thinking about welfare, one that is both widely acceptable and not at all based on medical values. It might also be possible to require that anyone appealing to welfare as part of capacity assessment justify their claims in terms of this framework. Once again, the main point is a simple logical one. Even granting the badness of Medical Welfarism, we have not yet encountered an argument showing that we *must* embrace an exclusive focus on process. Only if we could show that *any* policy allowing any consideration of the welfare impact of a choice would, if adopted, inevitably lead to Medical Welfarist thinking, would we have such an argument.

#### **§4.2 Competently Choosing Something Other Than Welfare**

A different worry about appeals to welfare arises as soon as we remember that individuals are not required to make decisions that promote their own welfare. People make the medical decisions they do for a variety of reasons, not all of which are related to personal welfare. An individual may choose a less good treatment because it allows him to save money that will go to his child's college fund. Or a person may accept risky procedures in the hope that these can stave off disability, not because disability would be so bad for him, but because he understands the burdens his disability would create for particular members of his family. Such decisions happen all the time, and there is nothing *per se* wrong with them. But if we consider the welfare impact of an individual's decision when assessing capacity we run the risk (so the argument goes) of labeling as incompetent people who are sacrificing a degree of personal welfare for the sake of some other value.

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always harmful in the sense of being worse than her other options from the standpoint of her welfare. It is precisely this tendency to equate medical values (saving life) with welfare (the best option for this person) that it is imperative to avoid.



It is certainly true that people make welfare sacrificing choices, and true that it is perfectly legitimate for competent adults to do so. However, once again, what this establishes is limited. It reveals (as did the earlier concern about the freedom to make poor choices) that any *unrestricted* policy of deeming incompetent all those who make choices that negatively impact their welfare would be ethically unacceptable. We now see that such a broad policy would not only rule out poor choices, it would rule out altruistic choices as well. It would also rule out choices that negatively impact welfare but which are made for the sake of religious values. For example it is widely recognized that adult Jehovah's Witnesses may refuse even life-saving blood transfusions because it is against their religious beliefs to accept such products (Annas 1992; Grisso and Appelbaum 1998a; Kim 2010).<sup>12</sup> Even without possessing an agreed upon account of how to draw the competence/incompetence line, we know it is not permissible to draw it *that way*.

Again, however, knowing that an unqualified appeal to welfare would be problematic does not establish that *any* appeal to welfare must be. For example, a policy might require that in any case where a patient is believed to be making a

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<sup>12</sup> Religious choice can be thought of in two different ways, either as a special case of prudential judgment or as a case of choosing something other than welfare. Either way, these choices turn out to be significantly different in kind from the usual judgments about welfare that are often the focus in medical contexts. A person who believes in an afterlife may believe she will be punished in that life for failure to follow certain rules in this one. Thus she may choose something that is bad from the standpoint of this-world welfare, but reasonable relative to the extended life (or lives) she believes she will have. If that's how she thinks of it, then there is a conflict between what we might call "this-life prudence" and "multi-life prudence." Alternatively, a person might simply think that God requires her to sacrifice some elements of her own welfare in this life for the sake of *other values*, which need not be welfare values at all. Someone acting on religious values may see herself as ignoring prudence entirely and acting on spiritual values that are of greater importance. Whichever way a person thinks of such a choice, it remains true that the choice is distinctly different in kind from ordinary this-life welfare judgments. And it therefore would be important to be sure that a person making a seriously harmful choice is not doing so on the basis of either type of religious reason.

choice that will negatively impact her welfare, this assessment may not actually factor into the final determination about competence, unless certain other possible explanations of the choice can be definitively ruled out. For example, a policy might insist that anyone assessing the welfare impact of a choice in relation to competence, must not only be confident that the choice is harmful but also able to rule out the possibility that the patient is making the choice *for the sake of others* and/or making it *because of the religious dictates of a group he belongs to*.

So far the argument has been entirely negative. I have not tried to show that consideration of the welfare impact of a choice is justified, merely that we can't assume justification is impossible. I concede there are many legitimate concerns one might have about appeals to welfare. Reflection on these helps us to see certain kinds of policies we definitely *don't* want. However, there may still be alternatives that are ethically acceptable.

