

# CRUEL CHOICES: AUTONOMY AND CRITICAL CARE DECISION-MAKING

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## ABSTRACT

*Although autonomy is clearly still the paradigm in bioethics, there is increasing concern over its value and feasibility. In agreeing with those concerns, I argue that autonomy is not just a status, but a skill, one that must be developed and maintained. I also argue that nearly all health-care interactions do anything but promote such decisional skills, since they rely upon assent, rather than upon genuinely autonomous consent. Thus, throughout most of their medical lives, patients are socialised to be heteronomous, rather than autonomous. Yet, at the worst possible time – critical care decision-making – when life and death consequences are attached to the choices, the paradigm shifts and real consent is sought, even demanded, thereby making an often traumatic situation even harder.*

*I go on, though, to also reject paternalistic models of beneficence as an alternative. Rather, I conclude that the problem is so fundamental in healthcare that a genuine solution would require a radical restructuring. I recommend steps that can be taken in the interim to improve the situation and to move toward such a restructuring.*

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It would seem that bioethics and autonomy have become mutually constitutive terms. The literature from all quarters – philosophy, medicine, nursing, law – overwhelmingly produces, as Carl Schneider puts it, ‘little doubt about the triumph of the autonomy paradigm.’<sup>1</sup> With rare exception, work in bioethics has argued, or worse assumed, that patient autonomy should be the first and last principle in medical decision-making. And nowhere is this more prevalent than in critical care settings. With so much at stake and so much educational emphasis on autonomy, physi-

<sup>1</sup> C.E. Schneider. 1998. *The Practice of Autonomy: Patients, Doctors and Medical Decisions*. New York. Oxford University Press.

cians are loath to make decisions, especially to withhold or withdraw treatment, without direct input from patients or families.

In his insightful analysis of how patients actually go about making healthcare decisions, Schneider concludes that the foundation of autonomy, what he calls 'hyper-rationalism', is neither theoretically sound nor reflective of actual decisions patients make. Hence, while autonomy is clearly of great moral import, its emphasis in bioethics should be downplayed, being replaced by a beneficence-based model of 'competent caring', in which physicians work to undercut the 'bureaucracy and impersonality' so prevalent in contemporary American medicine. This shift, he argues, will produce a decisional environment both respectful of patients' needs and well-being, and responsive to their variable desires for autonomous decision-making.<sup>2</sup>

In this paper I extend some of the themes raised by Schneider but reach a more pessimistic conclusion. Like Schneider, I argue that the heavy emphasis placed on autonomous (if usually surrogate) informed consent in critical care settings too often represents a disproportionate burden for patients.<sup>3</sup> Unlike Schneider, however, I reject beneficence as a valid alternative.

I base these conclusions on four arguments. First, genuine autonomy entails more than the mere making of decisions; it requires both the capacity to make free and informed decisions and the active development of character by which persons understand and are able to act upon self-defining choices. Second, throughout most patients' medical lives they are socialised into anything but an autonomy model; autonomy-undercutting power asymmetries prevail and decision-making in routine care relies much more on *assent* than on *consent*. Third, healthcare in general, and critical care in particular, represent profoundly difficult contexts for genuinely autonomous choices. Fourth,

<sup>2</sup> Schneider, *op. cit.* note 1, pp. 195–227. Although Schneider is one of the few to use an explicitly empirical method to question the autonomy paradigm, many others have reached a similar conclusion through different routes. Cf. S. Wear & L.B. McCullough. Respect for Autonomy and Medical Paternalism Reconsidered. *Theoretical Medicine* 1985; 6: 295–308; T. Ackerman. Why Doctors Should Intervene. *Hastings Center Report* 1982; 4: 14–17; J. Kultgen. 1994. *Autonomy and Interventions: Parentalism in the Caring Life*. New York. Oxford University Press; and J. Savulescu. Rational Non-Interventional Paternalism: Why Doctors Ought to Make Judgments of What is Best for their Patients. *Journal of Medical Ethics* 1995; 6: 327–331. See also the reply to Savulescu: H. Madder. Existential Autonomy: Why Patients Should Make their Own Choices. *Journal of Medical Ethics* 1997; 4: 221–225.

<sup>3</sup> Throughout the paper read 'or surrogate' whenever 'patient' is used.

