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## Beyond *Cruzan*: Dementia and the Best Interests Standard

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# BEYOND *CRUZAN*: DEMENTIA AND THE BEST INTERESTS STANDARD

Rebecca Dresser\*

## TABLE OF CONTENTS

I. INTRODUCTION .....	71
II. LEGAL CONCEPTIONS OF THE BEST INTERESTS STANDARD .....	73
A. THE <i>CRUZAN</i> DISSENTS .....	73
B. THE BEST INTERESTS STANDARD IN THE LABORATORY OF THE STATES.....	75
III. BEST INTERESTS DISAGREEMENTS .....	78
A. INCOMPETENT PATIENTS' FORMER INTERESTS .....	79
B. REASONABLE PERSON INTERESTS .....	81
IV. AN EVIDENCE-BASED APPROACH TO EVALUATING PATIENTS' INTERESTS .....	84
V. DETERMINING AN ACCEPTABLE RANGE OF BEST INTERESTS DECISIONS .....	87
VI. CONCLUSION .....	89

## I. INTRODUCTION

THE United States Supreme Court's decision in *Cruzan v. Director, Missouri Department of Health*<sup>1</sup> broke important legal ground in establishing a constitutional basis for the individual's control over life-sustaining treatment. Yet *Cruzan* offered little guidance to those making treatment choices on behalf of incompetent patients. The Court simply determined that it was constitutional for Missouri to require continued life-sustaining treatment in the absence of clear and convincing evidence that Nancy Cruzan would refuse such treatment in her current circumstances.<sup>2</sup>

*Cruzan* left states free to adopt less-demanding evidentiary requirements to establish incompetent patients' prior treatment preferences. The Court also left states free to apply other standards to determine treatment for patients who left no clear indication of their prior preferences. As Justice O'Connor observed in her concurring opinion, "[T]he more challenging task of crafting appropriate procedures for safeguarding in-

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1. 497 U.S. 261 (1990).

2. *Id.* at 286-87.

competents' liberty interests is entrusted to the 'laboratory' of the States." <sup>3</sup>

Writing for the majority, Chief Justice Rehnquist described some of the approaches states had taken to decision-making on behalf of incompetent patients.<sup>4</sup> He referred to cases adopting versions of the two major standards for such decisions: the subjective standard, which focuses on written, oral, or behavioral indications of a formerly competent person's treatment preferences; and the objective standard (traditionally referred to as the best interests standard), which focuses on how different treatment options would affect the incompetent patient's welfare.<sup>5</sup>

Like most legal and policy authorities, the Supreme Court focused on the subjective standard.<sup>6</sup> The competent individual's liberty to make contemporaneous medical choices is grounded in the values of self-determination and autonomy.<sup>7</sup> When patients lack the capacity to make their own choices, most authorities, as well as medical ethicists, regard the person's previous competent preferences as the ideal way to resolve treatment questions. But the subjective standard is insufficient to guide many treatment decisions because relatively few people express clear and precise wishes about their future care. In such cases, decision makers must look to the objective best interests standard for guidance on how to proceed.

Although courts and legislatures favor the autonomy-based subjective standard, it's often impossible to apply. The need for a robust best interests standard has become increasingly obvious in the decades since *Cruzan*. Yet, there is relatively little legal and scholarly guidance on this standard. With the growing population of people diagnosed with dementia, supplying greater guidance to treatment decision makers is imperative.<sup>8</sup>

Dementia presents special challenges to decision makers applying the best interests standard. People with dementia live for many years after

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3. *Id.* at 292 (O'Connor, J., concurring) (citing *New State Ice Co. v. Liebmann*, 285 U.S. 262, 311 (1932) (Brandeis, J., dissenting)).

4. There is no single legal definition of competency, but the generally accepted approach looks to the individual's ability to understand and appreciate the information relevant to a treatment choice. See generally Rebecca Dresser, *Autonomy and Its Limits in End-of-Life Law*, in OXFORD HANDBOOK OF U.S. HEALTH LAW 399, 401–02 (I. Glenn Cohen et al. eds., 2017) [hereinafter Dresser, *Autonomy and Its Limits*]. Unlike Nancy Cruzan, many incompetent patients remain conscious and capable of having emotions, desires, and views on how they want their lives to go. See *infra* text accompanying notes 99–134.

5. *Cruzan*, 497 U.S. at 270–78. For a discussion of the subjective standard and its potential to conflict with the best interests standard, see Rebecca Dresser, *Dementia, Disability, and Advance Directives: Defensible Legal Standards for Decisions about Future Dementia Care*, in DISABILITY, HEALTH, LAW, AND BIOETHICS 77–88 (I. Glenn Cohen et al. eds., 2020).

6. *Cruzan*, 497 U.S. at 286–87.

7. *Id.* at 272–73 (quoting *In re Conroy*, 486 A.2d 1209, 1224 (N.J. 1985)).

8. For an overview of these issues, see PRESIDENT'S COUNCIL ON BIOETHICS, TAKING CARE: ETHICAL CAREGIVING IN OUR AGING SOCIETY 1–4 (2005).

their diagnosis.<sup>9</sup> Though they experience a progressive decline in cognitive capacity, they remain able to participate in activities and interactions for much of that time.<sup>10</sup> As aging individuals, they are also vulnerable to cancer, heart disease, and other life-threatening conditions.<sup>11</sup> Determining whether to treat people with dementia for such conditions can be a complex and, at times, controversial endeavor.

In this article, I analyze the best interests standard, focusing on three topics that merit closer examination than they have received. In Part II, I review what *Cruzan* said about the best interests standard, as well as how state courts have applied the standard. Part III addresses two unresolved issues in best interests decision-making. First, in determining how to promote the patient's welfare, should the best interests standard consider the patient's life as a whole or only the patient's contemporaneous circumstances? Second, should the best interests standard consider only the benefits and burdens that patients themselves experience, such as pain and pleasure, or should it also consider broader concerns, such as dignity and personal privacy, even when patients are no longer concerned with such matters?

In Part IV, I examine the process of evaluating the subjective experiences of individual incompetent patients and suggest ways to improve the process. I conclude by highlighting uncertainties in applying the best interests standard to dementia patients. Surrogate decision makers and clinicians need more legal guidance to determine permissible and impermissible treatment choices for conscious dementia patients.