A final worry is about the possibility of arriving at an acceptable account of welfare. We have already seen that some such agreed upon framework would be needed if we were to allow in a limited number of cases some consideration of the welfare impact of choice. Without it there is too much room for arbitrariness of judgment. If it really is impossible to reach agreement on a framework, then we may be forced to stick to the exclusive focus on process. However, I see no reason for such skepticism. I now turn to consider what a useful, uncontroversial framework for thinking about welfare might look like.

### **§5 Can We Agree on an Account of Welfare?**

Any deviation from the exclusive focus on process in favor of even limited consideration of the welfare impact of a choice would be problematic without some general, widely accepted framework for thinking about welfare. In other words, we need clarity and agreement about the kinds of considerations that could potentially justify the claim that a particular choice will negatively impact welfare. Is such a framework available? I believe so, and to support this I offer a sketch of the kind of

view that might work. (Obviously any actual framework adopted would need to be much more specific). It strikes me that the way to proceed is to (1) focus on uncontroversial, general components of welfare and (2) acknowledge from the start that our framework should only be used to help us identify seriously bad choices (as these will be much easier to identify).

To start, we need a general sense of the kinds of things that count positively or negatively. I suggest on the positive side considering happiness and what I call “evaluative engagement.”

The very word “happiness” can be controversial, so we would need to specify its meaning carefully. We do not want to assign great value to happiness *if* “happiness” is just a synonym for pleasure or if it primarily refers to transient emotions or fleeting good moods. Happiness in any sense that matters is not the same thing as joy, euphoria, or exuberance. These are nice if you can get them, but they are neither common, nor foundational to a good life. We *do*, however, want a connection with affect, with how a person *feels* on a regular basis. I suggest we think of happiness as a potentially long term, relatively stable, emotionally sustained outlook on life that is generally positive (i.e. conducing to positive thoughts) but not distorted (it does not conduce to excessively positive, delusional thoughts) that makes it possible for a person to function well day to day and gives her a degree of resilience in pursuit of her goals. If that doesn’t sound like happiness, I have no objection to finding a different word. But it should be clear that what I just described is something almost universally valued by those with experience of it. Moreover, it is itself instrumentally valuable in relation to most other life goods (meaning that even those who don’t care about happiness so described, probably should). People who are happy in this sense are better able to do a range of things. They have more success in life, even allowing for the many ways people measure success (Fredrickson 2001).

However, I do not propose that happiness (or whatever you would like to call it) is the only welfare good. Engagement with the people we care about, engagement in the activities we love, and engagement in projects we deem important also matters greatly. For simplicity, I refer to these together as “evaluative engagement.” Most people recognize that what an individual values is importantly related to how well her life goes. However, merely valuing something does not seem to make life better. I may believe (indeed, I do believe) that it would be very good if the situation of women living in Iran could improve and become less oppressive. By itself, however, merely holding this belief does not seem to make my life better for me. On the other hand if, *because* I care about this, I engage in various activities to help women living under oppressive regimes, then my life comes to be bound up with this value to a greater extent. However, we have still not said enough. If I engage with something I care about and the result is disastrous for me (I pursue a relationship with someone I love but they turn out to be abusive) this will not improve my life. Hence, it is *successful engagement* (success relative to the individual’s standards for success) with people, activities and projects I care about that adds value to my life. Success can come in degrees, as can the degree of value attached to something. Plausibly then, the greatest value is created by highly successful engagement with the people and projects I value most of all.

I have suggested happiness and successful evaluative engagement as the two positives for our framework. Obviously they support one another in many ways, successful engagement often leading to happiness, and happiness often making possible more successful engagement. But they can come apart to some degree. Since we are merely seeking an acceptable general framework we need not take a stand on the relative importance of each or whether a life rich in one but deficient in the other can count as good. Recall from above that we are merely interested in identifying seriously bad choices, which means choices that significantly reduce both values or introduce significant amounts of bad.

What then, on this view counts as bad, apart from the absence of goods? Both physical and emotional pain are bad, but many forms of pain are not seriously bad. The word “suffering,” however, is typically used to identify forms of physical or psychological pain that are extremely intense, extremely long-lasting or both. I submit that the significant welfare bads we should consider are forms of physical or psychological suffering. As with the welfare goods, these two reinforce one another in many ways. Emotional distress can intensify the experience of physical pain. Chronic physical pain often leads to depression, a form of emotional pain. And the presence of suffering of either type lowers happiness and frustrates attempts at engagement.

