

## HEALTHCARE DECISION-MAKING FOR MENTALLY INCAPACITATED INCARCERATED INDIVIDUALS

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*Who will make healthcare decisions for prisoners if they become incapacitated and are unable to articulate their wishes is an important question that is too often left unanswered. As the number of elder prisoners increases across the nation, this is an area of law which is becoming of greater importance and which needs to be addressed.*

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*For purposes of this Article, the opinions expressed by Scott Smith are his own opinions and not those of the University of Utah.*

*In this Article, the author describes the challenges surrounding making healthcare decisions for prisoners who lack the mental capacity to express their own wishes. He first explores the common law right to avoid unwanted care and how that interacts with the constitutional mandate against cruel and unusual punishment in the prison context. The author next reviews statutes from various states which address advance directives and surrogate healthcare decision making in a broader context. He finally both examines and critiques different models that prisons have adopted to handle this delicate situation and concludes that the best approach would involve allowing members of a prisoner's "prison family" to act as surrogate decision-makers as they are often the ones most familiar with the prisoner's wishes.*

## I. Introduction<sup>1</sup>

Across the United States, the number of elder prisoners is steadily increasing, creating challenges of all kinds, including, how to provide appropriate medical care to this population.<sup>2</sup> For instance, imagine a situation that occurs with some regularity within the prison system: a 69-year-old man is serving a 20 year sentence and has now completed half his sentence. A few years ago he was diagnosed with Stage III lung cancer, which has been

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1. The authors would like to thank the following people for extremely helpful comments and discussions regarding the content of this Article: Patricia H. Berry, Ph.D, Associate Professor, College of Nursing, University of Utah; Kristin Gates Cloyes, Ph.D, Associate Professor, College of Nursing, University of Utah; Ruth E. Garritsen-McKane, Ph.D, Director of the Field Education Bachelor of Social Work Program, University of Utah; Maureen Henry, J.D., Health and Aging Policy Fellow; Holli D. Martinez, M.S.N., Family Nurse Practitioner and Adjunct Instructor, College of Nursing, University of Utah; Donna Russell, Director, Utah Office of Public Guardian; Thomas Schenkenberg, Ph.D., Professor, Neurology, School of Medicine, University of Utah; John Stillman, Director of the Institutional Review Board, University of Utah; Kathy Supiano, Ph.D, Director of Caring Connections and Associate Professor, College of Nursing, University of Utah.

2. See, e.g., Mike Mitka, *Aging Prisoners Stressing Health Care System*, 292 JAMA 423, 423 (2004) (noting that the number of prisoners who are at least 50 years old doubled between 1992 and 2002); Kevin Johnson & H. Darr Beiser, *Aging Prisoners' Costs Put Systems Nationwide in a Bind*, USA TODAY, July 11, 2013, <http://www.usatoday.com/story/news/nation/2013/07/10/cost-care-aging-prisoners/2479285/> (discussing the financial burden associated with an aging prison population). Many authors choose to use the terms "prisoner" and "inmate" interchangeably. See, e.g., Frederick R. Parker Jr. & Charles J. Paine, *Informed Consent and the Refusal of Medical Treatment in the Correctional Setting*, 27 J.L. MED. & ETHICS 240, 243 (1999) (noting that the Supreme Court has held that where "a convicted inmate" suffers from a serious mental illness, prison officials may forcibly administer medication "against the prisoner's will" to the extent that he "poses some threat to the general inmate population"). This Article reflects a terminological choice to use "prisoner" consistently. Though that choice is primarily stylistic, there may also be substantive reasons not to use the terms interchangeably. See Tom Whitehead, *Prisoners Should Not Be Called Inmates, Says MOJ*, THE TELEGRAPH, Dec. 31, 2008, <http://www.telegraph.co.uk/news/newstoppers/howaboutthat/4045354/Prisoners-should-not-be-called-inmates-says-Moj.html>.

treated, at times, within the prison's medical treatment facility and at times at hospitals outside of the prison. More recently, his diagnosis has evolved to Stage IV lung cancer and the advancing disease has led to a deteriorated neurological condition to the point where he lacks the capacity to direct his own medical care and is not likely to regain capacity.<sup>3</sup>

At the same time, he has been referred to a hospital outside the prison for aggressive chemotherapy that is believed will extend his life expectancy by a few months.<sup>4</sup> This referral was based on discussions among prison medical providers as to what care was indicated based on the patient's condition. Upon meeting the patient at the outside hospital for the treatment consultation, Dr. Jones attempts to engage in the normal process of identifying family members or friends close to the patient, who may assist in directing the patient's care. Dr. Jones would like to be informed of past decisions made by the patient in order to have a better sense for how the patient might decide in the present case, or to identify a substitute decision-maker familiar with past decisions made by the patient. Dr. Jones is informed that the prison is not comfortable, due to security risks, in disclosing to Dr. Jones the names of the prisoner's family members residing locally.<sup>5</sup> Moreover, unbeknownst to Dr. Jones, the prisoner's family members have not interacted with the prisoner for over five years because of resentment and separation arising from his incarceration.<sup>6</sup> His family members are not aware that he has lung cancer. Moreover, the patient

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3. See UTAH CODE ANN. §§ 75-2a-103(13), -104 to -105 (West 2013) (providing that where an adult does not have the capacity to understand the nature of his health status, to make a rational evaluation of his options, and to communicate his decision, he does not have the capacity to create an advance directive).

4. See John F. Linder & Frederick J. Meyers, *Palliative Care for Prison Inmates: "Don't Let Me Die in Prison,"* 298 JAMA 894, 899 (2007) (noting that "prisons are likely to offer or provide more aggressive curative attempts (and perhaps even unwanted care) as they seek to dispel any impression of deliberate indifference or withholding care from inmates; this can translate into doing 'everything possible' to revive a patient in extremis"). In addition, it is important to note this hypothetical does not involve an emergency medical situation, in which standard procedures for informed consent and surrogate decision-making may not be applicable. See, e.g., UTAH CODE ANN. § 26-8a-601(3) (West 2013) (consent not required for certain emergency medical services).

5. See, e.g., *Washington v. Harper*, 494 U.S. 210, 223 (1990) (holding that "[t]he legitimacy, and the necessity, of considering the State's interest in prison safety and security are well established" and that interests in prison security may justify prison officials making medical decisions on behalf of prisoners).

6. See Mitka, *supra* note 1, at 898 (noting that many prisoners are estranged from their families or are imprisoned in another state and do not have the resources to arrange visits).

has not prepared an advance directive which would indicate his desires in the event of incapacity.<sup>7</sup> Finally, Dr. Jones does not have access to a community surrogate who could assist in decision-making.<sup>8</sup>

Dr. Jones faces an ethical dilemma: should he provide the care as recommended by the prison administration,<sup>9</sup> in the absence of an advance directive, or surrogate decision-maker who speaks for the patient? In view of the hospital's contract with the prison, which compensates the physician and the hospital for providing care to the prisoner, the doctor wishes on the one hand to avoid his own biases and avoid providing care not wanted by the patient for the sake of remuneration.<sup>10</sup> On the other hand, in light of the extra security burden presented by the patient and the negative perception of prisoners shared by some other hospital patients,<sup>11</sup> Dr. Jones wishes to provide care to this patient at the same level as would be true for any other similarly situated, non-prisoner patient. Should he view the prison administrator or prison medical provider as the substitute decision maker for the prisoner? Should he view himself as being the surrogate decision-maker?<sup>12</sup> Should the care be provided or not?

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7. See Susan Franzel Levine, *Improving End-of-life Care of Prisoners*, 11 J. CORRECTIONAL HEALTH CARE 317, 323 (2005) (finding that only 1% of prisoners in the Connecticut Department of Corrections system were approached about completing an advance directive).

8. Compare IOWA CODE ANN. § 135.29 (2013) (providing for a "substitute medical decision-making board" with authority to make medical decisions on behalf of an incapacitated patient when there is no other substitute decision maker available), with UTAH CODE ANN. § 75-2a-108 (2013) (providing a list of individuals who can act as a surrogate on behalf of an incapacitated patient, but no alternative if no individual on that list is available).

9. See UTAH DEP'T OF CORRECTIONS POL'Y [hereinafter UDC POLICY] § 06/12.07(D) (on file with authors) (providing that consent to treatment for an incapacitated prisoner can be provided by "the licensed treating physician, attending physician, Clinical Administrator, or the referral facility physician of record for the offender patient").

10. See Ben Sutherly, *Hospital Might End Care for Prisoners: State Contract Now Less Lucrative, Bed Space at a Premium, OSU Says*, THE COLUMBUS DISPATCH, Dec. 31, 2012, <http://www.dispatch.com/content/stories/local/2012/12/31/hospital-might-end-care-for-prisoners.html> (discussing the pressure on a hospital that contracts to provide medical care to prisoners to use their available bed space in as lucrative a fashion as possible).

11. See *id.* (citing "issues relative to public perception" in favor of allowing the expiration of a contract for the provision of medical care to prisoners).

12. Compare TEX. HEALTH & SAFETY CODE ANN. § 166.039(e) (West 2013) (permitting a physician to make health care decisions on behalf of an incapacitated patient where no other surrogates are available), with UTAH CODE ANN. § 75-2a-108 (2013) (excluding physicians from the list of individuals authorized to act as surrogates for incapacitated patients).

This Article explores the legal context surrounding the challenges involved in providing medical care to prisoners who lack healthcare decision-making capacity. The State of Utah is used as a case study to explore this issue. Part II examines the common law right to avoidance of unwanted care and contrasts that right with the prison's requirement to avoid cruel and unusual punishment. Next, Part III reviews relevant Utah statutes, especially those dealing with advance directives and surrogate healthcare decision-making. Such statutes are not unique to Utah but are referenced to illustrate the types of statutes used in most states. Part IV identifies models used by prisons around the country in providing medical care to incapacitated prisoners, and highlights the strengths and weaknesses of each. Finally, Part V proposes that prisons, including Utah prisons, more widely promote the use of advance directives, particularly within the population of terminally-ill and chronically-ill prisoners, and establish mechanisms whereby members of a prisoner's "prison family" can act as surrogate decision-makers.

