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# The Right to Refuse Life Sustaining Treatment and Competency: Potential Solutions to Protect and Promote Patient Autonomy

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# **The Right to Refuse Life Sustaining Treatment and Competency: Potential Solutions to Protect and Promote Patient Autonomy**

Andrew LaVigne

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## INTRODUCTION

Competent patients have the right to refuse life sustaining medical treatment. This so called “right to die” is recognized because of the value that medical ethics and the law attribute to individual autonomy in the context of end-of-life medical decisions. The choice to refuse life sustaining treatment is conditioned on the patient’s competency. Competent individuals are best situated to make treatment decisions because the outcome of these decisions ultimately affects their lives. Also competent patients are able to express their wishes regarding life sustaining treatment. Conditioning the removal of life sustaining treatment on the determination of an individual’s competency inevitably raises the issue over what exactly it means for someone to be competent. When courts address the issue of competency, the court’s determination is regarded as an objective one reached in light of the evidence.

However, in most cases it is not clear what the relevant considerations are when courts “objectively” determine an individual’s competence. Without a clear standard to deal with the issue of competency, courts will inevitably base their decisions on subjective considerations. For example, two individuals who are adequately able to utilize a rationale thought process in order to determine their wishes in regards to the course of their medical treatment can be treated by courts differently based a value-laden analysis regarding the patient’s quality of life and the desirability of the outcome of the patients medical treatment decision. Whether a person’s decision to refuse treatment is rational becomes independent of their competency to make the decision. Unfortunately, competency becomes dependent on considerations that are different from a patient’s ability to choose their treatment. In the absence of clear standards the competency analysis inevitably turns into a subjective determination that does not reflect an individual’s actual competence. Resulting decisions based on considerations reflecting

underlying values, which may not necessarily be shared by the patient in our diverse society, fail to promote the competent patient's autonomy and protect the incompetent patient from his choices. Persons who are incompetent to refuse life sustaining treatment could be allowed to do so while persons who are actually competent could have their request to withdraw life sustaining treatment denied, forcing them to relinquish control over invasive treatment of their own bodies. Decisions based on subjective considerations will inevitably fail patients faced with these difficult circumstances. If the law's objective is to promote the competent individual's autonomy, then standards should be used to accurately determine competency.

This article examines competency determinations by courts when the individual is conscious and in a position to receive life sustaining treatment. This article seeks to establish that competency determinations, while labeled an objective determination, inevitably rely on subjective inquiries that do not reflect the competency or intent of individuals who allege that they want to discontinue life sustaining treatment. Part I will discuss the establishment and sources of the right to refuse life sustaining treatment. Part II examines competency, its vagueness, and will discuss judicial evaluations in cases involving the refusal of life sustaining treatment, where the issue of an individual's competency is raised. Part III advocates potential solutions to protect patient autonomy by making parties less reliant on the courts, so that determinations of competency better reflect the actual competency of a person refusing life sustaining treatment.

# I. THE RIGHT TO REFUSE TREATMENT

## A. Autonomy and Informed Consent

The right to refuse medical treatment, also known as the right to die, is rooted in the doctrine of informed consent developed by the law and principles of medical ethics. Generally, medical ethics focuses on three principles: autonomy, beneficence, and non-maleficence.<sup>1</sup> Autonomy refers to the principle that an individual has a right to make decisions regarding medical treatment because individuals are the sovereigns of their bodies.<sup>2</sup> In its purest form, autonomy presumes that no other person or institution should be allowed to overrule individual choice, regardless of whether the individual came to the “right” choice from another’s perspective.<sup>3</sup> Beneficence represents the principle in medical ethics that a physician has a duty to provide health care in the best interests of their patients, while non-maleficence represents the physician’s duty not cause harm to their patients.<sup>4</sup> Autonomy is counterbalanced in medical care and the law by paternalism. Paternalism reflects the notion that individuals other than the patient themselves desire to make medical treatment decisions on their behalf in what is perceived to be the patient’s best interest.<sup>5</sup>

Historically, in medical care, the purpose of disclosing information was not for the sake of the patient so he could make a decision regarding his care, but for the sake of the physician in order to get the patient to agree to what the doctor wanted.<sup>6</sup> Over the course of the nineteenth century, the doctrine of informed consent developed out of a strong judicial deference toward individual autonomy, the belief that individuals should be free from the interference of others

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<sup>1</sup> James E. Szalados, *Discontinuation of Mechanical Ventilation at End-of-Life: The Ethical and Legal Boundaries of Physician Conduct in Termination of Life Support*, in 23 CRITICAL CARE CLINICS 317, 319 (2007).

<sup>2</sup> *Id.*

<sup>3</sup> BARRY R. FURROW ET AL., HEALTH LAW: CASES, MATERIALS AND PROBLEMS 1420 (6th ed. 2008).

<sup>4</sup> Szalados, *supra* note 1, at 319-20

<sup>5</sup> *Id.* at 319

<sup>6</sup> FURROW ET AL., *supra* note 3, at 231

and accordingly should not be forced to act against their will.<sup>7</sup> The principle of autonomy applied to the medical context was articulated by Judge Cardozo when he stated “every human being of adult years and sound mind has a right to determine what shall be done with his own body.”<sup>8</sup> Stated briefly, the common law doctrine of informed consent stands for the proposition that “no medical procedure may be performed without a patient’s consent, obtained after explanation of the nature of the treatment, substantial risks, and alternative therapies.”<sup>9</sup>

## **B. Foundation of the Right to Refuse Medical Treatment**

The first United States Supreme Court case to deal with the issue of whether there is a constitutionally protected “right to die” was *Cruzan v. Director, Missouri Department of Health*.<sup>10</sup> The case involved Nancy Cruzan who became comatose as a result of an automobile accident.<sup>11</sup> Nancy Cruzan’s parents decided that they wanted to remove her from life sustaining treatment when it became clear that their daughter would not recover.<sup>12</sup> The hospital refused to remove artificial hydration and nutrition from her until there was a court order to do so.<sup>13</sup> The Supreme Court of Missouri found that Missouri law required a showing of clear and convincing evidence of an individual’s intent to remove life sustaining treatment and subsequently determined that there was insufficient evidence to meet that standard.<sup>14</sup> The United States Supreme Court upheld the Missouri Supreme Court’s decision on the basis that the State had an interest in protecting life.<sup>15</sup> The Court recognized that the right to die *could* be inferred from their earlier decisions based on the liberty interest in the Fourteenth Amendment and assumed “for the

