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Medicine and Well-Being

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The connections between medicine – both its science and practice – and well-being are myriad. This paper focuses on the place of well-being in *clinical* medicine. It is here that different views of well-being, and their connection to concepts like "autonomy" and "authenticity", both illuminate and are illuminated by looking closely at the kinds of interactions that routinely take place between clinicians, patients, and family members.

In the first part of the paper, I explore the place of well-being in a *paradigmatic clinical encounter*, one where a competent patient interacts with a clinician. The main question here is how, or even whether, the pursuit of patient well-being – however we construe it – figures into a paradigmatic clinical encounter. In the second part of the paper, I consider what I will call a *marginal clinical encounter* – one where the patient is, as Agnieska Jaworska (1999) puts it, at the "margins of agency" – to theorize about the nature of well-being and to show how different theories of well-being can have dramatic consequences for clinical decision-making.

1. Well-being and the ends of medicine

At first glance, the connection between clinical medicine (henceforth, simply "medicine") and well-being is relatively clear. We do not go to doctors to make ourselves worse-off. Usually, we go to make ourselves better-off or at least to stop things from getting worse (or, in some cases, to make the inevitable process of things getting worse as painless as possible). It seems, then, that a, if not the, goal of clinical medicine is to restore, promote, or protect a patient's well-being.

This claim is far from obvious, however. Promoting, protecting, or restoring well-being is far too broad an aim for medicine.[1] Medical professionals are not required to do whatever they can to increase a patient's well-being. This is not simply because time and resources are finite. There are all kinds of ways we might make someone better off that are clearly not *medical* in nature: giving a gift, offering a shoulder to cry on, or driving someone home to save them from a walk in the rain are not medical interventions. We do not think that medical professionals must do these things, at least not *as* medical professionals.

But the fact that not all ways of promoting, protecting or restoring well-being are medical does not show that promoting, protecting or restoring well-being is not the proper end of medicine. Rather, it suggests that the proper aim of medicine is to restore, protect or promote well-being *via the tools of medicine*. Now just what makes something a tool of medicine is hardly clear, both sociologically and normatively speaking.[2] Even so, there is what we might call a paradigmatic core of interventions that are clearly medical and it seems plausible to think that these intervention aim at promoting, protecting or restoring well-being.

But even this more limited claim faces several challenges. Robert Veatch has forcefully argued that clinicians are not well placed – and maybe are even especially poorly placed – to determine what is good for their patients (2009: 41). According to Veatch, this is true no matter what theory of well-being one is partial to (2009: 98).[3] The main concern for Veatch is that medical training, and the resulting expertise, doesn't equip clinicians with any special insight into with respect to is good for their patients. As a result, clinicians should see themselves as "assistants for patients," who help the patient achieve well-being not "according to the *physician's* ability and judgment, but rather according to the *patient's* ability and judgment" (Veatch 2009: 62).

Veatch's skepticism about clinicians' ability to make judgments about their patients' well-being is unwarranted (Groll 2011). First (as Veatch acknowledges) clinicians *do* have expertise with respect to the medical *means* of achieving some aspects of well-being, even if they have no special expertise with respect to what ends or goals constitutively contribute to a person's well-being.

Second, and more important, there are cases where clinicians can plausibly be thought to know which ends are best for someone even if they do not know it *qua* clinician.

To see why, consider the case of Horace Johnson:

> Mr. Johnson is a forty-year-old, wheelchair-bound patient who has been suffering for the past ten years from type 2 diabetes mellitus. He has wet gangrene on his fifth toe. He doesn't visit the outpatient clinic for care of his diabetes and infection as he is scheduled to. The infection is so severe that his physician, Dr. Garcia, concludes that

> the toe cannot be saved and that if it is not amputated, Mr. Johnson could die. Mr. Johnson has been seen by a psychiatrist, who finds him eccentric but believes that there is no evidence of mental illness and that Mr. Johnson must, therefore, be declared competent to make his own health care decisions (Groll 2011: 27).[4]

For reasons we'll get to shortly, one may think that at the end of the day Mr. Johnson's wishes must be respected. But if that is right, it is surely *not* because there is any real doubt about what is best for him. A clinician who respects the patient's wishes here does so despite justifiably and truly believing that it would better for Mr. Johnson to get his toe removed. But this knowledge – that (other things being equal) it is better to live minus a toe than to die – is not *medical* knowledge. It is, rather, a piece of common knowledge about what makes a life go well.

