



Winter 1988

## Government as Arbiter, Not Custodian: Relational Privacy as Foundation for a Right to Refuse Medical Treatment Prolonging Incompetents' Lives

Stanley E. Cox

### Recommended Citation

Stanley E. Cox, *Government as Arbiter, Not Custodian: Relational Privacy as Foundation for a Right to Refuse Medical Treatment Prolonging Incompetents' Lives*, 18 N.M. L. Rev. 131 (1988).  
Available at: <https://digitalrepository.unm.edu/nmlr/vol18/iss1/6>

# GOVERNMENT AS ARBITER, NOT CUSTODIAN: RELATIONAL PRIVACY AS FOUNDATION FOR A RIGHT TO REFUSE MEDICAL TREATMENT PROLONGING INCOMPETENTS' LIVES

STANLEY E. COX\*

## I. INTRODUCTION

A comatose body hooked to a respirator is obviously in need of others' care. Furthermore, it is generally accepted, and our society has in accord ratified via guardianship, that certain persons, such as the severely mentally retarded and infants, are incapable of governing their own lives. In one sense such persons are helpless, for they are extremely vulnerable and cannot act in their best interests on their own. In another sense, however, no one is helpless as long as he has others whom he can trust to care for and help him.

This Article will discuss how refusal of medical treatment decisions for mentally incompetent patients should be made, and who should make these decisions. The hardest type of case involving refusal of treatment for incompetents is that of patients such as Joseph Saikewicz<sup>1</sup> or Joseph Hamlin,<sup>2</sup> patients who were never competent and whose desires regarding treatment are unknowable. Under either a substituted judgment standard<sup>3</sup> or a best interests standard,<sup>4</sup> it is difficult, if not impossible, to determine

---

\*A.B., Harvard College; M.A.T., Duke University; H.Dip., Trinity College, Ireland; J.D., University of Kentucky; Associate, Stites & Harbison, Lexington, Kentucky. I would like to thank Douglas W. Cox and Mary Ann Born for reading and offering suggestions to a previous draft of this work. My wife Susan also helped me think through many of these ideas. While I hope she is never faced with hard decisions regarding my own welfare, she is certainly the one I wish to make them.

1. See *Superintendent of Belchertown State School v. Saikewicz*, 373 Mass. 728, 370 N.E.2d 417 (1977) (67 year old severely mentally retarded patient with I.Q. of 10 permitted to be denied treatment for leukemia under substituted judgment standard).

2. See *In re Hamlin*, 102 Wash.2d 810, 689 P.2d 1372 (1984) (42 year old critically ill pneumonia patient, blind and severely retarded since birth, permitted to be removed from respirator under substituted judgment standard). See also *In re Ingram*, 102 Wash.2d 827, 689 P.2d 1363 (1984) (66 year old severely delusional throat cancer patient permitted to refuse surgery in favor of probably futile radiation treatment under substituted judgment standard).

3. The substituted judgment standard involves the decisionmaker putting himself as much as possible in the shoes of the incompetent. The decisionmaker is to make the same decision the incompetent would make were he competent, but also taking into account the particular biases and capacities that are a result of the incompetence. See, e.g., *Saikewicz*, *supra* note 1.

4. The best interests or objective standard emphasizes objectively measurable criteria such as pain or body functions to determine whether the life being lived is on balance better continued or terminated. See, e.g., *In re Storar*, 52 N.Y.2d 363, 438 N.Y.S.2d 266, 420 N.E.2d 64 (1981). Whereas the substituted judgment standard risks abuse of the patient if an insensitive decisionmaker fails to adequately make a decision of which the incompetent patient would approve, the best interests/objective standard fails to allow any true choice for or on behalf of the incompetent. See *In re Jobes*, 108 N.J. 394, 403, 529 A.2d 434, 453 (1987) (Handler, J., concurring). This Article argues that neither standard adequately recognizes the true nature of the privacy right which should be given effect in refusal of treatment decisions.

what would best serve the total interests<sup>5</sup> of such incompetents.

It is precisely these difficult cases that illustrate the weakness in current thinking about the right to terminate medical treatment. Recently, Justice Handler, concurring in the "right to die" trilogy of holdings of the New Jersey Supreme Court,<sup>6</sup> noted that courts have not yet sufficiently confronted the problems involved in "[t]he difficult extreme case, where there is no basis for deciding what choice the patient would have wanted made. . . ."<sup>7</sup> He further suggested: "We can start by examining more critically the concept of self-determination as the primary or preferred basis for such treatment decisions. . . ."<sup>8</sup> This Article implements Justice Handler's suggestion and explores whether self-determination can provide a solid foundation for refusal of medical treatment decisions in regard to incompetents.

This Article concludes that self-determination, when speaking of treatment decisions made on behalf of incompetents, is often a misleading concept, not just for the Saikewicz and Hamlins of this world, but for all who become incompetent. In the case of the never competent, there is obvious frustration and inconsistency in trying to determine the extent to which such "persons" are like the rest of us and therefore possess rights which can be exercised in or on their own behalf. The more fruitful inquiry should be into what *relationships* are protected by recognition of a right to refuse medical treatment towards such incompetents. This relational privacy interest is of the same character, however, regardless of the reason the patient for whom a decision is to be made became incompetent. Whether the right being protected is a competent person's refusal,<sup>9</sup> refusal on behalf of a formerly competent person,<sup>10</sup> refusal in regard to clear non-persons,<sup>11</sup> or refusal in regard to an incompetent,<sup>12</sup> in each case the basic issue is whether the government should act as the primary

---

5. Total interests would include dignitary interests and other inherently subjective factors, which would be difficult if not impossible to ascertain for a never competent person.

6. *In re Farrell*, 108 N.J. 335, 529 A.2d 404 (1987); *In re Peter*, 108 N.J. 365, 529 A.2d 419 (1987); *Jobes*, 108 N.J. 394, 529 A.2d 434. *Farrell* involved the case of a competent patient desiring to terminate life support systems. See *infra* note 14, and accompanying text. *Peter* involved a situation where a formerly competent person had vested power of attorney in a close friend to make treatment decisions on her behalf. *Jobes* involved the situation where the formerly competent person had made no prior expression regarding what should be done if she ended up in a comatose/vegetative state. The three decisions were issued the same day, authored by the same justice, and constitute a major reevaluation and/or interpretation of earlier New Jersey decisions in this area (i.e. *Quinlan*, *infra* note 13, and *Conroy*, *infra* note 18).

7. *Jobes*, 108 N.J. at 413, 529 A.2d at 453 (Handler, J., concurring).

8. *Id.*

9. See *infra* notes 13-36 and accompanying text.

10. I.e. the living will situation. See *infra* notes 37-47 and accompanying text.

11. I.e. corpses. See *infra* notes 48-57 and accompanying text.

12. See *infra* notes 73-91 and accompanying text.

caretaker of the body, and in each case the answer is "no". The relational privacy interest protected by a right to refuse treatment is essentially a negative conclusion that government cannot define people's lives or deaths as well as those who are more closely involved in relationships of caring. The government should therefore intrude only in extreme cases and should always search for a proper caretaker rather than take on the caretaking task itself.

