Dworkin on Dementia: Elegant Theory, Questionable Policy

Rebecca Dresser

In his most recent book, Life’s Dominion: An Argument about Abortion, Euthanasia, and Individual Freedom, Ronald Dworkin offers a new way of interpreting disagreements over abortion and euthanasia. In doing so, he enriches and refines our understanding of three fundamental bioethical concepts: autonomy, beneficence, and sanctity of life. It is exciting that this eminent legal philosopher has turned his attention to bioethical issues. Life’s Dominion is beautifully and persuasively written; its clear language and well-constructed arguments are especially welcome in this age of inaccessible, jargon-laden academic writing. Life’s Dominion also is full of rich and provocative ideas; in this article, I address only Dworkin’s remarks on euthanasia, although I will refer to his views on abortion when they are relevant to my analysis.

Professor Dworkin considers decisions to hasten death with respect to three groups: (1) competent and seriously ill people; (2) permanently unconscious people; and (3) conscious, but incompetent people, specifically, those with progressive and incurable dementia. My remarks focus on the third group, which I have addressed in previous work,2 and which in my view poses the most difficult challenge for policymakers.

I present Dworkin’s and my views as a debate over how we should think about Margo. Margo is described by Andrew Firlik, a medical student, in a Journal of the American Medical Association column called “A Piece of My Mind.”3 Firlik met Margo, who has Alzheimer disease, when he was enrolled in a gerontology elective. He began visiting her each day, and came to know something about her life with dementia.

Upon arriving at Margo’s apartment (she lived at home with the help of an attendant), Firlik often found Margo reading; she told him she especially enjoyed mysteries, but he noticed that “her place in the book jumped randomly from day to day.” “For Margo,” Firlik wonders, “is reading always a mystery?” Margo never called her new friend by name, though she claimed she knew who he was and always seemed pleased to see him. She liked listening to music and was happy listening to the same song repeatedly, apparently relishing it as if hearing it for the first time. Whenever she heard a certain song, however, she smiled and told Firlik...

Rebecca Dresser

that it reminded her of her deceased husband. She painted, too, but like the other Alzheimer patients in her art therapy class, she created the same image day after day: "a drawing of four circles, in soft rosy colors, one inside the other."

The drawing enabled Firlik to understand something that previously had mystified him:

Despite her illness, or maybe somehow because of it, Margo is undeniably one of the happiest people I have known. There is something graceful about the degeneration her mind is undergoing, leaving her carefree, always cheerful. Do her problems, whatever she may perceive them to be, simply fail to make it to the worry centers of her brain? How does Margo maintain her sense of self? When a person can no longer accumulate new memories as the old rapidly fade, what remains? Who is Margo?

Firlik surmises that the drawing represented Margo's expression of her mind, her identity, and that by repeating the drawing, she was reminding herself and others of that identity. The painting was Margo, "plain and contained, smiling in her peaceful, demented state."

In Life's Domains, Dworkin considers Margo as a potential subject of his approach. In one variation, he asks us to suppose that years ago, when fully competent, Margo had executed a formal document directing that if she should develop Alzheimer's disease... she should not receive treatment for any other serious, life-threatening disease she might contract. Or even that in that event she should be killed as soon as and as painlessly as possible. (p. 226)

He presents an elegant and philosophically sophisticated argument for giving effect to her prior wishes, despite the value she appears to obtain from her life as an individual with dementia.

Dworkin's position emerges from his inquiry into the values of autonomy, beneficence, and sanctity of life. To understand their relevance to a case such as Margo's, he writes, we must first think about why we care about how we die. And to understand that phenomenon, we must understand why we care about how we live. Dworkin believes our lives are guided by the desire to advance two kinds of interests. Experiential interests are those we share to some degree with all sentient creatures. In Dworkin's words:

We all do things because we like the experience of doing them: playing softball, perhaps, or cooking and eating well, or watching football, or seeing Casablanca for the twelfth time, or walking in the woods in October, or listening to The Marriage of Figaro, or sailing fast just off the wind, or just working hard at something. 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 profligate. (p. 201)

But Dworkin deems these interests less important than the second sort of interests we possess: what Dworkin argues that we also seek to satisfy, our critical interests, which are the hopes and aims that lend genuine meaning and coherence to our lives. We pursue projects such as establishing close friendships, achieving competence in our work, and raising children, not simply because we want the positive experiences they offer, but also because we believe we should want them, because our lives as a whole will be better if we take up these endeavors.