## II. The Common Law Rights to Adequate Medical Care and Freedom from Unwanted Medical Treatment

Before exploring potential improvements to health care decision-making for incarcerated individuals who are incapacitated, it is important to first understand the unique tension in the prison setting between the state's duty to avoid cruel and unusual punishment on the one hand (by ensuring adequate provision of medical care to prisoners),<sup>13</sup> and the individual's liberty interest in avoiding unwanted care (which prohibits the prison from providing "too much" care).<sup>14</sup>

On the one hand, prisoners have a right to health care. The Eighth Amendment to the U.S. Constitution prohibits "cruel and unusual punishments."<sup>15</sup> Because "[a]n inmate must rely on prison authorities to treat his medical needs," prison authorities who delay or refuse medical care risk causing prisoners to endure "pain and suffer-

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13. See, e.g., *Estelle v. Gamble*, 429 U.S. 97, 104 (1976) (holding that "deliberate indifference to serious medical needs of prisoners constitutes the unnecessary and wanton infliction of pain . . . proscribed by the Eighth Amendment").

14. See, e.g., *Washington*, 494 U.S. at 221-22 (1990) (noting that a prisoner "has a significant liberty interest in avoiding the unwanted administration [of medical treatment] under the Due Process Clause of the Fourteenth Amendment").

15. U.S. CONST. amend. VIII.

ing” or “physical torture or a lingering death.”<sup>16</sup> Because unnecessary pain and suffering serves no legitimate penological interest, prison authorities who are deliberately indifferent to the medical needs of prisoners are liable under 42 U.S.C. Section 1983 and the Eighth Amendment.<sup>17</sup>

A prison official exhibits deliberate indifference when the official “knows of and disregards an excessive risk to prisoner health or safety; the official must both be aware of facts from which the inference could be drawn that a substantial risk of serious harm exists, and he must also draw the inference.”<sup>18</sup> As a result, mere medical malpractice or the provision of inadequate treatment will not alone trigger liability under the Eighth Amendment.<sup>19</sup> However, a significant departure from the applicable standard of care is evidence of deliberate indifference.<sup>20</sup> Deliberate indifference may take the form, for instance, of a refusal to investigate further when there is evidence that a prisoner may need medical care,<sup>21</sup> the choice to treat in a manner which is “easier and less efficacious” than the care actually necessary,<sup>22</sup> and the interference by prison officials with a treatment plan already in place.<sup>23</sup> The failure to provide adequate treatment can result in liability under the Eighth Amendment.

At the other end of the spectrum, states must avoid providing unwanted medical care to prisoners. By the time the Supreme Court considered this question, a variety of state courts had already found a liberty interest in freedom from unwanted medical treatment.<sup>24</sup> These

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16. *Estelle*, 429 U.S. at 103.

17. *Id.*

18. *Farmer v. Brennan*, 511 U.S. 825, 837 (1994).

19. *Id.*

20. *Moore v. Duffy*, 255 F.3d 543, 545 (8th Cir. 2001).

21. *Mandel v. Doe*, 888 F.2d 783 (11th Cir. 1989) (affirming a district court award of \$500,000 in a suit under 42 U.S.C. § 1983 where prison medical authorities refused to authorize an x-ray of a prisoner’s leg and the failure to properly treat resulted in the prisoner requiring a prosthetic hip).

22. *Williams v. Vincent*, 508 F.2d 541, 544 (2d Cir. 1974) (reversing summary dismissal of a prisoner’s Eighth Amendment claim for deliberate indifference where the prisoner alleged that prison medical officials consciously chose the “easier and less efficacious” treatment when they merely sutured his wound rather than reattaching his ear).

23. *Johnson v. Hay*, 931 F.2d 456, 461 (8th Cir. 1991) (where a prison pharmacist refused to fill a prescription for an anti-seizure medication prescribed to a prisoner prior to his imprisonment, noting that “the law clearly establishes that a prison pharmacist could not intentionally interfere with or fail to carry out treatment prescribed for a prisoner”).

24. *See, e.g., Rasmussen by Mitchell v. Fleming*, 741 P.2d 674, 683 (Ariz. 1987) (holding that “[t]he right to refuse medical treatment is a personal right sufficient-

courts had justified their holdings in various ways. Some had appealed to the common-law right to be “free from bodily invasion.”<sup>25</sup> Other courts had appealed to the right to privacy.<sup>26</sup> Just as the right to privacy and autonomy protects against “unwarranted intrusion into matters so fundamentally affecting a person as the decision whether to bear or beget a child,”<sup>27</sup> it protects against unwarranted intrusion into matters so fundamentally affecting a person as the decision how to spend the last days of one’s life or whether a slight chance of improved health justifies the pain and indignity associated with a particular treatment.

For its part, the Supreme Court has held that “[t]he principle that a competent person has a constitutionally protected liberty interest in refusing unwanted medical treatment may be inferred from our prior decisions.”<sup>28</sup> However, it also recognized, as had a number of courts before it,<sup>29</sup> that the liberty interest must be balanced against other legitimate interests.<sup>30</sup> Four state interests in particular are cited as requiring consideration in determining whether a competent individual should be free to exercise her liberty interest in refusing unwanted medical treatment: “(1) the preservation of life; (2) the protection of the interest of innocent third parties; (3) the prevention of

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ly ‘fundamental’ or ‘implicit in the concept of ordered liberty’ to fall within the constitutionally protected zone of privacy . . .”); *Bouvia v. Superior Court*, 225 Cal. Rptr. 297, 301 (Cal. Ct. App. 1987) (holding that there is a “basic and fundamental” right of a competent patient “to refuse *any* medical treatment, even that which may save or prolong her life”) (emphasis in original); *Matter of Spring*, 405 N.E.2d 629, 635 (Mass. 1980) (noting that “there is something approaching consensus . . . [that] [a] person has a strong interest in being free from nonconsensual invasion of his bodily integrity, and a constitutional right of privacy that may be asserted to prevent unwanted infringements of bodily integrity”).

25. See, e.g., *Rasmussen by Mitchell*, 741 P.2d at 683; *In re Conroy*, 486 A.2d 1209, 1221–22 (N.J. 1985) (noting that because “[e]very human being of adult years and sound mind has a right to determine what shall be done with his own body . . . a surgeon who performs an operation without his patient’s consent commits an assault, for which he is liable for damages”).

26. See, e.g., *Bouvia*, 225 Cal. Rptr. at 301; *Matter of Welfare of Colyer*, 660 P.2d 738, 742 (Wash. 1983); *Matter of Quinlan*, 355 A.2d 647, 663 (N.J. 1976).

27. *Eisenstadt v. Baird*, 405 U.S. 438, 453 (1972).

28. *Cruzan v. Dir., Missouri Dep’t of Health*, 497 U.S. 261, 270, 278 (1990).

29. See, e.g., *In re Conroy*, 486 A.2d at 1223 (noting that “the right to decline life-sustaining medical treatments . . . may yield to countervailing societal interests in sustaining the person’s life”).

30. *Id.*

suicide; and (4) maintaining the ethical integrity of the medical profession."<sup>31</sup>

While prisoners have the same liberty interest in avoiding unwanted medical treatment, that liberty interest is balanced against additional state interests. "Prison walls do not form a barrier separating prisoners from the protections of the Constitution."<sup>32</sup> The Supreme Court has held that there is "little doubt" that prisoners retain a liberty interest in being free from unwanted medical treatment.<sup>33</sup> However, the prisoner's right to avoid such treatment "must be defined in the context of the prisoner's confinement" and the legitimate prison interests associated with that confinement.<sup>34</sup> The question in individual cases is not whether the prisoner has a liberty interest in avoiding treatment, but whether that interest can be exercised given the unique context of confinement. As will be seen later, for instance, prison officials may decline to provide a surrogate's information to a health care provider for fear that that surrogate, knowing their family member or friend is receiving medical care at a facility outside the hospital, may, together with the prisoner, present a security or flight risk.

In *Turner v. Safley*, the Supreme Court announced a four-part test to determine whether a prison policy or action is "reasonably related to legitimate penological interests" that justify a violation of a prisoner's constitutional rights.<sup>35</sup> First, courts must determine whether "'there is a valid, rational connection' between the prison regulation and the legitimate governmental interest put forward to justify it."<sup>36</sup> Second, courts should look to "whether there are alternative means of exercising the rights that remain open to prison inmates."<sup>37</sup> Third, courts must consider "the impact accommodation of the asserted constitutional right will have on guards and other inmates, and on the allocation of prison resources generally."<sup>38</sup> Finally, the availability of

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31. *Superintendent of Belchertown State School v. Saikewicz*, 370 N.E.2d 417, 425 (Mass. 1977). See also *Bouvia*, 225 Cal. Rptr. at 304; *In re Conroy*, 486 A.2d at 1223.

32. *Turner v. Safley*, 482 U.S. 78, 78 (1987).

33. *Washington v. Harper*, 494 U.S. 210, 221–22.

34. *Id.* at 222.

35. *Turner*, 482 U.S. at 89–90. While *Turner* dealt specifically with restrictions on the ability of prisoners to marry, the court has since noted that "the standard of review we adopted in *Turner* applies to all circumstances in which the needs of prison administration implicate constitutional rights." *Washington*, 494 U.S. at 224 (1990) (emphasis added).

36. *Turner*, 482 U.S. at 89–90.

37. *Id.* at 90.

38. *Id.*

ready alternatives to the regulation may be evidence that the regulation is not reasonable, while the absence of such alternatives may be evidence that it is.<sup>39</sup> While “[t]his is not a ‘least restrictive alternative’ test . . . if an inmate claimant can point to an alternative that fully accommodates the prisoner’s rights at *de minimis* cost to valid penological interests, a court may consider that as evidence that the regulation does not satisfy the reasonable relationship standard.”<sup>40</sup>

The Court emphasized that in applying this test, courts must be “conscious of the measure of judicial deference owed to corrections officials . . . in gauging the validity of the regulation.”<sup>41</sup> The Supreme Court did not detail what measure of deference is required. However, other courts have held that it is quite substantial. The Tenth Circuit, for instance, has endorsed the view that “the judgment of prison authorities will be presumed valid unless it is shown to be such a substantial departure from accepted professional judgment, practice or standards as to demonstrate that the person responsible actually did not base the decision on such judgment.”<sup>42</sup>

The cases in which courts have most readily permitted the involuntary treatment of prisoners involve direct threats to the health or safety of other members of the prison population.<sup>43</sup> Even where there is no clear and direct threat to the health and safety of other members of the prison population, however, courts have appealed to a number of penological interests to justify involuntary treatment. For instance, where a prisoner refuses treatment in an attempt to manipulate prison officials, an interest in the orderly administration of the prison can jus-

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39. *Id.*

40. *Id.* at 90–91.

