Considering the Welfare Impact of a Choice When Assessing Decision-Making Capacity: 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[1] 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 only* focus on a patient's decision-making *processes*, i.e. 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

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[1] 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).

to this as the “exclusive focus on process.” One particular kind of 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 an exclusive focus on process, it places strict limits on the role welfare considerations can play. More specifically, it rules out allowing such considerations to serve as *justifications* for decisions about capacity.

The exclusive focus on process may be the most widely agreed upon ethical principle in the realm of capacity assessment. Nonetheless, I believe we should reject the idea that the *only* ethical way to assess capacity is to focus exclusively on process. Though widely taken for granted, I believe this is far too strong. In particular, as I shall demonstrate, considering the welfare impact of a choice is sometimes crucial. I have come to believe that, in at least *some* cases, taking account of welfare is the *only way* to fix problems with the dominant approach that have been identified by numerous authors over the past decades. Without giving at least limited weight in certain cases to the way a choice impacts a patient’s welfare, we simply can’t develop an approach to capacity assessment that consistently delivers acceptable verdicts. Therefore, rather than rule out any justificatory role for the welfare impact of a choice, we need instead to allow welfare 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 explain why I think addressing these criticisms will be impossible if we remain as limited as we are presently in the role we give to welfare considerations. The main body of the chapter considers *why* people are typically so convinced that *any* deviation from an exclusive focus on process must be ethically problematic.

Some of the concerns I identify are quite general, stemming from the thought that attention to outcome necessarily involves either inappropriate judgments about other people’s values or unacceptable restrictions on people’s freedom, or both. I argue this is not the case. I grant, of course, that the concerns people have are ethically important, but my point is that they do not rule out all consideration of outcome, as many appear to believe. At most, they underscore the problems that would arise were we to adopt an *unrestrained* consideration of outcomes.

Other concerns I identify are more closely tied to the concept of welfare and arise in response to the suggestion that sometimes we ought to allow consideration of the welfare impact of choice to play a larger role. 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 gives limited justificatory weight to the welfare impact of a choice in a limited number of cases. 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 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 giving limited justificatory weight to the welfare impact of a choice in carefully delimited circumstances is not *necessarily* unethical. Nor is there any reason to think that allowing some exceptions of this sort to ordinary practice 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 we can improve assessment of decision-making capacity in an ethical way.

§1.0 The Dominant Approach

Insofar as there is agreement about capacity assessment, the agreed upon factors are (1) a commitment to only assessing core cognitive abilities and (2) a commitment to the exclusive focus on process, i.e. focusing on how someone reaches a decision as opposed to what the decision is. For simplicity, I will refer to this pair of commitments as "the dominant approach" to capacity assessment.

One might naturally suppose that attending to process as opposed to outcome means entirely ignoring the outcome of process, i.e. the patient's specific choice. But that's not quite right, since even advocates of the exclusive focus on process allow that in certain cases or for certain purposes the patient's choice may be considered. It is thus important to be clear about what the focus on process allows, what it doesn't allow, and why.

The first way in which a patient's actual choice may permissibly be considered during assessment makes no reference to the *welfare* impact of the choice. Everyone appears to agree that in certain cases it is necessary to consider the degree of *rational fit* between an individual's specific choice and what she identifies as her most important values or goals. Consideration of rational fit is a way of checking for instrumental rationality broadly construed. For example, 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 lack of fit between choice and professed aims suggests something is wrong. Of course, it is possible that the patient has capacity and simply received incorrect information, but it could also be evidence of confusion, and/or inability to reason. Importantly, in these cases, even though the choice is part of what is considered, the choice itself is not *evaluated*. The only question is whether the specific choice makes sense in light of the patient's professed values.

Many theorists and clinicians recognize a second way in which the patient's specific choice may figure in capacity assessment. This way *does* require a judgment about the likely welfare impact of the choice. What I have in mind here is the use of a "variable threshold" or "sliding scale" approach to capacity assessment. This 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 refuse life-sustaining treatment in a case where this seems to conflict with her overall best interests, someone assessing her capacity may legitimately require that she demonstrate a higher than usual level of the same mental abilities typically assessed, for example, understanding, appreciation and reasoning.[2]

Even in these cases, however, final decisions about a patient's competence depend on whether the patient satisfies the heightened requirements, and not on judgments about the welfare impact of her choice. In other words, advocates of the sliding scale allow that concerns about welfare *may legitimately trigger* further attention to process and may even lead to the application of a heightened standard for cognitive ability. But ultimately reference to the patient's welfare is not allowed to serve as part of the justification given for finding someone competent or incompetent.

It should now be clearer what the commitment to considering only process is intended to rule out. It rules out allowing welfare considerations to count in the justification given for a final decision about competence. The fact that a choice is unwise may neither justify by itself, *nor lend any degree of justificatory support to*, a finding of incapacity.