Even so, Veatch is surely right that in arriving at a judgment about what is good for a patient, the clinician should take the patient's view of what is best very seriously indeed, even if not as wholly or automatically authoritative. This is because patients often *are* far better suited to know what is good for them than clinicians – at least when it comes to what ends or goals constitutively contribute to their well-being. One can think this is true without thinking, as Mill (1978) did, that people are generally the best judges of and most interested in their own good. For the nature of many clinical encounters – where a clinician has never met the patient or even thought about him prior to picking up the patient's chart minutes before having what is often altogether a very short meeting with him – are such that the clinician is often especially poorly positioned to make any informed judgment about which ends or goals are best for the patient.

Moreover, as the case above illustrates, even when clinicians do know which ends or goals are best for their patients, they do not know it *qua* clinicians. This means that any judgments clinician's make, let alone express, about what ends are best for their patients do not carry any medical authority.

But none of these points undermine the idea that the proper aim of medicine is to restore, protect or promote well-being *via* the tools of medicine. Rather, they give us good reason to think that *determining* what goals or ends are good for patients is i) not a medical task, ii) not something clinicians are particularly well-suited to figure out, and so iii) something that should be a *joint* endeavor between clinician and patient (with the patient taking the lead).

2. Autonomy, authenticity, and well-being: the standard case

A closer look at the example of Mr. Johnson, however, complicates even this qualified conclusion about the place of well-being as an end of medicine. For as we noted there, many people will think that if Mr. Johnson refuses to have his toe amputated, clinicians must, at the end of the day, respect that decision. Indeed, it is a tenet of contemporary medical ethics that if a competent patient refuses treatment, then it is almost always wrong for the clinician to *force* the treatment on him. Why? The short answer is that *respecting patient autonomy* is a central value of clinical medicine.[5] But what exactly does this mean? And is respecting autonomy an end that can be subsumed under the end of promoting, protecting, or restoring a patient's well-being?

These two questions are related. Indeed, part of what makes answering the second question difficult is that there is a sense of "autonomy" whereby respecting (promoting, protecting, restoring etc.) autonomy contributes to well-being, either instrumentally, non-instrumentally, or both.

Sometimes when we talk about an autonomous individual we have in mind someone who is doing something "her way": she is living her life in accordance with her conception of what matters. Ronald Dworkin (1993: 224) calls this living a life with "integrity". I will follow Daniel Brudney (2009: 32) in calling such a life an "authentic" one.

If we focus on autonomy-as-authenticity, then considerations of autonomy seem to be a subset of all welfare considerations. Why? What is the connection between leading an authentic life and your life going well for you?

First, we might think that individuals are best situated, in terms of motivation and knowledge, to actually pursue what is best for them (Mill 1978). Moreover, even if we have doubts about how well people know what is best for themselves or whether they are in fact more interested in their own well-being than anyone else's, we may doubt whether there are effective ways of making people do what is good for them that are not so coercive or invasive as to make the overall situation *worse* for the person who is the target of the intervention.[6] Consider our case above: even if it is true that it would be best for the patient to choose the treatment, it certainly doesn't follow that it would be best for the patient for us to *force* the treatment on him. The cure (forced intervention) might be worse than the disease when we tally up the psychological and physical costs to the patient.

The upshot is that it is plausible to think that living an authentic life, or at least letting people lead authentic lives, is *instrumentally* valuable with respect to well-being. But one might think that leading an authentic life is also non-instrumentally related to personal well-being inasmuch as it is a *constituent* of how one's life goes. So, Dworkin (1993: 205) claims that, "integrity…has great independent importance in life." And while they do not use the term "authenticity", Valerie Tiberius and Alexandra Plakias have argued for a Value-Based Life-Satisfaction Account of well-being according to which one's well-being is constituted by life-satisfaction as a "response to how life is going according to certain standards, and these standards are *provided by a person's values*." (Plakius and Tiberius 2010: 420. Emphasis added).

The common idea here is that living your life in accordance with what you take to be important is *part* of your life going well for you. Crucially, any plausible version of this idea will leave room for the idea that you can be mistaken about what is good for you. This might be because you are wrong about what will *lead* to your life going as you want to; or because you are wrong about what *counts* as living in accordance with your values on a particular occasion; or, more controversially, because your conception of how your life should go is distorted by misinformation. But even if we acknowledge the various ways we can go wrong in determining how to live or what to do, the idea is that doing things “my way” is part of my good even if “my way” is mistaken or misguided in various ways.[7]

So, leading an authentic life – a life that is lived in accordance with one’s deeply held values – is plausibly part of what makes a person’s life go well for her. If that’s right, then it looks like decisions that might initially appear bad for the patient in fact are not inasmuch as they are part of the patient leading an authentic life. But now we might worry that we’ve lost sight of the phenomenon we’re trying to give an account of, namely why there is a strong presumption in favor of respecting a patient’s poor decision. For if it is best for the patient to act – or to be allowed to act – in accordance with his authentic self in what sense can we understand the patient’s decision as a poor at all?