## II. IMPLICATIONS OF GRANTING COMPETENT PERSONS THE RIGHT TO REFUSE LIFE-SUSTAINING OR LIFE-PROLONGING TREATMENT

This Article's thesis is that the right to refuse medical treatment for incompetents is a right not necessarily exercised on behalf of the incompetent. Regardless of on whose behalf the right is asserted, however, the person asserting a right to refuse life-saving treatment must do battle with the state and answer its claims that such refusal is not permitted. The fact that the courts easily sustain the right of a competent adult to refuse life-sustaining treatment in face of the state's supposedly powerful *parens patriae* claims indicates the weakness of those claims. Further, the arguments which competent adults use in such cases derive from a source which may be tapped by others on behalf of incompetents. The reasons why and conditions under which competent persons are allowed to refuse treatment are similar to the reasons why and conditions under which treatment may be refused for incompetents.

To a visitor from another culture, one of the most striking features regarding the American competent's right to refuse treatment is its seeming absolute nature. The state claims that its interest in preserving life and preventing a person from harming himself or others requires that life-sustaining treatment be undertaken, and that under no circumstances will the state condone, much less be a party to someone's suicide or acting out a death wish.<sup>13</sup> Nevertheless, courts permit competent persons to choose to die. Among the most recent examples: A thirty-seven year old patient with Lou Gehrig's disease is permitted to have her respirator disconnected, although this will result in certain death.<sup>14</sup> A twenty-eight year old quadriplegic psychiatric patient is allowed to have a nasogastric tube removed, although this will result in starvation.<sup>15</sup> A fifty-five year

---

13. See, e.g., *Satz v. Perlmutter*, 362 So.2d 160, 162-64 (Fla. Dist. Ct. App. 1978), *aff'd*, 379 So.2d 359 (Fla. 1980); *Saikewicz*, 373 Mass. at 738 n.11, 370 N.E.2d at 426 n.11; *In re Quinlan*, 70 N.J. 10, 28, 32-33, 355 A.2d 647, 665, 669-70 (N.J. 1976).

14. *In re Farrell*, 514 A.2d 1342 (N.J. Super. Ct. Ch. Div. 1986), *aff'd*, 108 N.J. 335, 529 A.2d 404 (1987). *Accord* *Bartling v. Superior Court*, 163 Cal. App. 3d 186, 209 Cal. Rptr. 220 (Ct. App. 1984) (despite patient's earlier vacillation, and despite non-terminal nature of illness, patient permitted to be removed from respirator); *Satz*, *supra* note 13 (Lou Gehrig's disease patient permitted to be removed from respirator).

15. *Bouvia v. Superior Court*, 179 Cal. App. 3d 1127, 225 Cal. Rptr. 297 (Ct. App. 1986).

old woman dying of amyotrophic lateral sclerosis is permitted to compel hospital authorities to assist her, against their wishes, in carrying out her desire to die by starvation rather than undergo forced feeding.<sup>16</sup> A forty-five year old Jehovah's Witness is permitted to refuse a blood transfusion during a caesarian delivery, the court deciding in this wrongful death action that if there is to be malpractice liability for any of the doctors involved, such liability arises only because the doctors ignored the mother's instructions and tried to save her life via transfusions.<sup>17</sup> The question of a visitor from another culture would likely be, "Why are these people permitted to engage in behavior at odds with what others would probably choose, behavior opposed by the health care providers who have literal control over their bodies?"

The courts respond by saying that the answer is obvious. A right to refuse medical treatment is only meaningful when it can be exercised against the wishes of the state or health care provider. As the court in *In re Conroy* explained: "[I]f the patient's right to informed consent is to have any meaning at all, it must be accorded respect even when it conflicts with the advice of the doctor or the values of the medical profession as a whole."<sup>18</sup> Perhaps this answer is obvious to an American patient, but it would not be so to the foreign visitor. A right of choice can still exist without the state insisting that treatment be provided in only one manner. The state could decide that a patient would be permitted to refuse or permit treatment only in certain predefined circumstances; in all other situations the state would prolong life and allow no choice. The patient permitted options would still have a real right to refuse treatment when the proper circumstances arose. The right would simply be conditioned on the state's prior approval rather than be a nearly absolute right. This is *not* the type of right, however, which American courts seem to recognize.

---

16. *In re Requena*, 213 N.J. Super. 475, 517 A.2d 886 (1986). The hospital desired that Ms. Requena be transferred to a facility whose policy would permit refusal of nasogastric feeding. The court held that Ms. Requena's right to choose her form of treatment, including manner of death, must be honored, even though the hospital was ethically opposed to the withholding of food and water from its patients. The *Requena* decision received the New Jersey Supreme Court's implied endorsement in *Jobes*. See 108 N.J. at 410, 529 A.2d at 450. Cf. *Brophy v. New England Sinai Hosp.*, 398 Mass. 417, 497 N.E.2d 626 (1986) (hospital has right to refuse guardian's wishes, but guardian has right to remove ward from facility).

17. See *Randolph v. City of New York*, 117 A.D.2d 44, 501 N.Y.S.2d 837 (N.Y. App. Div. 1986). *Accord* *Mercy Hosp. v. Jackson*, 62 Md. App. 409, 489 A.2d 1130 (Md. Ct. Spec. App. 1985) (Jehovah's Witness allowed to refuse blood transfusions during caesarean delivery). See also *Bartling v. Glendale Adventist Med. Center*, 184 Cal. App. 3d 961, 229 Cal. Rptr. 360 (Ct. App. 1986) (discussing whether cause of action may exist when health officials refuse to honor guardian's wishes to refuse treatment); *Estate of Leach v. Shapiro*, 13 Ohio App. 3d 393, 469 N.E.2d 1047 (1984) (same).

18. 98 N.J. 321, 337, 486 A.2d 1209, 1225 (1985). See also *id.* at 338, 486 A.2d at 1226 (patient's non-invasion interest outweighs state's interest in preserving life).

When American courts speak of a patient's right of refusal, they speak in terms of autonomy,<sup>19</sup> dignity,<sup>20</sup> privacy,<sup>21</sup> self-determination,<sup>22</sup> and intrusion.<sup>23</sup> In essence, the courts speak of a right to define propriety of treatment independent of the state's definitions. Only suicide or active euthanasia cause the state to speak of clearly prohibited conduct,<sup>24</sup> and the courts often " 'dance' around the issue"<sup>25</sup> or employ subtle distinctions to avoid having to cut off the patient's refusal right in even these situations.<sup>26</sup> In reality, the state's definitions simply disappear when counter-definitions are offered by competent adults

The state need not so easily cave in when faced with a counter-definition, however. A state could as easily determine that the irrationality of the patient's refusal (i.e. its abnormal nature) is proof of the patient's incompetence, at least in that area. Yet the presumption seems to be that the individual, unless previously determined incompetent, is competent regarding his own medical choices. Even the choices of a previously adjudged incompetent or suspected incompetent are given presumptive weight regarding his own medical treatment.<sup>27</sup> The state simply does not insist on the primacy of its definition when faced with a contrary definition, which indicates that the state definitions are not presumptively valid but are merely back up definitions available if no valid counter-definition is being offered.

The competent person's choices regarding his own treatment are given strong protection when religiously based, and the courts often mention the patient's religious conversations or influences to justify non-interference with the patient's decisions.<sup>28</sup> Certainly in the Jehovah's Witness transfusion cases, first amendment free exercise claims play a large role

---

19. See, e.g., *Brophy*, 398 Mass. at 424-25, 497 N.E.2d at 633-34 (citing John S. Mill's *On Liberty* and *Saikewicz*).

20. See, e.g., *In re Torres*, 357 N.W.2d 332, 340 (Minn. 1984); *Requena*, 213 N.J. Super. at 480, 517 A.2d at 891.

21. See, e.g., *Conroy*, 98 N.J. at 334, 486 A.2d at 1222; *In re Colyer*, 99 Wash.2d 114, 118, 660 P.2d 738, 742 (1983).