41. *Id.* at 90 (internal quotation marks omitted) (quoting *Pell v. Procunier*, 417 U.S. 817, 827 (1974)).

42. *Lowry v. Honeycutt*, 211 Fed. Appx. 709, 712 (10th Cir. 2007) (quoting *White v. Napoleon*, 897 F.2d 103, 112 (3rd Cir. 1990)).

43. See, e.g., *id.* at 712 (holding that, given their legitimate concerns about the spread of sexually transmitted diseases and harms associated with sexual assault, prison officials could force a prisoner to undergo a rape examination); *Russell v. Richards*, 384 F.3d 444, 448 (7th Cir. 2004) (holding that the “obligation to ensure the safety and medical well-being of its inmates and its personnel” was sufficient justification to require the use of delousing shampoo); *Gilliam v. Martin*, 589 F. Supp. 680, 682 (W.D. Okla. 1984) (holding that the prison’s duty to protect other prisoners and prison guards from harm justifies the forced medication of a prisoner to suppress violent, psychotic behavior); *Langton v. Comm’r of Corr.*, 614 N.E.2d 1002, 1006 (Mass. App. Ct. 1993) (holding that, where a prisoner refused tuberculosis testing, “any right that the inmates had to refuse the TB test was outweighed by the State’s interest in maintaining the health of its prison population”).

tify forced treatment.<sup>44</sup> Courts have also appealed to concerns over limited budgets, along with other interests, in approving involuntary treatment.<sup>45</sup> Prison officials remain obligated to provide treatment in the future should a prisoner desire it.<sup>46</sup> As a result, where treatment would likely prevent or mitigate more serious health risks in the future, “[t]he state’s interest in averting potentially devastating healthcare costs is . . . substantial . . . .”<sup>47</sup> Finally, courts often appeal to the same state interests at play in considering a non-prisoner’s right to refuse medical treatment—interests in the preservation of life, the prevention of harm to innocent third parties, the prevention of suicide, and protection of the integrity of the medical profession.<sup>48</sup>

The jurisprudence surrounding a prisoner’s right to refuse medical treatment provides only limited guidance with respect to cases in which an incapacitated prisoner is in need of medical treatment. One might reasonably think that if prison interests can override a prisoner’s refusal to consent to treatment, then those same interests justify treatment in cases where the prisoner is incapable of providing consent. While almost certainly correct, most cases in which a prison-

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44. See, e.g., *Comm’r of Corr. v. Myers*, 399 N.E.2d 452, 458 (Mass. 1979) (holding that where a prisoner refused kidney dialysis treatment to protest his placement in a medium rather than minimum security prison, the “State’s interest in upholding orderly prison administration tips the balance in favor of authorizing treatment without consent”); *State ex rel. Schuetzle v. Vogel*, 537 N.W.2d 358, 361 (N.D. 1995) (holding that because “[c]ourts cannot condone a prisoner’s manipulation of his medical circumstances to the detriment of a state’s interest in prison order, security, and discipline,” a prisoner who refused treatment for diabetes to protest denial of his work release could be involuntarily treated). *But see Zante v. Prevatte*, 286 S.E.2d 715, 717 (Ga. 1982) (holding that the State failed to show “such a compelling interest in preserving [the prisoner’s] life, as would override his right to refuse medical treatment” and allow involuntary treatment).

45. See, e.g., *Russell*, 384 F.3d at 449 (7th Cir. 2004) (holding that allowing a prisoner to refuse unwanted treatment “would place additional burdens on jail resources” because the prison would subsequently need to respond to prevent more serious harm); *Comm’r of Corr. v. Coleman*, 38 A.3d 84, 105–06 (Conn. 2012) (holding that additional costs and support services for hunger striking prisoner militated in favor of forced treatment).

46. *Davis v. Agosto*, 89 Fed. App’x 523, 528 (6th Cir. 2004) (noting that where a prisoner refused treatment for an open wound, “[h]ad [prison officials] opted not to provide the treatment . . . [they] would of course have remained responsible for providing any further medical treatment prompted by the failure to close the wound”).

47. *Vogel*, 537 N.W.2d at 364.

48. *Thor v. Superior Ct.*, 21 Cal. Rptr. 2d 357, 365 (Cal. 1993) (noting that “[f]our state interests generally identify the countervailing considerations in determining the scope of patient autonomy: preserving life, preventing suicide, maintaining the integrity of the medical profession, and protecting innocent third parties” and holding that those interests do not justify forcing treatment on the prisoner at issue).

er is unable to consent to treatment will not involve the sorts of interests that have been cited by courts to justify overriding a prisoner's refusal of treatment. One cannot claim, for instance, that a prisoner who is unable to consent to treatment is attempting to manipulate prison administration by failing to provide it. Further, many—probably most—cases involving a prisoner who cannot provide consent to treatment will not involve an illness that presents a direct danger to other members of the prison community. The number of prisoners over the age of 65 has increased by 63 percent during the period from 2007–2010.<sup>49</sup> The result is a predictable increase in the number of prisoners who have the sorts of chronic illnesses—“heart and lung problems, diabetes, hypertension, cancer, ulcers, poor hearing and eyesight, and a range of physical disabilities”—that attend old age.<sup>50</sup> Unlike tuberculosis, for instance, such illnesses do not pose a direct threat to other members of the prison population.<sup>51</sup> Because the case law focuses almost exclusively on how prison officials may react when a prisoner refuses treatment, it provides no guidance whatsoever concerning who can act as a surrogate—provide consent on behalf of a prisoner—when a prisoner is incapable of providing consent. When prison administrators judge that an incapacitated prisoner is in need of medical treatment, the case law does not dictate how the prison should proceed.

Nevertheless, the case law illustrates some of the unique difficulties associated with medical care in the prison setting. On the one hand, a prisoner, like anyone else, has a liberty interest in freedom from medical treatment to which they have not consented. On the other, prison officials must provide a certain level of medical care, but may not have interests aligned with the desires and interests of the prisoner.

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49. HUMAN RIGHTS WATCH, *OLD BEHIND BARS: THE AGING PRISON POPULATION IN THE UNITED STATES* 6 (2012), available at [http://www.hrw.org/sites/default/files/reports/usprisons0112webwcover\\_0.pdf](http://www.hrw.org/sites/default/files/reports/usprisons0112webwcover_0.pdf).

50. *Id.* at 73.

51. *Langton v. Comm'r of Corr.*, 614 N.E.2d 1002, 1006 (Mass. App. Ct. 1993) (permitting forced tuberculosis testing due to the risk to other members of the prison population associated with a tuberculosis outbreak).

### III. Background Utah Statutory Analysis

Having established the common-law context for healthcare decision-making in prisons, we now turn to the statutory framework of one state (Utah).

#### A. Utah Law Permits a Friend, Including a Fellow Prisoner, to Act as a Surrogate Healthcare Decision-maker

Utah, like most states, statutorily provides that certain surrogates may make health care decisions for patients lacking capacity to make the decisions for themselves; these surrogates include appointed agents, legal guardians, or individuals who become surrogates by “default.”<sup>52</sup> Default surrogates are generally family members, but other individuals who are familiar with the patient’s wishes may also fill the role.<sup>53</sup> In the event a patient has not designated a health care decision-making agent, or an appointed agent is unwilling or unable to make medical decisions on the patient’s behalf, Utah law creates a hierarchy of potential default surrogates with priority ostensibly based on the closeness of the surrogate’s relationship to the patient: first, a spouse, then other family members, and finally, other individuals who have a relationship with the patient (“friend”).<sup>54</sup> Of states with default surrogacy statutes, about half, including Utah, allow a willing friend of the patient to act as a surrogate if no family members are available.<sup>55</sup> This is critically important in the case of prisoners, who may be estranged from their family members.<sup>56</sup> It is possible, if not likely, that those most familiar with incarcerated individuals’ wishes are not, in fact, family members, but rather fellow prisoners or

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52. UTAH CODE ANN. §§ 75-2a-103(23), 75-2a-108 (2013); *see also* WYO STAT. § 35-22-406 (2013); IDAHO CODE § 39-4503 (2013); NEV. REV. STAT. § 449.626 (2013); COLO. REV. STAT. ANN. §§ 15-18.5-101 to -103 (West 2013); ARIZ. REV. STAT. § 36-3231 (West 2013). For an unofficial state-by-state chart of default surrogacy rules, *see* DEFAULT SURROGATE CONSENT STATUTES, AM. BAR ASS’N (2009), [http://www.americanbar.org/content/dam/aba/migrated/aging/PublicDocuments/famcon\\_2009.authcheckdam.pdf](http://www.americanbar.org/content/dam/aba/migrated/aging/PublicDocuments/famcon_2009.authcheckdam.pdf).

53. UTAH CODE ANN. § 75-2a-108.

54. *Id.* § 75-2a-108(1). Importantly, this use of the term “friend” should be understood broadly to apply to anyone who satisfies the conditions—discussed immediately below—in UTAH CODE ANN. § 75-2a-108(2). A friend, in this sense, need not be someone who has an intimate relationship of the sort that would more colloquially be identified as a friendship.

55. *Id.* § 75-2a-108(2); *see* DEFAULT SURROGATE CONSENT STATUTES, *supra* note 51.