The answer is that our judgment that the patient is making a poor decision depends *on setting aside* the fact that the patient’s decision expresses his authenticity. That is, we judge that *setting aside* the fact that the patient authentically wants (or refuses) X, wanting (or refusing) X is bad for the patient. But then, when we consider the fact that he authentically wants (or refuses) X, we conclude that *all things considered*, getting (refusing X) is best for the patient. So, we respect the patient’s decision because, taking into consideration all relevant factors (including what the patient authentically wants), the patient is choosing what is best for him.[8]

This answer to the question, “Why respect a competent patient’s autonomous (and apparently poor) decisions?” assimilates considerations of autonomy to considerations of the patient's good. According to this view, there really is nothing else to consider in a clinical encounter beyond the patient's well-being, provided we have a suitably broad conception of what counts as contributing to the patient's well-being.[9]

The problem with this approach, or indeed any approach that subsumes considerations of autonomy to considerations of well-being, is that it doesn't do justice to the *kind* of consideration a competent patient's decision with respect to an available treatment is. Consider again Mr. Johnson's refusal of treatment. When he says that he does not want a procedure performed he is not *just* expressing a desire or value, authentic or otherwise. He is making a *demand*. Consider how odd it would be if, in response to this demand, Dr. Garcia said, "I completely understand. And we will consider that refusal as part of our determination of what is good for you." We can imagine Mr. Johnson being confused by this response. For surely whether to get the treatment or not is *his* decision and now, having made that decision, the clinician must respect it as a *decision* and not as a further consideration in determining what is good for the patient. This is not to say that clinicians cannot appropriately try to persuade a patient to reconsider. The point, simply, is that at the end of the deliberative day, so to speak, the decision belongs to the patient. So, when the end of the deliberative day is reached, the presumption is that the patient's decision settles the matter: further consideration of the patient's good, let alone acting for his good without concern for the decision, is (presumptively) inappropriate.

Respecting patient autonomy, then, involves respecting a competent patient's *right* to make decisions about his own care. And when patients assert this right, they are introducing a consideration that is not to be assimilated to judgments about what is *good* for the patient. The upshot, then, is that while considerations of *authenticity* are a subset of well-being considerations, considerations of patient autonomy are not. They are *sui generis*.

This doesn't mean that an account of *why* competent patients have the right to make decisions about their own care cannot ultimately be grounded in considerations of either patients' good or, more broadly, the good of letting patients make their own decisions. Indeed, we have already got on board the materials for how such an account might go: authenticity is deeply important to well-being, so important perhaps that on balance we promote patient well-being by giving competent patients the *right* to make decisions about their own care.[10]

Setting aside the fact that there are serious theoretical objections to this kind of account,[11] the central point remains: whatever grounds it, patient autonomy consists at least in part of a *right*, specifically the right of competent patients to make decisions about their own care. Consequently, a competent patient's decision in a clinical encounter provides a practical reason that is not a welfare reason (even if the existence of such a reason *is* to be accounted for by welfare reasons). When a patient demands that he not be treated that demand is not further data for determining what is best for the patient. It is a (presumptively) authoritative reason to stop thinking in terms of what is *good* for the patient.

The upshot, then, is that a clinician's pursuit of her patient's good is constrained by the need to respect her autonomy, where this is something quite apart from promoting, respecting, protecting, or restoring her well-being. To say that patient autonomy constrains the clinician's pursuit of the patient's good does not entail that it is always impermissible to act against a patient's autonomy for her good. In other words, my analysis of the relationship between autonomy and well-being in a clinical encounter does not entail that clinician paternalism is always impermissible. But the idea that patient autonomy consists, at least in part, of a patient's presumptively having the *right* to make decision about their own care means that acting against that right is at least presumptively impermissible.[12]

3. Autonomy, authenticity, and well-being at the margins of agency

So far, we've looked at how the pursuit of well-being figures into the ends of medicine and, more specifically, its place in a clinical encounter between a healthcare provider and a competent patient.

Oftentimes, however, patients are *not* competent decision-makers, or at least not obviously so. This is clearest in cases where patients are not even conscious. Here, the patient has no right to make a decision for herself since she is literally not capable of making a decision. In these cases, a surrogate decision maker is the one with the right to make healthcare decisions for the patient.

Things are considerably more complicated however when the patient is able to express preferences with respect to how he wants things to go, either in a particular situation ("I don't want to eat!") or in general ("I want to live!"), but where he does not rise to the level of competence required for him to have the right to make decisions about his care. Once again, a surrogate decision maker is the one with the right to make healthcare decisions for the patient. But how should the surrogate go about making decisions? And what do we learn about the nature of well-being in answering that question?

