Death talk: the case against euthanasia and physician-assisted suicide

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2 Should the Grandparents Die? Allocation of Medical Resources with an Aging Population

The question in my title – a deliberate inversion of the famous question asked by Helga Kuhse and Peter Singer: “Should the baby live?”[1] – is being asked more and more often. As Gerald Gruman has observed, “It is questionable if today the young comatose patient is the prototype for the discussion of issues of death and dying. A more probable crucial issue is that of the elderly: a reservoir of relatively defenceless persons, perceived, through bigoted ‘ageism,’ as unproductive and pejoratively dependent. In them, modernization has created a population stratum that, in a state of nature or conditions of scarcity economics, ‘ought’ to be dead.”[2]

Frequent topics of discussion today include the medical needs of aged people, and how we, as individuals and as societies, will fulfil these needs in an era characterized by a real or a perceived scarcity of medical resources. The “scarcity” is often a given in discussions of allocation. But what is meant by that word? What constitutes a scarcity? What causes it? Can it be alleviated by, for example, greater emphasis on preventive medicine? How do answers to these questions affect responses to the following questions: Should the grandparents be allowed to die? Should the grandparents die? And which of these two questions, if either, is appropriate? The conduct that would be mandated, permitted, or prohibited by the same answer to both, whether positive or negative, would not be the same.

Resources can be unavailable because they do not exist or because they are unavailable in practice. Unavailability can be either avoidable or unavoidable. Monetary resources, theoretically, always exist; the issue is their allocation *to* and *in* medicine. But the fundamental issue that must be addressed in every case, whether monetary or non-monetary, is whether the decision is acceptable in both process and outcome.

Allocation depends on a range of factors, including perceptions of a non-allocation decision that imposes harm or the risk of harm. The harm or risk can be perceived as being imposed by choice or by chance, directly or indirectly, through an act or an omission, by an overt or a latent decision-making process, by identified or unidentified allocators, and on identified or unidentified victims. To the extent that a harm or risk is, or appears to be, imposed by choice, directly, by an act, through overt decision-making, by an identified allocator, or on an identified victim, it is likely to be considered unacceptable. Conversely, to the extent that a harm or risk is, or appears to be, imposed by chance, indirectly, through an omission, through latent decision-making by an unidentified allocator, or on a victim unidentified at the time risk is created, it is likely to be considered acceptable. In short, seriousness and probability of risk and harm do not alone determine the acceptability of a decision that leads to their imposition. Features of the decision-making process that results in that outcome, too, are very important.

Another important factor is the difficulty presented by uncertainty. People might choose an approach to allocating health-care resources that promises to minimize this problem. They might focus only on demography, for instance, in allocating scarce medical resources to an aging population, thereby creating a greater sense of certainty and security. People might seek a "right" answer through demographic manipulation, because right (in the sense of apparently certain) answers are not available when other approaches are used. This approach enables them also to avoid facing "the challenges of competing social and political claims for health care resources."[3]

In some cases, we might have to alter our thinking. To cite but one example, there can be an almost conditioned response that inexpensive alternatives are less beneficial than expensive ones. In fact, however, some cost-saving alternatives can confer additional benefits. For instance, hemodialyzer reuse can be no more risky than the use of new dialyzers for each treatment, and could even be safer.[4]

The initial characterization of a problem influences both questions and answers – and outcomes as well. There is an important difference in the *prima facie* presumption governing decision-making when one refers to "medical resources" rather than "scarce medical resources" (the term more often used). Likewise, characterization of medical resources can be used to make them unavailable. A treatment can be identified as "experimental" or "extraordinary" to deny either access to it or the responsibility to continue providing it. Health-care insurance might not cover the costs of experimental treatment; consequently, to impose that label can be a money-saving device. Similarly, it can be held that there is no legal or moral obligation to provide "extraordinary" treatment. This category (which is much less used now them it was in the past) might include life-support treatment when patients' wishes are unknown. Non-allocation, whether through laudably reflecting respect for the wishes of competent patients who refuse treatment or the "best interests" of incompetent patients whose wishes are unknown, has the secondary effect of saving money.