## II. LEGAL CONCEPTIONS OF THE BEST INTERESTS STANDARD

### A. THE *CRUZAN* DISSENTS

Although the Supreme Court Justices focused on the subjective standard for treatment decision-making, *Cruzan* did include a brief discussion of the best interests standard. In his dissenting opinion, Justice Stevens argued that Missouri had violated what he saw as a constitutional mandate “to care for Nancy Cruzan’s life in a way that gives appropriate respect to her own best interests.”<sup>12</sup> These interests, he contended, were broader than any benefits and burdens that she herself would perceive if her life-sustaining nutritional support were continued or withdrawn.<sup>13</sup>

Doctors said that Cruzan was in a persistent vegetative state, with no awareness of her surroundings.<sup>14</sup> According to Justice Stevens, continued life without consciousness is insufficient to give patients a contemporane-

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9. See 2019 ALZHEIMER’S DISEASE FACTS AND FIGURES, ALZHEIMER’S ASS’N 5–6 (2019).

10. See *id.*

11. See *id.* at 43–45.

12. *Cruzan*, 497 U.S. at 331 (Stevens, J., dissenting).

13. *Id.* at 344–45.

14. *Id.* at 266 n.1 (majority opinion).

ous interest in receiving life-sustaining interventions.<sup>15</sup> If there were evidence that Cruzan herself had previously regarded mere biological life as valuable, then she would have an interest in continued nutritional support.<sup>16</sup> But no such evidence existed, he noted.<sup>17</sup> Moreover, like any other person, Cruzan's interests included an "interest in how she [would] be thought of after her death by those whose opinions mattered to her."<sup>18</sup> Because her parents believed she would not want to be sustained in a state of permanent unconsciousness, Stevens declared that her best interests would be served by a decision to withdraw treatment.<sup>19</sup>

At the same time, Stevens was careful to distinguish permanently unconscious patients like Cruzan from conscious patients. According to Stevens, conscious, incompetent patients "have *some* interest in continuing their lives, even if that interest pales in some eyes when measured against interests in dignity or comfort."<sup>20</sup> In cases involving those patients, he wrote, ascertaining the patient's constitutional interests would be more "complicated" than it is in patients with no reasonable prospect of restoration to conscious awareness.<sup>21</sup>

In a second dissenting opinion, Justice Brennan presented a similar conception of Cruzan's interests. For permanently unconscious patients like Cruzan, he wrote, "the sole benefit of medical treatment is being kept metabolically alive."<sup>22</sup> On the other hand, he observed, many people regard prolonged life "devoid of thought, emotion, and sensation" as both "humiliating" and an unacceptable burden on loved ones.<sup>23</sup> He cited empirical findings that a high percentage of people would reject life-sustaining treatment for themselves in such circumstances.<sup>24</sup>

According to Brennan, these findings, together with the lack of evidence that Cruzan herself valued life in an unconscious state, were sufficient to support her parents' request to remove the feeding tube.<sup>25</sup> More generally, he declared, unless they harbor "improper motives," families of permanently unconscious patients should be permitted to determine which treatment decision would be best for the patients.<sup>26</sup>

According to these two Justices, best interests evaluations should not rely solely on the impact a particular treatment decision will have on the

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15. *Id.* at 344–45 (Stevens, J., dissenting).

16. *Id.* at 351.

17. *Id.*

18. *Id.* at 344.

19. *Id.* at 356.

20. *Id.* at 347.

21. *See id.* at 350 n.22. A few state courts have also noted significant differences between evaluating the interests of conscious, incompetent patients and the interests of patients diagnosed in a state of permanent unconsciousness. *See* Rebecca Dresser, *The Conscious Incompetent Patient*, HASTINGS CTR. REP., May–June 2002, at 9, 9–10.

22. *Cruzan*, 497 U.S. at 309 (Brennan, J., dissenting).

23. *Id.* at 309–12.

24. *Id.* at 312 n.11.

25. *Id.* at 301–02.

26. *Id.* at 328.

incompetent patient in her current state.<sup>27</sup> In their view, such evaluations should also take into account burdens and benefits that would be important to competent persons considering the patient's situation.<sup>28</sup> On this view, matters like humiliation and dignity are relevant to the interests of patients unable to perceive or care about such matters. As I describe below, there is some legal and scholarly support for this conception of the best interests standard. Yet, as Justice Stevens observed, this approach can be complicated when applied to conscious, incompetent patients.

#### B. THE BEST INTERESTS STANDARD IN THE LABORATORY OF THE STATES

State court opinions offer the most extensive analysis of the best interest standard in end-of-life decision-making. Although there is substantial agreement on the standard's meaning and application, there is disagreement as well. I describe differences in how judges have interpreted the standard below.

Courts use a few different terms to refer to the traditional best interests standard, including the objective standard, benefit-burden standard, and reasonable person standard.<sup>29</sup> (Two other legal standards, the substituted-judgment and limited-objective standards, contain both subjective and objective elements.)<sup>30</sup> All objective standards involve assessing and balancing various considerations affecting a specific incompetent patient's treatment situation.<sup>31</sup> They incorporate judgments on what makes life good or bad for people in general, such as pleasure and enjoyment on one hand and pain and distress on the other.<sup>32</sup> As one advisory group put it, the best interests and other objective standards are based on "a societal consensus, or the perspective of 'a reasonable person,' choosing as most people would for themselves."<sup>33</sup> But as I discuss below, courts and commentators differ on the normative judgments that belong in a best interests evaluation.

Decision-making approaches are classified as objective when they depend on evidence about the patient's welfare, rather than on evidence about the patient's end-of-life preferences before losing decision-making capacity. Yet the objective label is somewhat misleading. Objective standards seek the best choice for a person *in the patient's circumstances*, thus adding a subjective element to the inquiry.<sup>34</sup> Moreover, objective stan-

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27. See *supra* notes 14–26 and accompanying text.

28. See *supra* notes 14–26 and accompanying text.

29. See Dresser, *Autonomy and Its Limits*, *supra* note 4, at 401–05.

30. See generally ALLEN E. BUCHANAN & DAN W. BROCK, *DECIDING FOR OTHERS: THE ETHICS OF SURROGATE DECISION MAKING* 112–22 (1989); Dresser, *Autonomy and Its Limits*, *supra* note 4, at 404.

31. See Dresser, *Autonomy and Its Limits*, *supra* note 4, at 404–05.

32. See *id.*

33. N.Y. STATE TASK FORCE ON LIFE & THE LAW, *WHEN OTHERS MUST CHOOSE: DECIDING FOR PATIENTS WITHOUT CAPACITY* 55 (1992); see also BUCHANAN & BROCK, *supra* note 30, at 123.