Schneider's systematic beneficence (his alternative to direct physician paternalism) represents possibly even a greater threat to patient autonomy and well-being.

The problem, I believe, rests in a structural contradiction: contemporary healthcare<sup>4</sup> relies on a predominant ethic of patient autonomy while also consistently undercutting that ethic. Furthermore, the healthcare system has evolved in a way that precludes reliance on a model grounded in beneficence. But since a major overhaul of this system is improbable, I conclude with a number of alternative recommendations, ones that will at least enhance patient autonomy and help mitigate the many factors that interfere with physicians acting in their patients' best interest.

### THE NATURE AND HABIT OF AUTONOMY

Agreeing upon a single conception of autonomy is almost as controversial as determining its appropriate role in medical decision-making.<sup>5</sup> Of the many versions present in the literature, the one that best captures both sound theory and clinical reality is a mix of Kant's and Mill's positions. It is Kantian in that autonomy is best understood as a basic structural capacity of persons; indeed, it is that capacity which separates persons, as moral agents, from all other beings: 'Autonomy is therefore the ground of the dignity of human nature and of every rational nature.'<sup>6</sup> It is Millian in that it is also a process of the development of selfhood, of what Mill, borrowing from Aristotle, calls 'character', i.e., acquiring and advancing 'the human faculties of perception,

<sup>4</sup> My knowledge base is limited primarily to healthcare as it is practiced in the United States and thus that is the focus here. Persons more familiar with other systems, however, have noted these problems are international, especially in technologically developed countries. (I am grateful to Alastair Campbell for his helpful suggestions here.)

<sup>5</sup> It is probably the most widely discussed principle in medical ethics. Some of the better analyses include: G. Dworkin. 1988. *The Theory and Practice of Autonomy*. Cambridge. Cambridge University Press; B.H. Levi. 1999. *Respecting Patient Autonomy*. Urbana, IL. University of Illinois Press; L. Haworth. 1986. *Autonomy: An Essay in Philosophical Psychology and Ethics*. New Haven, CT. Yale University Press; T. May. 1998. *Autonomy, Authority and Moral Responsibility*. London. Kluwer Academic Publishers; and by T. Beauchamp & J. Childress. 2001. *Principles of Biomedical Ethics*. Fifth edition. New York. Oxford University Press.

<sup>6</sup> I. Kant. 1967. *The Moral Law: Kant's Groundwork of the Metaphysic of Morals*. Translated and analysed by H.J. Paton. New York. Barnes & Noble, Inc.: 97. (By 'persons' Kant meant rational beings, inclusive of humans but not exclusively so.)

judgment, discriminative feeling, mental activity, and even moral preference . . .'<sup>7</sup>

The first of these theoretical foundations, structural capacity, gets implemented in practice (mainly in informed consent) as *genuinely free choice grounded in a sufficient base of informed understanding*. The freedom criterion precludes excessive coercion or constraint. The information criterion requires not only that the patient be given access to all relevant information necessary to a free choice, but that she can effectively understand it, including risks/benefits and whether various options are consistent with her life-plans.<sup>8</sup>

Clinical practice, though, tends to ignore or simply assume the second, developmental, foundation. The general presumption seems to be that if a person is of legal age and not suffering from mental impairment or undue coercion, she is by default autonomous. Mill is well known for having rejected this assumption, sharply criticising society's 'ape-like' imitators.<sup>9</sup> He says the autonomous person must develop the skills and presence of mind to 'choose [a] plan for himself, [using] observation to see, reasoning and judgment to foresee, activity to gather materials for decision, discrimination to decide, and when he has decided, *firmness and self-control to hold to his deliberate decision*.'<sup>10</sup> He rightly concludes that rational capacity is a necessary but not sufficient criterion for autonomy; one also needs the habitually acquired skills of formulating a plan of life, effectively evaluating options, and wilful choosing.

Despite his strong emphasis on the link between autonomy and morality, Kant is also sceptical about whether persons generally express the essential character traits: 'It is difficult for any man to work himself out of the immaturity . . . the inability to use one's understanding without guidance from another . . . that has all but become his nature. He has even become fond of this state and for

<sup>7</sup> J.S. Mill. 1956. *On Liberty*. Edited and with an introduction by C.V. Shields. Indianapolis, IN. The Library of Liberal Arts: 71.

