Experiential Interests and Proxy Decision-Makers: Dworkin, Dresser, and Decisions on Behalf of the Demented

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Abstract: A major question linked to personal identity is what sorts of interests should be defended on behalf of an incompetent patient, with implications for who best could make proxy decisions on the patient’s behalf. Ronald Dworkin’s distinction between ‘critical’ and ‘experiential’ interests emphasizes the ability to envision one’s overall life as the determiner of competence to determine one’s own interests. He argues that experiential interests — those informed primarily by current experiences like pain or discomfort — are insufficient for the types of decisions we ask competent patients to make. Rebecca Dresser finds more value in such contemporaneous, experiential interests of the demented, insofar as there are degrees of dementia. Plotting aspects of competence along a continuum that can still accommodate some patient preferences offers more personal respect than an all-or-nothing declaration of competence could. Dworkin’s dismissal of experiential interests would endorse inflexible, binding decisions made via advance directive when the patient was competent. Emotionally-uninvested decision-makers such as judges or most doctors are similarly likely to respect past preferences or to insert their own perspectives on what entails the patient’s best interests. Only by combining an intimate understanding of the patient’s life as a whole with an appreciation of the experiential concerns valued by Dresser, can full respect be given to the patient as a person. By appointing what we might call a ‘partner proxy’ when the patient is still competent, he can best hedge his bet of having someone respect both his critical and experiential interests. This paper is a brief section of a dissertation that defends the appointment of an emotionally-invested health care proxy decision-maker, over such professionals as doctors or attorneys and over government standards, for these and other reasons.

A major question linked to personal identity is what sorts of interests should be defended on behalf on an incompetent patient. To clarify the objectives presumed in defending one’s personal interests, Ronald Dworkin distinguishes between ‘critical’ and ‘experiential’ interests. When people define a good life, it is through ideas we hold intuitively and in the background; we do not reexamine them except in moments of special crisis or drama. But these background ideas are always there, guiding decisions and choices…. It is absolutely crucial to notice, however, that these various opinions and convictions… are critical in the sense that they concern what makes a life successful rather than unsuccessful…. They are not, that is, opinions only about how to make life pleasant or enjoyable minute by minute, day by day.\(^2\)

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\(^1\) This paper is a brief section of one chapter from a dissertation that defends the appointment of emotionally-invested health care proxy decision-makers over such professionals as doctors and attorneys or government standards.

Critical interests involve the broad perspective of analyzing one’s life as a whole, which he connects to competence.

Competence in the overall sense presupposed by the right to autonomy… means, not the capacity to grasp particular information or solve particular problems, but the more diffuse and general capacity for integrity: the capacity to see and evaluate particular decisions in the structured context of an overall life organized around a coherent conception of character and conviction.\(^3\)

Dworkin believes that mentally incapacitated patients have entered a later stage of continuous personhood—rejecting, as he does, the necessity of psychological continuity for personal identity. If self-determination was important for a person when competent, then it remains important as his life draws to a close, as well. After a life of autonomous decision-making, in Dworkin’s view our critical interests require the patient to determine how his life should end. Only then can the picture of the life-as-a-whole be complete. “If we accept the integrity view” he proposes, by which the right to autonomy exists in proportion to the patient’s ability to maintain relatively continuous and consistent choices, then

we will be drawn to the view that precedent autonomy must be respected, because it seems essential to someone’s control of his whole life that he be able to dictate what will happen to him when he becomes incompetent.\(^4\)

Because the incompetent lack the capacity to assess the stages of their lives-as-a-whole, Dworkin believes the best way of respecting autonomy is to rely on prior choices for how best to face the end of one’s life.

Experiential interests are based on experience, but specifically the contemporaneous experience of what it is like to feel pain and endure a particular event.

