

THE RIGHT TO HEALTH CARE
AND THE RIGHT TO DIE

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May 6, 1979

ABSTRACT

To establish a frame of reference for addressing the right to die question, I use Rawls's theory of justice to derive principles for the just distribution of health care --a primary good with distinctive attributes requiring distribution according to need, with lesser needs having priority. Where resources run out, or where care no longer functions as a primary good, the right to health care ends. This scheme of health care rights allows us to define three senses in which a patient may be said to have a right to die: he may lack the moral right to treatment necessary to life; he may have that right but choose not to exercise it; or he may have a moral right to treatment which shortens life.

The Right to Health Care and the Right to Die

I

As scientific and technological discoveries extend the range of possible actions, they raise new moral questions about which possibilities should be chosen. This is the nature of the question concerning the use of "extraordinary means" (sometimes called "artificial means" or "heroic measures") to sustain life.

Patients with previously fatal injuries, diseases, or defects may now be saved by medical procedures, such as extensive surgery or the use of mechanical respiration, circulation, and nutrition devices, which are extraordinary in their complexity, cost, and effect. In some cases, these procedures allow the patient's injury to be repaired or his disease or defect to be cured. In other cases, they can do no more than postpone his death. It is the use of extraordinary means in the latter case which poses the moral question: given that it is possible to prolong the lives of incurable patients, should this always, or ever, be done?

Most attempts to distinguish justifiable from unjustifiable omission of extraordinary means have focused on refining the definition of "death" or deriving a moral right to die (or to die with dignity) from more fundamental rights and values. Defining "death" more precisely, however, does not address the moral problem of sustaining hopeless life. Efforts to establish a right to die are more promising, but they often hinge on subjective or religious beliefs about the quality of life, the artificiality of means, or the purpose of human life and suffering.

Moreover, in the absence of a broader context of medical rights and duties, the point at issue is ill defined. To ask whether in extreme circumstances patients have a right to refuse treatment presumes that in ordinary circumstances patients are obligated to accept treatment. But in our health care system, where medical treatment is a commodity offered to consumers on a fee-for-service basis, it is not clear that one has a moral right to any medical care at all, much less a *prima facie* duty to accept it. Questions about the right to refuse treatment cannot sensibly be raised until the right to obtain treatment has been established.

I suggest that, by picking up the right to die issue from the other end, we will be in a better position to draw the moral line between justified and unjustified omission of extraordinary means. Instead of asking whether a patient has a right to be disconnected from a life support machine and, if so, under what conditions, let us ask whether he has a right to be connected to the machine and, if so, under what conditions. Instead of asking when a physician may justifiably discontinue treatment, let us ask when he is obligated to provide treatment. If we can determine the boundaries of the right to health care, then it will follow that patients have no right to care beyond those boundaries and that physicians have no duty to provide it.

In what follows, I will argue that justice, in the sense defined by Rawls's principles of justice, requires a qualified compensatory health care distribution system--those with greater needs should receive greater shares, but those with lesser needs should have higher priority rights to their smaller shares. Claims to the use of extraordinary means when there is no hope of recovery are too low on the scale of priorities to be morally compelling; in such cases, the right to die is more accurately the absence of a moral right to life sustaining treatment. In addition, the principles underlying this scheme of priorities justify two stronger senses of the right to die--the patient's right to refuse treatment, even life saving treatment, to which he is morally entitled, and the terminal patient's moral right to pain relieving medication, even when effective quantities shorten life.

By shifting the focus of inquiry, then, we are able to isolate the right to die in its several senses as residues of the right to health care.

II

The ethical context for my account of health care rights is provided by Rawls's theory of justice.¹ It may be helpful to summarize those features which will figure prominently in the account to follow:

- (1) Diversity of ends. Different people have different plans

¹John Rawls, A Theory of Justice (Cambridge, Mass., Harvard University Press, 1971). See also Peter Caws, Science and the Theory of Value (New York, Random House, 1967), for a concise account of why moral judgments must be restricted to the realm of common instrumental values.

of life, different purposes, goals, or terminal values.²

(2) Universality of means. Pursuit of one's ends, whatever they are, requires the freedom to act purposively, which in turn requires health, intelligence, material resources, etc. Thus, the instrumental values of freedom and its components are common to all.³

