

Personhood, Critical Interests, and the Moral Imperative of Advance Directives in Alzheimer's Cases

Samuel Dale

ABSTRACT

The moral authority of advance directives (ADs) is contingent on one of two metaphysical concepts of personhood common in the West. The first tradition originated in the ideas of David Hume and Jeremy Bentham. Hume asserts that the idea of personhood is socially fabricated and that we are nothing more than “bundles” of sensations.” Bentham is famous for developing a utilitarian ethical approach predicated on Hume’s reductionist theory, a person who asserts the morally right act is the one which maximizes pleasure and minimizes pain. The second metaphysical tradition, which grants moral authority to ADs, stems from the work of John Locke and John Stuart Mill. Locke conceived of persons as beings that are “rational, concerned, continuing, and self-conscious,” and Mill understood that persons act in a manner that maximizes their holistic goods, not only the sum of their experience of pleasure or pain. Dworkin’s framework of critical interests and Mill’s version of Utilitarian ethics support the moral authority of precedent autonomy by defending the narrative quality of life, the important pursuit of higher pleasures, and a dignified characterization of humanity.

Keywords: Advance directive, personhood, utilitarian, Dworkin, Bentham, Hume

INTRODUCTION

The moral authority of advance directives (ADs) is contingent on one of two metaphysical concepts of personhood common in the West. The first tradition originated in the ideas of David Hume and Jeremy Bentham. Hume asserts that the idea of personhood is socially fabricated and that we are nothing more than “bundles” of sensations.”¹ Bentham is famous for developing a utilitarian ethical approach predicated on Hume’s reductionist theory, a person who asserts the morally right act is the one which maximizes pleasure and minimizes pain.² The second metaphysical tradition, which grants moral authority to ADs,

stems from the work of John Locke³ and John Stuart Mill.⁴ Locke conceived of persons as beings that are “rational, concerned, continuing, and self-conscious,”⁵ and Mill understood that persons act in a manner that maximizes their holistic goods, not only the sum of their experience of pleasure or pain.⁶

In the 1980s, this metaphysical divergence on personhood materialized in a debate between Ronald Dworkin, whose reasoning parallels that of Locke and Mill, and Rebecca Dresser, who employs an approach that comports with that of Hume and Bentham. The debate focused on the real case of an incompetent patient named Margo who developed early-onset Alzheimer’s and, despite her condition, “or maybe somehow because of it,”⁷ led a remarkably cheerful life. She no longer identified with the provision in her AD to forgo any life-sustaining medical treatment after she could no longer recognize her loved ones. When she contracted pneumonia, an ethical dilemma emerged as her prior preferences recorded when she was competent conflicted with her contemporary preferences regarding her end-of-life care. Dworkin argues that Margo’s precedent autonomy, *i.e.*, her past ability to govern her future self through a directive and the corresponding obligation of her current self to follow the directive, has moral authority over her current treatment, but Dresser objects, asserting that because Margo is now a “new person”⁸ the AD is no longer relevant.⁹ In this essay, I argue that precedent autonomy morally authorizes ADs when dementia renders patients medically incompetent because it respects their dignity as persons, not merely pleasure-seeking creatures.

The Case: Margo, ‘the Happy Alzheimer’s Patient’

In *Margo’s Logo*, Dr. Andrew Firlik describes the life of an Alzheimer’s patient he visited frequently while interning in gerontology.¹⁰ Because she developed the disease at a relatively young age, Margo had virtually no physiological problems and lived a “carefree” life consisting of flipping through mystery novels and painting the same image every day during art class.¹¹ Firlik describes her life almost romantically, commenting that “there is something graceful about the degeneration her mind is undergoing, leaving her carefree, always cheerful.”¹² He does not mention Margo’s early stages of dementia which were perhaps characterized by confusion, anxiety, and existential fear, as is often the case with diseases that erode mental capacity.¹³ Still, arguably in her current state Margo is happy and therefore should be given non-invasive treatments, like oral antibiotics, to extend her life if she contracts pneumonia. The argument to adhere to her previous wishes against such life-prolonging treatments may seem cruel. However, Dworkin argues that to *ignore* her AD would compromise her autonomy and dignity and constitute the greater cruelty.