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<sup>7</sup> *Id.* at 230-32

<sup>8</sup> *Id.* at 231(citing *Schloendorff v. Society of New York Hospital*, 211 N.Y. 125 (1914))

<sup>9</sup> SZALADOS, *supra* note 1, at 320 (quoting Cantor, *A Patient’s Decision to Decline Life-Saving Medical Treatment: Bodily Integrity Versus the Preservation of Life*, 26 RUTGERS L. REV. 228, 43 (1973))

<sup>10</sup> 497 U.S. 261 (1990)

<sup>11</sup> *Id.* at 265-68

<sup>12</sup> *Id.* at 267

<sup>13</sup> *Id.*

<sup>14</sup> *Id.* at 267-69

<sup>15</sup> *Id.* at 279-85

purposes of this case... that the United States Constitution would grant a competent person a constitutionally protected right to refuse lifesaving hydration and nutrition.”<sup>16</sup> Although the Court avoided actually holding that the constitution grants the “right to die,” many authoritative sources presumed that the opinion recognized a constitutionally protected liberty interest rooted in the fourteenth amendment allowing a competent person to refuse unwanted medical treatment.<sup>17</sup>

Aside from the United States Constitution, there are three sources that courts generally refer to as the basis of right to refuse medical treatment: state constitutions, state law, and the common law doctrine of informed consent.<sup>18</sup> Some courts, such as the California Court of Appeals in *Bouvia v. Superior Court*, upheld the patient’s right to have life sustaining treatment removed based on the express right of privacy found in California’s constitution.<sup>19</sup> The right to refuse treatment can also be exercised through statutorily created advanced directives. The premise of advanced directives is to encapsulate patient intent so that their wishes may be executed in the event that those wishes can no longer be determined from the patient themselves. However, such documents tend to run into issues of interpretation and ambiguity due to the unpredictability inherent in the end of life treatment context; situations can arise during which an advanced directive does not give much guidance.<sup>20</sup>

### **C. Countervailing State Interests**

The ethical and legal justification supporting an individual’s choice to refuse life sustaining treatment is primarily rooted in recognition of individual autonomy from which the common law doctrine of informed consent developed. The issue over whether individuals should

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<sup>16</sup> *Id.* at 279

<sup>17</sup> *Id.* at 1420

<sup>18</sup> *See Cruzan*, 497 U.S. at 269-74

<sup>19</sup> 179 Cal.App.3d 1127, 1137 (Ct. App. 1986)

<sup>20</sup> SZALADOS, *supra* note 1, at 312-22

be allowed to refuse life sustaining treatment is controversial in the end of life context, especially when compared to other medical treatment choices. This is because of the stakes that are involved; the individual's choice regarding the course of treatment foreseeably affects whether that person lives or dies. When an individual decides that they do not wish to continue life sustaining treatment, the principles of autonomy and beneficence conflict. On the one hand we want to allow persons to make their own decisions regarding their own treatment, but when their decision foreseeably results in death, from an external perspective it would seem that the patient is choosing a course of action that results in bodily harm against their interest. Despite our society's reverence for individual autonomy and the law's emphasis on autonomy in the context of medical treatment, the advent of life sustaining treatment has created a contentious debate over the limits of autonomy. The fundamental issue related to this conflict is where the law draws the line between suicide and refusal of life sustaining medical treatment.

As Justice Scalia noted in his concurrence in *Cruzan*, the law in America has long recognized the power of the State to prevent individuals from committing suicide.<sup>21</sup> In addition to the prevention of suicide courts have commonly identified other state interests which justify preventing the cessation of life sustaining treatment. In *Superintendent of Belchertown State School v. Saikewicz* the Supreme Court of Massachusetts identified four state interests which conflict with the right to die: (1) preservation of life; (2) protection of the interests of innocent third parties; (3) prevention of suicide; and (4) maintenance of the ethical integrity of the medical profession.<sup>22</sup> Although this particular case involved an incompetent patient, the interests of the state asserted there have also been cited in cases involving competent patients.<sup>23</sup> When patients

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<sup>21</sup> *Cruzan*, 497 U.S. at 293 (Scalia, J., concurring)

<sup>22</sup> 373 Mass. 728, 741 (1977)

<sup>23</sup> FURROW ET AL., *supra* note 3, at 1432

attempt to exercise their autonomy at the end of life, courts balance the patient's autonomy against state interests.

The debate over whether or not an individual can actually exercise the right to refuse life sustaining medical treatment revolves around the determination of competence which consequently is a question of the intent of the patient. This is because autonomy is the basis for the legal doctrine of informed consent and therefore the right to refuse medical treatment. Without requiring a sufficient showing of the patient's intent to refuse medical treatment, a patient could be forced to accept treatment decisions against his will, thereby violating the principle of autonomy. The stronger the showing of a competent patient's intent, regarding end of life medical treatment, the greater the balance between state interests and individual autonomy tips in favor of autonomy.

As a whole our society disfavors medical treatment decisions which will result in the death of the patient, a bias which is evidenced by the increasing costs of palliative care that we have seen in recent years. While suicide itself is no longer treated as a criminal act, aiding and abetting or soliciting suicide both represent acts that are generally criminalized in state statutes.<sup>24</sup> If the intent of the patient who refuses life sustaining treatment is simply to die, and a court believes that the patient was incompetent, then the removal of life sustaining treatment is not viewed as a medical treatment decision, but as suicide. The most obvious issue is whether paternalism, deciding what is best for the patient, can be exercised by the courts in a manner that does not deprive competent patients of their autonomy and subsequently their right to refuse life sustaining treatment.