(3) Conditions of moderate scarcity. Resources are limited to an extent which makes cooperative arrangements for distributing the universal means possible and necessary.⁴

(4) Justice as fairness. Just arrangements for distributing the universal means are those which would be adopted by agents who were rational, equal, mutually disinterested, and ignorant of their particular ends, natural assets, and social positions.⁵

(5) Equality or fair inequalities of universal means. The universal means should be distributed equally, unless unequal distribution is to the advantage of those who are least favored.⁶

(6) Universal means the focus of morality. Moral rights and duties are defined by principles for the just distribution of the universal means. Moral evaluation of ends is possible only derivatively, by judging their compatibility with the just distribution scheme.⁷

Rawls calls the universal means to our diverse ends "primary goods." He classifies health as a natural primary good--primary because it is a necessary means to the pursuit of one's ends, whatever they are, and natural because one's share is largely determined by natural circumstances (e.g., heredity) rather than by social institutions.⁸ Now, a person's initial state of health

²Rawls, pp. 92-93, 127; Caws, pp. 120, 134.

³Rawls, pp. 62, 92-93; Caws, pp. 102-103, 108.

⁴Rawls, p. 127.

⁵Rawls, pp. 11-12.

⁶Rawls, p. 303.

⁷Rawls, pp. 94-95; Caws, pp. 109, 122-123, 130-134.

⁸Rawls, p. 62.

may be the result of the natural lottery, but whether or not his health is maintained or (if initially poor) improved depends on the health care he receives or fails to receive. Within constraints imposed by nature, significant differences in health are determined by the workings of the health care system. Thus, we must consider health care to be a social primary good. (Similarly, education is a social primary good correlative to the natural primary good of intelligence; native intelligence, like health, requires maintenance and cultivation if it is to function effectively as a means to one's ends.)

What is a person's fair share of health care?

Presumption (5) above, which governs distributive shares, is Rawls's general conception of justice: "All social primary goods . . . are to be distributed equally unless an unequal distribution of any or all of these goods is to the advantage of the least favored."⁹ To see how this conception might be applied to the design of a health care system, we must note several features distinctive of the good of health care.

Health care is a (universal) means, not to our (diverse) ends directly but to health, which is itself a (universal) means, a component of the freedom necessary to pursue our goals, whatever they are. Freedom to act purposively implies certain capacities definitive of physical and mental health--physical integrity, mobility, coordination, and strength; rationality and the capacity for social cooperation--and it is in terms of these capacities that states of health may be ranked "good" or "bad," "better" or "worse." The primary good of health, so defined, has a lower boundary, below which purposive action is impossible, and an upper boundary, above which the freedom to act purposively cannot be significantly enhanced. At the optimum health position--we may call it "good health"--a person possesses these physical and mental capacities to a degree likely to be useful in pursuing his ends, whatever they may be. Beyond this, more highly developed capacities are unlikely to be used and, unused, unlikely to be retained. Good health is that collection of physical and mental attributes which a rational person ignorant of his particular ends would choose, if natural assets could be chosen.

Although natural assets cannot be chosen, they can be protected and enhanced by appropriate health care, and health care shares are subject to choice. Health care is a primary good which every-

⁹Rawls, p. 303.

one needs and wants, yet the amount wanted is extremely variable, depending on how much is needed as a means to good health. We do not want or need ever larger shares, or even the right to an equal share, because share size has no direct correlation with our capacity to pursue our ends. A healthy person does not need an equal or larger share; he is already in an optimum health position relative to his ends. And for an acutely ill person, an equal share is nowhere near enough; it would improve his health position not at all, or only negligibly. What we want is the right to whatever amount of health care we need, to whatever share is necessary and sufficient to maintain or restore good health.

These quantitative peculiarities of the primary goods of health and health care suggest that a health care system in which shares correspond to needs would be most advantageous to each, since this would equalize the distribution of health at the optimum level. One might propose, as a principle for the just distribution of health care, that each person is to have an equal right to the health care which is necessary and sufficient to maintain him in or restore him to good health--an equal right, in effect, to good health. But clearly this is not tenable, for it ignores limitations of medical research and technology. In many cases, knowledge is inadequate to permit the maintenance or restoration of good health. It is for this reason that health remains a natural, not a social, good; it cannot be the object of a social right.