<sup>8</sup> Charles Fried aptly describes the physician role in promoting autonomy through informed consent: 'The doctor's prime and basic function is . . . the preservation of life capacities for the realization of a reasonable, realistic life plan. . . . [T]he doctor must see himself as the servant, not of life in the abstract, but of life plans of his patients.' Quoted in Dworkin, *op. cit.* note 5, p. 113.

<sup>9</sup> Mill, *op. cit.* note 7, p. 71.

<sup>10</sup> *Ibid.* emphasis added. He also notes education is critical to the process – recall again the 'informed' requirement in valid consent – even if he takes the point too far, claiming that persons from 'barbaric' cultures, in their 'non-age', cannot have the requisite skills for making autonomous decisions. *Ibid.* p. 14.

the time being is actually incapable of using his own understanding, for no one has ever allowed him to attempt it.’<sup>11</sup> Autonomy does not just spring into existence, but rather must be practised and wilfully maintained. Paraphrasing Kant from the same essay, ‘If I have a book to serve as my understanding, a pastor to serve as my conscience, a physician to determine my diet’, I never have to *act* autonomously.<sup>12</sup> I may have the basic capacity to do so, but unpractised, I lose it.

Kant considers the mature/autonomous person to be the norm, a position from which one strays out of ‘laziness and cowardice.’<sup>13</sup> I rather think it is the reverse, at least in the medical context.<sup>14</sup> Making decisions is *hard work*. For those carrying any significant import, one must carefully evaluate information, give thoughtful consideration to consequences and their relationship to life-plans, evaluate the extent to which one is being coerced or constrained (by internal and external factors), and be committed to the choice and its outcomes. In Aristotelian language, autonomous decision-making is an acquired skill, part of the development of practical wisdom and emerging from habituated dedication.

Thus if persons spend most of their medical lives avoiding, or not being given the opportunity to develop, these skills, they cannot then emerge full-bloom in times of crisis. To the contrary, a determination, for example, of whether to withdraw life support from a loved one brings with it a range of factors that damage the decision-making capacities of even fully autonomous persons.<sup>15</sup>

<sup>11</sup> I. Kant. 1983. *An Answer to the Question: What is Enlightenment? In Perpetual Peace and other Essays*. Translated and with an introduction by T. Humphrey. Indianapolis, IN. Hackett: 41. Given his autonomy-as-capacity position, Kant does not in this essay explicitly link ‘maturity’ to autonomy. Elsewhere, however, he suggests that the corollary to autonomy – responsibility – is directly related to the development of virtuous versus bad habits. See: I. Kant. 1979. *Degrees of Responsibility*. In *Lectures on Ethics*. Translated by L. Infield. Indianapolis, IN. Hackett: 62–66.

<sup>12</sup> Kant, *op. cit.* note 11, p. 41.

<sup>13</sup> *Ibid.*

<sup>14</sup> See: C.J. McKnight. *Autonomy and the Akratic Patient*. *Journal of Medical Ethics* 1995; 4: 206–210.

<sup>15</sup> As this language suggests, my conception allows that autonomy admits of degrees, ranging from Kant’s fully autonomous rational agent, to Mill’s heteronomous imitators, to a fifteen-year-old faced with whether to undergo chemotherapy. For example, persons can be under varying degrees of coercion, both external and internal, while also holding similarly varying levels of informed understanding. Haworth also addresses this aspect of autonomy, focusing on agents’ capacity for *growth*, with differing levels of autonomy correspondingly associated. Haworth, *op. cit.* note 5, p. 55.

Hence it is sadly ironic that most of medicine – the routine interactions patients have with their physicians throughout most of their lives – does anything but help nurture such autonomy.

### AUTONOMY AND ROUTINE CARE

Nearly all of bioethics focuses on medicine in extremis, devoting very little attention to routine care: bioethics case law has emerged predominately from end-of-life cases, routine care lacks the drama that makes for a better read and bioethics education occurs mainly in critical care, in part because of that drama and in part because all residents rotate through the ICU, thus better assuring at least some ethics contact.

What little ethics literature there is from routine care tends to focus on two related concerns – informed consent<sup>16</sup> and discourse-based analyses of physician-patient conversations.<sup>17</sup> It uniformly points to the same conclusion – if what is meant by autonomous decision-making even resembles the model described above, there is little to none of it present in the kinds of interactions that regularly occur in private offices and in clinics. There are, of course, negotiated conversations and ample circumstances in which treatment decisions are made, but most of these involve *assent*, rather than autonomy-based *consent*.

