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If This Baby Could Choose ...

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Many of the moral problems raised by the practice of medicine today require that decisions be made in cases where the patient cannot even participate in the decision-making process, much less actually make a decision. Some of the most difficult of these involve infants — e.g., whether to perform experiments which have potential for great benefit on infants who cannot give a free and informed consent, whether to carry out what were once called “extraordinary” treatments in order to preserve the lives of infants born with defects which are life-threatening. I will focus on the second of these issues — care of defective newborns (a term which today includes conditions as diverse as Down’s syndrome, spina bifida, and Tay-Sachs disease.

That we must make decisions in such cases is clear, but no one is too certain how best to do it. Many of us believe that we ought to seek whatever is in the child’s best interests. Not all will agree, of course. Some believe that where the child’s best interests conflict with the interests of its family or society, or where the child is comparatively devoid of potential for “meaningful” life, we should weigh other factors more heavily in determining and seeking a “greatest good.” Here I will not argue — but will presume — that we ought to seek whatever is in the child’s best interests. How to do this is, however, far from clear. Two approaches often used are (1) to attempt to substitute our judgment for the child’s (to ask what the child would choose if it could), and (2) to ask what a reasonable person would choose in similar circumstances.

The burden of my argument will be to suggest that — given what I think is a correct description of what takes place when competent patients make their decisions in similar circumstances — it makes little sense to attempt to use either of these standards in deciding for incompetent patients such as newborns. The reasonable person stand-

ard does not really arrive at a patient-centered decision, and the substituted judgment standard (applied to the case of newborns) is incoherent — or so I will argue. The most attractive alternative to these is Paul Ramsey's "medical indications" policy, which I will defend and then worry about. In order to delimit the scope of this discussion I will concentrate on the opposing positions of Ramsey and Richard McCormick.¹

The Point at Issue

It is best to begin by eliminating considerations which, however important elsewhere, are not really at issue here. Both men are agreed that treatment ought not simply prolong the dying of an incurably ill patient. Ramsey is now careful to say that a patient may be terminally ill and yet not be irretrievably dying (p. 187). But neither Ramsey nor McCormick would for a moment suggest that a patient whose life can be helped by no known treatment should receive anything other than the "treatment" now appropriate: care, comfort, and relief of pain in his dying.

There is also substantial agreement between McCormick and Ramsey with respect to the right of *competent* patients to refuse treatment. Rather than speaking of a right to refuse treatment, Ramsey prefers to emphasize that the patient is entitled to "free and informed participation in medical decisions affecting him" (p. 157), but there is no serious disagreement here. Similarly, Ramsey prefers — even in the case of competent patients — to speak only of treatments medically indicated or not indicated; however, in deciding whether a treatment is or is not indicated, he permits and encourages the participation of the competent patient. Indeed, he explicitly grants (though in a concessive clause!) that a competent patient may use quality-of-life considerations in deciding to refuse treatment (p. 155). McCormick holds that, although refusal of treatment by a competent patient may not be "frivolous," the patient may still make his decision by weighing a wide variety of factors (all of which could never be specified in advance): the burden of the treatment, the quality of life it is likely to offer, cost of the treatment in financial and psychological terms to family and friends, etc. (p. 36). There seems no reason to believe Ramsey would disagree with the substance of that position, however inclined he might be to formulate it differently.

The point at issue turns, therefore on what Ramsey calls the "voiceless, nondying patient"; that is, one who is neither irretrievably dying nor competent to make decisions about the future course of treatment. A Down's syndrome baby born with an intestinal obstruction and a spina bifida baby would both be examples of such voiceless, nondying patients. Neither is competent to refuse treatment. But also, neither is dying. For the Down's syndrome baby, a relatively simple

operation may be all that is needed; for the spina bifida baby a continuing series of operations may be required.