Everyone has what I shall call experiential interests. We all do things because we like the experience of doing them: playing softball, perhaps, or cooking or eating well… or walking in the woods in October, or listening to The Marriage of Figaro…. Pleasures like these are essential to a good life—a life with nothing that is marvelous only because of how it feels would be not pure but preposterous. But the value of these experiences, judged by one, depends precisely on the fact that we do find them pleasurable or existing as experiences…. Of course, a great many things are bad as experiences, too: pain, nausea, listening to most politicians. We take pains to avoid these experiences, and sometimes we dread them.\(^5\)

Experiential interests, however, he sees as incidental to life, which “is not a worse life to have lived” because of the pain or pleasures a particular individual has endured. Dworkin claims that experiential interests are like preferences that do not represent the life as a whole, compared to the more serious critical interests that are indicative of substantial life values. Although Dworkin

\(^3\) Dworkin (1986, 10).
\(^4\) Ibid. (11).
\(^5\) Dworkin (1993, 201).
does not associate emotions *per se* with experiential interests, emotional response would certainly be related. The presumptions some may have made that Dax Cowart and others were responding out of an intensified aversion to pain—a direct reaction to their immediate experiences—might be an example of experiential interests.

If we accepted a person’s choices based purely on their experiential interests, it would be at the expense of the bigger picture critical interests that in Dworkin’s view more accurately engage the essence of autonomy. We might say that critical interests require a sort of stepping back to assess the life from a more objective viewpoint than can be offered by experiential interests. With the obvious exception of masochists, we all have an interest in not feeling pain, but such experiential concerns about discomfort (recovery from surgery, the side effects of chemotherapy, etc.) are in our critical interests, as well, insofar as those experiences contribute to an overall picture of quality of life.

For some patients it is nearly impossible to ascertain what their overall perspectives would be, such as patients who have never been considered ‘competent.’ Joseph Saikewicz was a 67-year-old, severely mentally retarded man who when diagnosed with leukemia had the option of receiving chemotherapy. Because he was unable to understand his situation or communicate his preferences—assuming he was capable of discerning preferences—a court-appointed guardian was his proxy decision-maker. The 1977 ruling indicates an acknowledgement of his current and future interests, finding it necessary “to ascertain the incompetent person’s actual interests and preferences.” Dworkin would agree with this portion of the decision, insofar as it attempts to appeal to a ‘substituted judgment’ model of decision-making wherein the competent person’s (presumed) preferences prevail. Of course, it is not possible to rely on substituted judgment for patients who at no time were competent, because there is no precedent autonomy, previously-stated wishes, or reasonable estimation of the patient’s competent desires upon which to base such decisions.

The ruling continues:

… the decision in cases such as this should be that which would be made by the incompetent person, if that person were competent, *but taking into account* the present and future incompetency of the individual as one of the factors which would necessarily enter into the decision-making process of the competent person.

Because Saikewicz, institutionalized for 53 years, had no precedent autonomy upon which to rely for treatment preferences, the court looked instead to the ‘best interests’ of the patient. Emphasizing the incompetent patient’s right to refuse treatment, the appellate justices ultimately

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6 Masochists, too, might be emphatic about assurances of their personal autonomy; even voluntary submission—distinct from or in association with masochism—requires the initial consent to a dominant arrangement. See Soble (1998, 65). Also, pain is not always considered to be a bad thing. Many women voluntarily choose to experience natural childbirth. Men and women voluntarily run marathons, similarly subjecting themselves to both physical and emotional strain, with the goal of achieving something positive.


8 See later sections of this chapter.

decided that the side effects of treatment were not worth the possible year that could be added to his life. What is significant is that the patient’s “present and future incompetency” contributed to the court’s assessment of his overall interests; that is, the patient’s current and future experiential interests affected the decision. Saikewicz was cognizant enough to experience pain but incompetent in his understanding of the reasons. If we should take into account the contemporaneous experience for those with low intelligence, we should also account for the contemporaneous experiences of others who are similarly cognitively impaired.

For Dworkin, the solution to maximizing autonomy when incompetence has supplanted rational decision-making is to refer back to one’s interests as determined while still competent, when possible. Olick agrees, explaining that “to disregard the patient’s prior wishes is to violate the patient’s intrinsic worth, even if the patient is not aware that his or her prior wishes are being ignored.” Awareness is not the issue, clearly; Olick and Dworkin are concerned about causing genuine harm to the patient in devaluing his autonomous wishes. Relying on previous requests, however, is to forsake the value of current experiential interests. A benevolent acquaintance proxy retains the competence the patient has lost and remains capable of assessing the patient’s interests from a critical point of view—as well as experiential, insofar as the proxy is able to imagine the patient’s experience.