The standard response to the first question – which is developed and explored in-depth in Brock and Buchanan (1989) – is that there are three decision-making standards the surrogate can appeal to:

1. The advance directive standard.
2. The substituted judgment standard.
3. The best interest standard.

According to the standard view, surrogates should first check if the incompetent patient has an advance directive. An advance directive explicitly tells the surrogate or healthcare team what the then-competent, now-incompetent patient wanted done in the situation he finds himself.[13]

If there is no advance directive, then (according to the standard view) the surrogate should deploy the substituted judgment standard. This standard directs the surrogate to do her best to discern what the incompetent patient *would* choose were he currently competent enough to make a decision for her incompetent self.

Suppose, however, that the surrogate has no, or not enough, idea of what the now-incompetent patient would choose were she now competent (and deciding for her incompetent self). According to the standard view, the surrogate should make the decision that she thinks is in the best interest of the patient.

Why (according to the standard view) should the standards be deployed in this particular order (i.e. advance directive, substituted judgment, best interest)? The answer is partly found in our previous discussion about the relationship between autonomy, authenticity, and well-being. The advance directive standard is thought to respond to the importance of patient autonomy. The substituted judgment standard is thought to respond to the importance of patient authenticity. And, finally, the best interest standard is thought to respond to the importance of the patient's well-being.

But the discussion in section 2. also points to a problem for the standard account. For as we saw above, considerations of authenticity are not *distinct* from considerations of well-being. They are, rather, a subset of well-being considerations. This means that if the substituted judgment standard really is meant to respond to the importance of authenticity, it is not conceptually distinct from the best interest standard. It is, rather, highlighting the importance of authenticity *to* well-being. A more conceptually coherent version of the standard view, then, would advise surrogates to first check (and then appropriately respond to) an advance directive and then, if there isn't one, to act in the patient's best interest, where this means taking very seriously what choice would be consistent with the patient's authenticity.[14]

But even with this amendment to the standard view, serious questions remain.[15] Some are epistemic: how should surrogates *interpret* advance directives, which, in very many cases, will be too general to be straightforwardly applied? Are competent patients in a good enough epistemic position to make decisions *now* for a future self who will be in a position that the current self probably doesn't have a very good handle on? How can we reliably judge what a now-incompetent patient *would* want were she to suddenly become competent (and have to make a decision about her current situation)? Other questions are metaphysical: is it so clear that the person who made the advance directive is metaphysically identical to the person who is in front of the surrogate right now? And even if the now incompetent patient is metaphysically identical to his former competent self, has the change in his mental status come with a genuine change to his authentic self (such that imagining what the old authentic self would choose in the situation at hand would be inappropriate)?

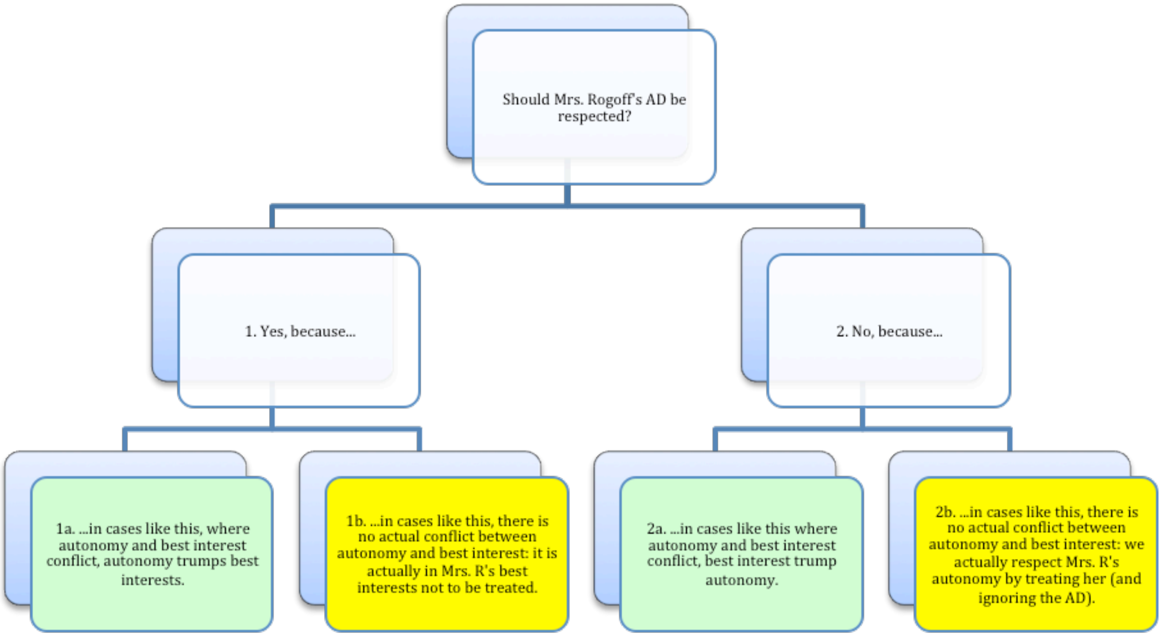
Finally, there is the following ethical question: what should the surrogate *do* when it appears that the patient's current best interest appear to dramatically conflict with the patient's previous authentic choice (*via* an advance directive for example)? This is the question I will focus on in the remainder of this paper since, in addition to being practically very important, it highlights interesting issues in debates about the nature of well-being and also draws in some of the questions above.