Obviously, for patients such as these, a proxy decision regarding treatment must be made by parents or guardians. How shall they do so, and what considerations should guide them? McCormick suggests that one must ask what, in the judgment of reasonable people, would be in the "best overall interests of the patient" (p. 36). He stresses that the mere fact of consensus by reasonable people is not itself the right-making characteristic. That is, I presume, because we might discover seemingly reasonable people reaching consensus on a policy we thought morally wrong. What he wants to insure as much as possible, however, is that the best overall interests of the patient be considered. And *if* we presume that an infant would choose (if it could) the treatment in its best interests, and *if* in turn we determine what is in the infant's best interests by consulting reasonable people, we can, with some measure of confidence, say that the infant would choose this treatment if he or she could choose. Thus McCormick combines the "reasonable person" and "substituted judgment" standards, using the former to help him determine the latter.

The appeal to what reasonable people would think is made because — if we are asking what a patient would choose if he could, and if this patient, an infant, has no past history or "track record" of choices — it is difficult to know how else to proceed. McCormick summarizes his position as follows:

If the situation is such that most or very many of us would not want life-preserving treatment *in that condition*, it would be morally prudent (reasonable) to conclude that life-preserving treatment is not morally required for this particular person (p. 36).

But notice, there is nothing particularly patient-centered about asking, "Would a reasonable person want this treatment?" That question asks not what would be in the best overall interests of *this* patient but, instead, whether most or many of the rest of us would choose treatment were we in a similar condition. And the question takes on the appearance of patient-centeredness only when conjoined with the attempt to substitute our judgment for that of the infant. Therefore, it is the attempt to make this substitution which requires our attention.

Why Substituted Judgment Won't Work

McCormick himself admits that it is "all but impossible" for us to "extrapolate backwards on what kind of life will be acceptable to the infant" (p. 36). Rather than eschewing the attempt, however, he decides that we must nevertheless try to do the "all but impossible." We can begin to understand the incoherence of this suggestion if we consider the nature of decisions made by competent patients.

The competent patient may — Ramsey and McCormick are agreed — consider a variety of factors in deciding whether to refuse or consent to treatment. He may consider the value (to himself) of continued existence, his personal aspirations which are not yet realized, the burden and expense of the proposed treatment, his responsibilities for others, the degree of relief which the treatment promises — in short, countless factors, none of them “frivolous.” In my view, however, we would be mistaken to imagine that the competent patient is *weighing* the relative value of these competing factors, for they are incommensurable, and the scale on which they could be weighed or the lowest common denominator to which they could be reduced does not exist. Morality here is not a matter of scientific measurement, and moral reflection is not a matter of technique. When, therefore, the competent patient considers the various — incommensurable and incompatible — goods involved, he is not arriving at a *discovery* about some single right choice to make in these circumstances. There is no such right answer to discover, no choice which someone else in the same circumstances would be “unreasonable” to veto.

Instead of making a discovery, the competent patient makes a *decision*. He decides how he will live — or how to live while dying. He chooses certain goods at the expense of other goods and, in so doing, shapes his own existence and character to some degree. If we insist on using language of “discovery” and “weighing” in such contexts, we must be clear about what it can mean here. The relative weight of the conflicting goods is known — and known *only* for the person deciding — *after* the decision has been made. For another patient similarly situated the relative weight of the goods may be different and will likewise be known only after the fact of decision. The only “discovery” we make in such circumstances is a discovery of something about ourselves, the kind of people we will be because we have chosen to be.²

If this account of decisions by competent patients is correct, we can see that it is incoherent — not just “all but impossible” — to “extrapolate backwards on what kind of life will be acceptable to the infant.” Were competent patients in such circumstances weighing commensurable goods in order to discover some truth, the discoveries they made about the relative claims of these goods would be applicable to decisions about incompetent patients in analogous circumstances. But since competent patients are not doing this, since they are freely determining the person they will be and the life they will live, it makes little sense to suggest that we can or should try to do this for the infant. Someone else’s *discovery* about how certain goods should be balanced might be applicable to infants in similar circumstances; someone else’s *decision* to be a self of a particular sort can have no such applicability.