DISCRIMINATION ON THE BASIS OF AGE

A semantic trap lies in the common formulation of the problem of "scarcity" as one of allocating resources to or among aged people. This terminology implies that "we" decide what to do to "them." In reality, we are a community, a global, dynamic whole, and aged people are part of that whole. That is why the title of this chapter refers to the allocation of medical resources *with* an aging population. I want this terminology not only to reflect or create a more neutral approach to age in allocating health care resources, but to cause the people needing medical care to be integrated as members of the general community.

Initially, we might consider "the aged" as a separate group in order to study them and their needs or for altruistic or paternalistic reasons. But the danger in distinguishing them as a group and treating them differently on that basis is in creating an opportunity to stigmatize them and discriminate against them.

Discrimination – whether intentional or accidental, conscious or unconscious, acceptable or unacceptable in terms of motive – can lead to unjust decisions. Surgery might be considered less desirable for old people than for young ones because the risk-benefit calculus is less favourable for the former than for the latter. But this denial could be based on wrongful discrimination on the basis of age rather than on valid medical justifications. Also, care should be taken to prevent unjustified paternalism from governing decisions. The paternalistic tendency to infantilise old people is regrettable. Yet, even though "paternalism" has come to be a dirty word, there is as much danger in excluding it entirely as in overusing it. So we need to find the right balance of autonomy and paternalism.

Should legislation prohibiting discrimination on the basis of age outlaw it at any age or only within an age range – up to the age of sixty-five years, for example, or only between forty-five and sixty-five, or only after the age of majority? When does discrimination (and most people discriminate a great deal of the time) become legally wrongful discrimination? The basis for discrimination, the situation in which it occurs, and its effects are all relevant. Most jurisdictions that prohibit discrimination include that on the basis of age or of physical or mental handicap (a provision that could be relevant to some aged people). Denying aged or handicapped people access to needed health care on the basis of these characteristics would almost certainly fall within the definition of prohibited discrimination. In general, the burden of proof of a *prima facie* case of discrimination is on the plaintiff. If the case is established, the defendant must show that discrimination either did not occur or that, if it did, it was justified.

Prohibition of discrimination does not provide a guarantee of access to medical care, because rights against discrimination are of "negative" content, not "positive." One has the right to be treated no worse than anyone else, not a claim to be treated better than others and according to one's needs. Because old people might need more health care than other members of society, protection against discrimination might not provide an adequate safeguard or remedy.

The crucial question becomes: Are there rights of access to health care? Most jurisdictions do not legislate a legal right of access to health care. The Quebec Health and Social Services Act[5] is one notable exception. In other jurisdictions, one might ask whether a government-funded health-care system that is required by law[6] to be universal (applicable to all residents), comprehensive (applicable to all illnesses), portable (applicable in all provinces), accessible, and publicly administered implies or amounts to "holding out" that there is a legal, moral, or even "political" right of access to necessary health care. In Canada, we hear frequent declarations by government and government-supported institutions that all people are, should be, and will be provided with necessary health care. Do these statements, in an era of limited medical resources, establish a right of access?

Redefining what is necessary treatment is one way to maintain the appearance of a right of access to health care while not providing access to all useful treatments. This approach can be a politically feasible option, but is it honest? What harm does it perpetrate? Sometimes – in fact, often – people are better off knowing that treatment is possible but not provided than they are believing, wrongly, that everything possible has been provided. In the former case, they can at least take steps either to challenge the decision to deny treatment or try to obtain it elsewhere; in the latter circumstances, they might not even be aware that treatment is being denied or that it exists.

To avoid all these situations, jurisdictions could mandate that patients must be informed when treatment indicated as appropriate will not be provided. This disclosure gives them opportunities to challenge the denial of treatment or to seek it elsewhere. "Treatment indicated as appropriate" should be defined to include all treatment that might benefit patients.

JUSTIFICATIONS FOR DISCRIMINATION

Sometimes discrimination can be justified. Several justifications, some of them very controversial, have been proposed in relation to withholding some medical care from elderly people.