Dworkin admits that not everyone has a conscious sense of the interests they deem critical to their lives, but he thinks that "even people whose lives feel unplanned are nevertheless often guided by a sense of the general style of life they think appropriate, of what choices strike them as not only good at the moment but in character for them" (p. 202). In this tendency, Dworkin seem us aiming for the ideal of integrity, seeking to create a coherent narrative structure for the lives we lead.

Our critical interests explain why many of us care about how the final chapter of our lives turns out. Although some of this concern originates in the desire to avoid experiential burdens, as well as burdens on our families, much of it reflects the desire to escape dying under circumstances that are out of character with the prior stages of our lives. For most people, Dworkin writes, death has a "special, symbolic importance: they want their deaths, if possible, to express and in that way vividly to confirm the values they believe most important to their lives" (p. 211). And because critical interests are so personal and widely varied among individuals, each person must have the right to control the manner in which life reaches its conclusion. Accordingly, the state should refrain from imposing a "uniform, general view [of appropriate end-of-life-care] by way of sovereign law" (p. 213).

Dworkin builds on this hierarchy of human interests to defend his ideas about how autonomy and beneficence should apply to Margo. First, he examines the general principle that we should in most cases honor the competent person's autonomy. One way to justify this principle is to show that the person generally knows better than what best serves their interests; these choices are the best evidence we have that it would most protect their welfare, the evidentiary view. But Dworkin believes the better way is to accord to individuals what he calls the integrity view of autonomy. In many instances, he contends, we grant people to act in ways that clearly conft with their own interests. We do this, he argues, because "we want to let people lead their lives as they feel is important to them" (p. 224)

The integrity view of autonomy counsels for Dworkin's claim that the person's prior choice to end her life does not change the fact that Dworkin's earlier decision, Dworkin obse 1: "[p]eople are not the best judges of their own interests, or that they would have no interest in controlling things in which others should permit Alzheimer patient to continue. Limitation would in Dworkin's view be "a form of moral paternalism" (p. 231).

Dworkin finds additional support for the integrity view in Margo's former interest in the moral principle of beneficence. It is incompetent to exercise autonomy if beneficence from those entrusted
or watching football, or seeing Cas-
e twelfth time, or walking in the woods.

re listening to The Marriage of Figaro, or
set off the wind, or just working hard at
pleasures like these are essential to a good
with nothing that is marvelous only.
ow it feels would be not pure but per-

n deems these interests less impor-
ted sort of interests we possess.
as that we also seek to satisfy our
s, which are the hopes and aims that
aning and coherence to our lives.
jects such as establishing close
ieving competence in our work.
dren, not simply because we want
ences they experience, but also be-
we should want them, because
ole will be better if we take up
mits that not everyone has a con-
the interests they deem critical to
he thinks that “even people whose
ned are nevertheless often guided
alent style of life they think
f choices strike them as not
the moment but in character for
. In this tendency, Dworkin sees
the ideal of integrity, seeking to
nt narrative structure for the lives
interests explain why many of us
the final chapter of our lives turns
ome of this concern originates in
void experimental burdens, as well as
families, much of it reflects the
y dying under circumstances that
acter with the prior stages of our
people, Dworkin writes, death has
bolic importance: they want their
ible, to express and in that way
firm the values they believe most
their lives” (p. 211). And because
s are so personal and widely varied
uals, each person must have the
the manner in which life reaches