22. See, e.g., *In re Visbeck*, 210 N.J. Super. 527, 531, 510 A.2d 125, 129 (1986).

23. See, e.g., *In re Spring*, 380 Mass. 629, 633, 405 N.E.2d 115, 119 (1980); *Colyer*, 99 Wash.2d at 119, 660 P.2d at 743.

24. See sources cited *supra* at note 13.

25. *Bouvia*, 179 Cal. App. 3d at 1137, 225 Cal. Rptr. at 307 (Compton, A.J., concurring).

26. The usual distinction is between actively seeking death and allowing death to come naturally to the patient. See, e.g., *Conroy*, 98 N.J. at 336, 486 A.2d at 1224; *Colyer*, 99 Wash.2d at 119, 660 P.2d at 743. See also sources cited *supra* at note 13. Several authors have argued that courts should explicitly recognize a right to die that includes actively promoting death in terminal or hopeless situations. See, e.g., 179 Cal. App. 3d at 1137-38, 225 Cal. Rptr. at 307-08 (Compton, A.J., concurring); Note, *Voluntary Active Euthanasia for the Terminally Ill and the Constitutional Right to Privacy*, 69 CORN. L. REV. 363 (1984); Note, *In re Storar: Euthanasia for Incompetent Patients, A Proposed Model*, 3 PACE L. REV. 351 (1983).

27. See, e.g., *Ingram*, 102 Wash.2d at 834, 689 P.2d at 1370.

28. See, e.g., *Brophy*, 398 Mass. at 422-23, 497 N.E.2d at 631-32 & n.23.

in the courts' decisions.<sup>29</sup> One possible reason that the state's definitions of what constitutes proper treatment disappear when counter-definitions are offered might be because definitions of medical treatment are inherently religious. The free exercise clause, however, cannot justify strongly prohibited conduct. Traditional first amendment religious analysis would support refusal of treatment decisions, therefore, only in cases where the conduct of refusal is in fact not of vital interest to the government.<sup>30</sup> Additionally, persons without strong religious beliefs are allowed to refuse life sustaining treatment. Traditional first amendment analysis thus seems to add nothing to the refusal of treatment rationale.

Nevertheless, there is something intuitively correct about the courts' deference to religiously based decisions. If the United States Supreme Court balks at defining when life begins or ends,<sup>31</sup> religion is less hesitant to attempt these definitions. Religion is at home with life and death situations, and with situations where what happens to one defines the quality of his future existence. Perhaps the courts in refusal of treatment cases are correctly realizing that the government simply has little to say about these matters and that such decisions are, at least in a broad sense, necessarily religiously based.<sup>32</sup> At any rate, in the area of refusal of life preserving treatment, the government scrupulously keeps its hands off. When confronted with an otherwise competent adult who asserts that his unpopular religious or personal beliefs require him to refuse treatment which would prolong his life, the government allows the person to choose to die.

Most courts do not ground the competent person's right to refuse treatment in the first amendment's religious proscriptions, but rather in constitutional principles of privacy<sup>33</sup> or in common law principles of informed consent.<sup>34</sup> The end result of such analysis is much the same as if the right had been grounded in religious belief. The government is

---

29. In addition to sources cited *supra* at note 17, see also *St. Mary's Hosp. v. Ramsey*, 465 So.2d 666 (Fla. App. 1985); *In re Brown*, 478 So.2d 1033 (Miss. 1985).

30. In other words, although the state claims that preservation of the individual's life is a strong interest, this government claim cannot even rise to the level of a compelling governmental interest.

31. See, e.g., *Akron v. Akron Center for Reproductive Health*, 462 U.S. 416 (1983); *Roe v. Wade*, 410 U.S. 113 (1973).

32. The problem may be with traditional first amendment religion analysis, which has never adequately reconciled the constitutional mandate to leave religious matters to the private sphere with the governmental duty as caretaker to define and prohibit certain conduct. A government, by its statements of what is and is not proper conduct, necessarily takes on a religious function. There is thus inherent tension in a government which professes not to be involved in matters of religion.

33. See, e.g., *Quinlan*, 70 N.J. at 26, 355 A.2d at 663; *Conroy*, 98 N.J. at 334, 486 A.2d at 1222.

34. See, e.g., *In re Storar*, 52 N.Y.2d 363, 369-70, 438 N.Y.S.2d 266, 272-73, 420 N.E.2d 64, 70-71 (1981). Most courts ground the refusal right alternatively in both sources. See, e.g., *Ingram*, 102 Wash.2d at 832, 689 P.2d at 1368.

forced to take a hands off policy, either because decisions involving one's own body are so personal that they invoke a constitutional zone of privacy into which the government dare not intrude, or because the physical inviolability of the body requires permission before others may invade. Most courts thus define the right of refusal as a personal right of privacy or as a common law right possessed by the individual not to have his body invaded.

If the right is ultimately seen as issuing from the constitutional right of privacy, however, as the author believes it should be,<sup>35</sup> exclusive focus upon the *individual* on whose behalf it is asserted may be misplaced. Most of the specific manifestations of the privacy right heretofore recognized by the United States Supreme Court have involved couples and families, rather than isolated individuals.<sup>36</sup> Although the privacy advocate is usually an individual, the privacy protected is often that of the individual within a unit or group. The government is told that it must not prosecute this individual, but the individual is tied to another, to a family, or to a family place. This point is important to this Article's central thesis. If the constitutional privacy right can be seen as not necessarily an individual right, then it may be possible for someone other than the incompetent to assert the right in regard to refusal of treatment for incompetents. This would be so because the privacy thus protected may not be actually or exclusively possessed by the individual incompetent.

At any rate, what we have seen so far in the case of a competent person's right to refuse life sustaining treatment is that the government feels itself very inadequate to place its will against the will of the competent. It is as if the government is saying, "We really have nothing to say in this area so long as we believe a truly human voice is saying something for itself."

### III. IMPLICATIONS OF ALLOWING COMPETENT PERSONS TO DETERMINE WHAT SHOULD HAPPEN TO THEIR BODIES IN THE EVENT THEY BECOME INCOMPETENT

The most basic question concerning living wills is why they should be listened to. The most conservatively drafted statutes allow the testator's

---

35. Support for such a constitutional right to privacy could be found under either majority or minority rationale as reflected in the Court's recent decision, *Bowers v. Hardwick*, 106 S. Ct. 2841 (1986). Under the Powell/White rationale, a family protection right for one's body is probably "deeply rooted in this Nation's history and tradition," *id.* at 2844 (quoting *Moore v. East Cleveland*, 431 U.S. 494, 503 (1977)); while under the Blackman rationale, the right would be central to an individual's self-definition. *Id.* at 2851.

