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# **Critical Care of Children: The Ethics of Using Contested and Expensive Medical Resources**

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One of the most difficult of all medical decisions is the continuing treatment plan for the critically ill or injured child. Like all critical care decisions, determinations to continue using expensive therapy rest on the ethics of the profession, the quality of care, economics, and social expectations.<sup>1</sup> These factors alone are complex enough. Traditionally, the ethics of the profession would underline the need for heroic measures to save a child. The quality of care factor, like the ethics factor, would seem to promote continued active interventions according to accepted practice in an intensive care unit.

On the other hand, economic pressures more and more devolve upon physicians. A recent GAO study revealed that 70% of health care costs, now exceeding 10% of the GNP, are under the direct control of physicians, through their orders.<sup>2</sup> Not infrequently, ICU care of children surpasses \$200,000 for hospital bills alone. Most of this burden is borne by taxpayers. Ironically, therefore, just as medical technology presents us with a chance to take heroic measures to save life, social expectations seem to have backtracked. Society has begun to question its allocation of resources.

Unlike the rest of critical care, that for children presents an additional complication. Children, unlike infants, have had time to

develop bonds with family and friends. These bonds tilt our treatment decisions toward the most active intervention possible. Children, unlike the aged (stroke victims, heart patients, etc.), have not yet had time to develop in life. This fact, too, offers counsel at the moment of decision about continued care.

Literature in ethics and medicine contains many articles on the treatment and non-treatment of defective newborns. Despite the recent warning by HHS that not treating defects may violate federal law, most physicians either follow some criteria established by experts,<sup>3</sup> treat all cases,<sup>4</sup> or rest decisions on bargains established through dialogue with the family of patients, as the AMA Judicial Council advises.<sup>5</sup> Only a small amount of this well-developed literature can be extrapolated to critical care of children, however, because of the differences cited. Furthermore, there is little agreement on the criteria which might be used, or even that all children must be treated.<sup>6</sup> In fact, there is no agreement at all on the role of economic considerations in such decisions.

An equally large number of articles has appeared on cost containment and the allocation of scarce medical resources.<sup>7</sup> However, most of the ideas and criteria for selection for treatment appearing in these articles have little or nothing to do with the allocation of the resources available in a pediatric intensive care unit. The reason is that, barring emergencies, the resources are currently readily available. As a result, physicians interested in the ethics of treatment decisions for critically ill children cannot turn to the newborn or scarce resources literature for direct guidance, particularly with respect to the role economic considerations should play in these decisions.

This paper is an attempt to shed some light on the subject. In it, we first restate the problem as it is posed for critical care of children. Next we will examine the claimed rights to health care with particular emphasis on the expectations of society. Third, we will review various theories of distribution of health care from the perspective of their applicability to critical care. Finally, we will propose a theory of the moral role of the physician in critical care decision-making.

### The Ethical Problem

At the conclusion of an excellent review of the scarce resources literature, John Kilner proposes his own theory for treatment selection. Based on the best thinking in that literature, Kilner argues that:

A moral allocation of scarce life-saving medical resources should thus at least resemble the following. Whenever treatment facilities become available, a patient should be selected from among the medically suitable who have not elected to forego treatment. Priority should be given to those whose death is imminent, followed by those requiring disproportionately few resources and those having unique moral duties — normally in that order.<sup>8</sup>

One can immediately discern the problem which critical care for children presents. Children are unable to elect or not elect to forego treatment. Thus, the criterion offered fails to apply. Even if they do so elect, as teenagers, our society does not afford this decision the same measure of rational respect as that made by a competent adult.<sup>9</sup>

The ethical decision facing the critical care physician is rather to be stated like this: *Is it ever wrong to withhold resources from children for financial reasons?* It should be emphasized that these resources are not "scarce." In fact, we would prefer to call them "contested and expensive." They are contested insofar as public policy in the United States today raises questions about the allocation of goods, including the good of critical care. They are very expensive goods, as well.

We now turn to health care rights and social expectations.