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, 1998; 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

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[2] In many clinical contexts a sliding scale approach is accepted as standard practice. However, for debate about the extent to which it fits with the aims of a process only approach see Brock (1991) and Buller (2001).

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 1998, 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 1998).

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 so, they both embrace as morally foundational the exclusive focus on process.[3]

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[3] 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).

Other models have been developed, and some of these are used, but most are versions of the dominant approach.[4] 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. There are various examples one could give. A number of theorists writing about capacity assessment have focused on the role of emotion in decision-making, arguing that the dominant model cannot account for those cases where extremely intense emotion undermines decision-making ability (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). They focus on individuals who experience severe emotional distress and who, because of this, are neither able to make decisions as well as most people ordinarily can, nor able to make decisions as well as they themselves *usually* can. The dominant approach deems these individuals to be competent because their emotional distress does not generally impair their cognitive functions.

Although such cases are important, I focus here on a different set of cases involving 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, recovery (not weight gain, but recovery from anorexia nervosa itself) remains highly likely with treatment, and yet the patient refuses any form of treatment involving weight gain. The dominant

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[4] Kim (2010, 61-65) lists and compares a number of different tools developed for assessing capacity.

approach deems some (though not all) such patients as having capacity. However, it seems a failure of the model that it deems competent *any* patient fitting that description.

Often, patients with anorexia nervosa who are found to lack capacity fail the four-abilities model's 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 few years ago, and although he has been underweight all along, he was fairly stable until recently when his weight began to drop precipitously.[5] 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, thereby establishing *appreciation* of his situation. 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.[6] The dominant approach deems Terence

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[5] 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.

[6] The case of Terence is based loosely on cases described by Tan et. al. (2006a) in a small study of capacity among anorexia patients. Most were deemed competent on the basis of assessment with the MacCAT-T. Two patients who were not deemed competent 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,

competent and tells us to view him as someone with unusual values that need to be respected.

Many people feel sure that Terence currently lacks the capacity to refuse treatment. However, if we stay within the bounds set by the dominant approach we can't identify anything wrong with Terence's decision making. If, on the other hand, we allow ourselves, even briefly, to step outside the bounds of the dominant framework, it becomes relatively easy to say what worries us about Terence's decision. Our concern traces in part to our sense that Terence is making a choice seriously detrimental to his welfare—a welfare mistake. By itself, of course, this cannot provide a justification for finding him incompetent. However our concern seems also to partly depend on what we know about anorexia nervosa, which underwrites our sense that his making this choice *is no accident*. These two facts together seem to explain our sense that he lacks competence.

At this point, I should clarify the notion of "welfare mistake." When I say Terence is making a welfare mistake, I do *not* mean that someone other than Terence, having applied their own values to his case, now thinks Terence is making a welfare mistake. Rather, I mean that Terence is making a mistake subjectively construed. More specifically, his choice is a mistake given the fact that if he lived, he himself would in the future most likely value the life that he is currently throwing away.

In bioethics, it is generally accepted that welfare should be understood *subjectively*, in terms of the values, preferences, and attitudes of the individual whose welfare is in question. However, there is also a common tendency in bioethics to equate a person's *current* values, preferences, or attitudes with what will promote her welfare. The latter assumption is problematic and not required by a commitment to thinking of welfare subjectively. To see why, consider that it is fairly common for people to value or prefer something at a given point in time, but then decide later,

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274-5). For more discussion of capacity in relation to these cases see Charland (2006), Vollman (2006), Stewart and Hope (2009); Whiting (2009).

once they actually have what they previously wanted, that they are no better off. Such cases remind us that although individual values and preferences are importantly related to welfare, the relationship is complex. It is not safe to assume that a particular set of values or preferences held at a particular time is a reliable guide to the individual's welfare at a different, later time. Instead, what really matters for determining welfare are facts about how a person feels and thinks about her life *while she is living it*. The important upshot is that even a decision that reflects a person's current preference and/or values can, on occasion, turn out to be a serious welfare mistake in the subjective sense. To see more clearly how this could be consider the following two types of case.

In the first case, a person values X and chooses something that will lead to it. However, after "getting X" and experiencing the effects of her choice, she no longer sees value in X. She now denies that having X in her life is good and regrets her earlier choice. From her own perspective, her earlier choice was a welfare mistake *subjectively speaking*.

In the second case, a person contemplates a choice between A and B, where she understands (correctly) that B will lead to her death. She indicates that she wants to choose B. However, let us imagine that the following is true. If she chooses A instead, she will live a long life *that she herself will value as she is living it*. Obviously, if she is currently choosing B, she doesn't value that possible life *now*. Nonetheless, it seems plausible to say that choosing B would be a welfare mistake for her, *subjectively speaking*.