Accordingly, the state should re-
using a “uniform, general view [of
-of-life-care] by way of sovereign
ilds on this hierarchy of human
end his ideas about how autonomy

beneficence should apply to someone like
Margo. First, he examines the generally accepted
principle that we should in most circumstances
honor the competent person’s autonomous choice.
One way to justify this principle is to claim that
people generally know better than anyone else
what best serves their interests; thus, their own
choices are the best evidence we have of the deci-
sion that would most protect their welfare. Dworkin
labels this the evidentiary view of autonomy.
But Dworkin believes the better explanation for
the respect we accord to individual choice lies in
what he calls the integrity view of autonomy. In
many instances, he contends, we grant freedom to
people to act in ways that clearly conflict with their
own best interests. We do this, he argues, because
we want to let people “lead their lives out of a
distinctive sense of their own character, a sense of
what is important to them” (p. 224). The model
once again assigns the greatest moral significance
to the individual’s critical interests, as opposed to
the less important experiential interests that also
contribute to a person’s having a good life.

The integrity view of autonomy partially ac-
counts for Dworkin’s claim that we should honor
Margo’s prior choice to end her life if she devel-
oped Alzheimer disease. In making this choice, she
was exercising, in Dworkin’s phrase, her “prece-
dent autonomy” (p. 226). The evidentiary view of
autonomy fails to supply support for deferring to
the earlier decision, Dworkin observes, because
“[p]eople are not the best judges of what their
own best interests would be under circumstances
they have never encountered and in which their
preferences and desires may drastically have
changed” (p. 226). He readily admits that Andrew
Fink and others evaluating Margo’s life with de-
mentia would perceive a conflict between her prior
instructions and her current welfare. But the in-
tegrity view of autonomy furnishes compelling
support for honoring Margo’s advance directives.
Margo’s interest in living her life in character
includes an interest in controlling the circum-
stances in which others should permit her life as an
Alzheimer patient to continue. Limiting that con-
trol would in Dworkin’s view be “an unacceptable
form of moral paternalism” (p. 231).

Dworkin finds additional support for assigning
priority to Margo’s former instructions in the
moral principle of beneficence. People who are
incompetent to exercise autonomy have a right to
beneficence from those entrusted to decide on
their behalf. The best interests standard typically
has been understood to require the decision that
would best protect the incompetent individual’s
current welfare. On this view, the standard would
support some (though not necessarily all) life-
extending decisions that depart from Margo’s
prior directives. But Dworkin invokes his concept of
critical interests to construct a different best
interests standard. Dworkin argues that Margo’s
critical interests persist, despite her current inabil-
ity to appreciate them. Because critical interests
have greater moral significance than the experi-
tential interests Margo remains able to appreciate,
and because “we must judge Margo’s critical interests as
she did when competent to do so” (p. 231), benefi-
cence requires us to honor Margo’s prior prefer-
ences for death. In Dworkin’s view, far from
providing a reason to override Margo’s directives,
compassion counsels us to follow them, for it is
compassion “toward the whole person” that under-
lies the duty of beneficence (p. 232).

To honor the narrative that is Margo’s life,
then, we must honor her earlier choices. A deci-
sion to disregard them would constitute unjusti-
fied paternalism and would lack mercy as well.
Dworkin conceives that such a decision might be
made for other reasons—because we “find our-
selves unable to deny medical help to anyone who
is conscious and does not reject it” (p. 232), or
deed it “morally unforgivable not to try to save
the life of someone who plainly enjoys her life” (p.
228), or find it “beyond imagining that we should
actually kill her” (p. 228), or “hate living in a
community whose officials might make or license
either of [Margo’s] decisions” (pp. 228–9). Dworkin
does not explicitly address whether these or
other aspects of the state’s interest in protecting
life should influence legal policy governing how
people like Margo are treated.