56. Linder & Meyers, *supra* note 3, at 898 (noting that many prisoners are estranged from their families).

prison officials, including prison medical personnel.<sup>57</sup> In Utah, for a friend to act as healthcare surrogate, that friend must have “exhibited special care and concern for the patient” and “know[n] the patient and the patient’s personal wishes.”<sup>58</sup> Assuming the default surrogate criteria are otherwise met, nothing in Utah law would prohibit a fellow prisoner from qualifying as a default surrogate for an individual.<sup>59</sup>

State statutes vary in terms of the specific individuals permitted to become the surrogate.<sup>60</sup> A few states allow a clergy or other religious member to act as a surrogate, or a treating or attending physician, provided there is consultation with and concurrence by a second physician.<sup>61</sup> Other states disqualify the patient’s health care providers.<sup>62</sup> A few states have provided for consultation with an ethics committee when no other default surrogates are available.<sup>63</sup> Utah law neither specifically permits nor prohibits a health care provider or clergy member from acting as a default surrogate, and does not ad-

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57. Tanya Tillman, *Hospice in Prison: The Louisiana State Penitentiary Hospice Program*, 3 J. OF PALLIATIVE MED. 513, 513 (2000), <http://online.liebertpub.com/doi/abs/10.1089/jpm.2000.3.4.513> (noting that because many prisoners serving long-term sentences have lost outside contact with their families, the prison becomes “their home, their community” and “other inmates have become their family”).

58. UTAH CODE ANN. § 75-2a-108(2) (2013).

59. Prisons guards, administrators, and medical providers may also have developed close relationships with prisoners. However, potential and actual conflicts of interest make them less than ideal surrogates. See, e.g., UTAH CODE ANN. § 75-2a-107(2) (prohibiting a health care provider of an individual from serving as the individual’s appointed agent under a written advance health care directive; also prohibiting an employee of the health care facility where patient is receiving treatment); *id.* § 75-2a-108(1)(d) (court may disqualify a person acting inconsistent with the position of trust).

60. See Default Surrogate Consent Statutes, *supra* note 51.

61. *Id.*; see IND. CODE ANN. § 16-36-1-5(d) (2013) (“religious superior”); TEX. HEALTH & SAFETY CODE ANN. § 313.004(c) (West 2013) (“clergy;” only applicable to patients in certain home health services or institutional settings); N.Y. PUB. HEALTH LAW §§ 2965(3)(a) (McKinney 2013) (physician); OR. REV. STAT. § 127.535(4) (2013) (attending physician).

62. See TENN. CODE ANN. § 68-11-1806(d) (2013) (individual and facility providers disqualified); W. VA. CODE ANN. § 16-30-8 (West 2013) (same).

63. See ALA. CODE § 22-8A-11(c) (West 2013) (consultation with ethics committee); FLA. STAT. ANN. § 765.401(1) (West 2013) (bioethics committee review). See also Naomi Karp & Erica Wood, *Incapacitated and Alone: Health Care Decision Making for Unbefriended Older People*, 31 A.B.A. HUM. RTS. MAG. (2004), available at [http://www.americanbar.org/publications/human\\_rights\\_magazine\\_home/human\\_rights\\_vol31\\_2004/spring2004/hr\\_spring04\\_incapacitated.html](http://www.americanbar.org/publications/human_rights_magazine_home/human_rights_vol31_2004/spring2004/hr_spring04_incapacitated.html) (discussing use of ethics committees).

dress referral to an ethics committee or other group in the absence of available default surrogates.<sup>64</sup>

### B. Advance Directives—A Useful Tool Needing More Attention Within Utah Prisons

Advance directives—generally recorded in a written document—express an individual's preferences regarding future medical care in the event that the individual has become incapacitated and is no longer capable of expressing her preferences regarding such care.<sup>65</sup> Documenting such preferences in advance helps to ensure that, in the event of incapacity, the patient nevertheless has some measure of control over her own medical care.<sup>66</sup> Advance directives may concern both the character of the medical care the person would choose to receive and the individual whom she would designate to make decisions on her behalf.<sup>67</sup>

In 1990, Congress passed legislation known as the Patient Self-Determination Act<sup>68</sup> ("PSDA") in order to "reinforce individuals' constitutional right to determine their final health care."<sup>69</sup> The PSDA federally recognizes advance directives as a recommended form of health care decision-making. The PSDA requires all health care providers that receive Medicare or Medicaid funding to "increase public awareness about the use of advance directives," specifically by providing information about living wills and health care powers of attorney.<sup>70</sup> The law does not apply to prison facilities,<sup>71</sup> in part because they operate independently of Medicare and Medicaid.<sup>72</sup>

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64. Utah law does, however, prevent treating health care providers and employees of treating health care facilities from acting as appointed health care decision-making agents. UTAH CODE ANN. § 75-2a-107(2) (2013); see *infra* Part III.B. It is possible this prohibition would extend to surrogates in some circumstances.

65. See Anita Cava, Advance Directives: Taking Control of End-of-Life Decisions, 14 ST. THOMAS L. REV. 5, 5 (2001).

66. *Id.*

67. *Id.* at 6.

68. Omnibus Budget Reconciliation Act of 1990, Pub. L. No. 101-508, §§ 4206, 4751, 104 Stat. 1388, 1388-115, 1388-204 (2014) (*codified* at 42 U.S.C. 1395cc(f) & 1396a(w) (2012)).

69. U.S. GOV'T ACCOUNTABILITY OFFICE, GAO/HEHS-95-135, PATIENT SELF-DETERMINATION ACT 1 (1995).

70. *Id.*

71. Susan Franzel Levine, *Improving End-of-life Care of Prisoners*, 11 J. CORR. HEALTH CARE 317, 319 (2005).

72. Linder & Meyers, *supra* note 3, at 895 (noting that prison facilities operate independently of Medicare, Medicaid, and private insurance).

On a state level, Utah's Advance Health Care Directive Act<sup>73</sup> ("Act") provides Utah citizens with a statutory right to execute advance directives.<sup>74</sup> The Act establishes that all adults are presumed to have health care decision-making capacity until determined otherwise by a health care professional.<sup>75</sup> Next, the Act provides that any adult with capacity may create an advance health care directive.<sup>76</sup> The standard Utah form creates a directive that is essentially two parts: first, a health care power of attorney that appoints an "agent" to make health care decisions, and second, a living will that provides specific directions with regard to particular life-sustaining treatments such as feeding tubes or dialysis.<sup>77</sup> The individual executing the directive may choose to appoint an agent, who will assume the power to make any health care decision the individual could have made, or may choose not to appoint an agent.<sup>78</sup> The form may also be used to nominate a guardian in case of mental incapacity.<sup>79</sup> Finally, the "living will" allows an individual to identify situations that would trigger the application of the advance directive, such as progressive illness or a persistent vegetative state, and to dictate what types of treatment should be pursued.<sup>80</sup> Unlike the federal law, the Utah statute does not impose an affirmative requirement on institutions (for instance, hospitals, nursing homes, or prisons) to provide patients with the opportunity to complete an advance directive.

With a few narrow exceptions, Utah law is open-ended as to whom the individual may appoint as an agent.<sup>81</sup> One important exception prohibits parties who complete an advance health care directive from designating their health care provider as the individual who will make health care decisions on their behalf in the event that

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73. UTAH CODE ANN. §§ 75-2a-101 to 75-2a-125 (2013).

74. *Id.* §§ 75-2a-106, 75-2a-108.

75. *Id.* § 75-2a-104.

76. *Id.* § 75-2a-107(1)(b).

77. UTAH ADVANCE HEALTH CARE DIRECTIVE, [http://aging.utah.edu/\\_documents/utah-coa/directives/ad-6-9-09.pdf](http://aging.utah.edu/_documents/utah-coa/directives/ad-6-9-09.pdf) (last visited Mar. 31, 2014).

78. UTAH CODE ANN. § 75-2a-107(1)(a) (2013).

79. Utah Advance Health Care Directive, *supra* note 76, at 2.

80. *Id.* at 3-4.

81. See UTAH CODE ANN. § 75-2a-107 (LexisNexis 2013); UTAH MED. ASS'N, UTAH ADVANCE DIRECTIVE FORM & INSTRUCTIONS 3 (2009 ed.), available at [http://aging.utah.edu/\\_documents/utah-coa/directives/ad-09-instructions-edited-090603.pdf](http://aging.utah.edu/_documents/utah-coa/directives/ad-09-instructions-edited-090603.pdf); UTAH COMM'N ON AGING, TOOLKIT FOR ADVANCE HEALTHCARE PLANNING (2012) [hereinafter TOOLKIT] available at [http://aging.utah.edu/\\_documents/utah-coa/directives/tool-kit-2012.pdf](http://aging.utah.edu/_documents/utah-coa/directives/tool-kit-2012.pdf) (discussing who can and cannot be an agent).

they are incapacitated.<sup>82</sup> Thus, Utah law does reflect a recognition of conflicts of interest—discussed in more detail, *infra* Part IV—that may attend situations in which health care providers are making decisions on behalf of their patients in non-emergent situations. Under this statute, a prisoner theoretically would not be permitted to appoint an employee of the prison medical facility as an agent due to a potential conflict of interest.<sup>83</sup> However, Utah law, on its face, would permit a prisoner to appoint another prisoner as an agent for healthcare decision-making purposes.<sup>84</sup> This may be advantageous for many prisoners who are separated from other potential agents for one reason or another, but may be problematic for other reasons as discussed in Part V.<sup>85</sup>

As an alternative or in addition to an advance directive, the Act also provides for execution of a “Life with Dignity Order,”<sup>86</sup> also known as a Physician Order for Life-Sustaining Treatment (“POLST”).<sup>87</sup> This is also commonly called a “do not resuscitate” or “DNR.”<sup>88</sup> The terminology can be confusing because a DNR order also refers to a non-transferable order made by a hospital physician for an inpatient, as contrasted with the POLST or Life with Dignity Order which is transferable.<sup>89</sup> A POLST is prepared by a physician in consultation with and on behalf of a patient, and may “specify the level of life sustaining care to be provided,” as well as “direct that life sustaining care be withheld or withdrawn . . . .”<sup>90</sup> In the event of a conflict between a POLST and an advance directive, “the provisions of the [POLST] take precedence.”<sup>91</sup>

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82. UTAH CODE ANN. § 75-2a-107(2) (LexisNexis 2013). *See also supra* note 58.

83. UTAH CODE ANN. § 75-2a-107(2) (LexisNexis 2013).

84. Though neither Utah law nor federal law requires prisons to provide prisoners with an opportunity to complete an advance directive, the Utah Department of Corrections appears to recognize that the statutory right to complete an advance directive provided by Utah law extends to prisoners. *See supra* notes 67–79 and accompanying text. *See infra* note 97.

85. *See Tillman, supra* note 56.