34. See Dresser, *Autonomy and Its Limits*, *supra* note 4, at 404–05.

dards focus on how various treatment options will affect the individual patient's well-being as an incompetent patient.<sup>35</sup> Applying objective standards thus demands an inquiry into the personal, subjective world of the incompetent patient. To the degree that objective standards require close examination of an individual patient's actual and anticipated responses to different treatment options, they are subjective.<sup>36</sup>

In 1985, the New Jersey Supreme Court issued an influential decision on treatment standards for incompetent patients in *In re Conroy*.<sup>37</sup> In a ruling on the care of Claire Conroy, a "barely conscious"<sup>38</sup> patient with advanced dementia, the court described factors that best interests evaluations should consider: "the degree of humiliation, dependence, and loss of dignity probably resulting from the condition and treatment; the life expectancy and prognosis for recovery with and without treatment; the various treatment options; and the risks, side effects, and benefits of each of those options."<sup>39</sup> As *Conroy* noted, potential treatment burdens include experiences like pain and suffering, and benefits include experiences like "physical pleasure, emotional enjoyment, or intellectual satisfaction."<sup>40</sup>

*Conroy* also described the balance of benefits and burdens that could justify forgoing treatment. According to the *Conroy* majority, treatment could be withheld or withdrawn under the objective standard if the "net burdens of the patient's life . . . clearly and markedly outweigh the benefits that the patient derives from life . . . [, and] the recurring, unavoidable and severe pain of the patient's life . . . [is] such that the effect of administering life-sustaining treatment would be inhumane."<sup>41</sup>

Though the *Conroy* decision has been influential, its articulation of the best interests standard has been criticized. A common criticism addresses the "inhumane treatment" requirement for forgoing treatment. Judges disagree on whether the best interests standard should permit withholding or withdrawing treatment in other circumstances too. For example, in his *Conroy* dissent, New Jersey Supreme Court Justice Joel Handler questioned the majority's reliance on pain as the deciding factor.<sup>42</sup> He favored a broader approach in which factors such as severe illness, extensive physical intrusion, and lack of dignity could also support a decision to

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35. *Id.*

36. See James F. Drane & John L. Coulehan, *The Best-Interest Standard: Surrogate Decision Making and Quality of Life*, J. CLINICAL ETHICS, Spring 1995, at 20, 23 (noting that the best interests standard involves an "attempt to objectify the content of subjective experience"); Eric C. Miller, *Listening to the Disabled: End-of-Life Medical Decision Making and the Never Competent*, 74 FORDHAM L. REV. 2889, 2901 (2006) (stating that the best interest standard applies "objective standards outside the person . . . and standards subjective to the person").

37. 486 A.2d 1209 (N.J. 1985).

38. Nancy K. Rhoden, *Litigating Life and Death*, 102 HARV. L. REV. 375, 376-77 (1988).

39. *Conroy*, 486 A.2d at 1231.

40. *Id.* at 1232.

41. *Id.*

42. *Id.* at 1249 (Handler, J., concurring in part and dissenting in part).

forgo life-sustaining interventions.<sup>43</sup>

In a later case, another New Jersey judge endorsed a position similar to that of Justice Handler. *In re Visbeck* examined the situation of an elderly woman who was cognitively impaired after having a stroke.<sup>44</sup> Elizabeth Visbeck was unable to eat on her own, and her son opposed surgery to implant a feeding tube, arguing that this would simply prolong his mother's suffering.<sup>45</sup> But the judge ordered the surgery, observing that, although Visbeck was severely impaired, she appeared to be aware, somewhat responsive, and unburdened by suffering.<sup>46</sup> Based on the evidence at hand, he noted, the benefits of the continued life that tube feeding would provide outweighed any burdens that surgery and tube feeding would impose on Visbeck.<sup>47</sup>

At the same time, the judge in *Visbeck* challenged *Conroy's* inhumane-treatment requirement, proposing that

suffering pain, even severe pain, is perhaps not the worst thing that can befall a human being. I would suggest that for most of us it would be far worse to suffer a very great loss of mental capacity, to become non-functioning, to be totally dependent upon others, to have no privacy in the most basic physical sense.<sup>48</sup>

Like Justice Handler, this judge believed that a broader array of human concerns, such as lack of privacy and complete dependence on others, should have material significance in best interests evaluations.<sup>49</sup> Without this broader approach, he predicted, "large numbers of people will be thoughtlessly and automatically compelled to continue lives of intolerable bleakness."<sup>50</sup>

Yet, the broader approach to best interests has its critics too. Critics fear that the approach opens the door to decisions that undervalue the lives of people with intellectual disabilities. A Massachusetts case, *In re Hier*,<sup>51</sup> shows how this can happen. Ninety-two-year-old Mary Hier had been institutionalized for psychiatric problems for much of her life.<sup>52</sup> A decade earlier, she had developed digestive system problems, and doctors had surgically implanted a tube to supply her with adequate nutrition.<sup>53</sup> Shortly after her transfer to a new living facility, she pulled out the tube and then seemed to oppose any effort to replace it.<sup>54</sup>

Hier was eventually transferred to a hospital, and the case went to

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43. *Id.* at 1249–50.

44. *In re Visbeck*, 510 A.2d 125, 126 (N.J. Super. Ct. Ch. Div. 1986).

45. *Id.* at 127.

46. *Id.* at 130.

47. *Id.* at 133.

48. *Id.* at 131.

49. *See id.* at 131–33.

50. *Id.* at 133.

51. 464 N.E.2d 959 (Mass. App. Ct. 1984).

52. *Id.* at 960–61.

53. *Id.*

54. *Id.*



court.<sup>55</sup> Based on a benefit-burden analysis, a trial judge refused to authorize surgery to replace the tube.<sup>56</sup> An appellate court agreed, stressing the intrusiveness of the procedure, Hier's resistance, and the likelihood that she would pull out the new tube.<sup>57</sup> The judges said nothing about the possible pain and distress that Hier, an otherwise healthy and ambulatory person, could experience if deprived of nourishment. Nor did they consider whether she would gain pleasure and enjoyment from the life that continued nutritional support would provide (she reportedly thought she was the Queen of England).<sup>58</sup>

The appellate court characterized Hier's actions as "a plea for privacy and personal dignity by a ninety-two year old person who is seriously ill and for whom life has little left to offer."<sup>59</sup> The judges failed to consider the possibility that she might have other motivations for behaving as she did, such as dissatisfaction with her new living quarters.<sup>60</sup> In short, the court's benefit-burden calculation seemed to devalue Hier's life, reflecting a potentially biased evaluation of her situation, rather than a patient-centered assessment of her interests.

These cases, together with the dissenting opinions in *Cruzan*, reveal disagreements over the nature and application of the best interests standard. Legal authorities have yet to resolve a central question raised by the standard: should treatment decisions rely only on burdens and benefits that a patient herself experiences or should other factors, such as the interests a patient had before becoming incompetent or the concerns of a generalized "reasonable person," also play a significant role? In Part III, I consider this question.