Suppose we qualify our proposed principle so that each person is to have an equal right to the health care which is necessary and sufficient to maintain him in or restore him to good health, or a level of health which is as near to good health as possible, given the current state of medical knowledge. This allows for cases in which little or no improvement in a patient's condition can be achieved. But it does not yet limit the right to health care to the realm of the possible, for it ignores limitations imposed by the moderate scarcity of health care resources. The benefits of medical research and technology cannot be provided to everyone who needs them, because there are not enough facilities, supplies, and personnel to go around. Since good health is by no means the only primary good, there are moral as well as practical limits to the resources which may be devoted to health care.¹⁰ Thus, the proposal

¹⁰For a discussion of how to determine the amount of resources to be devoted to raising the social minimum--an amount which would include need-oriented transfers for health care--see Rawls, Secs. 43 & 44, esp. pp. 285-286.

that each person's right to health care should correspond to his need breaks down.

III

Since health care resources cannot be distributed according to need, we must adopt a scheme of priorities for the provision of health care. An adequate system of priorities must allow types of patients and types of health care to be arranged, by pairs, in roughly transitive order, so that conflicting claims to limited resources may be resolved. It must allow for adjustments in that ordering in response to theoretical discoveries, new technologies, and increases or decreases in resources. And if the system is to be just, it must incorporate relevant ethical considerations.

I propose that a given person's right (or degree of right) to a given type of health care should be a function of three variables: the level of health at which he can be maintained or to which he can be restored, the probability of success in maintaining or improving his health, and (inversely) the cost. A person's right to a given treatment increases as the level of health to which he can be restored by that treatment goes up, probability of success goes up, and cost goes down. Patient x has a greater right to a given treatment than patient y if x can be restored by that treatment to a higher level of health than y (other things being equal), if the probability of success is greater for x than for y (other things being equal), or if the cost of treating x is less than the cost of treating y (other things being equal).

These three factors have an empirical tendency to vary together, and to vary with types of patients and health care: persons in good general health can, typically, be maintained in or restored to better health, more successfully, at lower cost, than those with progressively more debilitating diseases, injuries, or defects; preventive health care is, typically, less costly and more successful in maintaining better health than progressively more intensive forms of care.¹¹ Combining these two scales, we can arrange types of patients and treatments, by pairs, in a descending order of rights, with preventive health care for healthy persons at the top and intensive care for the severely and irreversibly ill, injured, or defective at the bottom.

¹¹For empirical evidence to support these generalizations, see, for instance, Kerr L. White, "Life and Death and Medicine," Scientific American, 229, 3 (Sept. 1973), 22-33.

A health care distribution system which incorporates this ordering of rights will meet the needs of the most healthy first and those of the least healthy last. Such a system will be most efficient in maximizing good health. But is it just? There are several reasons for thinking that this system is the one which best satisfies Rawls's general conception of justice.

First, it minimizes each person's chances of being in the least favored position. Those who are least healthy are least favorably situated relative to their chosen ends. In any health care system, this least favored position will be the same position--that of the terminally ill, injured, or defective. A person who did not know what his situation would be and who was interested in minimizing his risks could do so only by selecting the system which would make the proportion of persons in the lowest position at any given time as small as possible; a system which would raise the level of the lowest position is not an option. Therefore, the health care system which maximizes the proportion of people in good health and minimizes the proportion in poor health¹² is the one which would be adopted under conditions of fairness.

Second, by reducing competition for the more intensive forms of health care, the system described provides maximum access to intensive care for those patients who need it. In a system which gives priority to acute care over prevention and health maintenance, more people fall into ill health, so demand for acute care increases. Because of the exponential rate at which costs rise on the scale from preventive to acute, available care cannot keep pace with demand. Thus, individual patients in the less favored positions are in fact worse off in an acute-care oriented system than in the more efficient prevention oriented system.

Third, the system described works to the advantage of the individual who is least favored not in the intuitive sense of being the least healthy but in the sense intended by Rawls's difference principle--the individual who receives the smallest share of the socially distributed good. Due to the superior cost-effectiveness of preventive types of care, the smallest per capita expenditures are for health care for the healthy--for the persons who are, in the intuitive sense, the most favored. Increased expenditures would not make them better off; their shares, although minimal, permit them to

¹²In Rawls's theory of justice, social policies such as a plan for providing health care are adopted at the legislative stage. Information about social conditions, unavailable in the original position, is available at this stage, but the situations of individuals are still unknown. See Rawls, pp. 198-200.

enjoy the primary good of health at its upper boundary.¹³ Furthermore, the claims of those who are most healthy have highest priority; their shares are smallest, but they are guaranteed. And since their health care needs are subject to change, it is rational for those whose shares are smallest to support the system's provision of greater shares for those with greater needs.