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<sup>24</sup> SZALADOS, *supra* note 1, at 327

## II. DETERMINING PATIENT COMPETENCY

### II A. Variance in the Competency Standard

The determination of whether a patient is competent to make decisions regarding medical treatment is far from a straightforward evaluation; in reality it is a convoluted process, particularly when a patient refuses life saving medical treatment. Courts overall have been unwilling to clearly define standards for competency<sup>25</sup> and generally rely on physician determinations of decision making capacity.<sup>26</sup> The authors of a seminal article detailing judicial standards for competency, *Tests of Competency to Consent to Treatment*,<sup>27</sup> argued that a clear test for incompetence was unlikely stating “[t]he search for a single test of competency is a search for the Holy Grail,” due to the different contexts in which we try to evaluate competence.<sup>28</sup> Considering the negative consequences for a patient’s autonomy and subsequently their right to refuse medical treatment, with the stakes especially high in the context of terminal illness, this vagueness in the law is a critical issue because it provides an opening for subjective considerations to unduly influence judicial analysis when determining whether a patient is capable of making informed decisions regarding the course of their care.

Before discussing what legal and medical commentators articulate as the legal standard of competency, it is worth noting that there is a difference between a physician’s determination that a patient possesses decision making capacity versus a court determination that an individual is

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<sup>25</sup> John Robertson, *The Geography of Competency*, 52 SOCIAL RESEARCH 555, 561 (1985) (citing V. Abernathy, *Compassion, Control, and Decisions About Competency*, 140 AMERICAN JOURNAL OF PSYCHIATRY 53-5 (1984)).

<sup>26</sup> Thomas Hafemeister, *Guidelines for State Court Decision Making in Life-Sustaining Medical Treatment Cases*, 7 ISSUES IN LAW & MEDICINE 443-75 (1992), <http://ezproxy.shu.edu/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=f5h&AN=9608050460&site=eds-live>.

<sup>27</sup> Joseph J. Fins *et al.*, *Ethical, Legal, and Psychiatric Issues in Capacity, Competency, and Informed Consent: An Annotated Bibliography*, 18 GENERAL HOSPITAL PSYCHIATRY 155, 58 (1996).

<sup>28</sup> FURROW ET AL., *supra* note 3, at 1448 (quoting Charles W. Lidz *et. al.*, *Tests of Competency to Consent to Treatment*, 134 AM. J. PSYCHIATRY 279, 283 (1977)).

competent to refuse medical treatment.<sup>29</sup> Competence relates to “the mental cognitive abilities to perform a legally recognized act rationally,” while decision making capacity is a medical term which “relat[es] to the ability to make decisions in the direction of care, based on standards generally used by the court system.”<sup>30</sup> The latter is a determination made by the patient’s primary physician, not a judge.<sup>31</sup>

The goal of the competency analysis is to determine whether patients have made authentic decisions for the course of their medical treatment.<sup>32</sup> However, because competency involves an evaluation made by persons other than the patient, there exists the risk that a patient’s wishes will be overridden if others view the patient’s choice as irrational.<sup>33</sup> Put succinctly, competence refers to the patient’s ability to perform a specific task, in this case the ability of a patient to make medical treatment decisions.<sup>34</sup> The ability to make medical treatment decisions requires the patient to understand the nature and consequences of a particular course of action.<sup>35</sup> There is general agreement over what competence generally means, but the issues surrounding competence involve what evidence constitutes proof of competence and how that evidence is interpreted.<sup>36</sup>

In *Tests of Competency to Consent to Treatment* the authors assert, based on an analysis of legal literature and judicial commentary, that there exist several tests that courts use to

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<sup>29</sup> Ruth Lagman and Maria Aileen Soriano, *When the Patient Says No*, 29 AM. J. HOSP. PALLIAT. CARE 401, 402 (2012).

<sup>30</sup> *Id.*

<sup>31</sup> *Id.*

<sup>32</sup> Allen C. Snyder, *Competency to refuse lifesaving treatment: Valuing the nonlogical aspects of a person’s decisions*, 10 Issues in Law & Medicine 299 (1994), <http://ezproxy.shu.edu/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=f5h&AN=9502074425&site=eds-live>

<sup>33</sup> *Id.*

<sup>34</sup> ROBERTSON, *supra* note 25, at 561-62

<sup>35</sup> *Id.* at 562

<sup>36</sup> *Id.*

determine competency.<sup>37</sup> According to the authors, the standards used to determine competency generally fall into one of five categories: (1) evidencing a choice, (2) “reasonable” outcome of choice, (3) choice based on “rational” reasons, (4) ability to understand, and (5) actual understanding.<sup>38</sup>

The first test sets a very low threshold for competency and is therefore the most protective of autonomy; it only requires that the patient is able to show a preference for or against treatment.<sup>39</sup> An external evaluation of the “quality” of the patient’s choice regarding care is not a relevant consideration.<sup>40</sup>

The second test, by contrast, involves a qualitative evaluation of the patient’s decision and its outcome. The patient must reach the “reasonable” or “right” decision. How the patient came to that decision is not a relevant consideration, if the decision is not “reasonable” then the court will determine that the patient is incompetent.<sup>41</sup> The authors note that this test is used “more often than might be admitted by physicians and courts.... [w]hen life is at stake and a court believes that the patient’s decision is unreasonable, the court may focus on even the smallest ambiguity in the patients thinking to cast doubt on the patient’s competency.”<sup>42</sup>

Courts which base their analysis on what a reasonable person would do under the circumstances undermine the purpose of the competency analysis if the law genuinely seeks to protect the autonomy of the competent patient. Patients who are able to decide their choices with certainty through a rational thought process, but come to a decision that is deemed unreasonable, will be found by the court to be incompetent to make decisions regarding their medical

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<sup>37</sup> Charles W. Lidz *et al.*, *Tests of Competency to Consent to Treatment*, 134 AM. J. PSYCHIATRY 279 (1977), as reprinted in FURROW ET AL., *supra* note 3, at 1444