Assent, as a distinct concept, emerges primarily from paediatrics. The ethical standard in paediatric care is that children must assent, but not necessarily consent to treatment, especially that of an experimental nature.<sup>18</sup> The standard calls for sincere and reasonable attempts at explaining the intended treatment and for ‘soliciting an expression of the patient’s willingness to accept the proposed care.’<sup>19</sup> This lesser requirement evolved from

<sup>16</sup> Cf. D.P. Sulmasy, L.S. Lehmann, D.M. Levine & R.R. Raden. Patients’ Perceptions of the Quality of Informed Consent for Common Medical Procedures. *Journal of Clinical Ethics* 1994; 3: 189–194; and L.M. Lesko, H. Dermatis, D. Penman & J.C. Holland. Patients’, Parents’, and Oncologists’ Perceptions of Informed Consent for Bone Marrow Transplantation. *Medical and Pediatric Oncology* 1989; 17: 181–187.

<sup>17</sup> Cf. J. Nessa & K. Malterud. Tell Me What’s Wrong With Me: A Discourse Analysis Approach to the Concept of Patient Autonomy. *Journal of Medical Ethics* 1998; 6: 394–400; and A.D. Todd. 1989. *Intimate Adversaries: Cultural Conflict between Doctors and Women Patients*. Philadelphia, PA. University of Pennsylvania Press.

<sup>18</sup> American Academy of Pediatrics, Committee on Bioethics. Informed Consent, Parental Permission, and Assent in Pediatric Care. *Pediatrics* 1995; 95: 314–317.

<sup>19</sup> *Ibid.*

the realisation that while younger children are not capable of genuinely autonomous choosing – i.e., they have neither the freedom nor the comprehension nor the developed character necessary for valid autonomy – they should nonetheless have input into decisions that directly affect their well-being and lives.

In my experience, many clinicians see the assent standard as being sufficient for autonomous consent. So long as the patient has expressed a ‘willingness to accept the proposed care’, she has autonomously chosen. Surely, though, this is false. Assent requires merely that the patient *agree to* the recommendations of others, whereas autonomous consent requires a rich evaluation of information, of the full range of options, and of whether likely outcomes are consistent with life plans, along with the intentional selection of preferred alternatives. With assent, the patient *gives permission*; with consent, the patient *chooses*. With assent, the patient *accedes* to treatment; with consent, the patient *takes ownership* of or *identifies* with the choice made.<sup>20</sup>

My claim is that the vast majority of treatment decisions reached in routine care involves assent and not consent and, because of this, patients are socialised away from a model of autonomous choosing. The admittedly limited empirical evidence to support this conclusion is nonetheless telling. For example, Sulmasy et al. studied a routine care environment and found that nearly all physicians provided adequate information and that patients expressed a high degree of satisfaction with the informed consent process. Despite these favourable remarks, though, the researchers also found that too often, ‘informed consent may become synonymous with filling out forms’, that ‘despite high rates of [physician] disclosure . . . a third of consent-givers could not say why the procedure was performed’, that ‘nearly half of the consent-givers (43 percent) could not recall even one of the potential risks’, and that ‘while almost all consent-givers (98 percent) thought that the physician had genuinely asked their permission before performing the procedure, only 53 percent reported that the physician had explained the alternatives to the procedure.’<sup>21</sup>

These findings are also consistent with the few studies that videotape and then analyse physician-patient discourse. These

<sup>20</sup> Cf. F. Bergmann. 1977. *On Being Free*. Notre Dame, IN. University of Notre Dame Press: 37: ‘An act is free if the agent identifies with the elements from which it flows; it is coerced if the agent disassociates himself from the element which generates or prompts the action.’