36. See, e.g., the listing of the type of rights protected, in *Bowers*, 106 S. Ct. at 2843 ("child rearing and education," "family relationships," "procreation," "marriage," "contraception," and "abortion").



wishes to be heeded only when they involve a decision to shut off life support systems in the event of irreversibly degenerative disease or coma.<sup>37</sup> The basic question is why society should honor the testator's request regarding what should be done with a body which the testator no longer can control and which possesses none of the testator's normal personality or animus, a body which is possibly more vegetable than human. The traditional argument is that we are still dealing with the same human being, and that just because the person is in a persistent vegetative state, this does not mean the person is no longer human.<sup>38</sup> There are instances where persons returned to sapient life,<sup>39</sup> and the courts understandably desire not to terminate the life of someone who wished to be "unhooked" only when his degeneration was irreversible. For this reason there is usually judicial insistence that there be a concurrence of negative medical prognoses,<sup>40</sup> the presumption being that the person is not yet dead. There is much to be said for a judicial reluctance to mistakenly cut off life, but as discussed in the previous section, the courts are usually untroubled in allowing a competent person to refuse treatment, even though the refusal will certainly lead to a cutting off of life. What is there about the situation of the formerly competent person, now incompetent and arguably inhuman or soon to be so, that causes the courts to more seriously pause?

Courts which have specifically addressed the living wills issue have given these expressions of a person's desires regarding what should happen to him when incompetent only presumptive or persuasive weight, and have not made the existence of the living will dispositive of the issue of whether treatment should be refused.<sup>41</sup> Thus, although the dictates of the will have been followed in cases where the issue has arisen, and although the courts look with favor on the existence of such wills as providing them with the evidence they need to determine what should be done for the comatose, the statements in the living will are not seen as synonymous with what the actual physical body plugged into the respirator

---

37. See, e.g., discussion of the Florida act in *Corbett v. D'Alessandro*, 487 So.2d 368, 370-71 (Fla. Dist. Ct. App. 1986). See generally Note, *Living Wills—A Need for Statewide Legislation or a Federally Recognized Right?* 1983 DET. C.L. REV. 783 (provisions of other states' statutes). Cf. Note, *Proxy Decisionmaking for the Terminally Ill: The Virginia Approach*, 70 VA. L. REV. 1269 (1984) (discussion of problems involved in legislation attempting to provide refusal rights to those who may not have left living wills).

38. See, e.g., *In re L.H.R.*, 253 Ga. 439, 445, 321 S.E.2d 716, 722 (Ga. 1984); *Quinlan*, 70 N.J. at 27, 355 A.2d at 664; *Visbeck*, *supra* note 22.

39. See *Torres*, 357 N.W.2d at 335 & n.1 (discussing case of police officer pronounced irreversibly comatose who later regained consciousness).

40. See, e.g., *L.H.R.* 253 Ga. at 445-46, 321 S.E.2d at 722-23; *Quinlan*, 70 N.J. at 34, 355 A.2d at 671; *Colyer*, 99 Wash.2d at 126, 660 P.2d at 750.

41. See *John F. Kennedy Mem. Hosp. v. Bludworth*, 452 So.2d 921 (Fla. 1984); *Saunders v. State*, 129 Misc.2d 45, 492 N.Y.S.2d 510 (N.Y. Sup. Ct. 1985). See also *Conroy*, 98 N.J. at 341-42, 486 A.2d at 1229-30.

would desire to be done to him. Courts thus have insisted on a substituted judgment analysis which uses the living will as the most persuasive evidence available regarding what the "person" whose life support system is about to be cut off would actually want done.

The trouble with such substituted judgment analysis is that it assumes a continuity of desire which simply may not be present. The comparison Dr. Childress makes to Ulysses and the Sirens is apt.<sup>42</sup> By giving weight to the expressions of the living will, physicians and family members are not really respecting the wishes of the body hooked up to the respirator; they are instead honoring the desires of the person before he became hooked to the respirator. Yet Dr. Childress' suggestion that treatment decisions should be biased towards reversibility<sup>43</sup> is not as persuasive as it might first appear. Dr. Childress argues that a kidney patient who at the last moment indicates, "No, keep me alive" should be listened to, because the patient can always, when he returns to complete consciousness, say "No, damn it, I wanted you to keep me off the machinery."<sup>44</sup> The problem with this argument is that it leads to a vicious cycle. What happens when the patient again says at the last moment, "No, keep me alive?" Dr. Childress' argument only goes to the issue of whether the fully competent patient really meant what he said the first time. Assuming it can be determined that the fully competent patient really meant what he said in his first "living will" type statement, the question is not whether this statement was sincerely felt, but whether it should be binding on him later. The question is which patient should be listened to, the fully sane Ulysses or the hearer of the Sirens.

For a comatose patient there is simply no listening possible. In a sense then, the decision to listen to the voice of the living will is easy, for there is no competing voice. But it is also important to realize that it is a fiction in such situations to believe that the living will is a statement of what the respirator "patient" would really want. The state could easily assert that any comatose patient would be presumed to want to continue his "dim dreaming life,"<sup>45</sup> and therefore insist that these presumed desires be fully honored.<sup>46</sup> The fact is that nobody knows what, if anything, a comatose patient desires. By deferring to the desires expressed in a living will, the state chooses not to say anything in this refusal of treatment area, even though it could. It should be clear, however, that the rights

---

42. See Childress, *Refusal of Lifesaving Medical Treatment by Adults: An Ethical Analysis*, 23 J. FAM. L. 193, 208-09 (1984-85).

43. *Id.* at 207, 209.

44. *Id.* at 209.

45. Oliver Wendell Holmes, "The Chambered Nautilus," line 11.

46. Cf. *Storar*, 52 N.Y.2d at 371-72, 438 N.Y.S.2d at 274-75, 420 N.E.2d at 72-73 (presumption that person who has been unable to make wishes known would want to live).

being protected are not necessarily those of the body hooked to the respirator.

This again points to a right of privacy, or privilege of noninterference, which is arguably larger than the individual on whose putative behalf the right is asserted. One reason a person might make a living will is because he fears being coerced or dehumanized by the medical treatment which might later be inflicted on him. In other words, the concern is with what he as a continuing person might have to endure in pain or inconvenience. But another reason one might resist the dying process even though he would not resist dying itself,<sup>47</sup> might be because he simply feels it is improper for the state to make a person into a certain sort of creature. In other words, the concern is not so much with what the continuing body may or may not feel, as with the impropriety of the state's engaging in such action in regard to any body. The reason an individual would be allowed to assert this right in regard to his own body, rather than all bodies, would be because of each person's special ties to his own body. Since the individual was the one formerly responsible for the care of his own body, he might be allowed against others to say what should later happen to that body. In cases where others have been responsible for a person's care (e.g. incompetence), however, it might be possible for those others to assert rights not solely or necessarily on behalf of the incompetent, but rather on behalf of a relationship involving care for such a person. It is for such a privacy right of relational care that this Article argues.

#### IV. IMPLICATIONS OF RECOGNIZING RIGHTS IN REGARD TO CORPSES

Before examining situations where the government extends or denies a right to refuse treatment for another, it is worth considering whether next of kin have any recognizable right in pure bodies (i.e. corpses). Courts in refusal of treatment for incompetents cases have assumed that whatever refusal right exists, it must derive from the personhood of the incompetent.<sup>48</sup> Holdings that incompetents possess the same sort of rights as competents have been grounded in equal protection rationale and in the humanness of the incompetent.<sup>49</sup> But the argument of the preceding section is that it is not so clear that any rights of incompetents can actually be given weight in the case of comatose patients.