To help grapple with our question, consider an example from A. Jaworska (1999: 105):

> Mrs. Rogoff was always an independent woman. Raised in an immigrant family, she was used to working hard for what she wanted. Most of her life she ran a successful business selling liquor. She also developed local fame as an outstanding cook and hostess. After her third husband's death she lived alone, enjoying what she considered, by old-country standards, a luxurious lifestyle: keeping up a nice big house and indulging in restful leisure. She was an introvert, always carefully guarding the way she presented herself to others. Life interested her insofar as she could live according to her own sense of comfort, making her own mistakes and relying on her own strength and wisdom.
>
> In her early eighties Mrs. Rogoff developed severe motor impairments, which could only be corrected by a risky neurosurgery. She decided to undergo the procedure, insisting that she would rather die than be immobile. She prepared a living will, requesting not to have her life prolonged if she became a burden to her family or if she could no longer enjoy her current quality of life. The surgery was successful, but shortly thereafter Mrs. Rogoff developed early signs of dementia: memory and word-finding difficulties. As she became more and more disoriented, her daughter hired a housekeeper, Fran, who moved in with Mrs. Rogoff. Fran takes care of Mrs. Rogoff the way one would take care of a child. Mrs. Rogoff enjoys the long hours she spends with Fran, and with her grandchildren whenever they visit, telling them somewhat disjointed stories about her earlier ventures. She watches TV a lot and her stories often incorporate the more exciting episodes from TV as if they pertained to her own life. In her more lucid moments, Mrs. Rogoff tells her grandchildren that she is scared to die, that "she doesn't want to go anywhere." She usually cries when Fran is away and when her grandchildren wrap up their visits.
>
> […] What treatments should [Mrs. Rogoff's daughter] authorize if Mrs. Rogoff develops a dangerous but treatable infection?

It seems here that considerations of autonomy tell in favor of *not* (aggressively) treating Mrs. Rogoff should she develop a dangerous but treatable infection. But by not treating her, we would effectively be allowing someone to die who has clearly expressed an interest in living. If we consider what Mrs. Rogoff currently wants, it looks like being treated is in her best interest.

How might we resolve this apparent problem? There are four broad strategies (the colors will be explained presently):



Should Mrs. Rogoff's AD be respected?

1. Yes, because...

2. No, because...

1a. ...in cases like this, where autonomy and best interest conflict, autonomy trumps best interests.

1b. ...in cases like this, there is no actual conflict between autonomy and best interest: it is actually in Mrs. R's best interests not to be treated.

2a. ...in cases like this where autonomy and best interest conflict, best interest trump autonomy.

2b. ...in cases like this, there is no actual conflict between autonomy and best interest: we actually respect Mrs. R's autonomy by treating her (and ignoring the AD).

Notice that there is a sense in which 1a) and 2a) (shaded green) belong together: both positions admit that there is a genuine conflict between autonomy and best interest in cases like Mrs. Rogoff's. They differ, however, in what should happen in the face of that conflict.

Likewise, 1b) and 2b) (shaded yellow) belong together inasmuch as both deny that there really is a genuine conflict between autonomy and best interest in this kind of case. They differ, however, in why they think this is so. 1b maintains that it is actually in Mrs. Rogoff's best interest for the AD to be followed. 2b, however, maintains that following the AD does *not* respect Mrs. Rogoff's autonomy on the grounds that Mrs. Rogoff still has (limited) autonomy to make medical decisions.[16] I want to focus on R. Dworkin's defense of 1b since it, and the replies it has generated, reveal significant fault lines in debates about the nature of well-being.

How could it be in Mrs. Rogoff's best interest not to be treated when she wants to continue living? According to Dworkin, the answer lies in appreciating the connection between autonomy and authenticity, or "integrity" as he calls it. The reason, according to Dworkin, that we think that competent people have the right to make decisions about their own medical care is because giving them that right allows for people live authentically: they can shape their life in accord with the interests that reflect what really matters to them. Dworkin calls these interests "critical interests" (1993: 202).