<sup>38</sup> *Id.*

<sup>39</sup> *Id.*

<sup>40</sup> *Id.*

<sup>41</sup> *Id.*

<sup>42</sup> *Id.*

treatment. The patient effectively loses control over their own bodies. The converse of this outcome is also possible. A patient who is unable to effectively determine their own wishes, but nevertheless comes to the proper conclusion supported by the physician or the court, under this test is deemed to be competent. Either result is a judicial determination that jeopardizes the legal right of a competent person to make their own medical treatment decisions. To illustrate the point, the authors mention courts which find a patient's choice to refuse a blood transfusion based on their religious beliefs is an unreasonable refusal of medical care.<sup>43</sup>

The third test, whether the patient's choice is based on "rational" reasons, evaluates the patient's choice by determining whether that choice is due to mental illness.<sup>44</sup> Where the second test focuses on the reasonableness of the *outcome* this test focuses on the rationality of the patient's *decision making process*. Similar to the prior test, the patient's competence is rarely questioned if they consent to the course of treatment; the ability of a patient to make decisions regarding their medical care that reflect their wishes is not the measure of competence in this test.<sup>45</sup>

The fourth test, the ability to understand, involves the patient's ability to understand the risks, benefits and alternative courses of treatment.<sup>46</sup> The authors note that this test synergizes best with the doctrine of informed consent out of the various competency tests.<sup>47</sup> The fact that a patient weighs various criteria differently or chooses an outcome at odds with the recommendation of the physician does not mean that the patient is incompetent per se. The test determines competency based on the patient's ability to comprehend and manipulate these

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<sup>43</sup> *Id.*

<sup>44</sup> *Id.* at 1445

<sup>45</sup> *Id.*

<sup>46</sup> *Id.*

<sup>47</sup> *Id.*

elements in order to come to a decision regarding their care.<sup>48</sup> As with informed consent, perfect knowledge is not required in order to demonstrate understanding.<sup>49</sup>

Under the final test, called the “actual understanding” test, competency is not a legal construct or the weighing of variables regarding treatment decisions, but whether the patient provides a knowledgeable consent to treatment.<sup>50</sup> The authors state that this test is more reliable than the ability to understand test, despite the vagueness of actual understanding, because the test does not make the same assumptions that the prior test makes in regards to different medical choice decisions of similar complexity.<sup>51</sup> Under the ability to understand test, if a patient shows that he can understand a medical decision involving a certain level of complexity, if other medical treatment choices are similarly complex, the patient is competent to make those decisions as well. The actual understanding test does not make this assumption; thus it determines the competence of a patient to make a treatment decision in every instance a decision is made.<sup>52</sup>

When courts weigh in on the balance between the state interest of preserving life and the patient’s right to refuse medical treatment, some scholars argue that courts tend to rule in favor the state’s interests over patient autonomy, regardless of the patient’s capacity to make decisions regarding medical treatment.<sup>53</sup> It is also argued that courts articulate different standards of competency with various thresholds in order to achieve desired medical and social outcomes which reflect a strong societal bias in favor of treatment; if a patient refuses treatment when the court perceives the benefits of the treatment to greatly outweigh the risks, the more likely a court

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<sup>48</sup> *Id.*

<sup>49</sup> *Id.* at 1446

<sup>50</sup> *Id.*

<sup>51</sup> *Id.*

<sup>52</sup> *Id.*

<sup>53</sup> See e.g., Nancy Dubler & David Nimmons, *Ethics on Call* 26 (1992).

will utilize a higher standard of competency that the patient must overcome in order to exercise their right to refuse medical treatment.<sup>54</sup> Similarly, it has been observed that physicians are more likely to raise the issue of a patient's decision making capacity only if the patient refuses the physician's recommended course of treatment.<sup>55</sup> The law's aversion to articulating set standards for competency, and consequentially the vagueness surrounding the competency doctrine, allows courts to analyze medical treatment decisions with greater scrutiny based on subjective values instead of the patient's ability to perform the task of choosing the course of their medical treatment. This is not necessarily intentional, but may occur because of "strong societal bias in favor of treating treatable patients so long as it does not expose them to serious risks."<sup>56</sup>

Due to the abstract nature surrounding the judicial analysis of patient competency, it is not surprising that courts inevitably engage in discussion over subjective inquiries, such as the quality of a person's life, when determining whether or not that person is competent to refuse life sustaining treatment.<sup>57</sup> Often, courts utilize the tests for applying the concept of competency to individuals inconsistently; this may be due to underlying value positions which influence how judges view the outcome of a patient's decision and how the patient "should" exercise their autonomy.<sup>58</sup> If competency is a reflection of values regarding the worth of life and not a reflection of a patient's ability to make medical treatment decisions, then such biases must be acknowledged and accounted for if the law seeks to protect individual autonomy. The case of *Bouvia v. Superior Court* is a transparent example of a court which was influenced by value judgments concerning the quality of life of a patient who refused life sustaining treatment, a

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<sup>54</sup> See FURROW ET AL., *supra* note 3, at 1447 (discussing the authors' conclusion that when the benefit of treatment is likely to far outweigh the risk, in the mind of the evaluator, there is likely to be a low standard of competency when the patient consents and a high standard for competency when the patient refuses).

<sup>55</sup> ROBERTSON, *supra* note 25, at 573

<sup>56</sup> FURROW ET AL., *supra* note 3, at 1448 (quoting Charles W. Lidz *et. al.*, *Tests of Competency to Consent to Treatment*, 134 AM. J. PSYCHIATRY 279, 283 (1977)).

<sup>57</sup> ROBERTSON, *supra* note 25, at 564

<sup>58</sup> *Id.*

consideration that should be irrelevant in determining whether a patient is competent, but nevertheless was a central aspect of the court's opinion.<sup>59</sup>

## **II B. Judicial Evaluation of Competency**

The California case of *Bouvia v. Superior Court* is illustrative of the shortcomings of judicial efforts to evaluate competency. The vagueness surrounding the application of the legal doctrine of competency opens the flood gates to justices' subjective biases which influence their analysis of the patient's competence, potentially depriving patients of their right to control what is done to their own bodies for reasons that independent of the patient's ability to make decisions for their medical care.