Dworkin *contra* Dresser

Dworkin uses the framework of experiential and critical interests to defend the moral authority of precedent autonomy. Experiential interests roughly parallel Bentham’s conception of pursuing pleasure and avoiding pain, whereas critical interests are focused on the actions that lend “genuine meaning and coherence to our lives.”¹⁴ Critical interests comport with Locke’s valuing rationality and with Mills’ appreciation of the big picture taken holistically. Dworkin’s conception of personhood emphasizes our pursuit of critical interests over and above our pursuit of experiential interests, indicating that there is a moral superiority to critical interests. For example, parents willingly give up sleep to sustain the critical interest of raising children and athletes endure pain to improve their odds of victory. The pursuit of critical interests lends genuine meaning to our lives. In contrast, a life characterized by the constant pursuit of experiential interests is often meaningless.

Dworkin's dichotomy of interests grounds his view of precedent autonomy because the critical interests encoded in ADs represent the "whole person"¹⁵ - all the relationships, values, and narrative richness of personhood before the onset of late-stage dementia. If we ignore the AD, we disregard the autonomy of Margo's "whole person" in favor of her immediate preferences. Dworkin's view of autonomy argues that we should honor Margo's precedent autonomy even if we believe it conflicts with her best interest because persons have the right to act "out of a distinctive sense of their own character"¹⁶ in writing the narrative of their life. Ignoring her AD would be "an unacceptable form of moral paternalism"¹⁷ because it effectively authors a conclusion to the story of Margo's life that she explicitly wished to avoid, ignoring the strongest living articulation of her autonomy.

Dworkin further argues the moral authority of Margo's precedent autonomy through the principle of beneficence, the ethical obligation to promote the patient's welfare.¹⁸ It would be cruel to subject Margo to a chapter of life that she did not want to lead, a life that conflicts with her critical interests, even if she no longer remembers those interests. Thus, to genuinely act in the best interest of the patient, the doctor must adhere to her competent conception of what is best for her "whole person", not merely her current experiential interests.

Dresser argues that when patients with incurable dementia lead enjoyable lives, we should ignore their previous wishes. She raises an epistemic and a moral objection to Dworkin's argument in favor of precedent autonomy. Her epistemic argument points out that when she wrote the AD, Margo did not know what quality her life would have with dementia, therefore carrying out a preference based on such limited information would not respect autonomy.¹⁹ This argument fails to recognize that individuals make decisions all the time without knowledge of the outcome, so to disregard Margo's AD because she did not know whether her experiential interests would be fulfilled is unjustifiably paternalistic. Furthermore, Dresser implicitly asserts that if Margo were to know the quality of her life with dementia in advance, she would not have authored the same AD. However, this removes the possibility of Margo autonomously prioritizing her critical interests regardless of the experiential outcomes. Margo likely did know that people can (and often do) lead enjoyable lives with dementia yet she still chose to word the AD to not prolong life once her critical interests could not be satisfied.

Dresser's moral argument against precedent autonomy contends that because Margo can no longer recognize her previous preferences, she is a metaphysically distinct person, and that the AD is therefore not applicable. Dresser claims that the "drastic psychological alteration that has occurred" to Margo has "produce[d] a new person."²⁰ This metaphysical assertion carries significant moral weight. If we consider Margo the Alzheimer's patient to be a distinct individual from the woman who wrote the AD, then executing an AD is akin to sentencing an innocent person to death. However, Dresser's claim is predicated on the flawed assertion that dramatic psychological changes over time produce an entirely new individual. Children, for example, undergo substantial psychological changes from infancy to adolescence, yet we regard them as continuous individuals.²¹ Ultimately, we must consider *persons* rather than pleasure-seeking subjects to be the locus of autonomous decision making, therefore moral authority is granted to precedent autonomy in cases like Margo's.