<sup>21</sup> Sulmasy et al., *op. cit.* note 15, pp. 191, 192, 193.

studies focus in large part on how power asymmetries are revealed in conversations: who interrupts whom, who asks questions, how physical presence (e.g., standing vs. sitting) affects the dialogue, the use of professional titles, etc.,<sup>22</sup> and they show that the standard medical encounter involves physicians, as the holders of power, making decisions, with which patients comply. Very rarely do patients engage in a power-symmetrical dialogue in which their values, concerns and decision-making status are given equal weight. Rather, the physician asks the appropriate questions to determine a diagnosis and then prescribes a treatment. If there is any patient decisional involvement, it is generally relegated to a verbal acceptance of this recommendation. Even more striking is that this dynamic is present even in patients who subsequently express satisfaction with the consent interview and who believe they were the ones who made the decision. In short, even many patients who believe they have autonomously consented to a procedure have in fact only assented.

There are any number of good explanations for why the routine care interaction shapes up this way: what is at stake is, by definition, much less medically urgent or threatening; private physicians are less connected to the educational environment of a teaching hospital in which patient consent is emphasised; time constraints restrict the opportunity for extended conversation; and patients are socialised at a very early age, through watching parents interact with physicians and by watching the ubiquitous medical shows on television, to treat the physician as a person of higher authority. In short, routine medicine manifests a *de facto* paternalism and thereby promotes in patients heteronomous, rather than autonomous, skills.

## THREATS TO AUTONOMY

This socialisation into heteronomy would be problematic enough were there no other autonomy-threatening conditions in medical decision-making. But of course, there are. Beyond the obvious

<sup>22</sup> Cf. E. Mishler. 1984. *The Discourse of Medicine: Dialectics of Medical Interviews*. Norwood, NJ. Ablex; Todd, *op. cit.* note 16; S. Fisher. 1980. *The Selling of Treatment Decisions: How They are Accomplished in Doctor/Patient Interactions*. Association Paper. Society for the Study of Social Problems; S. Fisher & A.D. Todd, eds. 1983. *The Social Organization of Doctor-Patient Communication*. Washington, D.C. Center for Applied Linguistics; and N. Ainsworth-Vaughn. 1998. *Claiming Power in Doctor-Patient Talk*. New York. Oxford University Press. Ainsworth-Vaughn also shows ways in which patients use linguistic techniques to express power, even if the asymmetry is still heavily weighted toward physicians.

threats of immature age, mental illness and trauma-induced incapacitation, healthcare also brings reduced competency due to disease,<sup>23</sup> fear,<sup>24</sup> power asymmetries,<sup>25</sup> physician bias,<sup>26</sup> physician denial,<sup>27</sup> family conflict,<sup>28</sup> pressures related to economic<sup>29</sup> or managed care considerations,<sup>30</sup> the complexities of medical decisions,<sup>31</sup> and the bureaucratic structures of medical institutions.<sup>32</sup>

And, of course, autonomy-reducing factors exist in far greater numbers and intensity in the critical care environment where, ironically, the greatest emphasis on autonomy resides. Patients here are seriously ill or injured, usually in pain or under the influence of morphine or sedatives. They are often intubated and thus incapable of verbal communication beyond grunts. They are frightened and have almost no control over their lives.<sup>33</sup> And they are surrounded by men and women who hold much more status and authority, and who often speak in essentially a foreign tongue.

Furthermore, what soon becomes routine for ICU staff is exceedingly unusual, and thus exceedingly stressful, for their patients. With the exception of those who are chronically and seriously ill, the ICU admission is a once or twice in a lifetime

<sup>23</sup> Cf. Ackerman, *op. cit.* note 2, and Schneider, *op. cit.* note 1, pp. 47–108.

<sup>24</sup> Cf. Ackerman, *ibid.*

<sup>25</sup> Cf. Levi, *op. cit.* note 5; H. Waitzkin. 1991. *The Politics of Medical Encounters*. New Haven, CT. Yale University Press. Fisher & Todd, *op. cit.* note 22.

<sup>26</sup> Cf. C. Meyers. Managed Care and Ethical Conflicts: Anything New? *Journal of Medical Ethics*. 1999; 5: 384.

<sup>27</sup> Cf. C. Meyers. The Impact of Physician Denial on Patient Autonomy and Wellbeing. *Journal of Medical Ethics* 1992; 3: 135–137.

<sup>28</sup> Cf. Mark Kuczewski. Reconceiving the Family: The Process of Consent in Medical Decision Making. *Hastings Center Report* 1996; 2: 30–37; and D.M. Foreman. The Family Rule: Framework for Obtaining Ethical Consent for Medical Interventions from Children. *Journal of Medical Ethics* 1999; 6: 491–496, with replies in the same issue.