*Bouvia* involved a twenty-eight year old woman, Elizabeth Bouvia, who was born with cerebral palsy and was a quadriplegic.<sup>60</sup> Due to her illness, she was immobile and therefore totally dependent upon others to care for her basic needs.<sup>61</sup> She expressed her desire to die and attempted to do so by starving herself to death.<sup>62</sup> When the medical staff became worried that her weight loss posed a threat to her life, they inserted a feeding tube against her will, which was contrary to her express instructions.<sup>63</sup> The Court in *Bouvia* noted that "a person of adult years and unsound mind has the right, in the exercise of control over his own body, to determine whether or not to submit to lawful medical treatment."<sup>64</sup>

Despite the Court's declaration that a competent individual has the right to refuse medical treatment, the Court did not actually define competency. Additionally the opinion devoted few

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<sup>59</sup> *Bouvia v. Superior Court*, 179 Cal.App.3d 1127 (1986)

<sup>60</sup> *Id.* at 1135

<sup>61</sup> *Id.* at 1136

<sup>62</sup> *Id.* at 1136-37

<sup>63</sup> *Id.* at 1137

<sup>64</sup> *Id.* (citing *Cobbs v. Grant* 8 Cal.3d 229, 242 (1972))

words to its determination that Elizabeth Bouvia was competent.<sup>65</sup> Considering that competency is the linchpin in the legal analysis of a patient's ability to refuse medical treatment, it is surprising that the Court spent very little of its opinion on the subject. Equally surprising is the Court's lengthy discussion of the qualitative aspects of Elizabeth Bouvia's life<sup>66</sup>; in fact the Court explicitly stated that "the trial court mistakenly attached undue importance to the *amount of time* possibly available to the petitioner, and failed to give equal weight and consideration for the *quality* of that life; an equal, if not more significant, consideration."<sup>67</sup> The Court's elusive discussion regarding Elizabeth Bouvia's competency, coupled with the Court's overwhelming reliance on a qualitative assessment of the patient's life, suggests that whether Elizabeth Bouvia was competent depended on the quality of her life, not on her actual capacity to make a medical treatment decision. If competency is linked to qualitative assessments, which are subjective by nature, then the legal system cannot reliably protect patient autonomy.

An amicus curiae brief by Westside Self Advocates pointed out to the Court in *Bouvia* that if a nondisabled person with Elizabeth Bouvia's history of suicidal thoughts and emotional trauma were to refuse nutrition they would be diagnosed as suicidal and offered psychiatric treatment.<sup>68</sup> Assuming that the claim in the amicus curiae brief is true it provides more credence to the premise that courts will view the refusal of life sustaining treatment by a disabled patient who is terminally ill, not as suicide committed due to mental illness, but as a competent act by a person who does not have as much to live for as a healthy individual. Whether a person is

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<sup>65</sup> *Id.* at 1136, 42 ("She is intelligent, very mental competent. She earned a college degree.... It is indisputable that petitioner is mentally competent. She is not comatose. She is quite intelligent, alert and understands the risks involved."). This language constitutes the extent of the court's discussion involving whether Elizabeth Bouvia was competent and why that was the case.

<sup>66</sup> *See id.* at 1136, 42-44

<sup>67</sup> *Id.* at 1142

<sup>68</sup> Stanley S. Herr, *No Place to Go: Refusal of Life Sustaining Treatment by Competent Persons with Physical Disabilities*, 8 ISSUES IN LAW & MEDICINE 3 (1992), <http://ezproxy.shu.edu/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=f5h&AN=9608050469&site=eds-live>

physically disabled has no place in the competency evaluation, or at the very least only a tangential role in determining whether a person's choice is due to their *own* view of their life circumstances causing depression or other cognitive impairments that may affect the competency of the decision making. The problem is that it is assumed that these patients are competent because they live with circumstances that healthy individuals would not want to live with. But, this is not a determination of a person's competency; it is a ruling on the quality of a person's life and as such does nothing to protect vulnerable patients who are unable to exercise their autonomy to make an informed medical treatment decision.

After the California Supreme Court confirmed Elizabeth Bouvia's request to remove herself from life sustaining treatment, she changed her mind and decided to accept the care necessary to maintain her life.<sup>69</sup> The *Bouvia* Court's reliance on the patient's quality of life implies that individuals who, in the opinion of the court, have a poor "quality of life" will be held competent to refuse life sustaining treatment, regardless of whether they are able to make health care decisions in their own interests.<sup>70</sup>

Contrast the results of *Bouvia* with the more recent New Jersey case *In re J.M.*<sup>71</sup> This case involved a terminally ill patient who was admitted to the hospital with end-stage renal disease, hypertension, uremia, anemia, and lupus.<sup>72</sup> When she was admitted to the hospital, she consented to a blood transfusion to alleviate her symptoms of anemia,<sup>73</sup> but refused dialysis treatment contrary to medical advice based on her belief that "machines that duplicate bodily

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<sup>69</sup> FURROW ET AL., *supra* note 3, at 1431

<sup>70</sup> *See generally* HERR, *supra* note 68 (asserting that persons with severe disabilities exhibit depressive disorders which affect their decision making processes, but judicial and societal biases lead most non-disabled individuals to believe that a disabled person who chooses to end their life is making a rational decision, due to their perceived quality of life, independent of the patient's actual decision making process); *see also* SNYDER, *supra* note 32 (arguing that courts should take into consideration depression when determining patient competency).

<sup>71</sup> 416 N.J. Super. 222 (Ch. Div. 2010)

<sup>72</sup> *Id.* at 224-226. J.M. had a medical history of renal disease, hypertension, and lupus.