The Turn to Medical Indications

It seems, therefore, that McCormick's attempt to use "reasonableness" to get at the infant's best interests is a dead end as long as those "best interests" are couched in the subjective terms of what the infant would choose if it could. Can Ramsey do better? He attempts to bypass questions about what an infant would choose if it could by offering a more objective criterion. We should, he suggests, simply ask whether any available treatment will benefit the life the patient has. If a treatment offers such benefit, it is medically indicated. The strength of this position lies in the fact that it clearly recognizes the differences between the situations of competent and incompetent patients. It does not attempt to blur the line between the two by suggesting that competent patients have discovered something which we can now apply to incompetents such as infants — on the presumption that they too would be reasonable and make the same discovery. Competent patients *decide*; infants cannot. We are therefore forced to consider their best interests in strictly medical terms: what, if anything, can we do that will benefit the lives they have?

This is, beyond any doubt, a powerful alternative. It attempts to be genuinely patient-centered and avoids the conceptual bog of substituted judgment. It gives rise, however, to a troublesome problem. It seems to leave us in the unhappy position of making imperative for infants treatments which many competent patients would decline for themselves — accepting for *all* infants what only *some* or, perhaps, *few* of the rest of us might accept for ourselves.³

In one sense, this is simply the price we pay for recognizing the different situations of competent and incompetent patients. Yet, McCormick senses something puzzling about such an upshot, and perhaps he is right. McCormick had recognized that one of the reasons a proxy might decline treatment on behalf of an infant would be the "continuing burden" which the treatment would constitute for the child (p. 36). And that in itself is a purely patient-centered reason for declining treatment. But Ramsey's restriction of proxy consideration to the "indicated/not indicated" criterion tends to lose sight of this possibility. Thus, he can write with respect to treating a newborn with spina bifida:

I do not think that a series of ordinary treatments — closing the open spine, antibiotics, a contraption to deal with urinary incontinence, and a shunt to prevent hydrocephalus — today adds up to extraordinary medical care, except perhaps in the case of a conscious, competent patient who is able himself to refuse treatment (p. 193).

Here we see that Ramsey's criterion can too easily become what the ordinary/extraordinary distinction often was: a standard for what is customary and/or easily managed by physicians today. To let it

become that, however, is to lose sight of the humane wisdom which recognizes that we might properly refuse treatment for an infant simply on the grounds of that treatment's "continuing burden" to the infant. No doubt this would not apply to a single operation on a Down's syndrome baby. But it seems possible that the kind and amount of treatment required for some spina bifida babies constitute a burden so severe (for the child) that one might in good conscience refuse such treatment on behalf of one's child.

I argued above that in such treatment refusals (by competent patients), we cannot weigh costs and benefits. To say that, however, is not to say that we must always choose the benefits. Sometimes, at least, we may choose against — reject — the costs. If all the days and years of the child are equidistant from eternity and therefore of equal worth (as Ramsey might say), we need not purchase some future days and years at any price.

McCormick would probably suggest that, like it or not, I am really making some covert judgment about what a reasonable weighing of the costs and benefits would involve, and I have deliberately used language which elicits such a response. But I think it a mistaken response. Rather, I am trying to take with full seriousness the fact that in difficult cases of treatment refusal no such weighing is possible — and none, in fact, takes place. In most cases, therefore, it makes good sense to say with Ramsey that the only way to serve the best interests of the child is to do whatever can be done to benefit the life it has. This is, of course, to construe "best interests" more narrowly than we would in making our own decisions. But that is just the point. Until such time as a child can itself make these decisions it does not have "best interests" in the broader sense that the rest of us do, for that broader sense involves decision. At the same time, however, the child's best interests may be somewhat broader than Ramsey is inclined to think. Surely a parent, rather than focusing solely on physiological criteria, should be entitled to consider the emotional and psychological burdens (for the child) of treatment. If the child's "best interests" must be narrowly construed because, as a child, it cannot determine its best interests in any broader sense, "medically indicated" must be construed broadly enough to include emotional and psychological burdens. And — at least until they prove themselves irresponsible and inattentive to their child's best interests — we should permit parents to make these decisions (not discoveries) for their children, and we should learn to live with the differences in their decisions just as we do with differences in decisions made by competent patients. That, at least, would be the ideal.

