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Notes

Should ethics consultants help clinicians face scarcity in their practice?

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ABSTRACT

In an international survey of rationing we have found that European physicians encounter scarcity-related ethical difficulties, and are dissatified with the resolution of many of these cases. Here we further examine survey results to explore whether ethics support services would be potentially useful in addressing scarcity related ethical dilemmas. Results indicate that while the type of help offered by ethics support services was considered helpful by physicians, they rarely referred difficulties regarding scarcity to ethics consultation. We propose that ethics consultants could assist physicians by making the process less difficult, and by contributing to decisions being more ethically justifiable. Expertise in bringing considerations of justice to bear on real cases could also be useful in recognising an unjust limit, as opposed to a merely frustrating limit. Though these situations are unlikely to be among the most frequently referred to ethics support services, ethics consultants should be prepared to address them.

Growing pressure to contain costs is leading to a greater awareness of resource scarcity in healthcare. In practice, this means that physicians are increasingly confronted with situations of resource scarcity, and expected to endorse a resource stewardship role.1 2 This role poses ethical difficulties for which they are often ill-equipped but, despite these difficulties, they seldom use the assistance of ethics support services in facing scarcity.3 In this paper, we will examine whether ethics support services could help physicians in facing scarcity. Three questions are addressed: (1) Are physicians aware of ethical difficulties in facing scarcity? (2) Would they perceive the kind of assistance offered by ethics support services as helpful? And, (3) are there reasons to think that the assistance of ethics support services would indeed help physicians in facing scarcity?

PHYSICIANS AND RESOURCE ALLOCATION

It is increasingly recognised that setting *some* limits on care is inevitable. Rationing, defined as "any implicit or explicit mechanisms that allow people to go without beneficial services", is inevitable because the use of every single intervention that holds the smallest possibility of minute benefit seems financially untenable. While some may criticise forgoing benefits, setting limits is inescapable. The role that physicians ought to play in allocating resources is, however, debated. Height to advocate for patients, 4-6 9-11 as well as lack of trust that physicians' decisions will be of the right kind, have prompted reservations about physician involvement in healthcare allocation and

rationing. Their involvement, however, has also been defended on the grounds that physicians are entrusted with the stewardship of scarce resources,⁸ and could make cost control compatible with patient advocacy.¹³ ¹⁴ It has also been argued, convincingly in our view, that they may be in the best position to ration care in an appropriate and justifiable manner.² ¹³ ¹⁵

Contradictory data exist as to whether physicians are aware of facing scarcity in their practice. In the '80s, Aaron and Schwartz noted that British physicians rationalised, or redefined healthcare standards to face scarcity more comfortably. ¹⁶ Twenty years later, researchers conducting interviews with physicians regarding scarcity reported being struck with the strength with which scarcity was denied. ¹⁷ This, however, may reflect incomplete awareness of the impact of scarcity on clinical practice, rather than outright denial. ^{18–23}

In this paper we address the questions we outlined above, by summarising relevant results from an international cross-sectional mailed survey that we and our colleagues conducted, ^{24–27} and offering an empirically grounded analysis of how ethics consultants could contribute to resolving issues of scarcity in clinical care.

A SURVEY OF EUROPEAN PHYSICIANS

Our survey sample consisted of general physicians identified through the 2002 official list of the Norwegian Medical Association, the Swiss Medical Association, published listings of UK general practitioners and general physicians, and regional listings of Italian general practitioners as well as members of the Italian Society of Internal Medicine. A random sample of 400 individuals was drawn in each country in proportions of general physicians, general practitioners, and general internists reflecting that of each national physician population. This sampling strategy was designed to capture similar physician populations, who do the same kind of work in general internal medicine, in both in-patient and out-patient care.

We developed a survey instrument using a combination of new and existing questionnare items. Survey development was described elsewhere, ²⁶ ²⁷ and the questionnaire is available from the authors upon request. The finalised survey questionnaire explored a series of interrelated questions: physicians' experience of scarcity; physicians' agreement with clinical rationing; experience of ethical difficulties in general, and scarcity-related ethical difficulties in particular; physicians experience of dealing with an ethically difficult case; physicians' views on the usefulness of ethics support, and possible forms of support in such a

case. We gathered demographic information and explored how much prior training in ethics our respondents reported.

Participation was voluntary and responses were made anonymous before analysis to ensure confidentiality. Approval was given by the IRB of the National Institute of Child Health and Development at the US National Institutes of Health, and by the Trent Multi-Centre Research Ethics Committee in the UK. This study was examined and designated exempt from ethics committee review by IRBs in Norway, Italy, and Switzerland.

Respondents (n = 656, 43% of eligible sample) ranged in age from 28 to 82, and had been in practice for an average of 25 years, and 38.4% were at least partly hospital-based. Respondents were predominantly male (85%), with the proportion of women ranging from 42.1% under the age of 30 to 7.8% from 61 to 70 years of age. A third of respondents (35.6%) reported having had ethics courses in medical school. Just over half were somewhat confident (53.8%) of their knowledge of ethics. Only a minority (17.6%) reported having access to ethics consultation in individual cases, and only 13.6% had ever used such services.