86. UTAH CODE ANN. § 75-2a-106 (LexisNexis 2013).

87. *See* UTAH BUREAU OF EMERGENCY MED. SERVS., <http://health.utah.gov/ems/polst/> (June 9, 2011); *see also* TOOLKIT, *supra* note 80 (discussing meaning of terminology such as POLST, DNR order, and Life with Dignity Order).

88. *See* TOOLKIT, *supra* note 80.

89. *See* UTAH BUREAU OF EMERGENCY MED. SERVS., <http://health.utah.gov/ems/polst/> (June 9, 2011); *see also* TOOLKIT, *supra* note 80 (discussing meaning of terminology such as POLST, DNR order, and Life with Dignity Order).

90. UTAH CODE ANN. §§ 75-2a-106(5)(c), (d) (2013).

91. *Id.* § 75-2a-106(7).

As a general rule, prisons could improve their utilization of the advance directive as a tool for health care decision-making for prisoners who may later become incapacitated. “[A]dvance directives in the prison population are more rare,” than in the general adult population, of whom approximately 18–36% have completed an advance directive.<sup>92</sup> A 2005 study of end-of-life care in the Connecticut state prison system found that a significant barrier to use is the “practice of addressing advance directives primarily when [a prisoner] is critically ill,” which is the “least optimal time.”<sup>93</sup> Even more problematic, initiating a conversation about advance directives is futile if a prisoner has already been determined to lack health care decision-making capacity.

Other complicated systemic barriers include the “inherently complex nature”<sup>94</sup> of a prisoner’s refusal of medical care, sometimes attributed to factors other than purely medical considerations, and the confusion surrounding mental capacity and mental illness as they relate to the execution and continuing validity of advance directives.<sup>95</sup> For instance, a prisoner might make a decision about medical treatment based on the fact that a prison health care facility has air-conditioning, television, or recreational equipment, amenities that general prison facilities might lack,<sup>96</sup> or because refusal of medical care is one of the few areas where prisoners can exercise control and autonomy over some aspect of their lives.<sup>97</sup> These purely non-medical considerations nonetheless might contribute to a prisoner’s decision to consent (or withhold consent) to a particular course of medical treatment.

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92. U.S. DEPT. OF HEALTH & HUMAN SERVICES, ADVANCE DIRECTIVES AND ADVANCE CARE PLANNING: REPORT TO CONGRESS 13 (2008). According to one study conducted in 2004–2005, approximately 1 in 20 deaths in intensive care units occurred in patients who lacked both an advance directive and a surrogate decision-maker. In most cases, life support decisions were made by physicians without institutional or judicial review. Douglas B. White et al., *Life Support for Patients Without a Surrogate Decision Maker: Who Decides?*, 147 ANNALS OF INTERNAL MED. 34, 34 (2007).

93. Levine, *supra* note 70, at 328.

94. *Id.*

95. See generally David L. Thomas & J. Morrissa Watson, *Advance Directives in a Correctional Setting*, PSYCHOL. PUB. POL’Y & L., 881–82 (1998) (addressing differences between physical and mental illness in the context of advance directives); Bruce J. Winick, *Advance Directives for Those with Mental Illness*, 51 U. MIAMI L. REV. 57 (1996) (analyzing use of advance directives and living wills in the mental health context).

96. Thomas & Watson, *supra* note 92, at 886 (“To a population that perceives it has nothing, anything can be a reward.”).

97. *Id.* at 887–88.

As an additional complication, advance directives may operate differently in the prison setting because of the specific way a prison may choose to administer advance directives as contrasted with a hospital or other treatment setting. The Utah Department of Corrections (“UDC”) policy regarding end-of-life decisions states that advance directives and POLSTs are recognized methods of accomplishing prisoner end-of-life decisions and wishes.<sup>98</sup> However, the policy does not propose a standard mechanism by which all prisoners or all prisoners facing certain medical issues will, in fact, be given the opportunity to complete an advance directive. Rather, the policy depends upon the referral by prison staff (such as a prison facility chronic care nurse or other health care provider) or self-request by a prisoner, in which case the form will be provided and the prison will enter the form into the prisoner’s official medical record.<sup>99</sup>

Moreover, the policy also states that the prison medical staff will only take the advance directive “into consideration” when deciding treatment options, reflecting the fact that the federal PSDA, discussed above, is not binding on prison facilities.<sup>100</sup> Finally, the policy requires an independent review by a non-interested physician to occur before the advance directive is used to withdraw or withhold care.<sup>101</sup> This suggests that even for a prisoner with a valid advance directive, prison officials retain some discretion over treatment decisions. In contrast, a POLST is binding on prison staff and “follow[s] the patient upon transfer to another health care facility.”<sup>102</sup>

### C. Guardianship

The Utah Office of Public Guardian (“OPG”) provides “public guardianship . . . services to incapacitated adults.”<sup>103</sup> Through a guardianship arrangement, a guardian is legally authorized to make decisions for a ward, including decisions about medical treatment.<sup>104</sup>

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98. UDC POLICY, *supra* note 8, § 06/12.12(A).

99. *Id.* § 06/12.12(B). In contrast, Utah hospitals that accept Medicare funds are required by law to provide all patients with the opportunity to complete an advance directive. *See supra* text accompanying note 69.

100. *See supra* notes 70–71 and accompanying text.

101. UDC POLICY, *supra* note 8, § 06/12.12(B)(6).

102. *Id.* § 06/12.12(C)(6).

103. *See* UTAH CODE ANN. § 62A-14-101 to -111 (2013); *A Guide to Guardian Services in Utah*, UTAH DEPT. OF HUMAN SERVICES, OFFICE OF PUBLIC GUARDIAN 3 (2009), available at [http://opg.utah.gov/pdf/guide\\_to\\_guardian\\_services.pdf](http://opg.utah.gov/pdf/guide_to_guardian_services.pdf).

104. *See* UTAH CODE ANN. § 75-2a-110(1)(b) (2013).

As with appointed agents, the existence of a guardian removes the need to determine a default surrogate because the guardian assumes responsibility for medical decision-making for the ward.<sup>105</sup> If a ward has an advance directive in place, the guardian is bound by the ward's wishes as expressed in the advance directive.<sup>106</sup> If a ward has appointed an agent through an advance directive, the agent's decisions take precedence over the guardian's.<sup>107</sup> In practice, the OPG makes a POLST form available to each incoming ward to help guide the guardian's medical decision-making with respect to the ward's wishes.

While a public guardianship seems like a potential option for designating a surrogate health care decision-maker for a state prisoner lacking decision-making capacity, the OPG does not initiate guardianship proceedings involving state prisoners.<sup>108</sup> Although an adult already under guardianship may enter and exit the state or county correctional system from time to time, the OPG does not actively seek guardianship of incarcerated state prisoners because the state has effectively already assumed a form of custodial care for that adult.<sup>109</sup>

#### D. Application to the Incapacitated Prisoner

For state prisoners, advance directives and default surrogates are either not widely used or do not work properly in the prison context.<sup>110</sup> The most important distinction is that the legitimate penological objectives of the correctional setting may have a significant effect on prisoners' health care decision-making autonomy.<sup>111</sup> Advance directives seem like a practical option, but are not routinely offered or widely used due to a combination of factors, some of which are the same as those that discourage the non-incarcerated population from having advance directives, for example, cultural and personal difficul-

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105. See UTAH CODE ANN. § 75-2a-108(1)(a) (2013) (stating that default surrogacy occurs only if incapacitated adult has neither an appointed agent nor a guardian).

106. UTAH CODE ANN. § 75-2a-112(1) (2013).

107. *Id.* § 75-2a-112(2). UTAH CODE ANN. § 75-2a-112(2) (2013).

108. Telephone Interview with Donna Russell, Director, Utah Office of Public Guardian (Jun. 24, 2013).

109. *Id.*

110. Levine, *supra* note 70, at 317.

111. See *supra* Part II.

ty discussing end-of-life care on the part of both patients and providers.<sup>112</sup>

Other factors uniquely affect the prison population. Prisoners tend to be inherently suspicious of coercion by prison officials and may be especially skeptical with regard to matters affecting their health and physical well-being.<sup>113</sup> Spending time with each incoming prisoner to discuss and determine detailed health care decisions would be a time-consuming process and substantial administrative burden, especially when an advance directive may not be crucial for prisoners at low risk of facing end-of-life care decisions while in prison because of short-term sentences or generally good health.<sup>114</sup> Finally, because approximately 20 percent of adults in the United States have limited literacy skills, and prisoners tend to be overrepresented in this group, low literacy generally and low health literacy in particular add to the uncertainty surrounding a prisoner's comprehension of the advance directive process.<sup>115</sup> Finally, public guardianship is not a practicable option in Utah.

If a prisoner does not have an advance directive, an appointed agent, or a guardian, locating a default surrogate to make health care decisions is difficult because many prisoners do not have family members who are available or wish to be involved in care decisions. Even if there is an otherwise available family surrogate, because of legitimate security considerations, the prison may not make the surrogate available to physicians every time a prisoner is transferred outside of the prison for treatment, resulting in the outside provider's lack of access to the surrogate when a decision needs to be made.<sup>116</sup>

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112. Harvey M. Tettlebaum, *Quality Measurements, Payment, and the Law: Disincentives to Physician-Patient Discussions of End-of-life Care*, 6 J. HEALTH & LIFE SCI. L. 63, 67 (2013).

113. See Thomas & Watson, *supra* note 92, at 886–88; Linder & Meyers, *supra* note 53, at 899 (noting “inmate distrust that the correctional system acts with their best interests in mind”); Tillman, *supra* note 56 (noting that prisoners’ distrust of prison officials often extends to medical personnel).

114. Cf. Tettlebaum, *supra* note 109, at 68–69 (observing that many physicians have little financial incentive to have comprehensive end-of-life care discussions with patients).

115. See Linder & Meyers, *supra* note 53, at 895. See also NAT’L CTR. FOR EDUC. STATISTICS, U.S. DEP’T OF EDUC., *LITERACY BEHIND PRISON WALLS* xviii (1994), available at <http://nces.ed.gov/pubs94/94102.pdf> (noting that, on a scale from one to six, from least to most literate, seven out of ten prisoners fall in level one or two).

116. See Linder & Meyers, *supra* note 53, at 895 (noting prisoners’ lack of family support during medical visits).

The UDC policy handles this issue by superseding default surrogacy<sup>117</sup> and allowing prison facility providers to give consent for treatment.