Fair Innings

The "fair innings" concept means that people should no longer have access to life-prolonging treatment after a specified age – except to reduce their suffering. One issue is whether the fear of future denial constitutes present suffering; if so, it should be alleviated under the suffering-reduction exception. Fair innings is an absolute, not a relative, concept. Among those who have passed the "marker event," there would be no allocation according to age even of "spare" resources. All would be equally unentitled.

One can ask whether fair innings can be justified on the basis that it reflects life expectancy. Young people have longer life expectancies than old people, the argument goes; to invest medical resources in the former, therefore, is justified discrimination. But this variation is true only in statistical terms and in general; the life expectancy of any particular young person might in fact be lower than that of an old person. But does the application of fair innings to everyone make it acceptable? Or would letting people agree to have fair innings applied to themselves, in return for additional benefits at a younger age, make it acceptable?

I suggest that if discrimination on the basis of age in allocating medical resources is acceptable at all, it is acceptable only when it is the least invasive and least restrictive alternative reasonably available and is likely to be effective in achieving a justifiable aim. What would constitute such an aim is, of course, a value judgment on which we will not all agree.

Non-maleficence Compared with Beneficence

Some argue that it is acceptable to withhold a health-care benefit, but not to inflict harm. If so, when is withholding a benefit maleficence? I suggest that one is inflicting harm if the benefits withheld are of a kind usually provided, involve no special or unusual risks, and are readily available.

Similarly, some argue as follows: although harm-inflicting omissions are justified, harm-inflicting acts are not. This distinction might reflect a psychological reality, in that we bond psychologically with those people affected by our interventions, but not with those on whom we fail to intervene, especially when we are strangers with no previous emotional ties. We are more comfortable with harm-inflicting omissions, therefore, than acts. Moreover, the distinctions between maleficence and beneficence and between act and omission involve value judgments. And they can depend on the definitions of key terms and existing situations. These factors, in turn, will indicate whether or not conduct is morally and legally acceptable.

Opportunity Costs

In considering the costs of allocating medical resources to aged people, we must take into account the loss of the alternative benefits that these same funds could have generated. We might well find that no "no harm" options are available.

Making decisions under these conditions is often indirect and hidden, features that have been criticized as harmful. Yet direct and overt decisions, too, can involve harm. A direct, overt decision not to allocate resources for some purpose creates and symbolizes lack of caring for that purpose. This dearth of caring is especially likely to be recognized when the non-allocation harms a person or a group that can be identified before any decision is made.

Economic Costs

All medical care costs money, but the care of elderly people can be exceptionally costly. The same treatment can cost more for an older than for a younger person because the former needs more intense care and recovers more slowly. Yet similar cost discrepancies can exist between other groups, neither of which is aged. For instance, it might cost more to care for a sick baby than for a twenty year old with a similar condition. We would not be justified in discriminating against aged people, then, at least not on the basis of a cost discrepancy. Moreover, if different age groups receive different levels of care, these discrepancies will have to be justified to avoid the risk of discrimination.

Finally, we could wrongfully consider the cost not only of saving the lives of old people but of maintaining them thereafter. Cost-reducing incentives for health-care professionals or institutions – such as diagnostic-related groups or prepayment in health maintenance organizations – will make this an increasingly important feature of decision-making.

Treatment might be withheld not because it costs too much initially but because decision-makers believe the ongoing care would constitute too great an economic drain. We need to be extremely careful that decisions are not wrongfully influenced by such "second order" considerations.

We need also to consider alternative ways of paying the costs. Could some entity or person other than the health-care system be required to pay? Increasingly, children are required to provide necessary care for their parents when the latter are unable to do so (the corollary of parents' duties to support minor children).[7] The real difficulty arises when neither the "system" nor an alternative payer is able to pay.