### III. BEST INTERESTS DISAGREEMENTS

The legal disagreements described in Part II are traceable to a philosophical disagreement over how to evaluate the incompetent patient's welfare. The general disagreement concerns whether judgments about what was good for an individual in the past should influence decisions on what would be good for that person now. The debate is about the best interests standard's conception of patient welfare, not the conception of individual autonomy supporting the subjective standard. Thus, it applies

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55. *Id.*

56. *Id.* at 964.

57. *Id.*

58. See George J. Annas, *The Case of Mary Hier: When Substituted Judgment Becomes Sleight of Hand*, HASTINGS CTR. REP., Aug. 1984, at 23, 23-24.

59. *Hier*, 464 N.E.2d at 965. The court applied the substituted judgment standard, but because there was no evidence of Hier's prior competent preferences, the ruling was based on an objective analysis of the benefits and burdens of her medical options. *Id.* at 964-65.

60. Annas, *supra* note 58, at 25. Hier's guardian *ad litem* returned to court with more medical testimony and ultimately obtained an order authorizing the surgery. See Rebecca Dresser, *Missing Persons: Legal Perceptions of Incompetent Patients*, 46 RUTGERS L. REV. 609, 713 (1994) [hereinafter Dresser, *Missing Persons*]. According to one of her physicians, she lived for several years after the court-ordered surgery. *Id.*

to cases in which there is no clear evidence of a patient's former treatment preferences.

There are two main versions of the debate. One asks whether the best interests standard should include consideration of the desires and interests a specific patient possessed at an earlier time in life. The other asks whether the standard should include considerations that a reasonable person would have in the patient's situation. I examine each version of the debate below.

#### A. INCOMPETENT PATIENTS' FORMER INTERESTS

Legal philosopher Ronald Dworkin made one of the best-known cases for including individual patients' past interests in best interests assessments.<sup>61</sup> His argument rests on a general conception of human interests. Throughout our lives, he said, we strive to promote two types of interests.<sup>62</sup> We engage in some activities because they give us pleasure and enjoyment—good experiences.<sup>63</sup> Through these pursuits, we seek to satisfy what Dworkin called our experiential interests.<sup>64</sup> We also engage in activities to satisfy what he called our “critical interests”: working on relationships, careers, and other personally meaningful endeavors.<sup>65</sup> Though at times difficult, satisfying our critical interests is part of living a good life. Because it is the pursuit of critical interests that gives our lives genuine meaning and coherence, Dworkin contended, critical interests have the highest moral significance.<sup>66</sup>

Their interest in living their lives according to a coherent narrative structure gives people an interest in the way their lives end, Dworkin asserted.<sup>67</sup> This means that people have critical interests in the medical treatment they receive after the onset of incapacity. According to Dworkin, these critical interests affect patients' welfare even when they can no longer appreciate their previous concerns.<sup>68</sup> On this view, part of giving someone a good life involves satisfying the critical interests that an individual had before being diagnosed with dementia. Moreover, because critical interests have the highest moral significance, they take priority over a dementia patient's contemporaneous experiential interests in receiving care that promotes her current well-being.

Dworkin's conception of the best interests standard departs from the standard's traditional focus on patients' contemporaneous welfare.<sup>69</sup> Best

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61. RONALD DWORIN, *LIFE'S DOMINION* 199–237 (1993).

62. *Id.* at 201–02.

63. *Id.*

64. *Id.*

65. *Id.*

66. *Id.*

67. *Id.*

68. *Id.*

69. *See, e.g.,* Rasmussen v. Fleming, 741 P.2d 674, 688–89 (Ariz. 1987) (stating guardian for incompetent patient should promote the “best interests and temporal, moral and mental welfare of a living person” (quoting Countryman v. Henderson, 496 P.2d 861, 863 (Ariz. 1972))).

interests evaluations, he argued, should determine which decision would be best for the person's life overall.<sup>70</sup> Consider, for example, a person with dementia whose career as a philosophy professor was once essential to his well-being. That person's welfare as a dementia patient would continue to depend on his ability to pursue that career, even if he appears to be content and no longer concerned with his previous work. According to Dworkin, the individual's critical interests in maintaining his former career could justify a best interests decision to refrain from providing a treatment that would promote the individual's contemporaneous experiential interests.<sup>71</sup>

Other philosophers have a different view of human welfare, however, including the welfare of dementia patients. Jennifer Hawkins is one of them.<sup>72</sup> Hawkins questions the rationale for a best interests standard that encompasses a person's whole life, rather than the person's present circumstances.<sup>73</sup>

We generally recognize that people have different interests during the course of their lives, Hawkins observes.<sup>74</sup> And because a person's interests vary over time, they sometimes conflict,<sup>75</sup> as they do in the example of the dementia patient described above. The person whose welfare once depended on his philosophy career now has a different set of welfare interests. The most defensible conception of such a patient's welfare looks to his current interests, Hawkins contends, not his interests at some other time in his life.<sup>76</sup>

As Hawkins points out, we don't normally think about a person's welfare from the perspective of her life as a whole.<sup>77</sup> Ideas about what careers, relationships, and living circumstances would be best for an individual change through the years. To counter the whole-life conception of individual welfare, Hawkins adopts a form of the "experience requirement" for welfare evaluations.<sup>78</sup> According to Hawkins, when someone "has changed enough that she is no longer capable of responding positively to some putative good, then . . . that thing is no longer good for her."<sup>79</sup> Thus, although that person's past critical interests might shape application of the subjective standard for treatment decision-making, those interests should not influence decisions about her best interests as a person with dementia.

Competing views of the proper conception of individual welfare have important implications for applications of the best interests standard. Whole-life conceptions like Dworkin's permit best interests decisions

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70. See DWORKIN, *supra* note 61, at 199.

71. See *id.* at 229–33.

72. See Jennifer Hawkins, *Well-Being, Time, and Dementia*, 124 *ETHICS* 507 (2014).

73. See *id.*

74. *Id.* at 514.

75. *Id.* at 514–15.

76. *Id.* at 542.

77. *Id.*

78. *Id.* at 539.

79. *Id.*

based on concerns that incompetent patients are no longer able to appreciate. In contrast, welfare conceptions calibrated to the individual's existing abilities limit best interests assessments to the burdens and benefits that dementia patients remain able to experience.

Adopting an experience requirement for best interests assessments doesn't necessarily exclude individual patients' past welfare interests from treatment decision-making. Clear evidence of a patient's past interests can shape how the subjective standard is applied in that case. Moreover, people with dementia can remain capable of appreciating their former pursuits. For example, someone who was once a painter might continue to value and enjoy painting for years after a dementia diagnosis. Such an individual would benefit from receiving treatment that would enable him to continue painting. Conversely, someone who always preferred to live in solitude might have an extremely negative response to living in a dementia care facility. Such a response would be one factor to take into account in evaluating potential treatment options for that individual.