Why should we care about living authentically (or with integrity)? We've already seen Dworkin's answer, namely that integrity is an independent constituent of a good life: "Integrity…has great independent importance in life…. We admire the person who does it his way, even if that is very much not our way" (1993: 205). To put it in the terms I deployed above, Dworkin's view is that authenticity is a *part* of well-being and that autonomy – the right to make decisions about one's own care – stands primarily to protect this especially important constituent of well-being.[17] So, other things being equal, living a life that reflects one's values, or critical interests, is good for you and so in your best interest.

Suppose this brief account of Dworkin's view is correct. How does it help him to arrive at the conclusion that, contrary to appearances, it is in Mrs. Rogoff's best interest not to be treated despite her desire to continue living? The first claim Dworkin makes on the way to this conclusion is:

> **Narrative:** Having critical interests requires having a grasp of one's life as a whole or at least over a substantial stretch of time.

Dworkin's thought here is that our critical interests reflect our view of how we want our life to go as a whole (1993: 201). They provide a kind of structure for our whole life by marking out what really matters to us. They both give us a sense of where we're going (why we plan to do various things) and also where we have been (why we did what we did). To have critical interests, according to Dworkin, one must be able to take a kind of synoptic view of oneself and one's life.

Crucially, according to Dworkin, patients with relatively advanced dementia are not capable of thinking of their lives as a whole:

> By the time…dementia has become advanced, [its] victims have lost the capacity to think about how to make their lives more successful on the whole. They are ignorant of self – not as an amnesiac is, not simply because they cannot identify their pasts – but, more fundamentally, because they have no sense of a whole life, a past joined to a future, that could be the object of any evaluation or concern as a whole (1993: 230).

The upshot then is that, assuming **narrative** is right, they are not capable of forming new critical interests.

But how does this get us to Dworkin's conclusion that we actually act in Mrs. Rogoff's interests by letting her die? The basic idea, recall, was that by following Mrs. Rogoff's pre-dementia wishes, we are thereby allowing her to live (or finish her life) with authenticity. But if Mrs. Rogoff cannot currently generate critical interests, it might seem that the issue of authenticity drops off the table altogether. So we don't help Mrs. Rogoff live (or end) her life authentically by allowing her die.

In response to this line of through, Dworkin makes another claim:

> **Non-Experiential:** Critical interests usually have non-experiential states of affairs as their objects. That is, the objects of critical interests are usually not that the holder of the interest *experience* something.[18]

Consider, for example, that if you ask a typical parent what he wants out of life he will probably rank the well-being of his children quite highly. To put it in Dworkinian terms, one of the parent's interests is that his children do well. This interest is not in the parent *experiencing* his children do well: the object of the interest is the children, not the parent.

Crucially, **non-experiential** does not claim that critical interests usually have someone other than the interest holder as their object. The idea, rather, is that critical interests don't have as their object the holder having certain *experiences.* This means that Mrs. Rogoff's pre-dementia interest in living independently is *non-experiential*: she actually wants to live independently and not just *feel* like she is.

Non-experiential moves us closer to seeing how it could be good for Mrs. Rogoff to not be treated for the infection. This is because the non-experiential nature of most people's critical interests means that the interest can be fulfilled without the interest holder knowing: a parent's interest in his child doing well might be met while the parent is on solo trek to the middle of Antarctica (suppose the child turned his life around during that time).

Likewise, Mrs. Rogoff's interest in not living in a highly dependent state can be met, without her knowing, by refusing to treat her. Moreover, in not treating her we are responding to an interest that is central to Mrs. Rogoff's living an authentic life. And living an authentic life is central to her life going well for her. So we arrive at Dworkin's conclusion: there is no real tension in Mrs. Rogoff's case between autonomy and best interest. Following Mrs. Rogoff 's advance directive not only respects her autonomy but also is what is best for her.

Many people have rejected this conclusion. But they do so by rejecting different parts of Dworkin's view. Jaworska (1999), for example, rejects **Narrative**, (while accepting **Non-experiential**). She claims that in order to have critical interests one needn't be able to have a grasp of one's life as a whole. As a result, patients like Mrs. Rogoff can have new critical interests, or at least new arrangements of critical interests, to which we must respond if we care about the patient's authenticity. And, inasmuch as Jaworska endorses Dworkin's "integrity-based" (1993: 224) view of the importance of autonomy, she argues that patients like Mrs. Rogoff have limited autonomy (based on current critical interests): they can make claims on providers about *ends* (such as being allowed to continue living) even if they are not authoritative with respect to how to actualize those ends (because they don't understand treatment options for example) (1999: 136). So, she agrees with Dworkin that there is no conflict between best interest and autonomy here, but only because she thinks that Mrs. Rogoff has current critical interests that not only make it in her best interest to be treated but also ground a (limited) form of autonomy.[19] For Jaworska, both autonomy and best interest tell in favor of treating Mrs. Rogoff.