Perhaps it is unnecessary to determine whether the "person" for whom

---

47. See Childress, *supra* note 42, at 194.

48. See, e.g., *Ingram*, 102 Wash.2d at 830, 689 P.2d at 1366.

49. See, e.g., *Brophy*, 398 Mass. at 424-25 & n.27, 497 N.E.2d at 633-34 & n.27.

treatment is being refused really is a person.<sup>50</sup> If a refusal right could be found in regard to pure bodies (i.e. corpses), it would be clear that the right does not necessarily exist in the person for whom treatment is refused, but rather in the relationship of care for that person. Personhood lines would not necessarily need to be drawn. In the case of clearly competent persons, the right to refuse treatment could be exercised by the person himself; in the case of clear non-persons, the right would be exercised by those who have the duty to care for the body. In ambiguous categories, a refusal right would still exist. The problem would be determining *how* the right should be exercised, not whether there is a person on whose behalf it should be exercised.

In other words, treating the body hooked to the respirator as a non-person would not necessarily mean a lessening of concern over how the body should be treated. If the proper decisionmaker in regard to what should happen to a corpse is the individual who best cared for that former person or the one who most clearly can express how that former person would have desired that his body be treated—then it might be helpful to at least temporarily consider the Karen Quinlans of this world as more like corpses than human beings. Not that a comatose patient is necessarily a corpse, but that as between the interests of the government in regard to a body versus those who claim some more intimate connection to the body, existence of a relational privacy right in regard to corpses would explain why purported government interests must give way, even when it is not clear that refusal rights are being asserted as substituted judgments for real “persons.”

Cases involving conflicting government and private claims over what should be done with corpses are rare, probably because it is taken for granted that the government does not desire to assert positive rights in regard to dead bodies. Legitimate health regulations regarding manner of burial can be viewed more as negative governmental restraints. When the government asserts that the body belongs to it rather than to the next of kin, however, then it can be said that the government is asserting positive rights in regard to corpses. The question is whether the government can or should assert such positive rights.

Two 1985 decisions reached opposite conclusions regarding whether a right to privacy in a dead body can be asserted by the next of kin. In

---

50. One commentator has forcefully argued that courts' assumptions regarding the personhood of incompetents are questionable, and that courts should be required to determine when people in fact stop being human (i.e. whether in fact incompetents are the sort of persons to whom refusal rights should be extended). See Buchanan, *The Limits of Proxy Decision-Making*, in R. SARTORIUS, *PATERNALISM* 153 (1983). While in agreement with Professor Buchanan's critique of the courts' logic, this Article's conclusion is opposite to Professor Buchanan's. If treatment decisions are based on relational privacy, personhood lines need not be drawn.

*Georgia Lions Eye Bank v. Lavant*,<sup>51</sup> the Georgia Supreme Court found that no constitutional right of privacy in a decedent's body existed that would require a hospital to give notice to parents before corneal tissue of their dead infant was removed for transplant. The *Lavant* court found only a common law quasi-property right to a decedent's body, which the court felt the Georgia legislature had sufficiently invalidated.<sup>52</sup> The *Lavant* language regarding the Georgia legislature's power, presumably to do whatever it wanted to with dead bodies, was particularly sweeping, although the court also emphasized the beneficial nature and intent of the statute.<sup>53</sup>

In *People v. Roehler*,<sup>54</sup> on the other hand, a California court found that the next of kin could assert a privacy right in a dead body that would force the state to assert compelling interests and obtain a valid warrant before corpses in a private morgue could be intruded upon. It is not clear whether the *Roehler* decision found the privacy right to be constitutionally based, as the court cited California statutes and common law causes of action, in addition to the United States and California constitutions, as support to its claim that the privacy right existed.<sup>55</sup>

With a paucity of decisions and the most recent ones in conflict, it is not clear what most jurisdictions would decide regarding third party privacy interests in corpses.<sup>56</sup> The author raises this issue, however, in the belief that a case for relational privacy in regard to corpses could be successfully argued. The issue is not whether the corpse retains any of the privacy interests of the formerly living person, but rather how living individuals would view the fact that anything could be done to a corpse against the formerly living person's will, or against the will of those who were intimately associated with the formerly living person. Certainly it does not matter to the corpse what happens to it. Yet it probably does matter to a living person whether his dead body will be treated with dignity. As in the case of the living will, the right being protected by compliance with a dead person's wishes is not the right of the current body, but of the former person.

This protected dignity in regard to what should happen after one's death is probably better defined by intimates and individuals, rather than by a less personal government. This simply is another area where the

---

51. 255 Ga. 60, 335 S.E.2d 127 (1985).

52. *Id.* at 61-62, 335 S.E.2d at 128-29.

53. *Id.*

54. 167 Cal. App. 3d 353, 213 Cal. Rptr. 353 (Ct. App. 1985).

55. *Id.* at 367, 213 Cal. Rptr. at 367.

56. Cf. RESTATEMENT (SECOND) TORTS § 868 (quasi-property right in family to bury body); Annotation, *Enforcing Persons' Desires About What Should Be Done With Their Dead Bodies*, 54 A.L.R. 3d 1037 (1973), Annotation, *Liability for Withholding Corpse From Relative*, 48 A.L.R. 3d 240 (1973).

government has little to say. Dignity is determined according to an inherently subjective standard. Although a legislative majority would probably never pass a statute which authorized dissection of all cadavers or sale of same to foreign nations, the beneficial nature of such statutes could be argued. Unless a privacy interest stood in the way of such legislation, government could impose its majoritarian will against any who objected to such treatment of their own or their loved ones' bodies. Although well intentioned, the *Lavant* decision was therefore wrong. Recognizing a privacy interest in regard to corpses is a way of ensuring that the government reaches only into areas where it has a legitimate concern. To the extent that the government is permitted to say little about the treatment of corpses, *a fortiori* a living person, family unit, or group of caring associates knows that the government's ability to intrude into their life-defining affairs is limited.<sup>57</sup>

#### V. DETERMINING WHEN GOVERNMENT MAY INTRUDE INTO DECISIONS MADE FOR OR INVOLVING OTHERS

This Article has suggested that it might be possible for someone other than an incompetent to refuse treatment aimed at the incompetent. The basis for such refusal would not be primarily that the rights of the incompetent would be infringed upon (i.e. substituted judgment), for it is not clear that the incompetent has any personal rights which can be accurately

---

57. In *Strachan v. John F. Kennedy Memorial Hosp.*, 209 N.J. Super. 300, 507 A.2d 718 (1986), a New Jersey appellate court was faced with a situation which arguably bridges the arguments of parts IV and V of this article. After their son had attempted suicide and later been pronounced brain dead at the hospital, the Strachans were asked to consider donating his organs. Their son's body was kept hooked to life support systems while the Strachans made their decision. When the parents decided against organ donation and asked that their son's body be given them, the hospital refused to do so for two additional days while it determined what formal procedures would be necessary before the body could be disconnected from the respirator. The Strachans sued for damages. *Id.* at 301-05, 507 A.2d at 719-23.