#### B. REASONABLE PERSON INTERESTS

As I noted in Part II, some judges believe that the perspective of a generalized reasonable person should influence best interests decision-making. Many scholars share this position. Conceptual analyses of the best interests standard often refer to reasonable person views, adopting some version of the following statement: "[E]ven when the individual patient's wishes or preferences are not known, we can look at the patient's quality of life and make a judgment based on what a reasonable person would consider beneficial and, therefore, would prefer in such a circumstance."<sup>80</sup>

Such formulations of the best interests standard are common, but they typically fail to specify the precise role of reasonable person judgments. As I said earlier, best interests evaluations incorporate judgments on what makes life good and bad for people. For example, a choice to forgo treatment because it would result in overwhelming pain and distress relies on two findings. One is that a life involving overwhelming pain and distress is not one that reasonable people would consider valuable. The other is that the patient herself is likely to respond negatively to the kind of pain and distress that treatment would impose. But writers don't always clarify whether the second judgment is required. The question here is similar to the one discussed in the previous section: should the patient's capacity to appreciate reasonable person considerations be required?

It is widely agreed that best interests decision-making demands quality of life assessments: how would the burdens and benefits of different treatment options affect a particular incompetent patient? Rather than considering the utility or value a patient's life has to others, best interests

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80. Drane & Coulehan, *supra* note 36, at 23.

evaluations consider “the value or quality of an individual’s life *to that individual*.”<sup>81</sup> In this kind of quality of life assessment,

[t]he question is not whether the patient’s quality of life is below average, or worse than it used to be, or anything of the sort. Instead, the proper quality of life judgment is only whether the quality of the patient’s life with the life-sustaining treatment will be so poor as to be not worth living or worse than no further life at all.<sup>82</sup>

Adopting an experience requirement limits best interests considerations to the benefits and burdens that specific incompetent patients can appreciate. Thus, burdens like loss of dignity and personal privacy should be influential only when they appear to matter to the patients themselves. Unless there is behavioral evidence that a patient cares about these things, they should be excluded from best interests evaluations.<sup>83</sup>

But there is also support for a more expansive view of patient interests. Some scholars join Justices Stevens and Brennan in arguing that considerations like loss of dignity should play a role, even when patients themselves are unconcerned about these matters. They share the *Visbeck* judge’s worry that, with a narrow approach to best interests evaluations, “large numbers of people will be thoughtlessly and automatically compelled to continue lives of intolerable bleakness.”<sup>84</sup> They believe that imposing an experience requirement will lead to best interests decisions that omit much of what is important about being human, treating patients as “little more than objects in the world.”<sup>85</sup>

The question is whether the expansive approach supplies sufficient protection to vulnerable incapacitated individuals. Empirical research shows that people living with disabilities report having a better quality of life than healthy people think they have.<sup>86</sup> There is a “disability perspectives gap” between how people with disabilities rate their lives and how nondisabled people rate them.<sup>87</sup> Without an experience requirement, the best interests standard could permit withholding or withdrawing treatment from cognitively impaired people living lives that are valuable to them.

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81. BUCHANAN & BROCK, *supra* note 30, at 124.

82. *Id.* In contrast, “interpersonal” or “social utility” quality-of-life assessments “rank the worth of [the] individual relative to the worth of others, usually for the purpose of calculating the costs and benefits of expending resources upon the person.” *Id.*

83. See, e.g., Howard Brody & William G. Bartholome, *In the Best Interests of . . .*, HASTINGS CTR. REP., Dec. 1988, at 37, 37 (“[F]or me to have an ‘interest’ in something, whether or not I have that something must *make a difference* to me; and this requires in turn that I have the mental capacity to be aware of that something, and of myself as possessing or lacking it.” (emphasis added)).

84. *In re Visbeck*, 510 A.2d 125, 133 (N.J. Super. Ct. Ch. Div. 1986).

85. Rhoden, *supra* note 38, at 409; see also PRESIDENT’S COUNCIL ON BIOETHICS, *supra* note 8, at 171 (stating that aggressive treatment “may turn the person entirely into an *object*” and “a mere receptacle of technical intervention”).

86. See Elizabeth F. Emens, *Framing Disability*, 2012 U. ILL. L. REV. 1383, 1389–90 (2012).

87. *Id.* at 1389.

Some scholars look to empirical information to help reconcile these two positions. The most sophisticated idea to date comes from Annette Rid and David Wendler.<sup>88</sup> Their proposal, called the “Patient Preference Predictor,” would rely on survey data obtained from a representative group of people in a specific area.<sup>89</sup> The survey would collect demographic data, experiences with medical care, attitudes and values relevant to quality of life, and preferences for resolving an array of treatment questions that commonly arise in the care of incompetent patients.<sup>90</sup>

Rid and Wendler suggest that this information would help decision makers apply the subjective standard to treatment decision-making by “predict[ing] which treatment option an incapacitated patient is most likely to prefer in the circumstances based on the patient’s own characteristics.”<sup>91</sup> In light of the law’s insistence that applications of the subjective standard rest on evidence of a patient’s actual expressed preferences, however, I think it is more likely that the survey information would be used in applications of the best interests standard to ascertain the views of a reasonable person in the patient’s situation.<sup>92</sup>

Yet the Patient Preference Predictor wouldn’t necessarily offer reassurance to people worried about protecting incompetent patients from biased quality-of-life assessments. Rid and Wendler would include patients and people with disabilities in the survey sample, collecting information from individuals who know what it is like to live with different health conditions.<sup>93</sup> But the survey would collect data only from competent individuals, thus excluding the vast majority of people with dementia.<sup>94</sup> Because few of the respondents would have personal perspectives on what it is like to live with dementia, survey findings could reflect inaccurate ideas about dementia patients’ quality of life.<sup>95</sup>

The Patient Preference Predictor and other empirical investigations would generate information on how the members of the general population think about the benefits and burdens of life-sustaining treatment, thus producing evidence-based reasonable person judgments. To protect incompetent patients, however, such empirical evidence should be supplemented by evidence gleaned from close and systematic examination of

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88. Annette Rid & David Wendler, *Use of a Patient Preference Predictor to Help Make Medical Decisions for Incapacitated Patients*, 39 J. MED. & PHIL. 104 (2014).

89. *Id.* at 119–20.

90. *Id.*

91. *Id.* at 105.

92. See Rebecca Dresser, *Law, Ethics, and the Patient Preference Predictor*, 39 J. MED. & PHIL. 178, 180 (2014).

93. See Rid & Wendler, *supra* note 88, at 12.

94. *Id.*; see Jason Karlawish et al., *The Ability of Persons with Alzheimer Disease (AD) to Make a Decision About Taking an AD Treatment*, 64 NEUROLOGY 1514, 1514 (2005) (finding majority of interviewees with mild to moderate Alzheimer’s disease incompetent to make treatment decisions).