Olick compares a living will to a last will and testament, not for the purpose of asserting that interests may survive death, but because he mistakenly believes that the motivation for denying precedents (or prospective) autonomy is that people can get away with something:

[Denying self-determination] ‘permits obliteration of an incompetent’s panoply of rights merely because the patient could no longer sense the violation of those rights.” This straightforward statement of prospective autonomy has well-established analogues elsewhere in the law. For example, the law respects a person’s testamentary dispositions and estate plans even though the testator will never know whether his or her bequests have been carried out. Ignoring the decedent’s chosen means for distributing personal assets would offend his or her personal dignity.

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10 See my discussions of substituted judgment and best interests later in this chapter. See also my comments on mental illness.
11 This decision also emphasized the justices’ disagreement with the Quinlan case in affording “the patient’s guardian, family, attending doctors, and hospital ‘ethics committee’” decision-making authority in lieu of the court. In the Massachusetts state appellate court’s opinion, the court is better positioned to “represent the ‘morality and conscience of our society’” than would be alternative proxies. Superintendent of Belchertown State School v. Saikewicz, 373 Mass. 728 (1977): 758-759.
12 Olick (2001, 13).
13 Goldie has much to say about such possibilities; see Chapter 4 on understanding the emotions of others. David Hershenov has pointed out an interesting question in whether or not the pre-dementia interests survive the destruction of the part of the brain that dementia involves (so that the physical basis of such interests would be gone). If those interests are gone, we lose the basis for precedent autonomy, in which event the proxy who was given discretionary authority might be the more appropriate choice over a specific living will—except that the same interests that can be presumed to have dissipated with dementia are what influenced the pre-dementia choice of a proxy.
14 Cantor (1977), as quoted in Olick (2001, 13).
15 Olick (2001, 13).
There are several problems with his analysis. Except in the case of malevolent situations where someone stands to benefit personally from the patient’s death, the presumption that overriding earlier wishes can only be motivated by Gyges-style deception is unfair (and it turns out, misguided, as a closer reading of the quote explains, below). There are legitimate reasons to override explicit medical wishes, such as unanticipated complications, vague or ambiguous directives, or new treatments that might not have been available when the patient last considered his options. The denial of precedent autonomy does not necessarily entail overriding explicit wishes. Precedent autonomy recognizes the voice of the competent while neglecting the incompetent patient’s interests; that itself is a reason to question precedent authority, particularly if critical interests are defined as overseeing the whole life. This concept will be explored further momentarily.

Dresser and Jaworska find more value in the contemporaneous, experiential interests of the demented than Dworkin or Olick are willing to accommodate. Through several real-life examples, Jaworska asks this question: “Should we, in our efforts to best respect a patient with dementia, give priority to the preferences and attitudes this person held before becoming demented, or should we follow the person’s present preferences?”16 Especially relevant is this story:

Mr. O’Connor was a deeply religious man for whom thoughts of taking his own life or of withholding lifesaving measures for whatever reason were completely unacceptable. In his seventies he developed Alzheimer’s disease. He lost his ability to do many of the things he used to enjoy, such as playing the piano; soon he could no longer take care of himself. With the loss of capacity for complex reasoning, most of his religious beliefs gradually faded away. Then came a terrible emotional blow: the death of his wife. He has now begun saying that he does not want to go on, that he does not want to live. His daughters no longer know what would be best for him: Should they make decisions for him based on his earlier life-philosophy or should they respect and take seriously his current wishes?17

If religious views (or other perspectives) help define one’s preferences but are subject to fade away with one’s mental capacity, this gives credence to Buchanan’s problem with identity persistence and Dworkin’s concern that loss of competence sacrifices the ability to assess critical interests. In Mr. O’Connor’s case, his life values seem to have evaporated.18

We commonly understand depression, stress, and disruption of one’s environment to be traumatic for the elderly, particularly after having suffered the loss of a spouse. Noël et al. (2004) found depression in the elderly to have even more damaging consequences than certain physical