Dworkin pays much briefer attention to Mar-
go’s fate in the event that she did not explicitly
register her preferences about future treatment.
Most incompetent patients are currently in this
category, for relatively few people complete formal
advance treatment directives. In this scenario,
the competent Margo failed to declare her explicit
wishes, and her family is asked to determine her
fate. Dworkin suggests that her relatives may give
voice to Margo’s autonomy by judging what her
choice would have been if she had thought about
it, based on her character and personality. More-
over, similar evidence enables them to determine
her best interests, for it is her critical interests that matter most in reaching this determination. If
Margo’s dementia set in before she explicitly indicated her preferences about future care, “the law
should so far as possible leave decisions in the hands of [her] relatives or other people close to [her]
whose sense of [her] best interests is likely to be much sounder than some universal, theoretical,
abstract judgement” [p. 213].

Life’s Domination helps to explain why the “death with dignity” movement has attracted such strong
support in the United States. I have no doubt that many people share Dworkin’s conviction that they
ought to have the power to choose death over life in Margo’s state. But I am far from convinced of the
wisdom or morality of these proposals for dementia patients.

Advance Directives and Precedent
Autonomy

First, an observation. Dworkin makes an impressive case that the power to control one’s future as an
incompetent patient is a precious freedom that our society should go to great lengths to protect. But
how strongly do people actually value this freedom? Surveys show that a relatively small percentage of
the US population engages in end-of-life planning, and that many in that group simply designate a
trusted relative or friend to make future treatment decisions, choosing not to issue specific instructions
on future care. Though this widespread failure to take advantage of the freedom to exercise precedent autonomy may be attributed to a lack of publicity or inadequate policy support for advance planning, it could also indicate that issuing explicit instructions to govern the final chapter of one’s life is not a major priority for most people. If it is not, then we may question whether precedent autonomy and the critical interests it protects should be the dominant model for our policies on euthanasia for incompetent people.

Dworkin constructs a moral argument for giving effect to Margo’s directives, but does not indicate how his position could be translated into policy. Consider how we might approach this task. We would want to devise procedures to ensure that people issuing such directives were competent, their actions voluntary, and their decisions informed. In other medical settings, we believe that a person’s adequate understanding of the information relevant to treatment decision-making is a prerequisite to the exercise of true self-determination. We should take the same view of Margo’s advance planning.

What would we want the competent Margo to understand before she chose death over life in the event of dementia? At a minimum, we would want her to understand that the experience of dementia differs among individuals, that for some it appears to be a persistently frightening and unhappy existence, but that most people with dementia do not exhibit the distress and misery we competent people tend to associate with the condition. I make no claim to expertise in this area, but my reading and discussion with clinicians, caregivers, and patients themselves suggest that the subjective experience of dementia is more positive than most of us would expect. Some caregivers and other commentators also note that patients’ quality of life is substantially dependent on their social and physical environments, as opposed to the neurological condition itself. Thus, the “tragedy” and “horror” of dementia is partially attributable to the ways in which others respond to people with this condition.

We also would want Margo to understand that Alzheimer disease is a progressive condition, and that options for forgoing life-sustaining interventions will arise at different points in the process. Dworkin writes that his ideas apply only to the late stages of Alzheimer disease, but he makes implementation of Margo’s former wishes contingent on the mere development of the condition (pp. 219, 226). If we were designing policy, we would want to ensure that competent individuals making directives knew something about the general course of the illness and the points at which various capacities are lost. We would want them to be precise about the behavioral indications that should trigger the directive’s implementation. We would want them to think about what their lives would be like at different stages of the disease, and about how invasive and effective various possible interventions might be. We would want to give them the opportunity to talk with physicians, caregivers, and individuals diagnosed with Alzheimer disease, and perhaps, to discuss their potential choices with a counselor.