95. As one expert observes, “people with dementia often come to terms with the consequences of their disease and adapt” to their new circumstances. C.M.P.M. Hertogh, *The Role of Advance Euthanasia Directives as an Aid to Communication and Shared Decision-Making in Dementia*, 35 J. MED. ETHICS 100, 101 (2009).

the individual patient whose care is at issue. Justice Stevens and other judges defending the inclusion of reasonable person concerns in best interests decision-making have recognized the need for such an examination, especially in cases involving conscious, incompetent patients. In the remainder of this article, I describe how this approach can promote patient protection while respecting community values on what makes life worth living.

#### IV. AN EVIDENCE-BASED APPROACH TO EVALUATING PATIENTS' INTERESTS

In his discussion of best interests evaluations for incompetent patients, Justice Stevens acknowledged the need for procedural safeguards, including a "searching inquiry" into the individual patient's actual interests.<sup>96</sup> Applying the best interests standard requires decision makers to examine what life is like for a specific incompetent patient, as well as to predict how various treatment options would change that life for good or for bad.

Some scholars wonder whether such an inquiry is legitimate. Skeptics claim that incompetent patients' interests are mysterious, too difficult for outside observers to determine.<sup>97</sup> A related criticism is that the standard is too vague, giving decision makers too much room for speculation about appropriate treatment choices.<sup>98</sup>

Such skepticism is misplaced, in my view. To be sure, our ability to gain access to the inner worlds of other people is limited. Yet, in everyday life, as well as formal legal proceedings, we rely on judgments about the mental states of others, including those of infants and other people whose intellectual capacities are quite different from our own.<sup>99</sup>

Excluding people with dementia from this process would have serious moral implications, dismissing our responsibilities to this population. As philosopher Grant Gillett observed, "If there is nothing it is like to be a thing of a certain type then our treatment of that thing does not directly matter in a way that counts morally."<sup>100</sup> Such an exclusion would also be impractical. Approximating the dementia patient's point of view is an essential part of interacting with people with dementia, something caregivers and clinicians do all the time.

Moreover, there is a wealth of information available to help decision makers assess dementia patients' subjective experiences. A rapidly expanding literature describes the experiences of people living with dementia and the conditions that can make life good or bad for them. Patients themselves are a major source of information. Many people with demen-

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96. *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261, 353 (1990) (Stevens, J., dissenting).

97. See Loretta M. Kopelman, *Why the Best Interest Standard Is Not Self-Defeating, Too Individualistic, Unknowable, Vague or Subjective*, 18 AM. J. BIOETHICS 34, 34 (2018).

98. See *id.*

99. For further discussion of these points, see Dresser, *Missing Persons*, *supra* note 60.

100. Grant Gillett, *Consciousness, the Brain and What Matters*, 4 BIOETHICS 181, 181 (1990).

tia retain the ability to communicate about matters relevant to treatment decision-making and more of them are writing and speaking about their situations.<sup>101</sup> People with close relationships to dementia patients are writing and speaking about the condition as well, relaying a more complex and positive account than popular stereotypes convey.<sup>102</sup>

These accounts often emphasize the ongoing abilities of people with dementia to engage in valuable parts of human life. For example, psychologist Steven Sabat writes about many interactions in which affected individuals “feel and show love for and gratitude toward others; . . . display and appreciate humor and other valued emotions; . . . have meaningful thoughts even if they are unexpressed in words; . . . express themselves creatively”; and exhibit a multitude of other strengths and abilities.<sup>103</sup> He also describes what families, clinicians, and other unaffected people must learn to effectively communicate and interact with affected individuals.<sup>104</sup>

In sum, a growing body of literature offers personal perspectives on dementia patients’ quality of life and the potential effects of administering different treatment interventions. Experts have developed behavioral techniques for assessing patients’ well-being too.<sup>105</sup> They have studied how dementia patients respond to interventions like feeding tubes.<sup>106</sup> They have also studied how patients respond to hospitalization and other disruptions that can accompany treatment, as well as ways to reduce such disruptions.<sup>107</sup> Legal authorities should recognize and promote the use of such measures in best interests evaluations.

Legal authorities should also guard against overly simplistic interpretations of patient responses. People lacking decision-making capacity, including people with dementia, often have preferences about how they want their lives to go. Although their intellectual disabilities prevent such individuals from making fully informed and autonomous choices, the val-

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101. See, e.g., N.R. Kleinfield, *Fraying at the Edges*, N.Y. TIMES (Apr. 30, 2016), <https://www.nytimes.com/interactive/2016/05/01/nyregion/living-with-alzheimers.html> [https://perma.cc/V8S7-SAHQ]; Paula Span, *Dementia Is Getting Some Very Public Faces*, N.Y. TIMES (Nov. 9, 2018), <https://www.nytimes.com/2018/11/09/health/alzheimers-dementia-celebrities.html> [https://perma.cc/ZV96-B6VP].

102. See, e.g., Sharon R. Kaufman, “*Losing My Self*”: A Poet’s Ironies and a Daughter’s Reflections on Dementia, 60 PERSP. BIOLOGY & MED. 549, 549–50 (2017); Janelle S. Taylor, *On Recognition, Caring, and Dementia*, 22 MED. ANTHROPOLOGY Q. 313, 314 (2008).

103. STEVEN R. SABAT, ALZHEIMER’S DISEASE AND DEMENTIA: WHAT EVERYONE NEEDS TO KNOW 203–04 (2018).

104. *Id.* at 177–92.

105. See, e.g., Hanneke C. Beerens et al., *The Association Between Aspects of Daily Life and Quality of Life of People with Dementia Living in Long-Term Care Facilities: A Momentary Assessment Study*, 28 INT’L PSYCHOGERIATRICS 1323, 1324 (2016).

106. See, e.g., Joan M. Teno et al., *Does Feeding Tube Insertion and Its Timing Improve Survival?*, 60 J. AM. GERIATRICS SOC’Y 1918, 1918 (2012) (finding absence of benefits from tube feeding in people with advanced dementia).