17 Ibid. (107).
18 It is possible, of course, for a person’s interests to have been lost without ramifications for the persistence of the individual. If critical interests prevail, as Dworkin proposes, then Mr. O’Connor’s current experiential preferences should have no bearing on his decisions that were consistent with what his daughters understood of his life values. If depression constitutes incompetence in his case, they would have grounds to ignore his current requests. But if weight is given to his current experiences as elements in the formula that sums his life values, the decision is not so easy.
ailments. Psychosocial factors were likely compromising Mr. O’Connor’s health, but post-bereavement suicidal depression usually improves over time. “About a quarter of widows and widowers will experience clinical depression and anxiety during the first year of bereavement; the risk drops to about 17% by the end of the first year and continues to decline thereafter.”19 If Mr. O’Connor’s daughters would wait until after a period of bereavement, they might find his requests to die to have subsided, or, if he still insisted, then they could make a determination having given him an appropriate amount of time to grieve his loss. This presumes that such a waiting period would be free of pain for him—a tough standard to achieve when his current complaints reflect emotional strife. 20 The issue raises a complicated question about competence and abiding by someone’s direct wishes. How much of a wish to forgo medical intervention reflects the confused meanderings of Alzheimer’s, how much can be attributed to temporary depression, and how much weight should be accorded to requests that would be respected if not blurred by such complicating diagnoses?

In Dresser’s view there are still meaningful insights we might glean from the experiences of the demented, and as such, we should listen to their current requests. Two reasons emerge:

When competent people make judgments on the conditions under which they desire to live and die, their judgments reflect their existing capacities and the activities that make their present lives worth living. Decisions about the future health care that will advance their interests are inextricably intertwined with their current conceptions of the good. 21

Relying on precedent autonomy, as Dworkin advocates, requires deference to the person’s conceptions of value as defined during the competent, and comparatively healthy, period of his life. The conceptions of value that affect such perspectives are no doubt influenced by the experiential interests of that healthier time. Priorities can change when that health falters, however. Taking into account the altered mental state and pessimism that might result from the experience of pain, Dresser seems to be saying there is still the current perspective of the patient that contributes to the life-long narrative of his critical interests.

In fairness to Dworkin, his ‘integrity view’ of the right to autonomy offers the possibility of accommodating some of Dresser’s concerns, depending on the severity of incompetence.

When a mildly demented person’s choices are reasonably stable, reasonably continuous with the general character of his life before he became demented, and inconsistent only to the rough degree the choices of fully competent people are, he can be seen as still in charge of his life, and he has a right to autonomy for that reason. But if his choices and demands, no matter how firmly expressed one by one, systematically contradict one another, or reflect no coherent character whatever, or perhaps even if they are radically discontinuous with the values of his previous life, then he has presumably lost the capacity that it is the point of autonomy to protect. Recognizing a continuing right to autonomy for him would be pointless. So he has no right that his choice of a guardian, or

19 Jacobs (1993), as quoted in Parkes (1998, 856)
20 See also McHorney and Mor (1988); Rebollo et al. (2005).
choices about the use of his property, or about his medical treatment, be respected for reasons of autonomy.22

The more important question, however, (at least for Dresser) seems to be not whether the patient’s autonomy remains intact but what aspects of his experience can still be taken to contribute to decisions about his medical care. That is, even if full autonomy is no longer an issue, there may be experiential indicators the patient is capable of expressing in some way, which can influence the decisions of his proxy. Decisions in such a situation would not wholly be the patient’s, because his incompetence renders him incapable of comprehending the full complexity of the scenario (and because, as Dworkin notes, if the function of autonomy is to protect capacity, autonomy no longer accomplishes anything). But to the extent that he is still capable of experience—and those around him capable of ascertaining the quality of that experience—even an incompetent patient could have something to offer towards decision-making on his own behalf.

By excluding the voice of the incompetent patient, we bring bias to the equation. If the perspective of the incompetent patient is limited by his plight, we should say the same of competent perspectives—at least insofar as experiential interests are concerned. Granting that competence is required for the stepped-back assessment requisite to critical interests, the competent self is also subject to influence by his current experiences, and his conceptions of good affected accordingly. By removing all decision-making contributions from the incompetent patient, we discount not just his impaired assessment of critical interests and values, but his experiential considerations, as well.