Finally, for a mentally incapacitated prisoner in the situation described in the Introduction, the completion of an advance directive is a foregone option. At that point, the prison policy regarding default decision-makers applies. However, each of the individuals permitted to give consent under the prison policy—all members of the prison staff or the prisoners' treating providers—has a primary responsibility to an entity other than the patient and must consider other factors in addition to the prisoner's end-of-life wishes. Put another way, even assuming that all parties involved are trying to facilitate the appropriate care for the individual prisoner, the prisoner does not have a decision-maker who is institutionally uninterested. Prison staff follow the UDC policy, which requires "all care possible" in the event of incompetency.<sup>118</sup> Prisons are highly regulated, and, as risk-averse entities, tend to err on the side of over-treatment rather than under-treatment in order to ensure that levels of care are not criticized for deficiency.<sup>119</sup>

Physicians and hospitals, on the other hand, inevitably must consider the payment structures related to provision of services. In addition, while physicians presumably place the utmost importance on the Hippocratic ethical duty to provide appropriate care, in concert with the patient's wishes, the current consent structure for prisoners makes it difficult for a physician to discern whether the prisoner's wishes are being given appropriate consideration. This puts treating physicians at facilities outside the prison in an uncomfortable position when a prisoner refuses treatment that the prison has initiated; some physicians may prefer that a family member or other prisoner repre-

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117. As discussed in Part III.A, Utah's default surrogacy statute establishes an order of priority for default surrogates for patients in the general population: a spouse, other family members, and finally other individuals who have exhibited "special care and concern" for the patient. See UTAH CODE ANN. § 75-2a-108 (West 2013). The UDC policy instead directs that the surrogate decision-maker may be any of the following individuals, in no expressed order of priority: the prisoner's treating or attending physician, an administrator or director of the prison health care facility, or the prisoner's physician at an outside referral facility such as a hospital. See UDC POLICY, *supra* note 8, § 06/12.07(D). See also *supra* Part II (discussing legitimate penological interests, for instance, security, that may justify the UDC's decision to supplant state law with its policy); *infra* Part IV.C (discussing the ethical dilemma faced by physicians and prison officials who are asked to provide consent on behalf of a prisoner).

118. UDC POLICY, *supra* note 8, § 06/12.12(D)(1).

119. See Linder & Meyers, *supra* note 53, at 899 (noting "administrative concerns that resuscitative efforts be highly visible and ubiquitous to avoid accusations of neglect or indifference").

sentative, rather than a prison official, give consent or make treatment decisions.

#### **IV. Different Prison Models Explored**

At present, as is the case in most states, neither the common law nor Utah's statutory mechanisms provide an effective means of handling situations in which an incapacitated prisoner is determined to be in need of medical treatment. The former does not address cases in which a prisoner is incapacitated, focusing instead on cases in which prisoners refuse treatment but fairly strong interests in prison administration overcome that refusal. The latter, especially default surrogates and advance directives, have generally not been well-utilized in the prison context. Before proposing improvements for prisons in Utah and other similarly situated states, in the arena of health care decision-making, it is instructive to consider how prison systems in other states have approached these challenging questions.

##### **A. Prison Officials as Surrogates**

One approach is to permit prison officials to make treatment choices on behalf of incapacitated prisoners. For instance, the North Carolina Department of Correction's policy with respect to informed consent provides that where a physician judges that a prisoner lacks the capacity to consent to treatment and there is no family member or guardian available "the Director of Health Services/designee of the Division of Prisons is authorized to give substituted consent. The director of Health Services of the Division of Prisons may also withhold (on behalf of the prisoner) consent to proposed medical or surgical procedures."<sup>120</sup> Similarly, the Ohio Department of Rehabilitation and Correction's policy with respect to consent to and refusal of medical treatment provides that where a next-of-kin cannot be located, the prison warden "shall consult with the [primary healthcare provider] on the best course of treatment for the patient. The [prison warden]

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120. N.C. DEP'T OF CORR. DIVISION OF PRISONS, HEALTH SERVS. POL'Y AND PROCEDURE MANUAL, INFORMED CONSENT, POL'Y # AD IV-1 3 (2008), *available at* [http://www.doc.state.nc.us/div/Prisons/HealthServices/AD\\_Administration/AD\\_IV\\_PatientsRights/adIV1.pdf](http://www.doc.state.nc.us/div/Prisons/HealthServices/AD_Administration/AD_IV_PatientsRights/adIV1.pdf).

shall then make appropriate medical decisions on the behalf of the patient.”<sup>121</sup>

There are three primary difficulties with this approach. First, interests associated with prison administration may conflict with the best interests of the prisoner, even assuming that the prison knows what the patient’s wishes are.<sup>122</sup> Where, for instance, prison administrators are concerned with the best use of limited prison resources, those concerns may militate against a particular treatment plan that is in the best interests of the prisoner. Courts have acknowledged that concerns about limited prison resources are legitimate considerations in making health care decisions. However, those courts have focused on cases in which a prison official elects to force treatment on a non-consenting prisoner early in order to avoid more expensive treatments later.<sup>123</sup> Those cases do not suggest that a prison official might legitimately consider limited prison resources in choosing simply not to treat at all.

Second, just as fear of malpractice litigation can often influence a physician’s treatment decisions, a prison administrator’s decisions regarding treatment may be influenced by the fear of litigation.<sup>124</sup> Prison administrators are obligated to provide adequate medical treatment to prisoners in their custody.<sup>125</sup> Indifference to the medical needs of prisoners—whether that indifference is “manifested by prison doctors in their response to the prisoner’s needs or by prison guards in intentionally denying or delaying access to medical care or intentionally interfering with the treatment once prescribed”—is a violation of the Eighth Amendment’s ban on cruel and unusual punishment.<sup>126</sup> As a result, when a prison administrator is charged with providing or refusing consent on behalf of an incapacitated prisoner, there is likely to be pressure on the administrator to treat a prisoner as

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121. STATE OF OHIO DEP’T OF REHAB. AND CORR., CONSENT TO AND REFUSAL OF MEDICAL TREATMENT, NUMBER 68-MED-24, 3 (2010) available at [http://www.drc.ohio.gov/web/drc\\_policies/documents/68-MED-24.pdf](http://www.drc.ohio.gov/web/drc_policies/documents/68-MED-24.pdf).

122. See *supra* Part I.

123. See *supra* note 44.

124. See U.S. Dep’t of Health & Human Servs., Addressing the New Health Care Crisis: Reforming the Medical Litigation System to Improve the Quality of Health Care 7–8 (2003), available at <http://aspe.hhs.gov/daltcp/reports/medliab.htm> (discussing the phenomenon of “defensive medicine,” in which physicians feel pressure to treat in ways that they deem unnecessary out of fear of malpractice litigation).

125. *Estelle v. Gamble*, 429 U.S. 285, 291 (1976).

126. *Id.*

a means of avoiding a suit for civil rights violations. In such cases, a prisoner may be subjected to a treatment plan that the prisoner would have refused if capable of doing so.

Third, prison administrators may not be well-suited to fill the role of a surrogate decision-maker. The function of a surrogate decision-maker is to vindicate the patient's rights to autonomy in medical decision making even when the patient is unable to make those decisions.<sup>127</sup> "[T]he surrogate must make the medical choice that the patient, if competent, would have made, and not one that the surrogate might make for himself or herself, or that the surrogate might think is in the patient's best interests."<sup>128</sup> To vindicate the patient's right to autonomy in this way, the surrogate decision-maker must be familiar with the patient's values and beliefs. Depending upon the circumstances of a particular case, prison officials may not have accurate views regarding a prisoner's values and beliefs.<sup>129</sup>

#### B. Physicians as Surrogates

Alternatively, decisions regarding treatment might be left to the treating physician, who often will never have previously met the patient. For instance, the Tennessee Department of Correction's policy with respect to consent to treatment provides that where an incapacitated prisoner has not designated a health care surrogate, "the provider may implement a decision on behalf of the inmate after consultation with another physician who is not involved in the inmate's

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127. See, e.g., *In re Martin*, 538 N.W.2d 399, 408 (Mich. 1995) (noting that "the right the surrogate is seeking to effectuate is the incompetent patient's right to control his own life"); *In re Guardianship of Browning*, 568 So.2d 4, 13 (Fla. 1990) (noting that a surrogate exercises an incompetent patient's right to privacy on the patient's behalf).

128. *In re Guardianship of Browning*, 568 So. 2d at 13 (internal quotation omitted). See also AMER. BAR ASS'N. COMM'N ON L. AND AGING, MAKING MEDICAL DECISIONS FOR SOMEONE ELSE: A HOW-TO GUIDE 4 (2009), available at [http://www.americanbar.org/content/dam/aba/uncategorized/2011/2011\\_aging\\_bk\\_proxy\\_guide\\_gen.authcheckdam.pdf](http://www.americanbar.org/content/dam/aba/uncategorized/2011/2011_aging_bk_proxy_guide_gen.authcheckdam.pdf) (stating that the surrogate decision-maker must make decisions "as the patient would, even if the decision goes against the way you would decide yourself. . . [by] put[ting] yourself in the patient's shoes and speak[ing] with the patient's voice to the extent possible.")

129. It may be, however, that a guard or prison authority who has had regular contact with a prisoner over an extended period of time would be in position to fulfill the function of a surrogate decision-maker. However, such cases are likely to be the exception rather than the rule.

care . . . .”<sup>130</sup> Doing so, however, simply relocates many of the concerns regarding prison administrators acting as surrogates.

Physicians may well have interests and concerns that compete with the interests of the prisoner. The fear of potential liability can have a significant effect on judgments regarding treatment options.<sup>131</sup> Because “the anxieties felt by physicians and other health care providers about potential criminal, civil, and/or regulatory liabilities are real and palpable influences on the quality and humanity of medical care,” it is better for all concerned parties for physicians not to be forced to make such decisions.<sup>132</sup>

Similarly, treating physicians are unlikely to be well-placed to fulfill the primary function of a surrogate—to channel the patient’s views and values.<sup>133</sup> While it may be inevitable that parties unfamiliar with a particular patient will sometimes have to make decisions on behalf of that patient, a proper respect for patient autonomy suggests that those cases should be minimized.