Locke's emphasis on rationality also supports following the AD. Personal identity, in Locke's view, is meaningfully linked to persistence over time and the ability to rationally self-reflect – abilities which Margo presently lacks. He writes in *An Essay Concerning Human Understanding*, "a thinking intelligent Being, ... has reason and reflection, and can consider itself as itself, the same thinking thing in different times and places."²² From this diachronic view of identity, Locke characterizes persons as *agents*. Margo, in contrast,

no longer has these abilities and has lost her sense of personhood and agency. It is only through our ability to self-reflect and project our values onto the current situation that we can be said to be persons. Dresser makes an erroneous metaphysical assertion in saying that the late-stage Alzheimer's patient is a new person due to "substantial memory loss and other psychological changes." It is exactly these changes which rob late-stage Alzheimer's patients of their personhood.

Utilitarianism and Advance Directives

The two founding figures of Utilitarian ethics, Jeremy Bentham and John Stuart Mill, agreed that the 'right' action is the one which maximizes utility in a given situation, but they disagreed on what sorts of consequences constitute utility. Bentham focused merely on the *quantity* of pleasures, asserting that the right action would result in the most favorable balance between pleasure and pain.²³ Pursuant to this hedonistic calculus which disregards the quality of pleasure, the right action is to ignore Margo's AD by providing the life-saving treatment. This would be the most ethical choice according to Bentham because it produces a greater sum of pleasure than her death, regardless of her prior critical interests.

Hume's view of experiences also overvalues pleasure as opposed to cognition. When applied to Margo, who essentially experiences a bundle of sensations without the ability to rationally appreciate them, Hume's viewpoint would negate the AD vis a vis Bentham's calculus. Yet, Margo's AD concerned ranking the characteristics of life that would justify prolonging it which included experiences like remembering one's narrative and having meaningful relationships with friends and loved ones. These values transcend the immediate sense data that Bentham factors into the utilitarian sum. The philosophies of Hume and Bentham not only impede dignity, and negate autonomy, they impose a limited, outside view on what persons value.

Mill criticized Bentham's approach to utilitarianism because it was indiscriminate in its valuation of different pleasures, implicitly leading to the conclusion that distinctly human pleasures "of the intellect, of the feelings and imagination and of the moral sentiments" are no more valuable than animal pleasures "of mere sensation."²⁴ In Mill's view this degrades the moral status of humans. If our pleasures are no different, then Bentham suggests that our moral status is equivalent to that of animals, which is clearly problematic. In an example of the flaws of utilitarian applications, in a purely quantitative utilitarian calculus, the life of an immortal oyster is more desirable after a certain amount of time than the life of the jovial and accomplished composer, Joseph Hayden.²⁵ If given the choice, I suspect an overwhelming majority of people would prefer to live as a human being that feels pain over an animal that feels only simple pleasures.

Even though human life is often characterized by stress, uncertainty, and vulnerability, the profound heights of the human condition justify life according to Mill's philosophy. Mill's utilitarianism focused on the *quality* rather than the quantity of pleasures, and thus he would argue that following Margo's AD will result in the outcome with the greatest utility because she is no longer capable of pursuing higher pleasures.²⁶ Her current existence is characterized only by *experiential* pleasures, which according to Mill, is not a life worth living.²⁷

CONCLUSION

A consequence of the reductionist view of personhood endorsed by Hume, Bentham, and Dresser is an erroneous moral equivalence between animals and humans and a disregard for human dignity. Dworkin's framework of critical interests and Mill's version of Utilitarian ethics support the moral authority of

precedent autonomy by defending the narrative quality of life, the important pursuit of higher pleasures, and a dignified characterization of humanity.