It is plausible to view Terence as making a serious welfare mistake—a mistake in subjective terms. The plausibility is underscored by his youth and the fact that full recovery is likely for him if he accepts treatment. Of course, such a fact by itself should not be allowed to justify a finding of incompetence. Still, I want to suggest that in certain cases it may be ethical to allow the fact that a choice would be a serious welfare mistake to serve as a *partial* justification. Before sketching a proposal for how that might work, I want to consider the various worries and concerns that lead people to embrace the exclusive focus on process. Some of these are very general worries about any departure from the exclusive focus on process. Others are more specifically focused on welfare. I consider each 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? I first consider an answer many find intuitive but that, when examined closely, does not make sense in this context. I then consider two answers that make sense as statements of concerns we ought to have, 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. We could only know the practice to be objectionably paternalistic if (among other things) the practice was known to unfairly limit the freedom of competent people, for example, if it were known to declare competent adults incompetent and so unfairly 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.

However, 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 a goal the pursuit of which will undermine their chance 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* this concern does 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 that if made, that it can't be 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 to do as they please within the domain of self-regarding action. They have, and it is good that they have, the right to make both good and bad choices subjectively construed. 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 looking only at processes of decision-making as opposed to outcomes. People are supposed to be free to make mistakes. If we were to routinely consider the welfare impact of a person's choice and always declare individuals to be incompetent who wish to make choices that negatively impact their welfare, we would do away with the freedom to make mistakes. Even if we are careful to always make judgments about welfare in subjective terms, and even if we therefore only identify genuine welfare mistakes subjectively construed, if we then rule all such individuals incompetent, we will in effect be forcing 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 to be incompetent to make choices that negatively impact their welfare. 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 accepting the need to avoid *that* kind of unrestricted policy, does not in itself show us that we must embrace the exclusive focus on process. 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 already see that the non-capacity/capacity line we want to draw *cannot be the same as* the line dividing those who sometimes make poor choices and those who make only wise ones. Therefore, we already 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 an approach that sorts people using the second line, is not the same as knowing that any approach that considers a patient's choice will turn out to sort people using the second line (or some other inappropriate line). It remains to be seen. Thus, 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. I have already indicated that I think welfare can be construed subjectively. However, some people may fear that it will in fact be interpreted in terms of medical values. 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 the matter, 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 important point for our purposes is that medical values are themselves only derivatively 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 subjectively construed. 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 the intentions of those who suggest considering welfare, once we adopt a policy that opens the door to (even limited) consideration of welfare, we will inevitably 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 some particular medical value. If they count all such individuals as incompetent, they will end up forcing inappropriate medical values on some patients.

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. For example, 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 consideration of the welfare impact of a choice would, if adopted, inevitably be interpreted in Medical Welfarist terms, 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.

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 can now see that such a broad policy would not only rule out the freedom to make welfare mistakes, it would rule out the freedom to make altruistic choices as well. It would also unjustifiably limit 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 1998; Kim 2010).[7] 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*.

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[7] Religious choice of this sort can be thought of either as a special case of prudential judgment (judgment that considers next-life welfare as well as this-life welfare) or as a case of choosing some religious value (obedience to God) over personal welfare. Whichever way a person thinks of it, such a choice is distinctly different in kind from ordinary this-life welfare judgments. Thus it would be important to be sure that a person making a seriously harmful choice is not doing so on the basis of either type.

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 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 giving even limited justificatory weight to 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; Bishop 2014).

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 happiness and successful engagement 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 very 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 *serious* 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 continued to live 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 with treatment are quite high, though chances of full recovery decline significantly over time (Treasure et. al., 2015). Because Terence is in the early phase, 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 while living 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. 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 *un*likely.

§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 my point 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 that, in turn, is known to make those who have it more likely to make prudential mistakes than ordinary people.

The first requirement says we must have good reasons for thinking that the individual is making a serious prudential mistake. 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 or not. But then, if that can't be decided, or decided with confidence, the first requirement is not satisfied and my framework says that the choice should be left to the individual.

The second requirement refers to the idea of a "condition" known to lead to serious prudential mistakes in higher than usual numbers. To apply this requirement we would need to acquire evidence in support of this idea. 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, yet shock is not an illness, nor is it obviously a mental disorder. However, 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 disorder" since so many of the problem cases involve mental disorder).

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 choice in limited ways that do not open the door to widespread curtailment of freedom or abuse.

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.[8] Of 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.

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[8] 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."

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 when we try to consider matters subjectively, in terms of what we know about what the future will be like for Thomas and in light of his probable reactions to that future, 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.[9] 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 he 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, soon after he learns about this option, he has a nasty spat with his son and finds himself feeling a bit down. The 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 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.

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[9] This case is *very loosely* based on a case described by Atul Gawande (2002, chap. 1).

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 two defining 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 developed 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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