The concern for education is one that applies to advance treatment directives generally, but one

that is not widely recognized or addressed at policy level. People complete advance directives, perhaps after discussion with physicians, or attorneys, but oftentimes the meaning or import of their decisions. In one study of doctors who had issued instructions on the event of advanced Alzheimer disease, the inquiry revealed that almost two-thirds of them wanted families and physicians to help them to override the directives to subsequent best interests. The p

end of this statement in the article reflects that the instructions they received reflect their actual preferences. Twenty-nine percent of people participating in a care planning workshop found ten things that the following inconsistent would never want to be on a re

intensive care unit,” and “If a person is extremely intensive medical care can’t tolerate certain conditions,” I want. Meanwhile, some promoters of advance directives during interviews lasting fifty

We do not advance people’s auto effect on choices that originate in mistaken information. Indeed, inte.

choices are often considered a form of paternalism. Moreover, advance directives are generally not planning for other conditions, such unconsciousness. Before impleme.

to hasten death in the event of should require people to exhibit understanding of the choices they

Some shortcomings of advance directives are insurmountable, however. People who make advance directives are not asked to reexamine their choices to the clinicians, relations whose care and concern may be

imprudent individuals to alter them. Moreover, the rigid adherence to directives Dworkin endorses leaves no

changes of heart that can lead us to reexamine our earlier choices. All of us a
that is not widely recognized or addressed at the policy level. People complete advance directives in private, perhaps after discussion with relatives, physicians, or attorneys, but often with little understanding of the meaning or implications of their decisions. In one study of dialysis patients who had issued instructions on treatment in the event of advanced Alzheimer disease, a subsequent inquiry revealed that almost two-thirds of them wanted families and physicians to have some freedom to override the directives to protect their subsequent best interests.6 The patients’ failure to include this statement in their directives indicates that the instructions they recorded did not reflect their actual preferences. A survey of twenty-nine people participating in an advance care planning workshop found ten agreeing with both of the following inconsistent statements: “I would never want to be on a respirator in an intensive care unit,” and “If a short period of extremely intensive medical care could return me to near-normal condition, I would want it.”9 Meanwhile, some promoters of advance care planning have claimed that subjects can complete directives during interviews lasting fifteen minutes.10

We do not advance people’s autonomy by giving effect to choices that originate in insufficient or mistaken information. Indeed, interference in such choices is often considered a form of justified paternalism. Moreover, advance planning for future dementia treatment is more complex than planning for other conditions, such as permanent unconsciousness. Before implementing directives to hasten death in the event of dementia, we should require people to exhibit a reasonable understanding of the choices they are making.11

Some shortcomings of advance planning are insurmountable, however. People exercising advance planning are denied knowledge of treatments and other relevant information that may emerge during the time between making a directive and giving it effect. Opportunities for clarifying misunderstandings are truncated, and decision-makers are not asked to explain or defend their choices to the clinicians, relatives, and friends whose care and concern may lead depressed or imprudent individuals to alter their wishes.12 Moreover, the rigid adherence to advance planning Dworkin endorses leaves no room for the changes of heart that can lead us to deviate from our earlier choices. All of us are familiar with decisions we have later come to recognize as ill-suited to our subsequent situations. As Dworkin acknowledges, people may be mistaken about their future experiential interests as incompetent individuals. A policy of absolute adherence to advance directives means that we deny people like Margo the freedom we enjoy as competent people to change our decisions that conflict with our subsequent experiential interests.13

Personal identity theory, which addresses criteria for the persistence of a particular person over time, provides another basis for questioning precedent autonomy’s proper moral and legal authority. In Life’s Dominion, Dworkin assumes that Margo the dementia patient is the same person who issued the earlier requests to die, despite the drastic psychological alteration that has occurred. Indeed, the legitimacy of the precedent autonomy model absolutely depends on this view of personal identity. Another approach to personal identity would challenge this judgement, however. On this view, substantial memory loss and other psychological changes may produce a new person, whose connection to the earlier one could be less strong, indeed, could be no stronger than that between you and me.14 Subscribers to this view of personal identity can argue that Margo’s earlier choices lack moral authority to control what happens to Margo the dementia patient.