### C. Blended Approach

Finally, a number of prisons have adopted a blended approach to situations in which a prisoner is unable to consent to medical treatment. For instance, Illinois provides by statute that the “chief administrative officer” may consent to medical or surgical care on behalf of an incapacitated prisoner, but must first “obtain the advice of one or more physicians licensed to practice medicine in all its branches in this State.”<sup>134</sup> Similarly, the Utah Department of Corrections (UDC) uses a blended approach for health care decision-making.

In the context of informed consent for treatment at a referral facility, UDC policy provides that “[w]hen an offender patient at a referral facility is in need of a procedure requiring informed consent and the offender is unable to responsibly provide consent, then the con-

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130. State of Tennessee Dep’t of Corr., Admin. Policies and Procedures, Consent/Refusal of Treatment, Index # 113.51, available at <http://www.tn.gov/correction/pdf/113-51.pdf>.

131. See S. Van McCrary et al., *Treatment Decisions for Terminally Ill Patients: Physicians’ Legal Defensiveness and Knowledge of Medical Law*, 20 L. MED. & HEALTH CARE 364, 373 (reporting the outcome of a study showing that where physicians are forced to make treatment decisions at the end of life, those decisions are “constrained by . . . perceptions of legal risk . . .”).

132. Marshall B. Knapp, *Treating Medical Charts Near the End of Life: How Legal Anxieties Inhibit Good Patient Deaths*, 28 U. TOL. L. REV. 521, 545 (1997).

133. See Van McCrary et al., *supra* note 128.

134. 730 Ill. Comp. Stat. 5/3-6-2 (2013)

sent shall be provided by the: (a) licensed treating physician; (b) attending physician; (c) Clinical Administrator; (d) Clinical Director; or (e) the referral facility physician of record for the offender patient.”<sup>135</sup> Further, whether a patient is in need of a medical procedure “should in most cases be determined by the appropriate referral facility physician. . . .”<sup>136</sup>

It is not clear how, as a practical matter, this policy functions. For instance, is the list of those authorized to consent to treatment on the patient’s behalf in order of priority? Are the parties on the list required to confer with one another? What result if there is disagreement among the parties on the list regarding the proper treatment of the patient? Lack of clarity regarding these questions aside, it is clear that the policy shifts the burden of making health care decisions for incapacitated patients squarely to health care providers either within or without the prison system.

In the context of end-of-life decision-making, the UDC policy provides that:

[i]f the a [sic] medical condition renders a patient incapable of making health care decisions, then UDC medical staff, patient’s family and any involved outside medical providers’ shall consider all options. If no agreement can be made than [sic] UDC medical staff shall obtain legal assistance from the Attorney General and or the outside medical providers legal and or ethical experts. In all circumstances, existing family wishes will play a large role in determining an action plan.<sup>137</sup>

Again, it is unclear how the policy dictates that a decision is ultimately to be made, what party is ultimately responsible for the decision, or what considerations should control. While the policy does dictate that the views of family members should be an important factor, that consideration will not be relevant in cases where the prisoner does not have family available to help guide the decision.

A blended approach—requiring prisoner administrators and health care providers to act in concert to provide consent for incapacitated prisoners—comes with advantages and disadvantages. On the one hand, an increased number of parties involved in the process increases the chance that the decision-making coincides with the interests of the prisoner and decreases the chance that one party, with interests contrary to the prisoner’s, can dominate the process. This

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135. UTAH CODE ANN. § 06/12.07(D) (2012).

136. *Id.*

137. *Id.* § 06/12.12(E)(1).

advantage can be overstated, however. First, where neither a physician nor a prison administrator is in a position to “step in the shoes of the patient and make the decision the patient would make if the patient were competent,” the combination of a physician and a prison administrator will not likely be able to do so either.<sup>138</sup> To the extent that it is desirable to have a policy that vindicates, as far as is possible, a prisoner’s interests in autonomy, a blended approach such as Utah’s is not, in that respect, a significant advance over an approach that simply vests decision-making authority in a physician or a prison administrator alone. Second, the involvement of multiple parties will only prevent interests other than the prisoner’s from dominating the decision-making process if the parties involved do not share an interest contrary to the prisoner’s. However, prisoner administrators and physicians may well have the same interests. In particular, both parties may be under pressure to over-treat where prison administrators may be subject to liability under the Eighth Amendment and physicians may be subject to malpractice liability.

A blended approach also creates the possibility that the parties involved will not be able to reach a consensus. To accommodate such cases, the policy must provide a mechanism for resolving the impasse. Illinois, for instance, provides that “[i]f 2 or more surrogates who . . . have equal priority indicate to the attending physician that they disagree about the health care matter at issue, a majority of the available persons in that category . . . shall control . . . .”<sup>139</sup> A policy—like the Utah Department of Correction’s policy—that does not provide such a mechanism leaves the parties involved without a means of resolving the impasse and leaves the treatment decision unmade.

#### D. Ethics Board or Community Consent Model

In the context of medical research involving human subjects, review by an ethics committee or institutional board is standard practice. Ethics committee review is particularly judicious when a specific population’s characteristics could make it uniquely vulnerable to unethical research practices such as exploitation or discrimination. For example, the Institutional Review Board (IRB) for human research studies at the University of Utah routinely includes panelists who

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138. Rebecca C. Morgan, *How to Decide Decisions on Life-Prolonging Procedures*, 20 STETSON L. REV. 77, 88 (1990).

139. 755 ILL. COMP. STAT. 40/25 (West 2014)

have “representative capacity” for children or the economically disadvantaged.<sup>140</sup> The IRB includes “prisoner advocates” when a research study might be open to or involve prisoners.<sup>141</sup> Ethics committees are also used in the context of medical decisions for individuals; as discussed in Part III.A. above, several states solicit the opinion of an ethics committee in consultation with an incapacitated patient’s physicians when no surrogate is available to make treatment decisions. To the best of the authors’ knowledge, no state has called for the use of a formalized ethics committee or institutional review board specifically in the context of individual medical decision-making for incapacitated prisoners.<sup>142</sup>

An ethics committee model for health care decision-making could have several benefits for the incapacitated prisoner population. First, the committee would be in a position to make recommendations for individual prisoners free from the interests of the prison and of the health care providers involved in the prisoner’s care. Second, similar to prisoner advocates who participate in the IRB,<sup>143</sup> the committee could enlist members who are sensitive to the unique challenges presented by medical decision-making in the prison context, including the penological issues and cultural challenges described in Parts II & III.D. However, this model also has potential drawbacks. Financial and administrative challenges include creation and development of a separate institutional entity, solicitation of knowledgeable and available participants (who may already participate in other committees such as the IRB), and facilitation of meetings expeditious enough to affect time-sensitive care decisions for individual prisoners. The most significant limitation, however, appears to be that while a community

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140. See *Panel Rosters*, INSTITUTIONAL REV. BOARD, U. UTAH, <http://irb.utah.edu/about/panel-rosters.php> (last visited Mar. 31, 2014).

141. See, e.g., INSTITUTIONAL REV. BD., U. UTAH, PANEL 2 (2011), available at [http://irb.utah.edu/\\_pdf/Panel%204%20120213.pdf](http://irb.utah.edu/_pdf/Panel%204%20120213.pdf) (listing several representatives as “Prisoners”); INSTITUTIONAL REV. BD., U. UTAH, PANEL 4 (2010), available at [http://irb.utah.edu/\\_pdf/Roster%20Panel%204%20Dec%202010.pdf](http://irb.utah.edu/_pdf/Roster%20Panel%204%20Dec%202010.pdf) (listing several representatives as “Prisoners”).

142. Iowa provides for use of a community consent board for mentally incapacitated patients when no other surrogate decision-maker is available. See IOWA CODE § 135.29 (2013). While the statute is not directed specifically at incarcerated individuals, it is presumably applied to other institutionalized patients, such as nursing home residents. The only state that calls for an external review of medical decisions for state prisoners is Virginia, which provides a process for seeking court approval of treatment. See VA. CODE ANN. § 53.1-40.1 (West 2013).

143. In a community such as the Salt Lake City metro area, even the same prisoner advocates that sit on the University IRB panels could conceivably also serve on a prison medical ethics committee.

surrogacy group such as an ethics committee may be sensitive to the unique cultural context within a prison, the members of this group will not be acquainted with the desires of a particular prisoner. This type of panel, which can be effective in identifying ethical concerns within a larger population, is limited in the case where what is needed is specific knowledge about a single individual. Because of these obstacles, solutions within the existing institutional framework may ultimately be more effective.

## V. Proposal

### A. Promotion of Advance Directives, Especially in Certain High-risk Populations

Recognizing the administrative and bureaucratic difficulty of forming a specialized ethics committee or other community consent group, practitioners who have experience working with the prisoner population, including social workers and palliative care nurses, have suggested that existing statutory frameworks could be utilized more effectively to improve the decision-making process by ensuring that a prisoner's personal wishes are taken into consideration.<sup>144</sup> First, rather than the current UDC policy, which contemplates optional or upon-request distribution of advance directives to all prisoners, we propose that the prison automatically distribute to and discuss advance directives with certain targeted groups of prisoners who are most likely to be receptive to and to benefit from advance directives.<sup>145</sup> This would

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144. See, e.g., Margaret Ratcliff & Elizabeth Craig, *The GRACE Project: Guiding End-of-Life Care in Corrections 1998–2001*, 7 J. PALLIATIVE MED. 373 (2004) (discussing favorable impacts of expanding end-of-life care programs, including hospice, in correctional facilities); Nichole Kuhns, *An Evaluation of Prison Hospice Services and a Proposal for Implementation in Arizona* (2009), available at [http://www.nursing.arizona.edu/Library/Kuhns\\_Nichole\\_MS\\_Report.pdf](http://www.nursing.arizona.edu/Library/Kuhns_Nichole_MS_Report.pdf) (calling for implementation of a prison hospice system in Arizona). See also Interview with Maureen Henry, JD, Health and Aging Policy Fellow, in Salt Lake City, Utah (May 1, 2013) (promoting the concept of promoting advance directives to certain targeted populations within the prison); Telephone Interview with Holli D. Martinez, M.S.N., Family Nurse Practitioner and Adjunct Instructor, College of Nursing, University of Utah (June 19, 2013) (focusing advance directives on the chronically ill); Telephone Interview with Kristin Gates Cloyes, PhD, Associate Professor, College of Nursing, University of Utah (June 12, 2013).