Finally, by maximizing good health, the prevention oriented health care system most effectively conserves the society's human resources, with benefits flowing to all, including those who are in either sense least advantaged.

By making the best use of limited resources, this health care distribution system comes as close as possible to being a system in which each person has a right--an effective right--to the health care he needs to maintain or restore his good health, within the limits of medical knowledge. Since it works to the advantage of the least favored--both those least favored by the natural lottery (the least healthy) and those least favored by the social distribution scheme (the healthy who receive the least care)--this system is also the most just, in the sense of Rawls's general conception of justice.

Does this plan for distributing health care resources conform to the more precise statement given by Rawls's two principles of justice?

First Principle

Each person is to have an equal right to the most extensive total system of equal basic liberties compatible with a similar system of liberty for all.

Second Principle

Social and economic inequalities are to be arranged so that they are both:

- (a) to the greatest benefit of the least advantaged, consistent with the just savings principle, and
- (b) attached to offices and positions open¹⁴ to all under conditions of fair equality of opportunity.

¹³A person may desire some medical treatment (e.g., nontherapeutic cosmetic surgery) which exceeds basic care needed for good health. Medical treatment which is a particular means to the person's particular end (e.g., being a television news anchorman), but not a universal means to whatever ends one may have, is not a primary good; it does not fall within the realm of health care to which one can claim a moral right.

¹⁴Rawls, p. 302.

The second principle is the one which should govern the distribution of health care. We have already seen that the health care system described satisfies the difference principle, since inequalities in this system are to the greatest benefit of the least advantaged. The opportunity provision, however, should have priority: "One applies the second principle by holding positions open, and then, subject to this constraint, arranges social and economic inequalities so that everyone benefits."¹⁵

Health care inequalities, we have argued, should be attached to "health positions" assigned by the natural lottery--those with greater needs are to have lower priority rights to greater shares. It is impossible to improve one's priority position by choosing a better natural state of health, and it would be irrational to increase one's share of health care by choosing a worse state of health. Thus, health positions are "equally open to all" only in the vacuous sense that they are open to none. The proposed health care system, then, satisfies Rawls's second principle of justice, the opportunity clause occurring vacuously.

The fact that health care positions are not open but are arbitrarily assigned by the natural lottery does not, however, have as a consequence the stratification of society along morally indefensible lines--a result which the opportunity requirement is intended to avoid. Far from perpetuating arbitrary differences, this method of distributing health care tends to equalize the distribution of health at the optimum level; it tends to make good the arbitrary competitive disadvantage of poor health. Equalizing opportunity is thus an outcome, not a precondition, of the compensatory distribution of health care. (Similarly, the basic educational system is not itself an equal opportunity system, since it underlies equal opportunity.) Priority of the opportunity provision requires that compensatory distribution (by the difference principle) of basic education and health care must precede distribution (by the full¹⁶ second principle) of other primary goods such as income and wealth.

IV

Justice requires that limited health care resources be distributed by a qualified compensatory health care system--greater shares should

¹⁵Rawls, p. 61.

¹⁶This may clarify the way in which Rawls's principles of justice without inconsistency require, within a limited domain, the allocation of resources according to individual needs as a precondition of (or background institution for) pure procedural justice in the subsequent distribution of goods. See Rawls, pp. 87, 100-101, 276-277.

be assigned to those with greater needs, with the qualification that those with lesser needs should have higher priority claims to their smaller shares. Such a health care system might well include the three-tiered medical provision system described by White:¹⁷ Primary care, for the most common, least serious problems, should be most accessible to patients, in physicians' offices, clinics, or other centers located in their home communities; this level is prevention-maintenance oriented. Secondary care, for less common, more serious problems, should be available by referral in hospitals serving larger communities; this level is geared to early diagnosis and disability containment. Tertiary care, for the least common, most serious problems, should be available by referral in large medical centers serving large populations; this level is palliation-rehabilitation oriented.