Life Expectancy and Quality of Life

Both short life expectancy and inadequate quality of life can be used as justifications for withholding treatment, whether from old people or others. But how are these factors to be assessed? How can we compare one person's quality of life with another's? And can we compare quality with quantity? Is there a minimal or minimum extension of life that is not worth having or not worth the cost involved? Semantics can be used to justify withholding treatment. Provided that this form of analysis is undertaken honestly, with integrity and according to careful analysis, it can provide helpful insight and assist in making decisions. For example, one can define a treatment as being intended either "to prolong living" or "to prolong dying," and withhold it in the latter situation. Such a withholding could be justified when someone is terminally ill, death is imminent, and the suffering involved in treatment far outweighs any benefits it could confer. As both ethics and the law have developed it would be, however, for the patient (or the legal representative of an incompetent patient) to make the latter decision.

ALLOCATION SCHEMATA THAT ARE NEUTRAL IN THEORY BUT NOT IN EFFECT

Some allocation schemata, though meant to apply generally, might nevertheless deprive old people of treatment. The use of quality of life and quantity of life as criteria could "rank the disabled elderly a low priority, as the gains in terms of complete restoration of health would be small and residual disability high."[8] Refusing to allocate resources to patients with self-inflicted conditions, such as those arising from smoking or alcoholism, could affect older people, too, because these conditions tend to develop later in life.

LEVELS OF DECISION-MAKING

Decisions are made on at least three levels: individual, institutional, and governmental. The ethical principles that apply at each level are not necessarily the same.

Individual Level

Individuals involved in making decisions about medical treatment include the patients themselves, their physicians, other health-care professionals, and sometimes the families. Most important are the patients. But, in terms of the quantity of resources deployed, physicians are most important. Of course, patients, their families, and sometimes their representatives or advocates can influence physicians. More demanding patients or their representatives are more likely to obtain scarce resources.

Edmund Pellegrino has analyzed the physician's role as that of "gatekeeper."[9] He has identified three categories of gatekeeping. Physicians are unavoidably "*de facto* gatekeepers" because their decisions determine the flow of 75 per cent of health-care expenditures. In this capacity, they have a duty to ensure that the money is spent effectively and beneficially. Depending upon the definition used, sometimes only the latter goal is achievable. Palliative care is highly beneficial, but ineffective in some important senses of that word; it neither cures illness nor prolongs life. It is, however, highly effective in relieving suffering and pain and improving the quality of life of dying people. If we see health care as an investment – if we believe that treatment must somehow augment the productivity of patients – we are likely to provide it only when it is both beneficial and effective. In contrast, if we see health care as a social good, we are more likely to consider the benefit it confers as justification for its cost.[10] Physicians can be involved in "negative gatekeeping" too, as when they benefit from constraining the use of resources. Conversely, "positive gatekeeping" happens when they benefit from increasing the use of resources.

As Pellegrino notes, negative and positive gatekeeping dilute the physician's duty as primary advocate of the patient's interest. To avoid the ethical problems inherent in the gatekeeper role, he suggests that institutions establish decision-making structures based on a hierarchy of services and a rationing principle set by public policy, one that is communicated to all who seek care.[11]

Institutional and Governmental Levels

The principles that should apply at the institutional or governmental level might well differ from those that apply at the individual level.[12] Giving primacy to utility and efficiency can be seen as acceptable for governments, for example, but not for individuals. Why is this so, when the results – harming people or depriving them of resources – are the same? It could be that it is easier to deny medical resources to a class than to an individual, and easier for a group than for an individual to make that decision. These different responses would be consistent with Guido Calabresi's theory that we find it easier to harm unidentified victims,[13] and with the concept that higher levels of risk are considered tolerable when a decision to impose risk is a shared responsibility. Moreover, governments have ethical obligations that can sometimes conflict: providing health care for society as a whole and for each individual. The former might justifiably be given priority by them.