Dresser offers a second reason for listening to current requests: there are “different levels and kinds of cognitive impairments” that are not accounted for with an all-or-nothing determination of capacity.23 She advocates for a more educated population of those completing advance directives, so that they might consider “the effects dementia can have on a person’s subjective awareness and the need for people to think not only about how they might respond to procedures as they are now, but also” should their cognitive capacity be compromised.24

From a medical perspective, the fact is there are details about consciousness and mental activity that we simply do not yet understand. A recent study identified cognitive functioning in four of 23 PVS patients—two of whom showed “no voluntary behavior [that] could be detected by means of clinical assessment.”25 In other words, the MRI detected voluntary responses and indications of awareness that were not apparent through typical means of bedside testing.26 As with most research findings that threaten to shatter established presumptions and protocols, the

22 Dworkin (1986, 9).
24 Ibid.
25 Monti et al. (2010, 579). See also Owen et al. (2006).
26 There is a danger in presuming that the presence (or absence) of brain activity could extrapolate to competence (or incompetence), as Foley implies in his comments on emotions. “We too often assume that the absence of emotional display means that no emotion is being experienced. We too often assume that because communication is absent, internal mental process has stopped.” Foley (1992), as cited in Callahan (1995, 27). Research evolves, but also the experience varies by patient.
MRI studies have their critics. If proven to be a legitimate means of communication with otherwise non-responsive patients, precedent autonomy may no longer be relevant. As one doctor puts it, “The first and obvious use of mental signaling by means of functional MRI could be to preserve the patient’s autonomy by querying his or her wishes regarding continued medical care.”

It would be unfair to call existing standards for competence ‘arbitrary,’ as technological diagnostic aids are continuously improving. It would also be unwise to presume that distinctions for capacity are so clear-cut (and our measurement devices so static) as to assure that an incompetent patient has nothing worthwhile to say. What this means is not that we should resort to seeking participation from a patient whose competence is clearly impaired—although certainly, to the degree communicable, his experiential interests should be considered. The import for my position is that Dworkin’s solution of exclusive reliance on precedent autonomy is flawed also for the reason that it devalues the mental activity and experiences of the demented.

Jaworska agrees that the experiences of even the so-identified ‘incompetent’ should not be so hastily disregarded. She finds glimmers of capacity in simple sentences like, “Here you can see Alzheimer’s at work” (spoken by an Alzheimer’s patient)—capacity sufficient for the patient to speak not just towards his own experiential interests, but also to show some appreciation of what he has lost. It is precisely this ability to assess one’s life as a whole and to identify value, such as in retaining one’s memories, that critical interests are all about. It is not uncommon for patients in varying states of dementia to recall details of events from early in their lives, yet be unable to recognize present-day friends and family. The connection to that history indicates that there remains some essential aspect of the same person in the body that now experiences diminished capacity. If we consider that youthful memories are most of what survive then perhaps Dworkin would be right to defer to precedent autonomy; clearly the cognitive capacities of a demented patient lack consistency with the patient as he used to be. A personality cannot be reduced to memories alone, however, so neglecting the current experiences of the patient neglects an essential aspect of who he is, as well. Dworkin says, we fail to take seriously both the autonomy and the well-being of a demented patient unless we adhere strictly to the patient's earlier wishes, wishes that originated when she was still capable of acting autonomously and still able to judge what was required for her overall well-being.

Dresser says listen to the current wishes. Jaworska proposes a mid-ground approach that assesses autonomy not according to the patient’s ability to reason but to his capacity to assess value and to experience pleasure and pain.

That someone can value something does not necessarily make him capable of assessing his overall interests, nor of making appropriate decisions that directly affect his well-being. But discrediting the incompetent patient’s experiential interests forces reliance on precedent

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27 Ropper (2010, 649).
autonomy, which may not accurately reflect what would have been his preferences and interests were he capable of conveying them. Dworkin interprets critical interests as reflecting on and assessing what is best for one’s life as a whole and deems the living will as the best means of anticipating that. Because awarding sway to previously-held beliefs and desires cuts off any possibility of considering current experiential interests, Dresser and Jaworska have exposed a flaw in the reliance on living wills. The opportunity arrives for proxy decision-making as an alternative defender of what might be contemporary wishes.

31 In an exploration of personal utility, Hausman (1995) similarly notes that accomplishing the satisfaction of one’s preferences is not necessarily the same as having achieved well-being.
Works Cited