In a relatively affluent society, primary and secondary care should be available, as a matter of moral right, to all who need it. But resources cannot be stretched to cover all claims to tertiary care, given the premise of moderate scarcity. At some point on the descending scale of rights, patients' claims to treatment can no longer be met; therefore, those claims cannot be morally compelling.

Tertiary providers must translate that point into empirical criteria for use of the more costly, less effective types of care--criteria which will always decide conflicting claims in favor of patients more likely to benefit from that care. It is in terms of these criteria that the extraordinary means question must be answered. Not only does the tertiary patient have no prima facie duty to accept treatment by extraordinary means, he does not even have a presumptive right to such treatment. Unless it can be shown that he satisfies the criteria for the use of extraordinary means--unless, that is, it can be shown that his condition places him among those more likely to recover a higher level of health at lower total cost, as compared to other candidates for use of the same resources--the patient has no right to have his life sustained by extraordinary means.

¹⁷White, pp. 30-33. It should be noted that a system of medical care such as White describes would be included in, but not coextensive with, an efficient health care system. Even more accessible than primary medical care must be preventive environmental conditions which protect persons against disease and injury where they live and work. It is now understood that major killers such as cardio-vascular disease and cancer are, to a large extent, environmentally caused and, consequently, subject to environmental controls. See, for instance, Texas Reports on Biology & Medicine, 37 (1978): Environmental Cancer: A Report to the Public. The proposed system of health care priorities dictates that a person has a greater right to a carcinogen-free workplace than he does to surgery and therapy for cancer; correspondingly, the obligation for the health care system to provide the former is greater.

Exactly where on the scale of priorities the line is drawn limiting the right to treatment will depend on exactly how scarce health care resources are. Nonetheless, it is possible to draw a theoretical bottom line below which, regardless of resource availability, a patient has no moral claim to the use of extraordinary means.

To see where this line falls, we must recall the source of the moral right to health care. That right is rooted in the value of health, and thus of health care, as a (universal) means to our (diverse) ends. Health care which does not function in this way is not health care to which we have a moral right. Consequently, health care which merely sustains vital processes but does not serve, alone or in conjunction with other forms of treatment, to restore the patient to a level of health at which he can pursue at least some of his ends is not within the realm of health care to which the patient has a moral right. Correlatively, it is not health care which physicians or other health care professionals have a moral duty to provide.

It is possible to draw this bottom line more precisely. We have presumed that different people have different ends but that pursuit of any ends requires the freedom to act purposively. Now, action may be more or less physical. Some commonly held ends require relatively little in the way of physical capacities--conversing with friends, reading, listening to music, enjoying a television program. Health care which could restore capacities such as these, even though it could not restore physical mobility, coordination, and strength, would be a means to (at least some of) our ends. Consequently, it would fall above the line we are attempting to draw. That is, we would have a moral right to such care, assuming availability of resources. But while some ends may be pursued in the virtual absence of physical functioning, there are no ends at all that may be pursued in the absence of conscious mental functioning. Consequently, health care which cannot serve, alone or in conjunction with other forms of treatment, to restore conscious mental functioning is not health care to which the patient has a moral right.

Corresponding to this theoretical bottom line, an empirical description which incorporates the present state of medical knowledge can identify cases in which withholding or withdrawing life support systems or other forms of intensive treatment is certainly justified, regardless of available resources. For example, when a patient has no spontaneous brain activity for a certain length of time or, short of that, when he has brain damage of a certain kind or degree, the limits of medical knowledge make it unreasonable to anticipate restoration of conscious mental functioning. In such cases, the use of extraordinary means to sustain life cannot serve as a means to that person's ends, so he has no moral right to their use.

In practice, because of limited resources, the moral rights and duties must end at some point above this line. Not only must the right to the use of these scarce and costly measures be restricted to certain types of patients (those whose conditions make them the likeliest candidates for recovery or significant improvement) but that right must have temporal limits. There can be no moral right to the continuous, indefinite use of extraordinary means to maintain life. The "quality of life" being maintained is not at issue. Rather, the supply of such means relative to demand is necessarily such that claims to prolonged use could not be ranked. With a large number of persons occupying the same position on the descending scale of priorities seeking access to the relatively few life support systems, selection must be arbitrary from the moral point of view.