### Rights to Health Care

The first issue we must address in regard to critical care is the patient's right to health care. The question of right inevitably entails obligations. Given the fact that philosophers disagree regarding the nature of rights, it is no surprise that our society has not reached a consensus on whether or not citizens have a right to health care.

It is difficult to ascertain whether health care is an unrecognized right or no right at all. However, it is clear at least that some citizens have an entitlement to health care through federal legislation (veterans), and others lay claim to some form of basic health care. We hold that distinctions must currently be made, especially between levels of care.

Although we do not currently have a right to primary care, we perhaps ought to have that right.<sup>10</sup> Some sort of "right" to emergency care is recognized by society through its Good Samaritan legislation, permitting the skilled to come to the aid of those in need.<sup>11</sup> David Ozar argues that tertiary care may be a right precisely because justice demands we offer a life-sustaining service toward those in need, provided we have everything necessary to survive.<sup>12</sup> The argument parallels one proposed by St. Thomas Aquinas concerning private property, namely that a starving person is entitled to our bread, because ultimately all goods belong to God. We only share them, and have contingent custody over them.

Seen from perspectives like these, some obligation seems to exist to care for children, even intensively. Most physicians would hold that one is never justified in withholding treatment from a child for economic reasons, to answer our question. In fact, they may hold this position while agreeing that, with respect to newborn or to adult critical care patients, one might be justified in withholding care for

economic reasons. In the case of the former, the reason would be poor prognosis. In the case of the latter, the reason would be poor prognosis. But with a child, we are less likely to make this judgment, even though he or she may have difficult outcomes. Thus a disproportionately large share of health care costs arise from uncertain outcomes.<sup>13</sup>

In fact, the debate about health care rights with respect to critical care requires two caveats. First, the actual right we may have is *a right to be cared for*. This right may derive directly from the fact that we are persons and therefore are entitled to respect.<sup>14</sup> Similarly, the right may be derived from the principle of beneficence. It is not sufficient to do no harm. One must also act for the good of another. It may also be derived from the natural law observed cross-culturally and trans-historically as a form of kinship-piety or group solidarity. Groups take care of their own and especially, they take care of their children. Finally, the right to be cared for may be derived the way Rawls derives certain aspects of justice. A social contract may be imagined to have taken place when disinterested parties try to design a series of social rules and moral laws to insure the survival of the group.<sup>15</sup> One could imagine that care for one another would be a premier value in such a scenario.

We would hold that within the right to be cared for would be certain claims and entitlements. Because of special service to others, the state may (and has) determined that certain persons are entitled to care for their health. Veterans receive health care in return for their service to their country. That is, the right to be cared for is *extended* to include their health. About the rest of us, ambiguity reigns. Therefore, from time to time we might claim that our right to be cared for includes health care, but there are no laws to buttress this claim at present.

However, children do evoke socially more explicit claims to a right to health care, derived from a right to be cared for. It is difficult to postulate the reason. No doubt their inherent vulnerability is one. Another might be that society seems to expect that children have a special claim on health care resources because they are society's future. Further, because they are not yet fully mature persons, they have a constant *need* to be cared for which ranks ahead of that of adults. This need creates the obligation most physicians feel toward children.

A second caveat is more pragmatic. It is a warning voiced by Charles Fried. In an article published in the *Hastings Center Report* entitled "Equality and Rights in Health Care," he says:

Nevertheless, it is worth noting that at least in American public discourse, the idea of a right to health care developed into something which had the appearance of inevitability only recently, in what might be called the intermediate, perhaps golden, age of modern medicine. This was a period when advances in treating acute illness, advances such as the antibiotics could

really make a large difference in prolonging life or restoring health; but the most elaborate technologies which may make only marginal improvements in situations previously thought to be hopeless had not yet been generally developed. In this recent "golden age" we could unambiguously afford a notion of a general right to health care because there were a number of clear successes available to medicine, and these successes were not unduly costly. Having conquered the infectious diseases, medical science has undertaken the degenerative diseases, the malignant neoplasms, the diseases of unknown etiology; and one must say that the ratio between expense and benefit has become exponentially more unfavorable. So it is really only now that the notion of a right to health care poses acute analytical and social problems.<sup>16</sup>