The *Strachan* majority held that no claim for interference with rights in a dead body existed because no death certificate was signed until after the body was removed from the respirator; the body was not dead. *Id.* at 307, 507 A.2d at 725. The *Strachan* majority also held that no claim for negligent infliction of emotional distress to bystanders could lie since the body had in no way been harmed while remaining connected to the respirator; it was insensate. *Id.*

The inconsistency of these two positions should be apparent. By treating the body as still alive (to deny the claim of rights in a corpse), the court failed to recognize that someone's rights in regard to the still breathing body definitely were being violated by continuing to prolong artificial support. (*But see id.* at 309, n.3, 507 A.2d at 727, n.3 (continuation of treatment could constitute possible battery)). By holding on the other hand that there had been no harm to the dignity of the body (to deny the claim for bystander emotional distress), the court treated the body as essentially a corpse which could not be harmed since it possessed no feelings. By thus treating the body as alternatively living and dead, the court improperly removed rights from the family and in principle granted the hospital rights to do whatever it wished with artificially breathing bodies. This Article's theories more properly recognize that whether a body is living or dead, the rights in that body should generally be exercised by the family, rather than by medical personnel or administrators.

ascertained. An alternative basis for refusal rights is the relationship of care for the incompetent, and whoever is involved in that relationship of care could arguably assert those rights. The government's role would be to supervise the caretaker's exercise of rights. The justification for that sort of supervision is the subject matter of this section. Governmental supervision over parenting is an analogous area. Therefore, this section begins by comparing the justification for governmental intrusion in the child rearing area with the situation regarding governmental supervision of caretakers of incompetents.

There is support in United States Supreme Court decisions for at least some sort of protected right involving parenting. Whether springing out of privacy, religion, or other grounds, the common message of decisions such as *Pierce v. Society of Sisters*,<sup>58</sup> *Wisconsin v. Yoder*,<sup>59</sup> and *Parham v. J.R.*<sup>60</sup> is that parents presumptively have the right to determine what is best for their children, even when these decisions run counter to what the majority of parents might decide. At least one court, confronted with a decision regarding what to do about a terminally ill infant, specifically looked to these Supreme Court decisions for guidance. In *In re L.H.R.*,<sup>61</sup> Georgia's highest court determined that the decision regarding termination of treatment was a family decision, that once made by parents would be presumptively held to be in an infant's best interests.<sup>62</sup> Similar claims of family autonomy have been made involving the Baby Doe litigation and controversy.<sup>63</sup>

The *In re L.H.R.* court was careful to point out, however, that "in a case of suspected neglect or abuse or when the parent assumes a stance which in any way endangers the child, the parent's right to speak for the child may be lost."<sup>64</sup> The *Yoder* court had similarly noted that parental direction of a child is limited, and may be countermanded by the state "if it appears that parental decisions will jeopardize the health or safety of the child, or have a potential for significant social burdens."<sup>65</sup> The state thus grants to the parents a discretionary right to determine what would be in the child's best interests, but also seems ready to take away that right if it is not truly exercised in the child's best interests. How can the state determine what is really in the child's best interests? Why should it matter to the state how the right is exercised? In other words, why or

---

58. 268 U.S. 510 (1925).

59. 406 U.S. 205 (1972).

60. 442 U.S. 584 (1979).

61. 253 Ga. 439, 321 S.E.2d 716 (1984).

62. *Id.* at 445-46, 321 S.E.2d at 722-23.

63. See, e.g., Annas, *Refusal of Lifesaving Treatment for Minors*, 23 J. FAM. L. 219 (1984-85).

64. 253 Ga. at 445, 321 S.E.2d at 722.

65. 406 U.S. at 234.

where does the state have standing to contest how those more intimately connected should care for their own?<sup>66</sup>

In the area of child rearing, the state admits that it does not know the one proper way to rear children. Children are not under the guardianship of the state, but rather under the guardianship of their parents. The state permits parents to rear their children in various ways. The implicit admission is that something about the rearing process itself, even though it proceeds non-uniformly, is necessary for the successful development of the child. In line with the point made here are Professor Garvey's arguments concerning the derivative nature of a child's rights *vis a vis* the state. Professor Garvey argues that a state's assertion that it can determine the best interests of a child is arrogance, and that what the child is really owed is a duty to have decisions made for him by parents who will act in his best interests.<sup>67</sup> Both Professor Garvey's arguments and the points made earlier in this section lead to the same conclusion: The state is obligated to protect the relationship of parenting because it is that relationship which develops a child, and development of the child is what is truly in the child's best interests.<sup>68</sup>

Under this analysis, the apparently easy cases of governmental insistence that Jehovah's Witnesses permit blood transfusions for their children<sup>69</sup> or that parents consent to other forms of life saving treatment on behalf of their children<sup>70</sup> are harder than first appears. If it is the developmental process that is to be protected, and if the government is not allowed to say that any one type of child formation is to be preferred or insisted upon, why may the government insist that parents permit their children to be acted upon contrary to what the parents sincerely believe is in the best interests of their children?<sup>71</sup> The answer cannot simply be that a majority of parents would act differently and that this proves the parents

---

66. If this appears to be a backwards way of phrasing the question, this is because this Article proceeds on the assumption that the state does not have exclusive possession of all rights, parcelling out to its citizens only what the majority wills, but rather, that in order to have moral legitimacy, the state can have exclusive claim only to those rights which any reasonable citizen would allow it to maintain. Cf. Mill vs. Hobbes debate in *Brophy* (compare 398 Mass. at 424, 497 N.E.2d at 633 with *id.* at 431, n.1, 497 N.E.2d at 640, n.1).

67. See Garvey, *Freedom and Choice in Constitutional Law*, 94 HARV. L. REV. 1756, 1778-82 (1981).

68. See also Buchholz's Appeal from Probate, 9 Conn. App. 413, 416-18, 519 A.2d 615, 618-20 (1987) (parent has constitutionally recognized rights to companionship, care, and control of welfare of child).

69. See, e.g., *Crouse Irving Memorial Hosp. v. Paddock*, 127 Misc.2d 101, 485 N.Y.S.2d 443 (1985) (mother must submit for benefit of baby); *In re Dorone*, 349 Pa. Super. 59, 502 A.2d 1271 (1985) (son given transfusion over parents' objections).

70. See, e.g., *Custody of a Minor*, 375 Mass. 733, 379 N.E.2d 1053 (1978).

71. Actually the parents do *not* permit the action to take place. A new guardian must be appointed for the child, who is removed from his parents' custody while the consent for medical treatment is given on his behalf by the new guardian. See, e.g., *Dorone*, *supra* note 69.



are acting irrationally. *Yoder* stands for the proposition that parents are allowed to mold their children in directions contrary to what the majority would approve. Yet *Yoder* also stops short of a holding that approves molding of children such that they would be irrevocably cut off from mainstream society or become something less than productive adults.<sup>72</sup> The goal of parenting is that the child eventually become a person fully capable of exercising rights on his own behalf. Death obviously cuts off the potential that the child has to become a full person.

State intervention to preserve *potential* human life might therefore be permitted. The state can reasonably assert that only by its intervention will something better (the adult who will later develop from this child) be allowed to come into existence. *In re L.H.R.* draws the distinction between parental decisions made regarding a child's dying process (which are approved) versus parental decisions which might prevent an infant from living (which issue is left open).<sup>73</sup> In situations of comatose vegetative incompetents, it is clear that the future life is in decline (if in fact there even is life). In the case of incompetents such as Saikewickz, it is not clear exactly what quality of life is being lived, but it is clear that the incompetent (because he is irreversibly incompetent) will never be fully able to direct that life on his own. In both situations, there is not the same potentiality for a change in quality of the ward as is the case of a child under a parent's or guardian's care. If part of the state's justification to intervene in child rearing is the potentiality of the child, there is no similar potentiality for future development in the case of incompetents. It would be a mistake, however, to make too much of this distinction. Our living is in a large sense only a preparation for our dying, and potentiality and quality of life are largely marks along a continuum, rather than threshold issues. Nevertheless, if the state can intervene only in situations in which it is *clear* that there is a potential for greater quality of life in the future, this may indicate that state intervention is to be a relatively rare occurrence.