V

It has been necessary, to provide a context for validating the right to die, to determine the contours and boundaries of the right to health care. Health care rights are generated by principles for the just distribution of health care, which may be formally stated as follows:

Each person is to have equal access to a health care system which arranges health care inequalities so that they are to the greatest benefit of the least advantaged.

More specifically:

A person has a right to a given type of health care if and only if:

(a) that care may be expected to maintain him in or restore him to good health or (if good health is not attainable within the limits of medical knowledge) a level of health as near to good health as possible, so long as health at that level still functions as a means to his ends,

and

(b) there are sufficient resources to recognize the same right on the part of all other persons in the same and higher priority positions on a descending scale of rights, a scale which ranks types of patients and health care, by pairs, according to three related variables--level of health to be maintained or recovered, probability of success, and (inversely) cost.

Corresponding to the moral right to health care is the moral duty of appropriate health care providers to supply that care. Failing either condition (a) or condition (b), a person has no moral right to the given type of health care, and providers have no moral duty to supply it.

We shall now argue that these principles for the just distribution of health care justify the right to die in at least three distinct senses.

(1)

The principles stated provide a clear, negative answer to the question whether extraordinary means should be used to prolong life when recovery or significant improvement cannot be expected. Patients' families and physicians are concerned to know whether extraordinary means must be used lest the patient's very right to life be violated. To the contrary, there are conditions under which extraordinary means should not even be offered, much less forced upon the patient. Under these conditions, it is right that the patient be permitted to die; in this sense, he may be said to have a "right to die."

Although health care providers are not obligated to maintain the patient's life under such conditions, might they not, however, choose to do so, and if so, might not the patient be obligated to submit?

There are two possibilities. If the use of extraordinary means for patient x deprives patient y, higher on the scale of priorities, of treatment to which he has the moral right, then providers not only have no duty to treat patient x by those means; they have a duty to withhold that treatment. For example, if there is one life support system which could be used to postpone the death of x or to maintain y's vital functions while a surgical procedure likely to restore his health is performed, then the provider has a duty to honor y's higher priority claim. If the provider should capriciously choose to treat x instead, then x (among others) would have a right and a duty to reject this injustice.

But suppose there are no higher priority claims. The provider wishes to administer extraordinary treatment to patient x, who has no moral right to that care, because x is a particularly apt subject for research or for an organ donation. Does x have a right to refuse such treatment?

If patient x is kept alive for such a purpose contrary to his will, then he is being used for ends other than his own. This sacrifice of one person's ends to another's may well be required by utilitarian ethics, but it is doubtful that such sacrifice could be sanctioned by Rawls's theory, which demands a fair distribution of the burdens as well as the benefits of social cooperation. If there were an obligation for the dying to contribute their bodies for experimentation, transplants, etc., to benefit others, it would fall disproportionately and arbitrarily on those whose dying occurred from certain causes, at certain times and places. Further, the autonomy of the individual in defining his own ends and the means best suited to those ends (fundamental to Rawls's theory, in contrast to utilitarianism) would be denied. A terminal patient who has no right to refuse the administration of extraordinary means could not then choose to spend what he knows to be his final days at home, where he might be greatly

comforted by familiar surroundings and the continuing presence of family and friends. A person ignorant of his situation, plan of life, and moral and religious convictions would not accede to a system of rights and duties according to which he would have no right to live his last days as he wished, a duty to let his body be used for ends other than his own. The contribution of one's body to benefit others should, no doubt, be encouraged and rewarded. It is, however, a supererogatory act and not a duty which justice requires.¹⁸ The dying patient who chooses not to make this contribution does indeed have a "right to die."

But there are other contexts in which the question of a right to die may arise. A patient who has a high priority claim to the use of extraordinary means or other life saving treatment may wish to refuse that treatment, even though without it he will surely die. Or a terminal patient whose life is not being mechanically or medically prolonged may wish some drug to be administered to hasten death. In each case, the patient is claiming a right to die which is not satisfied by the withholding of care to which he has no moral right (the sense established above). We must pursue the implications of our principles for health care distribution to see if the right to die in these stronger senses may be justified.

(2)

Does a person have a moral duty to accept every treatment to which he has a moral right?