In a brief note co-authored with Robert Veatch, McCormick recently espoused a view quite close to the modified medical indications policy I outlined above.⁴ He and Veatch suggest that for incompetent and competent patients alike the choice to use or withhold

treatment must have some foundation other than "self-determination" (which I take to mean, other than the mere *decision* of the patient). This "moral foundation" is provided by the traditional view that treatments may be refused which are gravely burdensome or useless. This, I think, is merely to repeat McCormick's earlier view that treatment refusals ought not be "frivolous."⁵

The moral foundation for choices when the patient is incompetent needs more detail, however. McCormick and Veatch try to provide this by stating two principles to be used as a basis for decisions regarding care of incompetent patients — a principle of "patient benefit" and a principle of "familial autonomy." The first principle is only a restatement of McCormick's view that treatment should be in the patient's best interest; that is what "patient benefit" means for McCormick and Veatch.

The second — the principle of "familial autonomy" — is not really a second principle so much as a speculation of who should decide what will really ensure "patient benefit." McCormick and Veatch hold that, whenever possible, the family should decide. This may or may not be wise, but it clearly represents a different view from that McCormick expressed in his earlier writings on the subject. The values of the autonomous family may not be those of the reasonable person, and there is little reason why the family should be thought of as substituting its judgment for the incompetent patient's. The family is simply deciding whether to begin, continue, or withhold treatment — a decision based on its own values. McCormick and Veatch blur this by suggesting, in one of the reasons given to support "familial autonomy," that "the family is normally in the best position to judge the real interests of the incompetent patient. They know his or her life style, preferences, and values."⁶ Since this is obviously not true of incompetent patients like infants — who have no life style, preferences, or values yet — it is by itself an inadequate argument. And, in fact, McCormick and Veatch offer a second (and, they say, "more important") reason in support of their familial autonomy principle, namely, the character of the family as a basic moral community. I would not for a moment dispute the claim, but would only note that it leads to a position quite different from that previously espoused by McCormick. The autonomous family need not be bound by the reasonable person standard (though there are some outer limits beyond which McCormick and Veatch would seek legal action), nor is the autonomous family seeking to substitute its judgment for that of the patient. The parents are not asking what some independent individual would choose if it could. They are acting "paternally" — as parents often do and ought to do.

In short, Ramsey's medical indications policy can deal with decisions when treatments are useless but is less satisfactory in circumstances where treatment is not useless but is gravely burdensome.

McCormick's most recent suggestion can deal well with problems of "burdensomeness" but at the cost of forsaking his earlier position. What the McCormick-Veatch position (bracketing the talk about "substituted judgment" which remains as a vestigial reminder of an earlier stage in McCormick's thinking) really amounts to is that decisions about treatment in the case of incompetent patients should (a) seek the patient's best interests, and (b) normally let the family *decide* of what those best interests consist (considering both what is useless and what is seriously burdensome). That is not far from Ramsey's "medical indications" policy if we construe those indications in less strictly physiological terms than Ramsey does.

Perhaps, however, such an ideal — permitting families to decide, and decide differently, what treatments are too burdensome for their newborns, realizing that burdens are not only physiological — may today be unrealistic. In a day when people seem to find it almost impossible to separate burdens for the child from burdens for the rest of us, Ramsey may be wise to construe a medical indications policy rather narrowly. Perhaps his is, today, the only way to keep the child's best interests at the center of our concern. The possibility of abuse suggests that possibilities I discuss as appropriate might only serve as the "thin edge of the wedge" to prepare us for judgments of comparative worth of lives. If so, Ramsey's narrowly construed medical indications policy might still offer the best rule of practice for medicine to follow.