These shortcomings of the advance decision-making process are reasons to assign less moral authority to precedent autonomy than to contemporaneous autonomy. I note that Dworkin himself may believe in at least one limit on precedent autonomy in medical decision-making. He writes that people “who are repelled by the idea of living demented, totally dependent lives, speaking gibberish,” ought to be permitted to issue advance directives “stipulating that if they become permanently and seriously demented, and then develop a serious illness, they should not be given medical treatment except to avoid pain” (p. 231). Would he oppose honoring a request to avoid all medical treatment, including pain-relieving measures, that was motivated by religious or philosophical concerns? The above remark suggests that he might give priority to Margo’s existing experiential interests in avoiding pain over her prior exercise of precedent autonomy. In my view, this would be a justified limit on precedent autonomy, but I would add others as well.
Critical and Experiential Interests: Problems with the Model

What if Margo, like most other people, failed to exercise her precedent autonomy through making an advance directive? In this situation, her surrogate decision-makers are to apply Dworkin’s version of the best interests standard. Should they consider, first and foremost, the critical interests she had as a competent person? I believe not, for several reasons. First, Dworkin’s approach to the best interests standard rests partially on the claim that people want their lives to have narrative coherence. Dworkin omits empirical support for this claim, and my own observations lead me to wonder about its accuracy. The people of the United States are a diverse group, holding many different worldviews. Do most people actually think as Dworkin says they do? If I were to play psychologist, my guess would be that many people take life one day at a time. The goal of establishing a coherent narrative may be a less common life theme than the simple effort to accept and adjust to the changing natural and social circumstances that characterize a person’s life. It also seems possible that people generally fail to draw a sharp line between experiential and critical interests, often choosing the critical projects Dworkin describes substantially because of the rewarding experiences they provide.

Suppose Margo left no indication of her prior wishes, but that people close to her believe it would be in her critical interests to die rather than live on in her current condition. Dworkin notes, but fails to address, the argument that “in the circumstances of dementia, critical interests become less important and experiential interests more so, so that fiduciaries may rightly ignore the former and concentrate on the latter” (p. 232). Happy and contented Margo will experience clear harm from the decision that purports to advance the critical interests she no longer cares about. This seems to me justification for a policy against active killing or withholding effective, non-burdensome treatments, such as antibiotics, from dementia patients whose lives offer them the sorts of pleasures and satisfactions Margo enjoys. Moreover, if clear evidence is lacking on Margo’s own view of her critical interests, a decision to hasten her death might actually conflict with the life narrative she envisioned for herself. Many empirical studies have shown that families often do not have a very good sense of their relatives’ treatment preferences. How will Margo’s life narrative be improved by her family’s decision to hasten death if there is no clear indication that she herself once took that view?

I also wonder about how to apply a best interests standard that assigns priority to the individual’s critical interests. Dworkin writes that family members and other intimates applying this standard should decide based on their knowledge of “the shape and character of [the patient’s] life and his own sense of integrity and critical interests” (p. 231). What sorts of life narratives would support a decision to end Margo’s life? What picture of her critical interests might her family cite as justification for ending her life now? Perhaps Margo had been a famous legal philosopher whose intellectual pursuits were of utmost importance to her. This fact might tilt toward a decision to spare her from an existence in which she can only pretend to read. But what if she were also the mother of a mentally retarded child, whom she had cared for at home? What if she had enjoyed and valued this child’s simple, experiential life, doing everything she could to protect and enhance it? How would this information affect the interpretation of her critical interests as they bear on her own life with dementia?

I am not sure whether Dworkin means to suggest that Margo’s relatives should have complete discretion in evaluating considerations such as these. Would he permit anyone to challenge the legitimacy of a narrative outcome chosen by her family? What if her closest friends believed that a different conclusion would be more consistent with the way she had constructed her life? And is there any room in Dworkin’s scheme for surprise endings? Some of our greatest fictional characters evolve into figures having little resemblance to the persons we met in the novels’ opening chapters. Are real-life characters such as the fiercely independent intellectual permitted to become people who appreciate simple experiential pleasures and accept their dependence on others?