In other words, Fried points out that if these rights exist, such an open-ended commitment will be difficult, if not impossible to meet. Fried's caveat may be made into an argument against health care rights as follows. The "right" to health care arises not from deep philosophical obligations, but rather from recent custom and usage. So, the profession of medicine creates needless philosophic difficulties for itself in trying to meet the obligations entailed in "patient's rights." In so doing, the profession necessarily abridges a health care professional's right to exercise control over his or her services.<sup>17</sup> Hence, health care cannot be a right.

This argument is defective on three counts. First, the logic is faulty. One cannot move from a condition of current practice in which health care professionals can often reject the care of certain patients to a universal statement about health care not being a right. The reason is that current practice may not adequately reflect the status of our rights. Thus Lincoln could argue against slavery on the grounds that it violated the rights assumed by any liberal society. Second, as David Ozar has pointed out, the argument assumes that health care is a commodity like baseball cards which one trades in return for payment, and over which one exercises control. However, critical care is not a commodity, but a life-sustaining service provided by those who do not lack anything for sustaining life. To withhold it would be a violation of justice.<sup>18</sup> Third, the argument assumes that rights to health care need not be distinguished. However, to say that one has no right to primary care (a check-up, for example), differs in degree from saying that one has no right to critical care. Care in tertiary care represents an all-or-nothing phenomenon, with survival in the balance, rather than gradations of well-being.

Thus, the question of patient rights and the concomitant societal obligations may be abstract, but it is extremely clear to practitioners that rights do exist, and that professionals have an obligation to deliver health care to individuals as part of their role in society. Special obligations govern the care of children.

The question for the practitioner is more subtle than whether rights to health care exist. How extensive are those patient's rights? And what of society's rights, i.e., the classic problem addressed by infringe-



ment on other individuals' rights by redistributing income to pay for critical care?

At this point, one touches the realm of distributive justice. Issues in this realm are so crucial to all health care decisions that a discussion of them and their background may be useful, indeed essential, for the practitioners of critical care.

### Distribution and Critical Care

There are several major approaches to the relationship of the individual to society. We use three as illustrative of the principles and problems. The first, the libertarian view, is well represented in the modern literature by Nozick.<sup>19</sup> He argues that the basic element of life-together is liberty, and that liberty cannot be circumscribed except for the most pressing social reasons. One must abstain from murder and robbery as a citizen, but one is not necessarily obligated by the social contract to redistribute an income so that the more needy become less needy, if that is at the expense of someone's inalienable personal liberties. This boundary to one's obligation is viewed as sacrosanct.

Issues such as caring for one's fellow man arise, not out of a sense of obligation, but out of a sense of compassion. Nozick and others argue forcefully for the historical situation in which a tremendous outpouring of social beneficence grew from this sense of virtue and compassion, rather than rights and obligations.

Under such circumstances, insurance clearly is critical, and responsible individuals have such insurance. If insurance coverage in individual cases were not adequate, individuals and institutions would continue their best efforts for the patient out of compassion. The problems associated with such an approach are evident, given our current health care template. Hardly any insurance plan now extant can adequately cover the cost of catastrophic care. An insurance plan which might adequately cover the cost of care is essentially one which spreads the risk of catastrophic illness across a broad enough base to afford it, and for practical purposes, this would represent society as a whole.

Second, for those who cannot afford health insurance, equal status as persons is jeopardized. Thus, Paul T. Menzel argues that, with respect to health care, the poor ought to have a smaller dollar sign applied to their life and not receive critical care.<sup>20</sup> He claims this is a humanitarian approach, because the money not used for such care could be distributed better to provide housing, jobs, etc., for the poor. One of us found this proposal inadequate on the moral grounds of medicine itself, not to mention other major social norms.<sup>21</sup>

Third, to base one's rights to health care on insurance or voluntarism means that any efforts to curtail costs entails restriction of

services. This is a political decision. In this way, political decisions clash with medical-moral principles such as minimizing harm to patients, the patient's right to self-determination, and principles of the common good.<sup>22</sup>

Voluntarism, while a laudable aim, is already at an all-time high. It is and will remain woefully inadequate. There are also problems with voluntarism in the context of subspecialty medicine. Subspecialty care of ICU patients would find a larger percentage exhausting standard resources, and would require therefore, a much greater percentage of "voluntary" support when compared to a general range of practice. Thus the burden of voluntary care would most often fall on ICU staff and tertiary care centers rather than on medicine or even the population as a whole.