<sup>73</sup> *Id.* at 226

functions overly intrude into God’s domain.”<sup>74</sup> The hospital’s own psychiatrists disagreed over J.M.’s decision making capacity.<sup>75</sup> The psychiatrists who believed that J.M. lacked capacity argued that J.M. did not acknowledge the risk of refusing treatment, stating that according to J.M., God would cure her kidneys and prevent her from dying.<sup>76</sup> The supporting psychiatrist argued that J.M. was making a voluntary choice, understood the consequences, and had the capacity to refuse dialysis.<sup>77</sup> J.M. told him that she was aware that she might die;<sup>78</sup> when the court directly asked J.M. if she was aware of the consequences of refusing treatment she responded “I understand what they are saying to me... I’m going to die, and I say I shall live and not die.”<sup>79</sup> The psychiatrist further noted that it is not unusual for patients to disagree with their doctor’s findings and that many mentally sound patients have religious beliefs that are considered delusional, “while those same beliefs when held by a group of people are considered a religion.”<sup>80</sup> J.M. also testified that she had seen other patients placed on dialysis and stated that they seemed “tired and drained” due to the procedure and that she did not want to experience the side effects of the treatment.<sup>81</sup>

The Court found that J.M. was both competent to accept blood transfusions and to execute a resuscitation order, and incompetent to refuse dialysis because she was unable to properly “weigh the options.”<sup>82</sup> The Court relied on the inconsistency of her medical choices in coming to its decision by stating “[s]he refused to acknowledge the risk inherent in her refusal of

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<sup>74</sup> *Id.* at 227

<sup>75</sup> *Id.* at 224

<sup>76</sup> *Id.* at 227

<sup>77</sup> *Id.* at 230

<sup>78</sup> *Id.* at 229

<sup>79</sup> *Id.* at 229-30. J.M. explicitly states that she understands the doctor’s view of the probable outcome of her decision to refuse treatment, but still she refuses based on her religious beliefs. Contrast her refusal of medical care because of her belief that God will cure her and that machines overreach into God’s domain with the beliefs of Christian Scientists who refuse all medical treatment based on their belief that prayer invokes God’s healing power.

<sup>80</sup> *Id.* at 229

<sup>81</sup> *Id.*

<sup>82</sup> *Id.* at 232

treatment and through her other medical choices had demonstrated an unequivocal desire to live.”<sup>83</sup> The Court noted that she had no long-lasting psychiatric disability.<sup>84</sup>

It is difficult to reconcile the different results of *Bouvia* and *In re J.M.* Courts have been less able to sympathize with patients who have unusual religious beliefs versus cases where patients have a disability that lowers their “quality of life.”<sup>85</sup> Most of society would not choose to withhold life sustaining treatment based on a religious objection. Elizabeth *Bouvia* was a disabled, terminally ill patient, with a history of depression, while J.M. was a terminally ill patient, who was not disabled, and did not have a history of depression or other mental illness. The only discrepancy is the presence of a physical disability. While judges are able to sympathize with a disabled patient who refuses treatment because they want to end their life, they are less willing when the patient refuses treatment due to a religious objection based on a belief not held by society at large. Different patients rationally decide medical treatment decisions based on their evaluation of competing factors that vary in importance from person to person. Given that this medical decision making process is unique for every person, courts should not weigh in on the “rationality” of patient’s thought processes (which arguably is not an evaluation of the rationality of the process itself, but an evaluation of the rationality of the weight that a person gives to a particular element in their thought process) or the desirability of the outcomes of patient’s medical treatment decisions, if the law seeks to protect patient autonomy. Equally important is the need of courts to not shape shift the test of competency to conform with subjective biases. Setting the bar higher or lower based on whether the court believes a person has a certain quality of life does not protect autonomy, but altogether undermines it.

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<sup>83</sup> *Id.* An ironic conclusion, considering the Court’s own inconsistency by holding J.M. is both competent to make some medical treatment decisions and incompetent to make others.

<sup>84</sup> *Id.*

<sup>85</sup> FURROW ET AL., *supra* note 3, at 1436-37

### III. POTENTIAL SOLUTIONS

Competency is not by any means an easy determination to make due to the assortment of legal issues and fact patterns that arise.<sup>86</sup> Even amongst physicians, there is disagreement over how to best measure a patient's decision making capacity.<sup>87</sup> Often courts have encouraged their legislatures to take steps in order to resolve these issues.<sup>88</sup> Many courts in the years following the Supreme Court's decision in *Cruzan* have argued that life sustaining medical treatment decisions are inherently private decisions which should be resolved by discussions between the patient, their physician, and their family.<sup>89</sup> Legislation has the potential to create viable alternatives to the legal system that adequately safeguard patient autonomy and reduce the risk that competent patients will be unable to exercise their right to refuse medical treatment due to subjective considerations. State lawmakers should pass legislation which requires the use of mediation in end of life disputes and allows individuals with terminal illnesses to seek physician aid in ending their lives without requiring court approval, but using courts as a forum of last resort. In addition we see that right to die legislation has been gaining traction in the United States with more ballots be voted on in states such as Massachusetts.<sup>90</sup> These are cases of terminally ill individuals who in other states would have to go before a court and may not be allowed to refuse life sustaining treatment depending on the severity of their illness and whether they are actually being maintained by life sustaining treatment. The purpose of these proposed solutions is to

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<sup>86</sup> HAFEMEISTER, *supra* note 26

<sup>87</sup> See, Barry Edelstein *e.t. a.l.*, *Empirical advances in the assessment of the capacity to consent to medical treatment: Clinical implications and research needs*, 26 CLINICAL PSYCHOLOGY REVIEW 1054, 1063 (2006) (analyzing studies which found that physicians inconsistently weigh different cognitive abilities in capacity assessments due to their specialty, their personal biases, and whether the patient refuses treatment or accepts treatment).

<sup>88</sup> HAFEMEISTER, *supra* note 26, n.21

<sup>89</sup> *Id.*

<sup>90</sup> See *infra* III B. i. Public Opinion,

create a safety valve that allows a patient to exercise their autonomy at the end of life in a manner that does not require them to litigate their issues in an adversarial context, but involves others in the decision making process so that patients are still protected from making irrational decisions.

### **III A. Mediation**

Mediation is a potential solution to the use of courts in disputes over the withdrawal of life sustaining treatment. The American Society for Bioethics and Humanities has endorsed the mediation approach to resolve end of life dispute treatments.<sup>91</sup> State legislatures could pass laws which would require parties in dispute to engage in a formal mediation process presided by an impartial mediator trained to resolve disputes, before the parties would be able to bring their case before a court.