Finally, is the goal of respecting individual differences actually met by Dworkin’s best interests standard? Although Dworkin recognizes that some people believe their critical interests would be served by a decision to extend their lives as long as is medically possible (based on their pro-life values), at times he implies that such individuals are mistaken about their genuine critical interests. In reality no one’s critical interests are served by such a decision. For example, that after the onset of dementia, not only can be added to a person’s life, because one no longer capable of engaging in necessary to advance her critical interests. A similar judgment is also evident in an actual case of a brain-damaged patient who did not seem to be in pain or recognize familiar faces with apparatus (p. 233). A court-appointed guardian has the patient’s life-prolonging medically kept, but the family was strongly opposed to the outcome, and a judge denied the request. In a remark that seems to concur for family decision-makers, Dworkin questions whether the family’s consent of the patient’s best interests (p. 233). It leads me to wonder whether Dworkin is to defend an objective norm that should be applied to all individuals, not just the mentally impaired, whose death should be hastened. If so, the provision would provide additional argument for this position.

The State’s Interest in Margo

My final thoughts concern Dworkin’s claim that the state has no legitimate reason to interfere with Margo’s directives or her family’s judgement to end her life. A great deal of Dworkin’s position addresses the intrinsic value and the nature of the state’s interest in the patient’s life. Early in the book, Dworkin acknowledges that only conscious individuals possess interests in not being destroyed. Harm to an individual’s state of mind and other capacities, human beings of their own will to pursue to live, is not a valid concern. But Dworkin calls a detached state interest in the patient’s life. Conversely, a policy that affects the state of being after death is based on viability is supported by the state’s interest in valuing life, so called because the fetus’s own interests are served.
have shown that families often do not see sense of their relatives' treatment. How will Margo's life narrative be in family's decision to hasten death? Could her indication that she herself once thought about how to apply a best interest's panel's priority to the individual's wishes? Dworkin writes that family members expressing this standard based on their knowledge of the "real character of the patient's life and his integrity and critical interests". Parts of life narratives would support curtailing Margo's life? What picture of her life might her family cite as justifying her life now? Perhaps Margo had legal philosopher whose intellectual of utmost importance to her. They think a decision to spare her from which she can only pretend to read, was also the mother of a mentally impaired who she had cared for at home, adored and valued this child's mental life, doing everything she could to enhance it? How would we interpret the interpretation that they bear on her own life with respect to whether Dworkin means to suggest that Margo's relatives should have a complete role in evaluating considerations such as whether to permit anyone to challenge the narrative outcome chosen by her relatives? Or is it in Dworkin's scheme for surprise regarding dementia care should be overridden, nor that family choices should always be disregarded. I think directives and family choices should control in the vast majority of cases, for such decisions rarely are in clear conflict with the patient's contemporaneous interests. But I believe that state restriction is justified when a systematic evaluation by clinicians and others involved in patient care produces agreement that a minimally intrusive life-sustaining intervention is likely to preserve the life of someone as contented and active as Margo.

Many dementia patients do not fit Margo's profile. Some are barely conscious, others appear frightened, miserable, and unresponsive to efforts to mitigate their pain. Sometimes a proposed life-sustaining treatment will be invasive and immobilizing, inflicting extreme terror on patients unable to understand the reasons for their burdens. In such cases, it is entirely appropriate to question the justification for treatment, and often to withhold it, as long as the patient can be kept comfortable in its absence. This approach assumes that observers can accurately assess the experiential benefits and burdens of patients with neurological impairments and decreased ability to ensuring respect for the value of life justify state prohibitions on abortion only after pregnant women are given a reasonable opportunity to terminate an unwanted pregnancy. Prior to this point, the law should permit women to make decisions about pregnancy according to their own views on how best to respect the value of life. After viability, however, when fetal neurological development is sufficiently advanced to make sense possible, the state may severely limit access to abortion, based on its legitimate role in protecting creatures capable of having interests of their own (pp. 168–70).