It could be argued that the individual ethic should be the same or at least consistent with the communal one. Then we would have to argue over the appropriate content of this ethic. Or we could suggest that one of the two show a stricter degree of respect for persons and for life in terms of providing access to health care – or at least by not denying it. Alternatively, inconsistency could be seen as desirable and, here several perceptions are possible. According to one, inconsistency provides the best of two worlds: appropriate symbolism and also a "way out" in some circumstances. Inconsistency of this kind can either reflect or cause change, because an individual ethic is likely to change faster than a communal one, and because the former can influence the latter (which might change more slowly and less extensively). Yet another view would be that a community ethic is merely fiction, albeit one that is necessary for societal coherence and education, and that the ethic applied in practice is an individual one. Or a communal ethic could be considered an amalgam, or "mean," of various individual ones and, therefore, not applicable in individual cases.

LOGICAL AND INTUITIVE DECISION-MAKING

It is not enough to make decisions about the allocation of medical resources only on a logical, or rational, basis. We need a decision-making structure that will accommodate and integrate intuition and "examined emotions" as well as logic. (I use the term "examined emotions" to distinguish between emotional responses that people review – in connection with their sources, appropriateness, and validity – and unexamined emotionalism.) Moreover, that structure must facilitate both horizontal and vertical analysis. Horizontal analysis helps to identify additional factors relevant to the decision, often not readily obvious ones. Vertical analysis examines not only the conscious level of a decision but also its origins and causes, and its less immediate or direct effects. The latter would include intangible factors such as symbolism and the values being explicitly or implicitly brought into play.

To summarize: A rational and largely demographic approach to allocating health-care resources with an aging population is inadequate by itself. We must give a great deal of attention also to how people feel about the provision or non-provision of health care, and such extra-demographic factors as the social and political context of health care.[14] In other words, we must avoid "too ready a belief that the right answer as to what is better and appropriate can be found from analysis [only] of objective data … [R]eaching solutions will require as many decisions about values as about facts."[15]

There might be no "right" answer either to the allocation problem in general or to any particular case – that is, none that provides a "no harm" option. An adequate decision-making structure, however, could be expected to result in a "right" *process* by ensuring that every issue is dealt with fully, fairly, and openly.

Some argue that including examined emotions would open up a slippery slope of ungovernable decision-making with undesirable outcomes. But most decision-making involves some slippery-slope aspects; handling these factors is simply a matter of control and good judgment rather than avoidance. Feelings exist and can be ignored only at our peril. Moreover, including examined emotions in the decision-making process does not mean that reasoning and rationality are excluded. Each component is necessary, but not, by itself, sufficient. The inclusion of all these components could lead to conflicts that would have to be resolved or tolerated. But it is better to face conflict than to avoid it by artificially excluding factors. Indeed, the effort to resolve conflicts could prove unexpectedly fruitful, giving decision-makers greater insight into situations or into the implications of their decisions.

TRUST

Trust[16] is another important component in making decisions about the allocation of medical resources. Individuals and communities must be able to trust those who make these decisions and the mechanisms they use to do so. Some decision-makers are paternalistic and require "blind trust" (I know what is best for you; simply trust me, because I will act in your best interests); others are egalitarian and use the model of "earned trust" (Trust me, because I have proved to you that you can trust me). Trust is necessary between health-care professionals and their patients, colleagues, institutions, and communities, but also between communities and governments. Health care allocation decisions can prevent the establishment of trust or threaten the trust present in each of these relationships. Moreover, maintaining trust in the context of health care can be a very important factor in maintaining the more general ethical fabric of every community.

By understanding the importance of trust, we will be much less likely to ignore the harm or suffering allocation decisions might cause. Instead, when these decisions risk imposing or do impose harm, we would recognize a duty to seek ways of avoiding that harm, in particular by carrying out research.

CONCLUSION

Unfortunately, we might not be able to find any "right" answers – ones that harm no one – in allocating medical resources with an aging population. We are able, however, to use "right" principles and processes. General goodwill and personal conscience and integrity are essential, but not sufficient, approaches or safeguards. Examined cognitive and emotional responses are necessary, along with structured and disciplined procedures. To develop these responses and procedures is a major challenge for contemporary health law and ethics. Development is essential in the search for answers to the companion questions mentioned at the beginning of this chapter: Should the baby live? and Should the grandparents die?