107. See, e.g., Saskia N. Sivanathan & Kimberlyn M. McGrail, *Diagnosis and Disruption: Population-Level Analysis Identifying Points of Care at Which Transitions Are Highest for People with Dementia and Factors That Contribute to Them*, 64 J. AM. GERIATRICS SOC’Y 569, 569 (2016) (noting the value of high quality primary care and recommended dementia care in reducing stressful hospitalizations and moves from one location to another).



ues of respect and liberty support giving them a role in decisions about the medical treatment they receive.<sup>108</sup> The emerging practice of supported decision-making gives incompetent patients such a role.<sup>109</sup> Yet, because incompetent patients are relatively susceptible to confusion, misunderstanding, and undue influence, their preferences shouldn't necessarily determine whether they receive treatment.<sup>110</sup>

Observers assessing the interests of incompetent patients must interpret patients' responses in light of their mental capacities. People unable to understand or remember the reasons for medical interventions are more likely to be frightened by the demands and effects of such interventions. Their incapacities can make even minor treatment efforts more burdensome than they would be for someone with a higher level of understanding.<sup>111</sup> On the other hand, patients' lack of understanding can reduce treatment burdens. For example, when people with dementia cannot comprehend that they are facing a life-threatening situation, they escape some of the psychological burdens typically experienced by competent people in such a situation.<sup>112</sup>

I don't mean to suggest that it's always easy to evaluate the interests of people with dementia. As in the case of Mary Hier, interpreting patients' behavior can be challenging. To the judges, Hier seemed to be expressing a wish to be left alone, even if the consequences would be discomfort and eventual death.<sup>113</sup> But critics of the ruling suggested that she was instead reacting to a change in her surroundings.<sup>114</sup> They cited evidence that she experienced hunger, based on her tendency to steal food from others.<sup>115</sup> They also pointed to evidence that she enjoyed her life, countering the image presented in the two court opinions.<sup>116</sup> As a result, they said, depriving Hier of nutrition would devalue her life and impose unacceptable burdens on her.<sup>117</sup>

Surrogate decision makers and clinicians must not allow patient preferences to become an automatic excuse for decisions to forgo life-sustaining measures.<sup>118</sup> The best response to the challenge of evaluating dementia

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108. See Jason Adam Wasserman & Mark Christopher Navin, *Capacity for Preferences: Respecting Patients with Compromised Decision-Making*, HASTINGS CTR. REP., May–June 2018, at 31, 35–36; see also Miller, *supra* note 36, at 2924–25 (arguing that incompetent patients' expressed preferences are a form of autonomy that should receive serious consideration in best interests decision-making).

109. See Renu Barton-Hanson, *Reforming Best Interests: The Road Towards Supported Decision-Making*, 40 J. SOC. WELFARE & FAM. L. 277, 280 (2018).

110. See Miller, *supra* note 36, at 2913–15.

111. See PRESIDENT'S COUNCIL ON BIOETHICS, *supra* note 8, at 171–92 (describing examples of this phenomenon).

112. See, e.g., Diana Whitney, *Dementia's Gift: Facing Cancer Without the Fear*, N.Y. TIMES (Mar. 16, 2018), <https://www.nytimes.com/2018/03/16/well/family/dementias-gift-facing-cancer-without-the-fear.html> [<https://perma.cc/CUY9-C9Q5>].

113. *In re Hier*, 464 N.E.2d 959, 964–65 (Mass. App. Ct. 1984).

114. Dresser, *Missing Persons*, *supra* note 60, at 655–56.

115. *Id.*

116. See *id.*

117. See Annas, *supra* note 58, at 25.

118. See Barton-Hanson, *supra* note 109, at 293; Miller, *supra* note 36, at 2924.

patients' interests is to require systematic and rigorous assessments of their capacities and perceptions, including any verbal or behavioral indications of their subjective quality of life and attitudes toward treatment. Legal authorities should require a thorough assessment by knowledgeable professionals and caregivers familiar with the individual patients' daily lives. Mandating assessment by multiple persons can reduce the chance that observer biases will improperly influence treatment choices.<sup>119</sup>

Legal authorities should also require decision makers to explore treatment alternatives to determine the least burdensome care options, including palliative measures when interventions are withheld or withdrawn. If it is difficult to predict how a specific patient will react to a medical intervention, authorities should advise a treatment trial to determine the patient's actual response. Measures like these can protect patients from unjustified decisions to administer or forgo life-sustaining interventions.

#### V. DETERMINING AN ACCEPTABLE RANGE OF BEST INTERESTS DECISIONS

Decisions based on the best interests standard are more defensible when supported by informed and systematic examinations of incompetent patients' subjective experiences. Such examinations will help decision makers develop a reliable picture of the positive and negative effects different treatment options could have on a patient.

But there is another essential element of the best interests evaluation: determining the balance of burdens and benefits that justifies a particular treatment decision. In *Conroy*, the New Jersey Supreme Court allowed life-sustaining interventions to be forgone only if they would lead to "recurring, unavoidable and severe pain" for incompetent patients.<sup>120</sup> As I have described, however, many courts, as well as scholars, favor a more expansive approach that allows nontreatment in a wider range of circumstances. Advocates for an expanded approach focus on two groups of patients. One group includes people with low levels of conscious awareness due to dementia. The other includes people who would experience considerable burdens if treatment were provided, although not the severe and unremitting pain that *Conroy* required.

Judges and scholars defending nontreatment in a broader range of situations than *Conroy* allows often focus on the situation of permanently unconscious patients like Nancy Cruzan. These judges and scholars take positions similar to those of Justices Stevens and Brennan, arguing that permanently unconscious patients lack the experiential interests that

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119. See Carolyn Johnston, *The Weight Attributed to Patient Values in Determining Best Interests*, 39 J. MED. ETHICS 562, 562–63 (2013) (describing case in which nursing home staff presented more positive view of dementia patient's life than family did).

120. *In re Conroy*, 486 A.2d 1209, 1232 (N.J. 1985).

could give them a personal stake in continued life.<sup>121</sup> Defenders of this position say that surrogate decision makers should be permitted to choose to forgo treatment, for there is good evidence that most competent persons would see this as a reasonable choice.

This argument cannot be applied in most cases involving people with dementia, however. End-stage dementia can produce unconsciousness, but treatment questions often arise before that stage. Dementia patients typically have experiential interests that best interests decisions must protect. What combination of benefits and burdens gives conscious patients a clear interest in receiving treatment? Conversely, in what situations are conscious dementia patients' interests in continued life slight or uncertain enough to permit forgoing treatment? Few judges and scholars offer in-depth analysis of these questions.

In an effort to promote such analysis, I offer the following thoughts. There are many different variables at play in individual patients' situations, so each dementia case requires its own benefit-burden analysis. At the same time, some general observations apply to patients sharing certain characteristics relevant to treatment decision-making.