Dworkin's analysis of abortion provides support, in my view, for a policy in which the state acts to protect the interests of conscious dementia patients like Margo. Although substantially impaired, Margo retains capacities for pleasure, enjoyment, interaction, relationships, and so forth. I believe her continued ability to participate in the life she is living furnishes a defensible basis for state limitations on the scope of her precedent autonomy, as well as on the choices her intimates make on her behalf. Contrary to Dworkin, I believe that such moral paternalism is justified when dementia patients have a quality of life comparable to Margo's. I am not arguing that all directives regarding dementia care should be overridden, nor that family choices should always be disregarded. I think directives and family choices should control in the vast majority of cases, for such decisions rarely are in clear conflict with the patient's contemporaneous interests. But I believe that state restriction is justified when a systematic evaluation by clinicians and others involved in patient care produces agreement that a minimally intrusive life-sustaining intervention is likely to preserve the life of someone as contented and active as Margo.
Rebecca Dresser

communicate. I believe that such assessments are often possible, and that there is room for a great deal of improvement in meeting this challenge.

I also believe that the special problems inherent in making an advance decision about active euthanasia justify a policy of refusing to implement such decisions, at the very least until we achieve legalization for competent patients without unacceptable rates of error and abuse. I note as well the likely scarcity of health care professionals who would be willing to participate in decisions to withhold simple and effective treatments from someone in Margo’s condition, much less to give her a lethal injection, even if this were permitted by law. Would Dworkin support a system that required physicians and nurses to compromise their own values and integrity so that Margo’s precedent autonomy and critical interests could be advanced? I seriously doubt that many health professionals would agree to implement his proposals regarding dementia patients whose lives are as happy as Margo’s.

We need community reflection on how we think about people with dementia, including our possible future selves. Dworkin’s model reflects a common response to the condition: tragic, horrible, degrading, humiliating, to be avoided at all costs. But how much do social factors account for this tragedy? Two British scholars argue that though we regard dementia patients as “the problem,” the patients are rather less of a problem than we. They are generally more authentic about what they are feeling and doing; many of the polite veneers of earlier life have been stripped away. They are clearly dependent on others, and usually come to accept that dependence; whereas many “normal” people, living under an ideology of extreme individualism, strenuously deny their dependency needs. They live largely in the present, because certain parts of their memory function have failed. We often find it very difficult to live in the present, suffering constant distraction; the sense of the present is often contaminated by regrets about the past and fears about the future.  

If we were to adopt an alternative to the common vision of dementia, we might ask ourselves what we could do, how we could alter our own responses so that people with dementia may find that life among us need not be so terrifying and frustrating. We might ask ourselves what sorts of environments, interactions, and relationships would enhance their lives.

Such a “disability perspective” on dementia offers a more compassionate, less rejecting approach to people with the condition than a model insisting that we should be permitted to order ourselves killed if this “saddest of the tragedies” (p. 218) should befall us. It supports as well a care and treatment policy centered on the conscious incompetent patient’s subjective reality; one that permits death when the experiential burdens of continued life are too heavy or the benefits too minimal, but seeks to delay death when the patient’s subjective existence is as positive as Margo’s appears to be. Their loss of higher-level intellectual capacities ought not to exclude people like Margo from the moral community nor from the law’s protective reach, even when the threats to their well-being emanate from their own former preferences. Margo’s connections to us remain sufficiently strong that we owe her our concern and respect in the present. Eventually, the decision to allow her to die will be morally defensible. It’s too soon, however, to exclude her from our midst.

Acknowledgment

I presented an earlier version of this essay at the annual meeting of the Society for Health and Human Values, 8 October 1994, in Pittsburgh. I would like to thank Ronald Dworkin and Eric Rakowski for their comments on my analysis.

Notes


2 See, for example, Rebecca Dresser, “Missing Persons: Legal Perceptions of Incompetent Patients,” Rutgers Law Review, 609 (1994): 636-47; Rebecca
to thank Ronald Dworkin and Eric Orner for their comments on my analysis.