A person has a clear moral duty to obtain treatment if failure to do so would pose a threat to the health of others (e.g., he has a duty to be treated for a contagious disease). And a person has a prudential duty to obtain treatment which would serve to maintain or restore his own good health, or a level approximating good health, since health is a means to his ends and one ought (in the prudential sense) to choose the means to one's ends. But sometimes the means to our ends have undesired side effects, and this can nullify our prudential duty to choose them. An operation may involve risks; a program of therapy may require enormous time and effort; drugs which relieve anxiety may cause depression. When the treatment is worse than the disease, a person has no duty--even a prudential one--to accept it.

¹⁸See Hans Jonas, "Philosophical Reflections on Experimenting with Human Subjects," in Daedalus (Spring 1969: Ethical Aspects of Experimentation with Human Subjects), reprinted in Robert Hunt & John Arras, eds., Ethical Issues in Modern Medicine (Palo Alto, Calif., Mayfield, 1977), pp. 317-339. Jonas argues that the melioristic goal of medicine cannot justify individual sacrifice without consent, in contrast to the social survival goal of war, which is thought temporarily to justify individual sacrifice without consent, disproportionate burdens on some, and disproportionate benefits to the rest of the community.

Since different people have different ends, one person's choice may seem to another to be imprudent. But with the exception of children and persons for whom there is independent evidence of mental deficiency (because individuals in both classes lack the knowledge and judgment to make consistent choices in their own interests), each individual must be the judge of his own ends and means. This autonomy is implied by the presumed moral equality of agents. Unless refusal threatens others, a person has no duty to accept treatment.

What about refusal of treatment which is necessary to life?

This type of case is farther along a continuum, but not different in kind, from cases described above. Life itself is ordinarily a means to our ends, so it would be imprudent to reject it. Life has value, as a means, because it enables us to do or enjoy the things we value, as ends. But when health deteriorates to the point that life no longer serves our chosen ends, then it loses its instrumental value, which is its only value. If our minds or bodies are so debilitated by injury, disease, or deformity that we cannot do any of the things we find worthwhile, and if there is no reasonable chance of significant improvement, and if there is also no reasonable chance of our developing alternative, attainable goals, then there is no duty--even a prudential one--to accept treatment which would sustain life.

Again, one person's choice may seem to another to be imprudent. But with the same exceptions noted above (children and mentally defective individuals), each person must be the judge of his own ends and means. Even when death is certain and imminent, the patient has no duty to accept treatment.

Thus, a patient may have a moral right to treatment, but whether or not he exercises that right is, like the exercise of other moral rights, a matter for his discretion. This discretionary facet of the patient's moral right to treatment may be described as a consumer right to accept or refuse that treatment (unless refusal would threaten others) and to be given the information he needs to make this decision prudently. Correspondingly, the health care professional has a moral duty to offer the treatment to which the patient has a moral right and a provider duty to inform him fully and to respect his deliberate decision.

By disentangling the moral and consumer-provider dimensions of medical rights and duties, then, we can establish a second sense in which a patient may have a "right to die"--the sense in which the patient has a consumer right to refuse treatment to which he is morally entitled, even in a terminal case.¹⁹

¹⁹Special care must be taken to ensure that incapacitated patients retain their moral and consumer rights to obtain or refuse health care. So long as the patient gains access to the medical system (and it would

(3)

May a patient have a moral right to treatment which hastens death? We have argued that patients have a right to refuse life-sustaining treatment, whether or not it is treatment which they could claim as a moral right. Here, the question is whether patients have a right to obtain life-shortening treatment.

The scale of priorities described in condition (b) of the principles for distributing health care ranks patients and treatments by pairs. A patient who has no effective moral right to the use of extraordinary means to prolong life may have a high priority right to less costly means of improving his condition, means which are likely to be effective and which are not so scarce that his use would deprive others with higher priority claims. Specifically, so long as a terminal patient has any degree of consciousness, he has a moral right to medication which would relieve him of pain, because this would, with high probability and at low cost, improve his condition significantly, increasing his capacity to do or enjoy the things he values (e.g., to concentrate on a book or to engage in conversation with a visitor). If the severity of pain without medication is such that the patient is unable to do or enjoy any of the things he values, and if there is no rational possibility that his situation will change for the better, then there is no reason to withhold pain relieving medication, even if effective quantities are such as to shorten life.