State intervention in a parenting decision basically tells the parent that he has lost his parenting rights. In order to implement its interference, in fact, the government must temporarily appoint a new guardian for the child, who is temporarily removed from the parent's custody.<sup>74</sup> If the parent were to refuse return of custody to himself after the state's intervention, it is at least conceivable that the state would honor such a refusal and would be forced to look for a new guardian for the child it had removed from his parent's control. The government, in other words, is

---

72. See 406 U.S. at 234.

73. See 253 Ga. at 445-46, 321 S.E.2d at 722-23.

74. See *supra* note 71.

not desiring to take complete control over the child's life, but simply wants to find the child a better parent. It can at least be asserted, and has in fact been asserted in the Baby Doe type controversies,<sup>75</sup> that unless the government is willing to shoulder the burdens of caring for a dependent or incompetent, it should not have any right to tell the caretaker how or whether he must care for the dependent or incompetent. There is only partial truth to this idea, for if in fact the government could find a caretaker who would fully shoulder the type of burdens the government wants shouldered, the government might very well be permitted to take the ward from one guardian and give it to another. This approach has been advocated in the Baby Doe context,<sup>76</sup> and was adopted by one California judge who changed custody from natural parents to volunteer workers who proved they were more willing and better knew how to care for a Down's Syndrome patient to whom they had become emotionally attached.<sup>77</sup> The issue becomes what quality of parenting or guardianship the government has a right to insist upon.

When the government itself chooses or is forced to act as guardian for an incompetent, the type of duties it lays upon itself provide insight into what type of caretaking it expects of others. Sadly, the government is sometimes faced with situations where there is no willing guardian for an incompetent. Saikewicz' family did not want to get involved;<sup>78</sup> Rudolfo Torres apparently had few close associates;<sup>79</sup> Joseph Hamlin was a ward of the state.<sup>80</sup> In such situations, the government, and more particularly the court, becomes the incompetent person's guardian of last resort. One implication of this Article's arguments for rights of relational privacy is that the government should always feel uncomfortable when exercising such a guardianship role. What the court really should be seeking is someone who can assert the sort of family or associational ties that give rise to a dependency relationship. The court's usual insistence that it does not need regularly to become involved in determinations of what should be done with dying patients<sup>81</sup> is an indication of its proper discomfort with the caretaking role.

A court's proper role is to be arbiter among contentious or possible custodians.<sup>82</sup> The court should not rush in to speak when other guardians

---

75. See, e.g., Annas, *supra* note 63, at 236.

76. See, e.g., Burt, *The Ideal of Community in the Work of the President's Commission*, 6 CARDOZO L. REV. 267, 272 (1984).

77. See *id.* at 270-71 (discussing *In re Phillip B.*, 92 Cal. App. 3d 796, 156 Cal. Rptr. 48 (Ct. App. 1979) and subsequent litigation).

78. See *Saikewicz*, 373 Mass. at 731, 370 N.E.2d at 420.

79. See *Torres*, 357 N.W.2d at 335.

80. See *Hamlin*, 102 Wash.2d at 813, 689 P.2d at 1375.

81. See, e.g., *L.H.R.*, 253 Ga. at 446, 321 S.E.2d at 723.

82. See *Jobes*, 108 N.J. at 397, 529 A.2d at 437.

are present. The court, since it has not been previously close to the incompetent, cannot best know the incompetent's wishes. The legitimacy of the court's claim to speak "on behalf" of the incompetent cannot be based on knowledge of the incompetent's nature but must be based, like the claims of more natural or voluntary guardians, on the fact that, as guardian of last resort, the government is the one who is caring for the incompetent.<sup>83</sup> The caring relationship gives rise to a right of privacy or autonomy concerning the dependent, yet the court can only faintly imitate how it thinks a good parent or guardian would act.<sup>84</sup> The standard usually adopted is labelled "substituted judgment,"<sup>85</sup> but in reality the court or its agent, the appointed guardian ad litem, is not substituting its judgment for the incompetent's. In reality, the court is substituting its judgment for that of the conscientious custodian which could not be found.

What custodial values are encouraged by use of a substituted judgment standard? As the *Storar* court points out, it is arguably ludicrous to speak of determining what an incompetent person would want were he competent when he has in fact never been competent.<sup>86</sup> Nevertheless, the *Storar* solution of keeping the body breathing at all costs<sup>87</sup> has been rejected by most courts.<sup>88</sup> Such rejection is proper, and in fact any decision system weighted towards purely objective criteria should be rejected. To this extent the *Conroy* court's nearly exclusive focus upon pleasure and pain was also misguided,<sup>89</sup> whereas the *Saikewicz* search for subjective factors is more commendable.<sup>90</sup> To treat the surviving body as only a collection of clinically measurable impulses is to dehumanize that body. As in the case of corpses, treating the body as more than just a body may not make perfect sense in so far as the body's rights are concerned, but it does preserve rights deemed important to the persons involved in that body's care, and it protects a right of choice in situations where it may not be clear whether the body is a person or not.

---

83. The government cares for him through institutions, if no others will or should.

84. The imitation is necessarily faint both because the court cannot have had much time to develop a relationship and, more importantly, because as an *institution* the government cannot act as people act.

85. See *infra* note 86.

86. See *Storar*, 52 N.Y.2d at 371-72, 438 N.Y.S.2d at 274-75, 420 N.E.2d at 72-73. The subjective substituted judgment standard implicitly criticized in *Storar* is explained in *Saikewicz*, 373 Mass. at 742, 370 N.E.2d at 431, and has been adopted by most courts faced with similar situations. See, e.g., *Ingram*, 102 Wash.2d at 833-34, 689 P.2d at 1369-70. See also *supra* notes 2-4.

87. See *Storar*, 52 N.Y.2d at 372, 438 N.Y.S.2d at 275, 420 N.E.2d at 73.

88. See, e.g., *Brophy*, 398 Mass. at 424-25, 497 N.E.2d at 633-34; *Torres*, 357 N.W.2d at 339; *Ingram*, 102 Wash.2d at 833-34, 689 P.2d at 1369-70.

89. See 98 N.J. at 337-38, 486 A.2d at 1232-33, criticized *id.* at 358, 486 A.2d at 1246 (Handler, J., dissenting in part) and in *Visbeck*, 210 N.J. Super. at 533-34, 510 A.2d at 131-33. But see *In re Clark*, 210 N.J. Super. 548, 510 A.2d 136 (1986) (*Conroy* objective standard applied to deny family members right to refuse treatment on behalf of incompetent patient).

90. See sources cited *supra* at notes 86, 88.

Perhaps strict materialists are correct and each of us is no more than a collection of impulses with ultimate meaning no greater than a stone's. *But we do not live our lives as if this were true.* The subjective viewpoint implicit in the substituted judgment standard formulated by *Saikewicz* and followed by other courts protects a right of choice or of non-interference. Perhaps the ultimate underpinnings for such a right are that without a perceived ability to make unique decisions, or at least move in unique directions, we would see our lives as ultimately meaningless because inherently fixed. If all dying bodies were to be treated in exactly the same way, no bodies would receive the unique care that is the hallmark of human relations.