<sup>29</sup> Cf. D.M. Mirvis. Managed Care, Managing Ethics. *Journal of the American Geriatrics Society* 1998; 3: 398–390.

<sup>30</sup> Cf. K.S. Gottfried. Informed Consent Meets Managed Care. *Health and Social Work* 1998; 1: 25–33; Mirvis, *op. cit.* note 31 and Meyers, *op. cit.* note 28.

<sup>31</sup> Cf. Schneider, *op. cit.* note 1, pp. 109–136.

<sup>32</sup> Cf. P. Backlar. Will the 'Age of Bureaucracy' Silence the Rights Versus Needs Debate? *Community of Mental Health Journal* 1995; 31: 201–206.

<sup>33</sup> The literature tends to focus on the kinds of control associated with consent for major procedures or the withholding or withdrawing of treatment, rather than over the relatively smaller, but still important, choices in life (clothing, meal choices, visitors, routine disruptions) of one's life. A nice exception is: P. McGrath. Autonomy, Discourse and Power. *Journal of Medicine and Philosophy* 1998; 5: 516–532. I will return to this point below.

experience, and often the *last* experience, of patients' lives. Central lines, intubation, catheters, heart monitors, and nasal gastric tubes, while run-of-the-mill for physicians and nurses, are weird, frightening and alienating for patients and especially for their families or other surrogates. As Willard Gaylin once described this phenomenon to a group of physicians, 'seeing a loved one in these circumstances for the first time is a terrifying moment. They see all the tubes and wires and machines and (sometimes wrongly) believe they are in the presence of imminent death.'<sup>34</sup> And, often as not, it is an unexpected circumstance, the result of trauma, stroke, heart attack or devastating infection. Combine all this with anxiety about the economic impacts of the illness or death, intra-family conflict and surrogates' own fear of mortality and what emerges is hardly a circumstance for unfettered, rational, fully autonomous decision-making.

All this paints a pretty bleak picture. Even the most habitually autonomous person would have difficulty in the face of these constraints, let alone the typical, heteronomously socialised patient. Should bioethics, then, abandon the autonomy model? Schneider thinks so, recommending a beneficence-based alternative. In what follows, I will first argue against Schneider's model and then suggest a number of steps that will enhance patient autonomy through appropriate education and socialisation into an ethos of autonomy.

## BENEFACTENCE AS THE ALTERNATIVE

Schneider argues that the emphasis on autonomy runs contrary to basic human psychology – i.e., some, maybe even most persons, do not *want* to be autonomous, or at least not all the time. Thus, he concludes, mandatory autonomy is not only empirically suspect, it is also normatively so. Why should there be a presumption to promote a value that is undesired?

It seems, though, there is a chicken-egg problem here. Is it that persons embrace heteronomy so as to avoid autonomy? Or, alternatively, do persons resist autonomy because they have been socialised into heteronomy?

Furthermore, Schneider's argument is against *mandatory* autonomy, a seeming straw person. There is little in the literature,

<sup>34</sup> Gaylin is the co-founder of The Hastings Center. These comments came in an informal discussion on end-of-life issues, Mercy Hospital of Bakersfield, November 1991.

and far less in practice, that argues patients *must* be autonomous. There is undoubtedly a presumption in its favour, but it is certainly commonplace for physicians to pick up on patients' resistance to retain autonomous control and to take over decisional authority, just making sure superficial legal niceties are satisfied (i.e., forms signed). If anything, this probably happens *more* often than is appropriate, not less.

Should there, though, be even the *presumption* in favour of autonomy? The long history in moral and political philosophy overwhelmingly holds this view and Schneider gives no compelling argument against it. Indeed he finds much in its support, including that it serves to protect patients against physician authority, often leads to increased health and promotes patient responsibility.<sup>35</sup> He just rejects that it should be mandatory, a conclusion with which I have no quarrel.

Granting this, however, still does not effectively address the primary concern here. That is, even if as a rule persons seem to prefer self-control over compulsion, choice over limitation, autonomy over heteronomy, and if autonomy is a habituated skill, then routine medical care is seriously flawed, since it discourages rather than promotes that skill. Then, when patients are faced with emotionally wrenching, life-altering (or *ending*) decisions in the ICU, they are asked to step up and be autonomous, even though many do not have the decisional competence necessary to make a genuinely autonomous choice. Yet, sometimes for the first time, this is exactly what is asked, even demanded,<sup>36</sup> of them. They have spent their medical lives assenting to physician decisions. Then, at the most stressful time, with the greatest stakes, they are expected to be fully autonomous, true *consentors*.