Under these circumstances, the patient's right to treatment is, in effect, a "right to die." In this third sense of the phrase, the right to die at least borders on being a right to euthanasia, depending on how that concept is defined.

be the moral duty of others to assist him in this), the moral duties of health care providers assure that he will receive appropriate care to which he has a moral right. Since that care is a primary good, there is a presumption in favor of acceptance. However, patients may prudently refuse forms of health care that do not function as means to their particular ends; if those ends may be known with reasonable certainty, then the patient's consumer choices may be inferred. The patient may have given his physician instructions concerning kinds of impairments for which he would not want to accept certain kinds of treatments, or his family may have good reasons to believe that he would, if he could, refuse some forms of care. If the objective of health care is to serve the ends and interests of the patient, then the fact that they must be articulated by others should not cause them to be discounted, although the need for careful safeguards is acknowledged. It is, after all, when we are helpless to defend our own interests that we most need to have our rights--including our right to refuse unwanted medical treatment--recognized and respected by others.

VI

I have outlined a scheme of health care rights and duties with reference to which the right to die might be located. Those rights and duties are defined by principles for the just distribution of health care. Health, considered as a natural primary good, is a value which varies between upper and lower bounds; near the upper boundary, the need for health care approaches zero, while near the lower boundary, it approaches infinity. Health care, as a social primary good, is a means to health and, indirectly, to our diverse ends. Because the correlation between share size and ends depends on needs and because resources to meet those needs are moderately scarce, the demands of justice are best met by a qualified compensatory system for distributing health care. That system assigns highest priority to the claims of generally healthy persons to low cost, highly effective preventive and maintenance care and lowest priority to the claims of severely and irreversibly impaired patients to high cost, marginally effective rehabilitative care. This system works to everyone's advantage, including those who are least healthy and those whose health care shares are smallest. Thus, it conforms to Rawls's general conception of justice and, more precisely, to the difference principle as this governs the justice of compensatory background institutions.

Types of patients for whom costly treatment cannot, within the realm of rational possibility, restore a level of health at which they can pursue or enjoy at least some of their ends have no moral right to that treatment. This rules out treatment which cannot serve to permit recovery of conscious mental functioning, regardless of resource availability. Because resources are in fact moderately scarce, the cut-off line below which patients have no effective right to certain types of treatment must be drawn somewhere above this point, exactly where depending on how scarce the resources are. In any event, a patient has no moral right to the continuous use of extraordinary means to maintain life indefinitely, regardless of the "quality of life" maintained.

Unless refusal would unjustly threaten the health of others, patients have discretion over the exercise of their moral rights to health care. That is, patients have consumer rights to accept or refuse treatment and to the information they need to make this decision prudently. Health care professionals have corresponding moral duties to make care available and provider duties to inform patients and respect their decisions.

Terminal patients may request medication to relieve pain, in order that their remaining days may be spent in activities which they find enjoyable and worthwhile. If withholding medication would strip life of its value as a means to the patient's ends, then he has a right to that medication, even if effective dosages hasten death.

By shifting the focus of inquiry to questions about the right to health care and the duty to provide it, we find that questions about the right to die, the omission of extraordinary means, and the provision of life-shortening treatment have fallen into place. (1) In some cases, it is not so much that the patient has a "right to die" as that he has no right to the extraordinary measures required to maintain his life. (2) In other cases, his "right to die" is his consumer right to refuse treatment, so long as no one else is unjustly harmed. In either case, the withholding or withdrawal of extraordinary means is morally justified. (3) Under certain conditions, the patient may have a right to treatment which shortens life; in this sense, the "right to die" at least borders on being a right to euthanasia. Finally, the question of how "death" is to be defined is seen to be philosophically peripheral to the extraordinary means issue. The morally exonerating conditions for cessation of extraordinary means include but are not limited to death, however defined.

A health care system designed in accordance with these priority principles would place the emphasis where, I think, it belongs--on health, and not on life. To save life without health, to salvage and prolong life below even a minimal level of healthful functioning, is a perversion of health care. It is all the more perverse when, in conditions of moderate scarcity, such care results in the loss of recoverable health to others, by restricting their access to facilities, supplies, and personnel.

Solution of the right to die problem will require the resolution of a fundamental disorder in our present health care system--its tendency, all too often, to treat moral rights and duties as if they were discretionary consumer matters and, sometimes, to treat consumer-provider rights and duties as if they were moral imperatives. What is needed is a reorientation of the health care system, guided by principles firmly grounded in ethical theory. I hope to have suggested a fruitful approach to this endeavor.

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