Nevertheless, the *Storar* court is correct to note that the substituted judgment standard is a fiction at least as it purports to represent the actual views of incompetents, since these opinions are either unknowable or unintelligible to the competent person purporting to speak "for" him. A substituted judgment standard actually protects the ability to exercise compassion reflected in individualness towards the incompetent, what the author has labelled a right of relational privacy. The search for unexpressed views of an incompetent regarding what should happen to him, the probing into the minds of the severely retarded or mentally ill for clues as to how they will feel about what is done to them—in reality these may very well be shadow games. Yet such searching and probing at least identifies those who are qualified to *care* for the incompetent. The question is not so much "Do you really know what this incompetent would want?" as "Did you really attempt to know this incompetent?" In other words, what the court most wants of its caretakers and what the court tries to create in itself when it acts as caretaker is primarily sincerity and the development of intimacy. The court puts its stamp of approval on a guardian, not because it is in agreement with the particular decisions the guardian will make for the incompetent, but because it is convinced the guardian is the type person who will sincerely try to make a humane decision in regard to the incompetent.

Such a standard of humaneness or compassion may seem so nebulous and unprincipled as to be meaningless. Certainly it is possible that under nearly identical circumstances decisions to unplug the respirator or keep it pumping could be justified as equally "compassionate." Yet the formulation is not so vague that a court cannot intervene in clear situations of selfishness, neglect, or abuse.<sup>91</sup> And perhaps that is enough. What we probably most want for ourselves should we become incompetent is not a particular decision, but rather a particular type of decisionmaking. What we probably least want is to be removed from the influences of those to

---

91. See, e.g., *L.H.R.*, 253 Ga. at 446, 321 S.E.2d at 723.

whom we are closest and who have formerly best cared for us. And if it does not really matter to us as bodies what is done to us, what we probably most want, as members of society and as potential caring persons who might be caretakers for others who may or may not in reality be human beings, is the ability to expend on them our unique kind of care. The right protected out of a relational privacy rationale is as much the right to care for as the right to be cared for. It probably does not ultimately matter which half of the right is emphasized as long as the end result of personal versus apersonal care is achieved.

#### VI. WHY THE MEDICAL COMMUNITY SHOULD NOT NORMALLY HAVE AN IMPORTANT SAY IN REFUSAL OF TREATMENT DECISIONS

Implicit in the preceding arguments is a rejection of the medical community as the proper caretaker of incompetents. Although *Quinlan* and several other courts have required or encouraged medical ethics committees to be part of the ultimate decisionmaking process,<sup>92</sup> this approach is misguided. If the doctor's role in treatment of competents is merely to provide medical information which the patient then has a right to act upon,<sup>93</sup> that role should not change based on the patient's status. If doctors do not have any inherent right to control the treatment of their competent patients, they should not be granted such a right to control the lives of incompetents. As Justice Jones wrote in dissent in *Storar*: "Medical care providers have at best only a tangential interest in the outcome of the litigation [regarding treatment of incompetents] and can have no legitimate individual stake in the institution (or continuation) or the discontinuance of the medical procedure."<sup>94</sup> The issue is not whether doctors or other health care providers are compassionate or caring people. The issue is whether they should be guardians of incompetents when other qualified caretakers are available.

To the extent the medical community is allowed to exercise the decisive vote regarding what should happen to an incompetent, there ceases to be a relational right of privacy involving those formerly more intimately associated with the incompetent. The situation is analogous to the parental educational right protected by the Supreme Court in decisions such as *Yoder*, *Pierce*, and *Meyer v. Nebraska*.<sup>95</sup> If public educators were given exclusive control to determine how children should be educated, parents

92. See, e.g., *Requena*, 213 N.J. Super. at 481, 517 A.2d at 892; *Quinlan*, 70 N.J. at 32, 355 A.2d at 669; *Torres*, 357 N.W.2d at 341 & n.4. Cf. *Hamlin*, 102 Wash.2d at 815, 689 P.2d at 1377 (agreement of prognosis committee with family decision obviates need for guardianship hearing).

93. See, e.g., *Conroy*, 98 N.J. at 334, 486 A.2d at 1222.

94. 52 N.Y.2d at 376, 438 N.Y.S.2d at 279, 420 N.E.2d at 77.

95. 262 U.S. 390 (1923).

would lose nurturing rights in regard to their children. The special danger in the sort of "professionalism" often practiced or advocated by doctors and teachers is that the "profession" too easily can preempt the field and convince non-specialists that they have nothing to say about matters supposedly exclusively within the professional's field of competence.<sup>96</sup> It is simply too easy for the professional to slip into a misplaced paternalism which deludes the true possessor of rights and abilities into thinking that he no longer has any rights or abilities.

Doctors possess a certain competence regarding the ability to keep people breathing or to predict how long the breathing might go on unassisted. But to misperceive this expertise as an ability on the part of doctors to determine what constitutes life (or death) is to grant to the medical field more power than it should have. A doctor simply cannot determine any better than a non-doctor the quality of life his patient is likely to enjoy. The doctor can provide a patient or the patient's caretaker with medical information regarding treatment options, but the decision regarding what care is best for the patient is one that must ultimately rest on non-medical grounds.

Therefore, even in situations where medical personnel become court approved caretakers for incompetents, the courts should be careful to grant the caretaking to the doctor as an individual who has established some substitute personal relationship with the incompetent, rather than solely on the basis of the doctor's professional expertise.<sup>97</sup> What the courts as arbiters should insist upon is that the incompetent be provided with decisions based on as true a *personal* relationship as can be established. This means that in most cases someone other than the doctor should serve as caretaker.

## VII. CONCLUSION

Professor Burt has expressed concern that our society may be in the process of encouraging dying and discouraging dependency relationships, and he urges that we should not even inadvertently deny to incompetents or less than competents the right to be cared for.<sup>98</sup> Sympathetic to this concern, the author believes that the best way to ensure that dependency

---

96. See B. BLEDSSTEIN, *THE CULTURE OF PROFESSIONALISM* 80-120 (1976); I. ILLICH, *MEDICAL NEMESIS: THE EXPROPRIATION OF HEALTH* (1976).

97. But see Perr, *Refusing Treatment—Who Shall Decide?* 10 AM. ACAD. PSYCH. & L. BULL. 233 (1982). Although many specialists, especially in psychology or social work, might claim their decisions, since relationally oriented, should be given special weight, it is precisely in these areas that professional paternalism should be resisted. See sources cited *supra* at note 96. The specialist is a provider of information. Caring persons do not have to be specialists.

98. See Burt, *supra* note 76, especially at 281-83, 285.

relationships will be allowed to thrive in the future is not to insist that all bodies be kept alive, but to more forthrightly and directly recognize that the source of the right of care is as much in the person doing the caring for others as in the person cared for. Especially in the case of incompetents, where it is not clear that the "person" being cared for actually has any rights, and where it is far from easy to determine what the incompetent himself would think might be in his best interests, the issue of treatment or refusal of treatment effectively becomes a question of who shall be allowed to make the decision, and how many checks or controls shall be placed on that decision. This Article's argument that those most intimately associated with the body should make the decision, and that the government should only intrude on this decision in exceptional circumstances, is based on a faith that it is primarily the intimacy of the caring relationship itself that should be protected. Out of that protected privacy are likely to come decisions and actions which will increase, rather than decrease, instances of compassionate care.