But suppose we accept both **narrative** and **non-experiential**. We might still resist Dworkin's conclusion. To see why let's return to the comparison of the Antarctic trekker and Mrs. Rogoff. The idea there was that just as the trekker's interest in his child doing well could be fulfilled without his knowing it, so too could Mrs. Rogoff's interest in not living in a highly dependent state.

There are at least three reasons we might reject the appropriateness of this comparison. First, to the extent that we have the intuition that the trekker is benefited by his child doing well during his (the father's) trek, this might be because we imagine that the time *will* come when he comes to learn about his child's success. But suppose now that the father *never* finds out. Even if there's a sense in which his interest is fulfilled, does the father *benefit* from that if the interest's fulfillment has *no* positive impact on his experience? Likewise, even if we admit that Mrs. Rogoff has a critical interest in not living in a highly dependent state, does it benefit her to not be treated assuming that, given the irreversibility of her dementia, this will have no positive impact on her experience?

Notice that if we are inclined to answer "no" to these questions we are not thereby committed to rejecting **non-experiential**. We can admit that the *object* of the trekker's interest is something non-experiential. The idea here is just that in order for the fulfillment of an interest to benefit its possessor, the interest's fulfillment must have *some* positive impact on the interest holder's experience.[20]

Suppose, however, we side with Dworkin in thinking that the father is benefited by his child doing well even if he will never find out. We can still point to a difference between the trekker and Mrs. Rogoff that blocks the conclusion that Mrs. Rogoff is benefited by not being treated. To see why, notice how differently the trekker and Mrs. Rogoff *would* react to learning that their critical interests have been met. The father, presumably, will react very positively. Mrs. Rogoff, on the other hand, will not: she wants to live. The experience of not being treated, especially if we imagine that she is aware she's not being treated, will be highly negative for her.

This leads to the idea, which Jennifer Hawkins has recently argued for, that what is good for a person cannot be *alien* to her. What this means is that, "a person's good must enter her experience, if it does, in a positive way" (2014: 526.) This **nonalienness principle** (Hawkins 2014: 526) does not demand that the good in question *actually* be experienced in a positive way by the person.[21] It must only be the case that *if it does*, it will be experienced in a positive way by the agent as she currently is. We have every reason to think that this is true of the trekker and every reason to think it is *not* true of Mrs. Rogoff. So, contrary to Dworkin, it is not good for Mrs. Rogoff not to be treated.

Finally, even if we reject the **nonalienness principle**, we might still reject the comparison between the trekker and Mrs. Rogoff by simply rejecting the claim that Mrs. Rogoff still has a critical interest in not being dependent on others in the way she now is. Imagine again that we stop our trekker and ask him if he is still interested in his child doing well. He will say "yes." But if we ask Mrs. Rogoff whether she would rather be allowed to die than to continue living as she is she will say "no."

This test is clearly closely related to the **nonalienness principle**, but the emphasis is in a different place. The question here is not about Mrs. Rogoff's experience, actual or hypothetical. Rather, it's about whether she still even has the critical interest Dworkin attributes to her. And we might say "no" on the grounds that in order for someone to have a (non-instrumental) interest in something it must be the case that they would agree that they do if asked.[22] Let's call this the **endorsement principle**. If it is correct, then we are not responding to any interest of Mrs. Rogoff's in not treating her.

My goal here is not to endorse any of these ways of rejecting Dworkin's conclusion about how to deal with dementia patients whose current interests seem to conflict with their past interests. Each of the proposals above faces plausible objections which I leave to the reader to discover. There are, however, several broad conclusions we can draw from the above discussion.

First, Dworkin's own view and the possible responses to it highlight some major questions about the connections between a person's interests and experiences, as well as how they relate over time. Any compelling theory of well-being must answer these questions. Second, our discussion of Mrs. Rogoff shows that the kinds of cases that routinely arise in a medical context provide an excellent testing ground for theories of well-being.

But the third, and final, conclusion is perhaps the most important: how we answer the questions raised throughout the discussion – what is the relationship between well-being, authenticity, and autonomy? What is the role of actual experience in determining whether something is good for someone? What is the role of possible experience? What's involved in something being in a person's interest in the first place? – are of far more than theoretical interest. They can profoundly impact how we deal with those we love when they are at their most vulnerable.