Schneider's recommended alternative, unfortunately, is worse. He is careful to move away from traditional, physician-based paternalism. Indeed, he is sharply critical of that model:

Perhaps all professions are not conspiracies against the laity. But they are all invitations to arrogance. It is hard to train yourself in a specialty for many years, to learn a powerful new way of thinking, to have clients come to you for help and advice . . . and to have your clients, your employees, and your colleagues defer to you without coming to believe that you are better than most of the world and it would do well to accept

<sup>35</sup> Schneider, *op. cit.* note 1, pp. 176–179.

<sup>36</sup> *Ibid.* pp. 9–32.

your guidance. The medical profession may be particularly susceptible to this temptation. Doctors are trained and often live in surprisingly insular environments. Many of the doctors who populate that environment are oddly bitter people who feel unappreciated and even beleaguered by the world in general and by people—bioethicists and lawyers not least among them—they perceive as their attackers.<sup>37</sup>

He ends up, however, recommending instead a form of *social* or *institutional* paternalism. His model would rely on a social science method to survey average patient desires and then create institutional mechanisms to promote them: 'Patients can be helped toward some of what they want from medicine through what I have called the consumer-welfare model. This model asks for identifying subjects about which many patients agree and for instituting social norms that guide doctors and patients in their decisions.'<sup>38</sup>

I see three particularly problematic flaws in this recommended approach. First, it would bureaucratise what should be individual and, surely, the primary vehicle for promoting patient autonomy – informed consent – is already far too bureaucratized. As Sulmasy et al. showed, the signing of a consent form has become a bureaucratically mandated component of informed consent with too many health professionals treating it as the *equivalent* thereof. Extending this bureaucracy to create mechanisms that promote social norms would seem to give busy health professionals all the more excuse to rely on those mechanisms and concomitantly to avoid the careful conversations needed to enhance autonomous consent.

Second, since Schneider's approach relies on *average* patient wishes, it by definition will exclude those who fall outside the norm. This would not necessarily be a problem if health professionals, especially physicians, were to continue to otherwise engage in autonomy-enhancing activities. But since, on Schneider's model, individualised autonomous consent will be downplayed, and since non-typical patients' values will not fall under the definition of average social norms, they will only see further degradation of autonomy, without (paternalistic) beneficence-enhancing alternatives implemented in their place.

Third, Schneider's model does not give adequate attention to the ways in which institutional values impede or alter the creation

<sup>37</sup> Ibid. p. 230.

<sup>38</sup> Schneider, *op. cit.* note 1, p. 227.

and enforcement of structural mechanisms of the sort he describes. The more bureaucratic a procedure, the more likely it is that institutional self-interest will become imbedded in its creation, and especially in its implementation. The infringement of institutional values upon those held by patients has always been of concern, and it has only become worse with the assorted mixed motives imposed by ongoing changes in reimbursement structures.<sup>39</sup> If, for example, a hospital knows it will be reimbursed for only two days of maternity care, and if that same hospital is directly responsible for instituting structural mechanisms intended to promote the average patient's values, it is simply naive to believe that there will not soon be a coincidence between the reimbursement structures and 'patient value mechanisms.' As Kenneth Boyd puts it, '... the organisational and practical constraints of a modern health service make [genuinely beneficent paternalism] impossible for even the most trustworthy and virtuous doctors.'<sup>40</sup> This is why the autonomy model, for all its flaws, has consistently been championed as the best way to assure promotion of the patient's *own* conception of what is of value.

Finally, even if Schneider's model is intended to move away from traditional paternalism, it will still generally be physicians who implement the determined social norms, physicians who, as noted above, are already sorely tempted to rely upon the signing of forms, rather than on autonomous informed consent. Similarly, physicians, especially those in a hospital environment in which they have limited repeat contact with patients, already fall back on what the average or 'reasonable' patient would value. And, of course, they also face an array of motivations (social pressures, institutional pressures, personal biases, fatigue, self-interest, etc.) that may directly conflict with an objective assessment of what would be in patients' best interest.