Utilitarianism has a long and illustrious history in this country. Exemplified in the statement, "The greatest good for the greatest number," it represents a second approach to the problem of critical care. The foundations of our particular form of utilitarianism are rooted in the writings of John Stewart Mill.<sup>23</sup> With respect to health care, utilitarianism can summon some powerful arguments. Health care has approached 11% of the gross national product, and it is clearly straining other worthy sectors of the social fabric. Critical care, with allocation of some scarce medical resources in disciplines from neonatal intensive care to post-operative surgical care, is a major contributor to that 11%, and the improvement in overall well-being has been limited, especially when compared to the advances referred to earlier with respect to antibiotics, etc. An approach to limiting that call on our resources might be to eliminate areas which are wasteful, or of marginal importance in the larger context of health care. Cost-benefit analysis would play an important role in this view. Thus, for instance, cost-benefit analysis might play a principal role in outlining our goals as a society with respect to health, and how we might best attain these goals. Regionalization of health care is just one example. Health care could be rationed in an appropriate fashion, and primary care might then receive its just due, preventing disease before it became "expensive."

Unfortunately, despite all sorts of rational plans to allocate health care on the basis of maximizing the good, utilitarianism provides little help when tackling difficult questions of individual treatment. In fact, the individual is swamped by social concerns in utilitarian thinking.

A third, and potentially productive approach to issues of equity in balancing society and individual needs is through the theory of distributive justice proposed in a general context by Rawls, and fleshed out with respect to health care issues most extensively by Norman Daniels. In Rawls's theory there is, in fact, a distinct charge to society for providing justice to the members of that society. "Justice is fairness" summarizes, in slogan form, the approach.



It is based on the notion that each individual is, or should be, guaranteed equal or "fair" access to a set of goods and services that society offers its members. The list of goods is general and exhaustive.

Health care is not directly considered in Rawls's listing. Yet health care clearly occupies a special place in our society. Norman Daniels suggests that

We can account for the special importance ascribed to health care needs by noting the connection between meeting those needs and the opportunity range open to individuals in a given society . . . specifically, health care institutions will be among the variety of basic institutions (for example, educational ones) which are important because they insure that conditions of fair equality of opportunity are obtained.<sup>24</sup>

To take a specific example, if a child is a quadraplegic, society has an obligation to minimize that child's handicap by physical therapy, surgery, or support systems that will allow the child's participation in society to the extent possible. Critical care, in this view of society's organization (and our concern for fair equality of opportunity — in theory if rarely in practice — has a long historical tradition in this country), is clearly an instrument for maintaining or restoring equality. Individuals requiring intensive care are often random victims of catastrophic illness and correction of their illnesses is not solely the province of their individual efforts or the beneficence of an Arabian sheik, but the proper obligation of a society to its citizens.

Rawls's theory of distributive justice raises almost as many problems as it answers. However, with respect to intensive care, it provides a resourceful argument. The argument might look like this. The goal of critical care would be to re-establish at least the possibility of function to compete in a contest for self-determination required for equity among persons.<sup>25</sup> As such, it must rank as a primary good, which should take precedence over all other secondary goods. If this view is adopted, cuts would be necessary in offensive weapons rather than in critical care. It would be the right of all citizens to have access to critical care.

There are clearly limits to what a society can afford to spend on health care. There are limits to what that spending can accomplish. There are efficiencies that can be affected to provide critical care in such a way that more resources are available for other uses. Depending on one's philosophical system, one may wish to distribute these resources in different ways, and a society clearly needs to call on the medical profession to provide guidance.