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[1] Rather, it might seem that medicine is concerned with a particular *element* of well-being, namely health. Of course, whether "health" is more restricted than "well-being" as a category depends on how one construes the former. The World Health Organization's Constitution (1960), for example, simply defines health as "A state of complete physical, mental and social well-being." Leon Kass (1974) criticizes this conception of health on the grounds that it is far too broad and well beyond the purview of what clinicians should aim for.

[2] What should we say, for example, about so-called "alternative medicine"? Talk therapies? Cosmetic surgery? Are these part of medicine? Or something else altogether? It's even more difficult to know what to say about certain social skills we expect clinicians to have, such as good bedside manner and a certain degree of empathy. Are these "medical tools"?

[3] Veatch specifically mentions hedonism, desire-satisfaction, and objective list theories of well-being.

[4] This case is a slightly modified version of one found in Veatch et al, 2010.

[5] The classic discussion of this idea is in Beauchamp and Childress 2012.

[6] Although for a different view see Thaler and Sunstein (2008) and Conly (2013).

[7] This idea is nicely expressed in popular song. For example, in "My Way" Frank Sinatra sings, "I've lived a life that's full//I traveled each and every highway//And more, much more than this, I did it my way." More recently, Kevin Barnes, the frontman for of Montreal, sings in "The past is a grotesque animal": "At least I authored my own disaster."

[8] This idea is discussed in slightly different terms in Groll 2012.

[9] This is basically the view of Pellegrino 2001.

[10] This is basically Dworkin's view. I say a little more about it below.

[11] There are, however, significant theoretical obstacles to providing a *good-based* account of rights or entitlements. In short, the problem is that there appears to be an unbridgeable conceptual gap between it being good or desirable that S is entitled to X and S actually being entitled to X. This idea is discussed in depth in Darwall 2006.

[12] I defend this idea in Groll (2014). Beauchamp and Childress (2012: 222), think there isn't even a *presumption* in favor of anti-paternalism.

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[13] This quick articulation of what an Advance Directive is glosses over the difference between an *instructional* AD and a *proxy* AD (Brock and Buchanan 1989: 95). The former gives guidance about what should be done in particular situations. The latter says *who* should make decisions for the patient when she is no longer able to make her own decision. Of course, an AD might be both instructional and proxy. My emphasis here is on the instructional part of advance directives (since a proxy AD on its own isn't very useful for the proxy decision maker!)

[14] Dan Brudney comes very close to making this point, but does not suggest folding the substituted judgment standard into the best interest standard as I am doing here.

[15] These, and other issues, are discussed by Brock and Buchanan (1989).

[16] The implicit assumption here is that an AD cannot bind a future self that still has autonomy. This idea is reflected in the very idea of the advance directive which is meant to direct a *surrogate*. But of course a surrogate is only required in cases where the patient does not have the right (because she does not have the ability) to make decisions for herself.

[17] Dwokin does contrast the "integrity-based view of the importance of autonomy" with a welfare-based view (1993: 224), but the welfare-based view he has in mind is one that does not construe integrity, or authenticity, as a *part* of welfare. Given what I said above about how considerations of authenticity should properly be seen as a subset of welfare considerations, I think Dworkin's view is accurately captured by saying that integrity is a fundamental and independently important constituent of well-being.

[18] Dworkin's distinction between critical and "experiential" interests (as he call them) is not as clear as it might be. In some places (and as the name of the interests suggest), it sounds like he thinks that not having experiences as their object is *criterial* for an interest being a critical interest. But in other places, it sounds like the distinction is more about whether the person in question genuinely *values* whatever the object of his interest is or simply idiosyncratically enjoys it. The problem with the first way of making the distinction is that the dedicated hedonist would seem not to have any critical interests.

[19] In other words, Jaworska occupies position 2b in the chart above. Shiffrin (2004) also occupies this position but for different reasons than Jaworska.

[20] Griffin (1988: 13) calls this the experience requirement.

[21] Here is Hawkins' formal articulation of the principle:

> NA says it is a necessary condition of X's being intrinsically good for A at T_1 that either (1) A respond positively to X at T_1 if she is aware of X at T_1 or (2) A be such that she would respond positively to X at T_1 if she were aware of X at T_1 (2014: 527)

[22] This is proposed as a necessary, not sufficient, condition.

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Further Reading

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Jaworska, A. (1999) "Respecting the margins of agency: Alzheimer's patients and the capacity to value," *Philosophy & public affairs*, *28*(2), 105-138. (A wonderfully written and deeply incisive response to Dworkin's views on advance directives and end-of-life decision making).

Veatch, R. (2009) *Patient heal thyself.* New York: Oxford UP. (This is a provocative take on the proper nature of the clinician-patient relationship).

Related Topics

Autonomy and well-being; Experience Requirement; Health; Shape of a Life; Autonomy and Paternalism