End of life disputes involve a variety of interested parties such as the patient, their physicians, and their families. When parties disagree over the patient's choice to refuse life sustaining treatment, mediation creates a forum where all parties involved attempt to get to the bottom of the patient's professed desire to end their lives.<sup>92</sup> Mediation creates a dialogue where the patient and the other parties involved can evaluate their motives, not through the abstract legal construct that is the competency analysis, but through discussion that involves the emotions of the parties involved.<sup>93</sup> An individual who evaluates their own motives in this context enhances their ability to make a choice regarding their treatment.<sup>94</sup> Mediation provides several benefits aside from the self examination of the patient: it creates an outlet for emotions, involves

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<sup>91</sup> See American SOCIETY FOR BIOTETHICS AND HUMANITIES, CORE COMPETENCIES FOR HEALTH CARE ETHICS CONSULTATION 6 (1998).

<sup>92</sup> See David M. Shelton, *Keeping End-of-Life Decisions Away from Courts After Thirty Years of Failure: Bioethical Mediation As an Alternative for Resolving End-of-Life Disputes*, 31 Hamline L. Rev. 103, 133 (2008).

<sup>93</sup> *Id.*

<sup>94</sup> *Id.*

mediators who have expertise in bioethics, enhances the probability that the parties involved will be able to amicably come to a solution, avoids the costs involved in litigation, and provides an outlet for resolution over the parties' competing moral views.<sup>95</sup> If Elizabeth Bouvia had engaged in a mediation process, there is a possibility that she could have arrived to the ultimate conclusion that she wanted to live, instead of fighting a legal battle before the court over her professed desire to be removed from life sustaining treatment at the time of litigation, only to change her mind after she won her case.<sup>96</sup>

The concept of promoting autonomy through mediation, with individuals who have stances different from the patient himself, at face value seems contradictory. Indeed the active role of family members in individual decision making is regarded as contradictory in Western bioethics, but in other cultures families play an active role in individual decision making processes.<sup>97</sup> The emphasis on a western conception of autonomy in our legal jurisprudence has been criticized because it fails to take into account the cultural differences within our diverse society.<sup>98</sup> The fact that patients in mediation will take into account their family's perspective on the issue of life sustaining treatment is not mutually exclusive with their personal autonomy. Many of the choices we make in our daily lives take into account our families, yet we do not argue that those choices are not the product of autonomous decision making. Arguably, as a result of mediation, individuals are better informed on their family and physician's positions regarding their treatment decisions. And by becoming aware of their own motives for accepting or refusing life sustaining treatment, patients are better equipped to exercise their autonomy due to the knowledge they gain from examining their medical treatment choices. Lastly, due to the

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<sup>95</sup> *Id.* at 134-37

<sup>96</sup> *See supra* note 69

<sup>97</sup> *See* Andrew J. McCormick, *Self-Determination, the Right to Die, and Culture: A Literature Review*, 56 National Association of Social Workers 119, 125

<sup>98</sup> *Id.* at 120

difficult nature of these decisions, it is important to have as many people involved in the discussion as possible in order to help the patient come to their ultimate conclusion. The more viewpoints and information that are conveyed to the patient on the issue, the better able the patient will be to make an informed decision, and the more support that person will have to make the difficult choices that occur at the end of life.

### **III B. Right to Die Legislation**

#### **III B. i. Public Opinion**

The right to die movement, which originated in the 1970's as a reaction to the technological advances in life sustaining treatment that followed World War II, enjoys the support of a large majority of Americans.<sup>99</sup> In January of 2006, the Pew Research Center performed a survey that reported eighty-four percent of Americans supported laws which allowed patient to decide whether they wanted to continue life sustaining treatment, an increase from seventy-nine percent of Americans who supported such legislation in 1990.<sup>100</sup> However, the trend towards greater public acceptance of right to die legislation has not been matched by increased legislative efforts.<sup>101</sup> The only states which have passed laws which allow physician to aid the wishes of a dying patient are Oregon and Washington.<sup>102</sup>

Recently a ballot initiative in Massachusetts advocating for legislation similar to the right to die acts in Oregon and Washington, which would allow terminally ill patients to end their lives with medication prescribed by their physician, was narrowly defeated in November of 2012.<sup>103</sup> Despite polls which showed that a large majority of Massachusetts citizens supported

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<sup>99</sup> *Id.* at 119

<sup>100</sup> *Id.*

<sup>101</sup> *Id.*

<sup>102</sup> *Id.* It is worth noting that neither of these laws originated from the states' respective lawmakers. Both acts came into being as a result of citizen passed initiatives.

<sup>103</sup> Carolyn Johnson, *Assisted suicide measure narrowly defeated; supporters concede defeat*, THE BOSTON GLOBE, Nov. 7, 2012, <http://www.boston.com/2012/11/07/dying/gBqan95E7zK3elChciPBOP/story.html>.

right to die legislation, when it came time to vote for the ballot there was a fairly narrow split. After ninety-five percent of precincts reported, the vote count show that fifty-one percent of voters opposed the measure.<sup>104</sup> Groups in favor of the initiative argued that the “terminally ill have the right to end their suffering, because today dying people needlessly endure in our Commonwealth and do not have the right to control their most personal medical decision,” while those opposed argued against the initiative on the grounds that it was a flawed as written and consequently contained insufficient safeguards for vulnerable patients.<sup>105</sup> Statistics required by Oregon’s Death with Dignity Act,<sup>106</sup> were relied on by proponents of the ballot measure as empirical evidence that such legislation does not lead to patient coercion and abuse.<sup>107</sup> The ballot measure, if passed would grant terminally ill patients with less than six months to live the ability to request their physicians for medication to end their lives.<sup>108</sup>

### **III. B ii. Oregon’s Death With Dignity Act**

When Oregon’s Death with Dignity Act was initially adopted in 1994 by the state’s voters it passed by a narrow margin of fifty-one percent to forty-nine percent.<sup>109</sup> When the implementation of the act was delayed due to an injunction lasting until 1997, the citizens of Oregon defeated a repeal measure by sixty percent to forty percent.<sup>110</sup> The Death with Dignity Act allows those years eighteen or older with a terminal illness that will lead to death within six months to take their own lives through the use of lethal medication prescribed by the individual’s physician.<sup>111</sup>

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<sup>104</sup> *Id.*

<sup>105</sup> *Id.*

<sup>106</sup> Furrow et al., *BIOETHICS: HEATH CARE LAW AND ETHICS* 398 (6th ed. 2008).