In short, McCormick properly recognizes the importance of considering the burdens a treatment imposes on an infant when we are considering the best interests of the infant. However (at least in his earlier arguments), he encounters a host of difficulties by failing to appreciate that, in determining to refuse treatments for themselves, competent patients make a decision, not a discovery. Because this is the case, recourse to what reasonable people would decide can tell us little about what we should decide for an infant. All we can do is seek the best interests of that infant, and in this search Ramsey's medical indications policy is — if not fully satisfactory in every case — a rule of practice which embodies genuine moral discernment. Most of the time it will be wisest to do what is possible to preserve and enhance the lives these infants have, in the hope that they may some day share with us the anxiety but also the joy of making decisions which shape their lives.

REFERENCES

1. Ramsey's position is spelled out in *Ethics at the Edges of Life* (Yale Press, 1978). McCormick's "early" view is given fullest expression in two articles: "To Save or Let Die: The Dilemma of Modern Medicine," *The Journal of the American Medical Association*, 229 (1974), pp. 172-176; and "The Quality of Life, the

Sanctity of Life," *Hastings Center Report*, 8 (Feb., 1978), pp. 30-36. Cf. also his "Notes on Moral Theology," *Theological Studies*, 36 (March, 1975), pp. 121ff. References to Ramsey's book and McCormick's article in the *Hastings Center Report* will be given by page number within parentheses in the body of the text.

2. Cf. Peter Winch, "The Universalizability of Moral Judgments," *Ethics and Action* (Routledge & Kegan Paul, 1972), pp. 151-170. Nothing in my argument suggests that it would be morally permissible to aim at the death of oneself or another. I am discussing only treatment refusals which, though they might result in death, are intended as choices of other specifiable goods. Hence, I am not suggesting that the whole of morality is agent-relative and purely a matter for decision. Cf. Gilbert Meilaender, "Is What Is Right For Me Right For All Persons Similarly Situated?" *Journal of Religious Ethics*, 8 (Spring, 1980), pp. 125-134.

3. John R. Connery, S.J., has pointed this out in his article, "Prolonging Life: The Duty and Its Limits," *Linacre Quarterly*, 47 (May, 1980), pp. 151-165. He asks, "Is it reasonable to make incompetent people bear burdens that competent people do not have to bear?" (p. 161). However, since Connery does not clearly recognize that decisions by competent patients are just that — decisions, not discoveries — he falls back on "substituted judgment" in cases where decisions must be made for incompetents. Even here, however, he clearly accepts some part of Ramsey's position, for he writes: "What must be kept in mind is that the proxy does not have the freedom the patient himself has regarding extraordinary means" (p. 157).

4. McCormick, Richard and Veatch, Robert, "The Preservation of Life and Self-Determination," *Theological Studies*, 41 (June, 1980), pp. 390-396.

5. The rejection of "frivolity" in such choices is related to the point I made in note 2 above. The decision must be aimed at some specifiable good which the patient aims to realize in his or her life. Since, however, countless goods may be choiceworthy (and incommensurable) here, the patient is better thought of as making a decision than a discovery. It may be worth noting that the "moral foundation" which makes treatment refusals for reasons other than uselessness or burdensomeness "frivolous," may be more stringent than Veatch's own earlier position. In *Death, Dying, and the Biological Revolution* (Yale Press, 1976), Veatch wrote: "From the patient-centered perspective it should be sufficient for competent patients to refuse treatment for themselves whenever they can offer reasons valid to themselves — that is, out of concern about physical or mental burdens or other objections to be discussed shortly" (p. 110).

6. McCormick and Veatch, "The Preservation of Life and Self-Determination," *op. cit.*, p. 395.