145. See Interview with Maureen Henry, *supra* note 141. See also Linda S. Whitton, *Planning for End-of-Life Health Care Decisions—What National Survey Results Reveal*, PROB. & PROP., Jan./Feb. 2006, at 38 (finding that education about and access to advance health care planning tools greatly increase effectiveness).

include those who are terminally ill, or who have attained a particular stage of a chronic illness.<sup>146</sup>

In addition, we propose that mechanisms be established for knowledgeable prisoners to be involved in the process of training other prisoners about the use of advance directives. The Louisiana prison system, for instance, has implemented a successful volunteer-based hospice and palliative care program at the Louisiana State Penitentiary using carefully screened prisoner volunteers.<sup>147</sup> We propose that volunteers could be equally valuable in terms of educating fellow prisoners about advance directives in the Utah prison system. Aside from providing meaningful opportunities for the volunteer prisoners,<sup>148</sup> a program administered by prisoners could help reduce concerns that prison officials are promoting the advance directives at the expense of the prisoners.<sup>149</sup> Moreover, with respect to use of advance directives, there are unique cultural issues within particular races or age groups where involvement of demographic peers in the education process may assist prisoners in being more receptive to the tool.<sup>150</sup>

Similar to the idea that some racial or ethnic groups are more comfortable discussing and receiving care from providers who are members of the same group,<sup>151</sup> prisoners may be more comfortable accepting long-term care options such as advance directives from simi-

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146. See Interview with Kristen Gates Cloyes, *supra* note 141; Sheila T. Murphy et al., *Ethnicity and Advance Care Directives*, 24 J.L. MED. & ETHICS 108, 113 (1996) (finding that the likelihood of having an advance directive increases with personal experiences with illness and decreased levels of functioning); Dorcas Mansell et al., *Roles of Physicians, Attorneys, and Illness Experience in Advance Directives*, 2 S. MED. J. 197, 200–01 (1999) (finding that increased age and severity of illness increase receptiveness to advance directives); Gloria J. Alano et al., *Factors Influencing Older Adults to Complete Advance Directives*, 8 PALLIATIVE & SUPPORTIVE CARE 267, 271 (2010) (finding that “most subjects reporting having an [advance directive] had undergone major surgery”).

147. See Tillman, *supra* note 56.

148. See *id.* As one prisoner put it, “What I get from this, money can’t buy,” noting the “emotional and spiritual growth” for prisoner volunteers of the hospice program. *Id.*

149. See *supra* text accompanying note 110.

150. See ADRIENNE L. JONES ET AL., USE OF ADVANCE DIRECTIVES IN LONG-TERM CARE POPULATIONS, NCHS DATA BRIEF NO. 54, at 5 (2011), available at <http://www.cdc.gov/nchs/data/databriefs/db54.pdf> (finding that cultural and religious beliefs may affect perceptions of advance directives in particular racial or age groups).

151. See S. Saha et al., *Patient-Physician Racial Concordance and the Perceived Quality and Use of Health Care*, 159 ARCH. INTERN. MED. 997 (1999) (finding that black or Hispanic patients who saw black or Hispanic physicians, respectively, were more likely to rate their care as “excellent” or report that they were “very satisfied” with their health care those who saw white physicians).

larly situated individuals, i.e., other prisoners. At the same time, the volunteer prisoners who provide information about advance directives are themselves becoming educated about options for end-of-life care. In addition, a system in which fellow prisoners educate each other about advance directives could reduce the costs<sup>152</sup> associated with health care providers having extended discussions about options for end-of-life care with large numbers of prisoners.<sup>153</sup> At minimum, even if legitimate penological interests limit the applicability of advance directives in the prison setting (for instance if the prison lacked the financial resources to confer regularly with an appointed agent about a particular prisoner's medical treatment), a document contained in the official prison facility medical record that states the prisoner's wishes would be highly informative to the individual tasked with providing consent on the prisoner's behalf, whether that individual is a member of the prison staff, a physician, a family member, or other substitute decision maker.

#### B. Use of "Prison Family" as Surrogates

Second, many aging prisoners, especially those serving long-term sentences, lack close family relationships.<sup>154</sup> For those prisoners, members of a "prison family"<sup>155</sup> may be more likely than outside family members to know the prisoner's personal wishes regarding end-of-life care because they have spent extended amounts of time with the

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152. See Tillman, *supra* note 56 (discussing how the Louisiana State Penitentiary hospice program was built "by necessity without any funds"); Ratcliff & Craig, *supra* note 142, at 376-77 (describing how pilot end-of-life care programs were able to conduct training despite budget limitations).

153. See Tettlebaum, *supra* note 109, at 69.

154. See Linder & Meyers, *supra* note 53, at 898; RONALD H. ADAY, AGING PRISONERS: CRISIS IN AMERICAN CORRECTIONS 183 (2003); James Ridgeway, *The Graying of America's Prisons*, PRISON LEGAL NEWS, [https://www.prisonlegalnews.org/\(X\(1\)S\(ertbwb55iuled245zfo5vj55\)\)/displayArticle.aspx?articleid=22769&AspxAutoDetectCookieSupport=1](https://www.prisonlegalnews.org/(X(1)S(ertbwb55iuled245zfo5vj55))/displayArticle.aspx?articleid=22769&AspxAutoDetectCookieSupport=1) (last visited March 3, 2014).

155. Here, "prison family" refers to individuals in the prison system with whom long-term incarceration prisoners have developed close relationships, perhaps much closer than any relationships they have maintained with outside family members. See *Quality Guidelines for Hospice Care and End-of-life Care Standards of Practice for Inmates in Correctional Settings*, NHPKO (2009), available at <http://www.nhpco.org/sites/default/files/public/Access/Corrections/CorrectionsQualityGuidelines.pdf> (definition of "family" "can include other inmates"). While "prison family" would generally include other prisoners, it might also include other prison staff, such as guards, who have developed a relationship with the prisoner. In the context of a default surrogate, any prison staff member would be subject to the same problematic institutional influences discussed in Part III.D and may not be an appropriate surrogate.

prisoner while inside the prison.<sup>156</sup> Even if an advance directive is not completed, a volunteer program that provides for the exchange of end-of-life care information between prisoners puts other prisoners in a better position to know the wishes of a particular prisoner in times of mental incapacity. Setting aside for a moment the security considerations associated with permitting a “prison family” member, such as another prisoner, to act as a health care decision-making surrogate, such an arrangement would presumably be permitted under the Utah statute allowing an individual with “special care and concern” for the patient to act as a surrogate.<sup>157</sup>

With appropriate safeguards, the UDC policy could be amended to include “a member of the prisoner’s prison family” on the list of individuals permitted to provide consent for medical treatment. For an appointed health care decision-making agent or surrogate (“surrogate,” for brevity) within the “prison family,” security considerations would likely dictate that the surrogate would generally not be permitted to travel to an outside hospital or facility with the prisoner. However, an outside treating physician may still be able to interact with the surrogate primarily by phone, Skype, Facetime, or other technology in order to provide the physician with guidance on how the prisoner might prefer his treatment to proceed.

Alternatively, for a prisoner who has a family member or other outside individual willing to act as a surrogate, security considerations include the logistics of the surrogate having an opportunity to confer with the prisoner about his or her wishes, whether in person, by phone, or potentially by visiting the prisoner at the hospital when the prisoner is outside the prison facility. The prison may have concerns about allowing a surrogate to visit the prisoner in person in a hospital setting, due to security risks, flight risks, or other penological concerns (for instance, the costs associated with extending the prisoner’s time away from the prison to accommodate the interaction between surrogate and prisoner).<sup>158</sup> A procedural safeguard could include the use of other methods of communication via modern technology to minimize the security risks and allow the prisoner to communicate effectively with his or her surrogate.

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156. See Tillman, *supra* note 56.

157. UTAH CODE ANN. § 75-2a-108(2) (2013).

158. See Nancy Neveloff Dubler, *The Collision of Confinement and Care: End-of-Life Care in Prisons and Jails*, 26 J. L. MED. & ETHICS 149, 152–53 (1998) (discussing the logistical difficulties of agent appointments for incarcerated individuals).

This proposal is not without significant challenges. First, the success of an approach dependent upon prisoners educating each other about advance directives and end-of-life decision-making presupposes a certain level of trust within that community. A significant political, operational, and likely financial commitment by the prison itself to foster such education and trust would also be necessary.<sup>159</sup> Second, one can imagine some subset of the prisoner population taking advantage of these mechanisms—for example, by claiming a need to communicate more regularly with other prisoners in order to confer about their health care wishes or claiming a need to be accompanied by other prisoners to medical visits. Screening of prison participants and volunteers could mitigate against this gaming risk, but would not eliminate it.<sup>160</sup> Third, confidentiality of sensitive health care information could be problematic. One prisoner could obtain sensitive health care information about other prisoners that is then used as a basis for extortion or control. Fourth, as has been noted, prison populations often face significant literacy issues which would require outside assistance to properly comprehend the advance directive process.<sup>161</sup> Such concerns are legitimate and would need to be addressed for any modification to the status quo to be effective.

Thus, while there are legitimate penological interests that might limit the effectiveness of a prisoner appointing a health care decision-making agent, through an advance directive or other means, allowing a treating physician the opportunity to confer in some way with a prisoner's surrogate, whether the surrogate is a "prison family" member or other appointed individual, would, from a patient autonomy point of view, be a significant improvement over the status quo, in which no opportunity for a meaningful surrogate decision-maker exists. Ultimately, the increased use of advance directives and inclusion of "prison family" in the decision-making process are potential solutions for improving the quality and individual nature of end-of-life care for mentally incapacitated state prisoners both in Utah and nationwide.

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159. See Tillman, *supra* note 56 (noting that from the outset, the Louisiana State Penitentiary Hospice Program had "high-level administrative support," that inmate volunteers are "[personally invested] in its success," and that prison security personnel provide substantial support and participation).

160. See, e.g., Tillman, *supra* note 56 (describing extensive screening procedures for volunteer inmates).

161. See LITERACY BEHIND PRISON WALLS, *supra* note 112.