<sup>107</sup> JOHNSON, *supra* note 102

<sup>108</sup> *Id.*

<sup>109</sup> Charles E. Drum et al., *The Oregon Death with Dignity Act: Results of a literature review and naturalistic inquiry*, 3 *DISABILITY AND HEALTH JOURNAL* 3 (2010).

<sup>110</sup> *Id.*

<sup>111</sup> *Id.* (citing The Oregon Death with Dignity Act, OR. REV. STAT. § 127.800 (2007), available at

Since the law was passed in 1997, a total of 935 people have had their physicians prescribe lethal medication and 596 patients have died.<sup>112</sup> In 2011, in Oregon, the majority of individuals who took advantage of the law were cancer patients.<sup>113</sup> Consistent with previous years, a large majority of individuals stated that their end of life concerns were related to their decreasing ability to participate in activities that made life enjoyable, loss of autonomy, and loss of dignity.<sup>114</sup> When the Oregon initiative was challenged immediately after its passage in 1994, it faced a wide range of challenges; the opposition argued that it was discriminatory against the disabled because it would coerce people with disabilities to choose physician assisted death.<sup>115</sup> Whether the act disproportionately affects people with disabilities has not been resolved by the data collected, because the forms that individuals fill out do not ask whether the person has a preexisting disability.<sup>116</sup>

Aside from the recent initiative in Massachusetts, groups that support death with dignity legislation tried to pass similar initiatives in Maine in 2000, which was narrowly defeated.<sup>117</sup> In other states, legislatures have made efforts to pass right to die legislation.<sup>118</sup> The Death with Dignity Act has arguably marked the start of a trend in American society where we are becoming less hostile to the idea of allowing individuals with terminal illnesses to end their lives. It is likely that there will be further ballot initiatives and legislation that promote the terminal patient's choice of whether or not they wish to continue.

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[https://www.oregonlaws.org/ors\\_chapters/127](https://www.oregonlaws.org/ors_chapters/127)).

<sup>112</sup> OR. PUB. HEALTH DIV.: OREGON'S DEATH WITH DIGNITY ACT, 1 (2011), *available at* <http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year14.pdf>.

<sup>113</sup> JOHNSON, *supra* note 102

<sup>114</sup> *Id* at 2. The report states that of the individuals who took advantage of Oregon's Death with Dignity Act, 90.1% stated that they were concerned about their decreasing ability to participate in activities that made life enjoyable, 88.7% were concerned about their loss of autonomy, and 74.6% were concerned about their loss of dignity.

<sup>115</sup> FURROW ET AL., *supra* note 88, at 401

<sup>116</sup> DRUM ET AL., *supra* note 92, at 12.

<sup>117</sup> FURROW ET AL., *supra* note 88, at 402

<sup>118</sup> *See id.*

Legislation like Oregon's Death with Dignity Act, are a potential alternative for the conscious person who is facing resistance to their decision regarding the refusal of life sustaining treatment. If California had such an act during Elizabeth Bouvia's battle for her right to choose her own medical treatment and control her body, she may not have had to litigate the issue of her competency in the first place. One could argue however that Ms. Bouvia eventually decided not to end her life and without the courts as a barrier, she may very well have prematurely ended her own life contrary to her ultimate wishes. In response to this argument, going through the legal process was not necessary for Ms. Bouvia to come to the conclusion she did. The fact is that after the case was decided she had the right to end her life by removing herself from life sustaining treatment, a choice that she did not exercise when she had the freedom to make it. A better alternative would have been for her to avail herself to the type of mediation that this paper suggests legislator's implement. But, in taking such concerns into account that the disabled could be predisposed to taking advantage of these statutes disproportionately against their interests, I believe that mediation could also be required before a patient is allowed to take advantage of right to die statutes, if that is not currently the practice.

#### **IV. Conclusion**

The law claims that the competency analysis is utilized in order to protect and promote an individual's autonomy and their right to refuse medical treatment by deciding whether the patient made an authentic medical treatment decision. However, the competency analysis, due to the ambiguities surrounding its proper application, invites underlying value judgments of the courts that can be at odds with the individual autonomy that the law seeks to protect. Individuals have their own values that influence their thought processes and the outcomes of those values may not

be the same values that the court holds.<sup>119</sup> The courts may not only disagree with the outcomes of medical treatment decisions based on a patient's particular set of values, but may also interpret evidence through their own subjective biases. Although the Court in *Bouvia* declared that Elizabeth Bouvia's life was not worth living, there probably many persons with disabilities in similar situations to Ms. Bouvia's who do not share that view. Aside from court determinations of competency, even physicians themselves do not agree upon a single set of criteria for determining a patient's decision making capacity. If the courts rely on physician determinations of decision making capacity, and the physicians themselves cannot reliably and consistently determine a patient's ability to make a decision regarding their medical treatment, then it seems unlikely that courts will ever be able to find "the holy grail," the ideal competency analysis, that both protects patient autonomy and prevents the coercion of vulnerable patients. Due to the uncertainty involved in competency decisions and the potential to deprive individuals of their autonomy, their right to refuse medical treatment, and their sovereignty over their own bodies; legislatures should enact laws that seek to minimize the use of the courts by parties who dispute life sustaining medical treatment decisions. A combination of required mediation in end of life disputes and the use of right to die legislation can provide a buffer for the protection of individual autonomy from judicial subjectivity that undermines the very thing which the law seeks to protect.

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<sup>119</sup> Courts which refuse to declare an individual competent due to decisions based on their religious beliefs is an example of this.