Returning to the issue of choice, we can say that a choice is a prudential mistake if it guarantees (or makes much more likely) a level of welfare in the future that is less than the level a different choice would produce. We are only interested, however, in seriously prudential mistakes, ones that leave a person *much* worse off than she could have been had she chosen differently. If, for example, a person chooses death when the life she most likely would have if she lived is one *she herself would find great value in while living it*, this seems like a serious prudential mistake.

Arguably the choice Terence makes to refuse treatment is like this. Terence is young, with potentially many years of life ahead. What if anything can we predict about this life? We know that in the early stages of anorexia nervosa the chances of full recovery are quite high with treatment, though chances of full recovery decline significantly over time (Treasure et. al. 2015). Because Terence is in the early phase of the disorder, we know his chances of full recovery are good. Given the likelihood of full recovery there is no reason to think Terence will not live well. In other words, minus the anorexia, he has as good a chance as anyone of achieving happiness and finding ways to engage with things that matter *to him*. In such a case we do not even need to know a great deal about the kinds of things Terence would most likely find fulfilling, since nothing about the future suggests he will be significantly limited in his options. Of course, right now Terence does not want this

possible future. But even so, it is plausible to think that if he lives and recovers, he can live a life that *he himself will value as he lives it*. Given all this, the refusal of treatment looks like a seriously harmful choice for Terence in these circumstances.

The assessment focuses on future potential for happiness and evaluative engagement as well as future potential for suffering. Since most lives have a complex mix of good and bad, and since many futures are hard to predict, it will often be extremely difficult to determine whether a choice is a serious prudential mistake. But if that can't be decided, requirement (1) is not satisfied, and the choice should be left to the individual. The assessment is subjective in the sense that we are to try and determine what life will be like for the individual if she or he lives it. This requires trying to understand the person and how they will most likely experience life. What it does not do is treat as authoritative the particular outlook or preferences of the individual at the moment of choice. So the question becomes whether in the living of a certain life a person is likely to find more happiness and/or successful engagement than suffering. In many cases it is enough if we have no reason to think this is *unlikely*.

## **§6 Concrete Illustrations**

It is one thing to accept that it is possible to ethically deviate from the exclusive focus on process. It is quite another to have a sense of what that might look like. For that reason I want to briefly consider a proposal that has the potential (but only with much further work and refinement) to solve the problem cases faced by the dominant approach. The aim is not to defend this proposal here (that is a task for another day) but to use it to illustrate that properly constrained, limited consideration of the welfare impact of a choice need not be ethically problematic.

Suppose we assume that possession of the four-abilities to an appropriate degree (or something close to that) is necessary but not always sufficient for decision-making capacity. Suppose as well that if *both* of two further requirements are met, an individual possessing the four-abilities may still be deemed incompetent to make

a particular choice. Since the number of cases where this applies would be small, it could also be part of a policy that more than one person, and at least one psychiatrist should be involved whenever these two additional requirements are invoked. The two requirements are:

(1) There must be good evidence for thinking that the patient is making a serious prudential mistake here and now, and

(2) The patient must be known to have a condition<sup>13</sup> that, in turn, is known to make those who have it more likely to make prudential mistakes than ordinary people.

Whatever its other merits or flaws, the proposal does not consider the welfare impact of a patient's choice *in isolation*, nor would it apply to very many cases. It thus demonstrates the possibility of appealing to the welfare implications of a

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<sup>13</sup> I use the word "condition" because it is broad enough to encompass bodily illness, mental illness/disorder, and known types of temporary (but still significant) mental disturbance (such as being in shock). The case of shock, in particular, is one that interests me and partly explains why I chose such a broad term. It is true that people can make very poor, self-harming choices when they are in shock (e.g. after receiving terrible news), and though we would need to study the matter, it seems plausible in the abstract that they do so at higher than usual rates. However, shock is not an illness, nor is it obviously a mental disorder. How to define disorder is, of course, a whole other complex debate I cannot enter into here. However, I would like to register one point.