### The Moral Role of the Critical Care Physician

Having explored the issue of the ethics of critical care, and the ethical obligation to provide that critical care once it has been demonstrably proven to be effective, we turn now to the role of the physician.

What should be the physician's role in the provision for or withholding of contested and expensive medical resources? It is quite different from that of advisor to political bodies, as a general member of society, or as a member of a for-profit or not-for-profit organization providing general care. In these other roles, the physician is able to step aside from his role as provider, and look objectively at outcomes and expenditures, matters of cost effectiveness, etc. Detsky, et al., state forcefully the clash between these two separate roles of the physician: objective analyst of health care versus provider of that health care.<sup>26</sup> The two "individuals" may be one and the same person, but the two functions are exclusive.

Given obligations both to patients and society, it seems that physicians at least need some guidelines. Our theory of the physician's role in critical care quandaries rests on a series of principles which may help to establish those guidelines. It is presented in the hope that other theories and guidelines could be proposed toward the aim of reaching a consensus satisfying the expectations of members of society, including those who are critically ill, and providers themselves.

1) In order to protect both doctor and patient, it should not be the proper role of the physician in ordinary circumstances to make triage and economic decisions. If the physician is forced into this role as *physician*, then he or she must necessarily violate one of at least three moral axioms arising out of medicine, and must choose a theory of distribution sometimes at odds with the aim of medicine itself.

2) The three relevant axioms have been proposed by Thomasma with Pellegrino: do no harm, respect the vulnerability of the patient, and treat each patient as a class instance of the human race.<sup>27</sup> To select one person for treatment over another violates all three axioms. Not to attempt to save a child's life, despite the cost, would do harm. It would not respect the special needs of children and would violate vulnerability. The problem with critical care is precisely this, that patients in need of care require greater technological and personal attention to re-establish at least a minimum of function. In many cases we cannot predict outcomes. Lacking sufficient evidence to stop the expensive methods respecting vulnerability, the physician must continue, in order not to violate his or her moral obligations.

3) In turn, patients are protected in this model because they know that physicians are looking after their best interests. The bond created between physicians and patients is too important for patients' recovery to sacrifice for economic obligations.

4) This is not to claim that physicians should not participate in discussions of public policy regarding health care allocation. However, with respect to decisions about continued care of critically ill patients, a committee, ideally composed of disinterested persons, should recommend treatment decisions. This committee, distinct from PSRO, hos-

pital committees, or health systems agencies, ought to be established for the sole purpose of making critical care decisions.<sup>28</sup> The committee would establish the ground rules of the critical care context. In this regard, the physician must lobby strongly for care in any cases of conflict, becoming, as it were, the patient advocate.

Parents are often not ideal spokespersons for the child. This role would underline the medical-moral obligations of the physician in any one-on-one relation to patients. The disinterested body of informed individuals, on the other hand, would have as its charge the development of concrete policies and case recommendations which would bring about the greatest degree of justice in a consensus among parents' needs, social needs, and patient care.

In essence, what is necessary in critical care decision-making is a sequential decision-making process. The first decision is by society at large, and physicians should participate fully in that process, defending their personal point of view. That debate results in the distribution and allocation of those medical resources we have called contested. These then become available to the individual practitioner of intensive care at the time of his or her contact with a new patient.

The second decision occurs in the patient encounter. It should take place free of that first debate. Economic decisions which do not affect the quality of care can, of course, be made during the term of patient care. (If a CT scan is judged on a professional basis to be equally as useful as an angiogram in diagnosing an intracerebral bleed, then choosing the CT scan makes economic sense as well.)

Only in this way can the conflict between society's demands and patient's needs be resolved. In any case, the physician provider must be removed from the dangerous role of establishing treatment allocation criteria while at the same time administering critical care. Such a role, when analyzed carefully, is intrinsically contradictory. If one can remove the direct critical care team from that conflict, attention can be focused on the issues at hand, reserving the all-important, but irrelevant, questions of allocation of contested medical resources to a more objective and different arena.

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