¹ Hume, D. & P. H. Nidditch (ed.). (1978). *A Treatise of Human Nature*. Oxford: Clarendon Press. Hume posits a distinct ontology of self: "each of us is nothing but a bundle or collection of different perceptions that follow each other enormously quickly and are in a perpetual flux and movement" (Hume, 1978, p.131)

² Bentham, J. (1789, 1907). *An Introduction to the Principles of Morals and Legislation*. Oxford: Clarendon Press.

³ Locke, J. (1948). *An essay concerning human understanding*, 1690.

⁴ Mill, J. S. (1861, 1998). *Utilitarianism*, Roger Crisp (ed.), Oxford: Oxford University Press.

⁵ Rich, B. A. (1997). Prospective autonomy and critical interests: A narrative defense of the moral authority of advance directives. *Cambridge Quarterly of Healthcare Ethics*, 6(2), 138-147. Chicago

⁶ Mill, J. S. (1861, 1998). *Utilitarianism*, Roger Crisp (ed.), Oxford: Oxford University Press.

⁷ Firlirk, A. D. (1991). Margo's logo. *JAMA*, 265(2), 201-201.

⁸ Dresser, R. (1995). Dworkin on dementia: elegant theory, questionable policy. *Hastings Center Report*, 25(6), 32-38.

⁹ Dresser, R. (1995). Dworkin on dementia: elegant theory, questionable policy. *Hastings Center Report*, 25(6), 32-38.

¹⁰ Firlirk, A. D. (1991). Margo's logo. *JAMA*, 265(2), 201-201.

¹¹ Firlirk, A. D. (1991). Margo's logo. *JAMA*, 265(2), 201-201.

¹² Firlirk, A. D. (1991). Margo's logo. *JAMA*, 265(2), 201-201.

¹³ Menzel, P. T., & Steinbock, B. (2013). *Advance Directives, Dementia, and Physician-Assisted Death*. *The Journal of Law, Medicine & Ethics*, 41(2), 484-500.

¹⁴ Dresser, R. (1995). Dworkin on dementia: elegant theory, questionable policy. *Hastings Center Report*, 25(6), 32-38.

¹⁵ Dworkin, R. (1994). Life's dominion. An argument about abortion, euthanasia and individual freedom. *New York: Books V*, 69-101.

¹⁶ Dworkin, R. (1994). Life's dominion. An argument about abortion, euthanasia and individual freedom. *New York: Books V*, 69-101.

¹⁷ Dworkin, R. (1994). Life's dominion. An argument about abortion, euthanasia and individual freedom. *New York: Books V*, 69-101.

¹⁸ Dworkin, R. (1994). Life's dominion. An argument about abortion, euthanasia and individual freedom. *New York: Books V*, 69-101.

¹⁹ Dresser, R. (1995). Dworkin on dementia: elegant theory, questionable policy. *Hastings Center Report*, 25(6), 32-38.

²⁰ Dresser, R. (1995). Dworkin on dementia: elegant theory, questionable policy. *Hastings Center Report*, 25(6), 32-38.

²¹ Rich, B. A. (1997). Prospective autonomy and critical interests: A narrative defense of the moral authority of advance directives. *Cambridge Quarterly of Healthcare Ethics*, 6(2), 138-147. Chicago

²² Locke, J. (1948). *An essay concerning human understanding*, 1690.

²³ Bentham, J. (1789, 1907). *An Introduction to the Principles of Morals and Legislation*. Oxford: Clarendon Press.

²⁴ Mill, J. S. (1861, 1998). *Utilitarianism*, Roger Crisp (ed.), Oxford: Oxford University Press.

²⁶ Mill, J. S. (1861, 1998). *Utilitarianism*, Roger Crisp (ed.), Oxford: Oxford University Press.

²⁷ Mill, J. S. (1861, 1998). *Utilitarianism*, Roger Crisp (ed.), Oxford: Oxford University Press.