If it were to turn out to be too difficult to rein in a policy framed in terms of something as vague as "condition," I would then endorse a more precise term with a narrower extension (perhaps 'mental illness' since so many of the problem cases involve mental illness). I grant, at any rate, that it would be extremely important to avoid any interpretation of "condition" that allows too many things to count and/or makes it easy to "discover" new fine-grained conditions that just happen to align with a circumstance in which someone might make a poor choice. In short, I am well aware that wisdom and judgment would have to be used in the development of any policy from this sketch of a proposal, and I do not endorse just any old way of developing it.

choice in limited ways that do not open the door to widespread curtailment of freedom or abuse.<sup>14</sup>

It should be clear that the proposal would count Terence as lacking the capacity to refuse treatment. This is because, as I argued earlier, it is highly plausible to think he is making a serious prudential mistake. Moreover, he has anorexia nervosa, a condition that frequently leads people to make choices that lead to their death.<sup>15</sup> Of

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<sup>14</sup> Often the requirement to focus exclusively on process is explained in terms of the need for “value neutrality.” My proposal avoids some of the obvious worries expressed by this phrase, such as the worry that others will impose their own personal values on other people, or the worry that narrow medical values will be allowed to stand in for welfare. But it obviously does not rule out value in every possible sense. Craigie (2013) understands value neutrality in this strong sense—as ruling out any role for any value judgments in capacity assessment. Interestingly, she also recognizes that the dominant approach has difficulty yielding the right answers in the context of certain mental disorders, and thinks that only a diachronic perspective can explain what is going wrong. But she sees this as in tension with value neutrality, and so is uncertain whether an ethical solution is possible. I recognize the tension she points to, but think ethics does not require value neutrality *so understood*, and that we should therefore aim to change law and policies to reflect this.

In general, I have come to believe that it is virtually impossible to keep all forms of value judgment out of capacity assessment and still have a system that serves people well. If that is right, then it seems better to try and avoid the problems associated with misuse of value judgments by (1) appealing to very widely held, very general values, (2) giving even these values a limited scope of operation, (3) making it very clear what specific value terms mean (e.g. what welfare is taken to mean) and how they are to be applied, and finally by (4) making these policies clear and transparent. My proposal gives weight in a small range of cases to the value of future welfare subjectively construed. In other words, in a few cases it gives greater weight to diachronic welfare than to the current preferences of an individual. In doing so, it does not imply that all people should care about their future selves and future welfare. Rather, given that most people do care about this to some degree already, it makes use of this *relatively* uncontroversial value for a limited purpose.

<sup>15</sup> I assume this for the purposes of illustration, and it seems plausible based on general knowledge. However, I am not suggesting we rely on general assumptions about such matters. I wish to emphasize again that before such a policy could be implemented we would need to become more precise in our understanding of what it takes to satisfy requirement (2) and *acquire evidence* for claims about various “conditions.”



course merely choosing death is not obviously mistaken. But it seems plausible that at least for many young people with anorexia nervosa such a choice is a serious prudential mistake. Obviously more defense of this would need to be given. But for now it should be clear how the proposal is intended to work. Here, because both of the two extra conditions are satisfied, Terence lacks capacity to make this particular choice right now.

A central virtue of the proposal is that it does not license broad conclusions that would be objectionable. It certainly does not license the conclusion that patients with anorexia nervosa lack capacity with respect to *most decisions*. That would be unacceptable, but since the proposal only applies in cases where someone is making a seriously bad choice, it only applies to a small subset of all the choices such patients make. More importantly, it doesn't even license the conclusion that patients with anorexia generally lack the capacity to refuse *life saving treatment*. To see this, consider Thomas.

Thomas has struggled with anorexia nervosa for twenty years, and has been involuntarily hospitalized multiple times without significant improvement. Thomas frequently suffers from depression as well as other physical side effects of long-term, slow starvation. His self-reported quality of life is very low. Unlike Terence, who has a good chance at full recovery, Thomas has very little chance of achieving full recovery at this point, which means that any future he has will most likely be shaped by the on-going experience of chronic anorexia. Though it is hard to say exactly what that would be like for him, it is unlikely that his current quality of life will significantly improve. Now imagine that at a certain point in time, Thomas's weight cycles downward again and he realizes he will probably need to accept medically supervised weight gain to survive. Still, he wishes to refuse such treatment. The question is whether he has the capacity to do so.