By the time they enter the final stages of dementia, patients have lost many of their previous cognitive and physical capacities.<sup>122</sup> At some point, these patients appear "barely conscious,"<sup>123</sup> as was the case with Claire Conroy. She rarely responded to those around her, sometimes moaning when caregivers moved her or changed her bandages and sometimes smiling when they combed her hair.<sup>124</sup>

Their cognitive impairments leave patients like Conroy capable of experiencing sensations like pain and pleasure but not much else.<sup>125</sup> Patients reaching this stage of the disease also have a relatively limited life expectancy no matter what medical efforts are made.<sup>126</sup> Philosopher Dan Brock has argued that patients with severe dementia have "an interest in receiving pleasure . . . while, they continue to live, but not an interest in continuing to live in order to receive any pleasures that might be possible for them."<sup>127</sup> As long as they are kept comfortable in the dying process, many commentators think the best interests standard should permit decisions to forgo potentially burdensome interventions like feeding tubes.<sup>128</sup>

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121. The general consensus is that the small possibility of misdiagnosis or future cure is not enough to give such patients significant interests in continued treatment. See BUCHANAN & BROCK, *supra* note 30, at 126–32.

122. See generally Rebecca Dresser & Peter J. Whitehouse, *The Incompetent Patient on the Slippery Slope*, HASTINGS CTR. REP., July–Aug. 1994, at 6, 9.

123. Rhoden, *supra* note 38, at 376–77.

124. *Conroy*, 486 A.2d at 1217.

125. See Greg A. Sachs, *Dying from Dementia*, 361 NEW ENG. J. MED. 1595, 1595–96 (2009) (describing people with late-stage dementia).

126. See Susan L. Mitchell et al., *The Clinical Course of Advanced Dementia*, 361 NEW ENG. J. MED. 1529, 1535 (2009) (citing infections and eating problems as associated with low survival rates in people with advanced dementia).

127. Dan W. Brock, *Justice and the Severely Demented Elderly*, 13 J. MED. & PHIL. 73, 90 (1988).

128. See, e.g., Mitchell et al., *supra* note 126, at 1533–35; Sachs, *supra* note 125, at 1596.

Other dementia patients are severely impaired but more aware than Conroy was. People in this group resemble the patient in *Visbeck*, who was somewhat responsive to others and did not appear to be suffering.<sup>129</sup> Because placement of a feeding tube would not inflict the level of suffering *Conroy* described, the judge in that case ordered the procedure.<sup>130</sup> At the same time, he voiced his opposition to *Conroy*'s strict approach.<sup>131</sup> The demand for severe suffering, he contended, meant that patients like Elizabeth *Visbeck* would be condemned to lives of "intolerable bleakness."<sup>132</sup>

It's likely that many people would agree with this sentiment. For them, a decision to forgo treatment for someone in *Visbeck*'s situation would be respectful and reasonable as long as she could be kept comfortable during the dying process. Continued life offers such restricted benefits to patients like this that any potential treatment burdens are sufficient to justify nontreatment under the best interests standard. The discomfort, distress, fatigue, and other potential negative effects of medical interventions should be enough to permit nontreatment in these kinds of cases.

At the same time, many people with dementia remain capable of participating in activities and interactions that are meaningful to them.<sup>133</sup> They may be confused and unhappy at times, but they are for the most part content and comfortable. Although many competent people might consider such an existence unsatisfactory, even undignified, withholding low-burden treatments from patients like this would devalue the lives of individuals with significant experiential interests in continued life. Unless there is solid evidence that treatment would impose heavy burdens on such patients, the best interests standard should require a decision in favor of treatment.<sup>134</sup> Legal decision makers should require treatment trials and a search for less burdensome treatment alternatives before authorizing nontreatment of patients like *Mary Hier*.

## VI. CONCLUSION

Scholars assign two different roles to the best interests standard in legal and clinical decision-making. One is to "express moral, legal, medical, or other social goals or ideals that should guide choices."<sup>135</sup> In this role, the best interests standard encourages decision makers to focus on the individual patient's well-being and to recognize that a patient's subjective quality of life depends not only on health and medical care, but on living

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129. *In re Visbeck*, 510 A.2d 125, 130 (N.J. Super. Ct. Ch. Div. 1986).

130. *Id.*

131. *Id.* at 131.

132. *Id.* at 133.

133. *See supra* note 10 and accompanying text.

134. *See Hawkins, supra* note 72, at 508–09, 538.

135. Loretta M. Kopelman, *The Best Interests Standard for Incompetent or Incapacitated Persons of All Ages*, 35 J.L. MED. & ETHICS 187, 187 (2007).

situations, social interactions, and so forth.<sup>136</sup>

This aspirational part of the best interests standard has been neglected in the debate over treatment decision-making for people with dementia. Certain environmental and social conditions can make life better for people with dementia, offering ways to improve their subjective quality of life and reduce the burdens that life-sustaining interventions can impose. Decisions on life-sustaining care for dementia patients should take into account developments in this area.<sup>137</sup>

The best interests standard's second role is to delineate the scope of permissible decisions. The standard does not require decision makers to choose a single best option; instead, it requires them to choose an option within the "zone of discretion" for such decision makers.<sup>138</sup> Legal applications of the best interests standard delineate the kinds of decisions within the zone of discretion, as well as decisions exceeding the bounds of acceptability.

Ethicists and other scholars generally rely on the concept of reasonableness to establish the boundaries of best interests decision-making. But neither a legal nor scholarly consensus exists regarding reasonable decisions for a large number of conscious dementia patients. In what circumstances is it reasonable to withhold or withdraw life-sustaining treatment from patients like Conroy, Visbeck, and Hier? There is an urgent need for legal clarification of those circumstances.

The boundaries of acceptable best interests decisions for people with dementia are not as clear as they should be. According to the Supreme Court's *Cruzan* decision, authorities in the "laboratory of the states" are empowered to establish these boundaries.<sup>139</sup> State authorities have been too slow to exercise their responsibilities in this area. Families, clinicians, and the public need more legal guidance on permissible treatment options for people with dementia. Legal authorities must join with clinicians, scholars, and the public to develop an informed and defensible approach to protecting dementia patients' interests in decisions about life-sustaining treatment.

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136. See, e.g., Johan Christiaan Bester, *The Harm Principle Cannot Replace the Best Interest Standard: Problems with Using the Harm Principle for Medical Decision Making for Children*, 18 AM. J. BIOETHICS 8, 9 (2018); Janet Malek, *What Really Is in a Child's Best Interest? Toward a More Precise Picture of the Interests of Children*, 20 J. CLIN. ETHICS 175, 181 (2009).

137. See Shih-Yin Lin & Frances Marcus Lewis, *Dementia Friendly, Dementia Capable, and Dementia Positive: Concepts to Prepare for the Future*, 55 GERONTOLOGIST 237, 240–42 (2015); Antonio Guaita & Marc Jones, *A "Prosthetic" Approach for Individuals With Dementia?*, 305 JAMA 402, 402–03 (2011).

138. See Thaddeus Mason Pope, *The Best Interest Standard for Health Care Decision Making: Definition and Defense*, 18 AM. J. BIOETHICS 8, 36–37 (2018).

139. *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261, 292 (1990).