## PROMOTING GENUINE AUTONOMY

Although achieving a sophisticated level of autonomous decision-making represents a much greater challenge than much of the

<sup>39</sup> Cf. Gottfried, *op. cit.* note 32 and Mirvis, *op. cit.* note 31.

<sup>40</sup> Deciding about Resuscitation. Editorial. *Journal of Medical Ethics* 2001; 5: 292. See also in the same journal edition the series of essays on patient control and resuscitation commenting on the (included) Joint Statement from the British Medical Association, The Resuscitation Council (UK) and the Royal College of Nursing: 308–323.

literature, even some of the most influential,<sup>41</sup> contends, there is no reason to believe that it is wholly impossible. Given, though, my argument that the described problems are endemic to current healthcare, achieving this would require a systematic overhaul, one that resulted in patient autonomous decision-making becoming truly the standard in routine care, in emergency care, in surgical care, in critical care – across the board. Further, economic, power, bureaucratic, and institutional structures would all have to change in order to create a relationship in which patients and physicians are genuine partners, with mutual respect and comparable power.

Such a radical restructuring is of course anything but likely. Thus, in an important sense, the problem is intractable. Some helpful steps, though, can realistically be taken. These would at least enhance patient autonomy, reduce some of the harms associated with critical care decision-making and also push the system a bit farther along the path of needed change.

1. Resident education should place greater importance on autonomy in routine care. One means of achieving this is through the inclusion of ethics education on ward rounds and in outpatient clinics. This should not come at the exclusion of ICU ethics education, but be in addition to it.
2. Genuinely promoting patient autonomy is about enhancing patient control over, and identification with, medical decisions. Thus resident education must stress that autonomy is about much more than simply getting agreement to a procedure. Consent forms should be seen as merely *confirming* what has already occurred in careful conversation.
3. The environment in which these decisions occur is often frightening, coercive and alienating for patients. While the gadgets, the noise, the activity, the poking and prodding quickly become routine for medical staff, they rarely do for patients. Staff, thus, must be regularly reminded of this difference so as better to achieve more compassionate and effective communication.
4. The task of promoting autonomy is not only the responsibility of physicians. Its importance should also be stressed in the education and local training of nurses, technicians (radiology, respiratory and lab) and orderlies, since they are the ones with the closest daily contact with patients. They can assist in

<sup>41</sup> Cf. R. Veatch. 1981. *A Theory of Medical Ethics*. New York. Basic Books.

promoting patient choice in such simple ways as describing what is about to occur, making sure patients understand the reasons behind the actions, and, when feasible, giving them choices.

5. Related, patient control can be enhanced in subtle ways during hospital stays. The number one complaint of patients who otherwise have successful admissions is that they lost control over their lives while in the hospital. Much of this is unavoidable. Too often, however, procedures are designed for the convenience of staff, rather than out of genuine medical need, let alone with respect or concern for patients as the highest priority. For example, no sufficiently compelling reason justifies making patients wear degrading gowns, provided their own clothing allows sufficient access for necessary procedures. Similarly, more varied food choices, greater control over the number and time of visitors, and control over entertainment and external noise all would augment patient power and concomitant autonomy.
6. Although advance directives are problematic, they do enhance patient autonomy by both directing future choices and by reinforcing an on-going attitude in patients that their healthcare is at least partly theirs to determine. Thus, despite the well-discussed concerns about vagueness, predicting future mind-sets, etc., they should still be a major component in patient and community education.
7. So as to reduce the 'cruelty' of ICU decision-making, effort should be made to rely upon the person in the unit with the most finely developed communication skills to discuss treatment options with patients or family. The physician in charge is often not the best suited to direct the conversation. It might better fall, with oversight by medical staff, to social workers, nurses, ethicists, even the patient's chosen clergy.
8. Medical staff must also work to be as self-reflective as possible, to recognise personal or institutional factors that might motivate actions or recommendations for reasons other than, or in addition to, the patient's best interest, including personal financial or political gain, and pressures associated with institutional politics and culture.

Followed conscientiously, these steps will better promote patient autonomy and reduce some of the trauma associated with end-of-life decision-making. While not a comprehensive solution, they will help to create a compassionate decisional environment from which patients will more likely complete their hospital stay think-

ing well of the hospital and its personnel, regardless of the medical outcome.<sup>42</sup>

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