The current proposal says he *does* have the capacity to decide and therefore *should* be allowed to refuse. The conclusion here is different from the conclusion in

Terence's case because here only one of the two additional requirements is satisfied, namely, Thomas has a condition, anorexia nervosa, known to make people who have it much more likely than ordinary people to make choices seriously opposed to their interests. Yet despite knowing Thomas has this condition, we can't make a strong case for the claim that this particular decision is a serious prudential mistake. In other words, it is not clear given what future life holds for him that he is making a *very bad* choice. In saying this I am *not* saying he is making a good choice. There is a big difference between saying it is not clear a choice is very bad and saying it is clear it is good. It could be that if he lived, his life would be difficult, but would still, from his own perspective, offer him more good than bad overall. The point, however, is the more limited one that we cannot say with confidence that the choice is very bad. If we can't, then the first requirement is not met, and the proposal would deem him competent to decide for himself.

Finally, it is important to see that the proposal can draw the right distinction between ordinary cases of poor choice and cases where poor choice is not accidental. Consider the case of Edgar, a widower in his 70s with advanced metastatic cancer. Edgar's wife died some years ago, and he has only one son with whom he has a difficult relationship. Edgar is sometimes moody and sometimes impulsive. He now finds himself with a difficult choice. It is a fixed fact that he has at most a few months to live. A tumor is pressing on his spine causing paralysis in his legs. He could simply accept the paralysis, return home, receive comfort care, and try to make the most of the time he has left. Alternatively he could have a surgery to remove the tumor and undo the paralysis, allowing him to walk for all or most of his remaining time. The surgery, as a kind of surgery, has a good chance of reversing the paralysis. However, this is likely to be irrelevant to Edgar, since given his overall weakness from the cancer *he* has only a very small chance of surviving the surgery and leaving the hospital. Up to now Edgar has been clear that what he wants most is to get out of the hospital and return home. He has been clear that fears the ICU and machines, and wants at all costs to avoid a painful death. For these reasons, although informed of his options, he doesn't seriously consider the surgery at first.

However, one day after a nasty spat with his son, he finds himself feeling a bit down. His son somehow conveyed to his father that he (the son) views his father as weak and cowardly in relation to this illness. Recall that Edgar is still in hospital. On an impulse shaped by his mood Edgar picks up the surgical consent form that was left with him, calls someone to his room and signs it. He is now set for surgery in the morning despite the fact that surgery is a poor choice *for him given his priorities*.

Edgar's choice is both unreflective and unwise, but there is nothing to suggest it is anything more than unwise. There is no reason to think he lacks decision-making capacity, and a virtue of the current proposal is that it deems him competent. Although the first requirement is probably satisfied in his case, the second is not. He has no condition known to affect decision-making in harmful ways. Edgar's case highlights the fact that because of the way the two conditions work together, the proposal poses no significant threat to the general freedom to make choices both good and bad. The proposal gives us permission to consider the harmfulness of a choice in a very small set of cases where we also have reason to suspect that the harmfulness of the choice is in no way accidental. The two additional requirements are crafted to achieve a different result in a very small set of cases, but they are not crafted arbitrarily, but rather in a way that explains and justifies the different result for this small set of cases. The two requirements are not in keeping with the exclusive focus on process, yet I submit that they yield good conclusions in an ethical manner.

## **§7 Conclusion**

Over time a number of problems have been identified with the dominant approach to capacity assessment. Despite this, and despite various attempts to diagnose the problem(s), most people remain convinced that we must not depart from the exclusive focus on process that is one of the main features of the dominant approach. Many reasons are given for this, but while it is clear that the concerns are legitimate and that an exclusive focus on process is sufficient to handle these

concerns, there is no real reason to suppose that an exclusive focus on process is the *only way* to handle these concerns. Exclusive focus on process is not necessary for ethical assessment of capacity. To illustrate this I have sketched a proposal that introduces two necessary requirements for finding someone to be lacking capacity despite possessing the four abilities to a normal degree. These requirements work together to limit the reach of either requirement taken on its own, and allow a very limited appeal to the welfare impact of choice. As such the proposal does not (1) impose outside values on individuals, (2) reintroduce Medical Welfarism, (3) rely on any controversial assumptions about welfare, nor (4) limit the freedom to make mistakes. I submit that this proposal (or something somewhat like it, but more well-worked out and evidence based) should be seriously considered because of its potential to solve the standard problems and improve the assessment of decision-making capacity.

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