Scarcity and clinical rationing

Most respondents perceived some degree of scarcity in their practice (87.6%, Cronbach's alpha 0.84).²⁶ Perceived pressure to ration was reported to have occurred in the prior six months by 46.2% of respondents. In addition, 44% agreed that their job or financial situation was threatened by current pressures to contain costs in healthcare. Despite this, 73.3% felt free to utilise available resources in their patients' best interest.

Scarcity-related ethical difficulties

Experience of ethical difficulties in general, and scarcity-related ethical difficulties in particular was explored using items worded as follows:

Below is a list of situations where medical decision-making can be difficult. Please tell us how often you have faced each kind of situation in your work in the last two years. In the last two years, how often have you been in the following situations?

Listed situations included treatment of patients with impaired or uncertain decision-making capacity, disagreement among caregivers, limiting life-sustaining treatment, requests for assisted suicide or euthanasia, but also issues such as scarcity of resources. Respondents were then asked to identify the type of ethical dilemma or problem they found the most difficult to resolve.

Ethical difficulties related with resource scarcity were indeed reported.²⁷ The most frequent were: scarcity of resources requiring a difficult choice (14.3%), and rules for payment of services preventing the use of the preferred course of treatment (7.7%). As shown in figure 1, scarcity requiring a difficult choice was less frequently reported than issues of treatment limitations at the end of life, but was more frequent than issues relating to euthanasia or assisted suicide in every country except Switzerland. There were significant differences between countries in the frequency with which these ethical difficulties were reported. Scarcity of resources requiring a difficult choice was more frequently reported in the UK. Rules for payments of services were reported as a difficulty more often in Switzerland and Norway than in the UK or Italy. Moreover, some respondents (4–9%) even found scarcity of resources to be the most difficult ethical problem they faced. Among scarcity-related ethical difficulties, the situation considered most difficult varied between countries. Scarcity of resources requiring a difficult choice was ranked higher in the UK, whereas difficulties with insurance status were ranked higher in Switzerland.

When asked to describe a recent ethical difficulty, and to rate their satisfaction with the resolution of this situation, 11% of respondents gave an example in which they identified the main issue as a scarcity-related difficulty. Overall, with regard to all ethical difficulties described, a little under half of respondents (47.2%) reported a satisfaction level of at least 7 on a scale ranging from 1 to 10. A quarter (25.7%) expressed dissatisfaction (score of 3 or lower). In the subgroup describing a case that they identified as a scarcity-related ethical difficulty, 40.4% reported a satisfaction of at least 7, and 44.2% reported a score of 3 or lower. In situations where respondents identified the main issue as a scarcity-related difficulty, satisfaction was significantly lower (p<0.01).

Facing scarcity, then, is perceived as posing ethical difficulties and satisfaction with the resolution of these cases is less than for other types of ethical difficulties. Nor does this seem to be entirely specific to Europe. In a study where US general internists, oncologists, and intensive care specialists were asked to give an example of a recent ethical difficulty, 18% chose issues related to resource constraints.¹⁸

Physician perception of help

Physicians' views on the usefulness of ethics support was explored using items worded as follows: "In reflecting back on the case, could you have used:...". Listed forms of help included clarification of the issue, help in reviewing standard of ethics, help in weighing possible outcomes, alternative suggestions and the provision of ethics literature, but also professional reassurance that the decision was correct.

Most respondents (81%) thought that at least one type of help would be useful in the case they had described.²⁷ Interestingly, physicians who reported difficulties with scarcity were as likely as others to find that help would be useful in facing ethical difficulties. The types of help most often identified as potentially useful were: professional reassurance that the decision was correct (47.5%), someone capable of providing specific advice (41.1%), help in weighing outcomes (36%), and clarification of the issues (35.9%). The types of help less often identified as useful were: provision of relevant ethics literature (20.9%), help in talking things through with the patient (24.3%), and mediation of conflict (29.4%). There were few differences between countries regarding the perceived

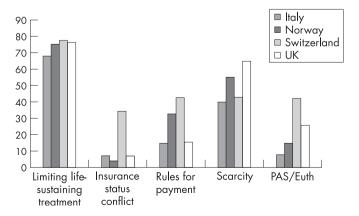


Figure 1 Scarcity-related ethical difficulties, as compared with end-of-life decisions.

usefulness of help. Physicians who identified their case example as a scarcity-related ethical difficulty were slightly more likely to think that specific advice would be useful (p = 0.044).

Thus, physicians in the countries we surveyed indeed report facing scarcity-related ethical issues, and also perceive the kind of help that ethics consultation can offer is the sort they could have used in solving these situations.

USEFULNESS OF ETHICS SUPPORT SERVICES IN FACING SCARCITY

These above empirical findings suggest that that physicians in several European countries seem to view the kind of help offered by ethics consultation as potentially useful in facing scarcity-related ethical difficulties suggests that such help may be useful. However, as this kind of perception can be mistaken, it goes only part of the way. So could ethics consultants indeed help physicians face scarcity in their practice? Would such help truly be useful? In the following section, we will attempt to answer this question by offering an empirically grounded analysis of how ethics consultants could contribute to resolving issues of scarcity in clinical care.

While there is growing evidence of the usefulness of ethics support services in general, 28-33 these assessments have focused on the US and have not addressed this question. In attempting to assist physicians who face scarcity, ethics consultants could have two different, though overlapping, aims. First, they could provide assistance to physicians in the process by which these physicians make resource allocation decisions. In other words, they could make the process less difficult. Second, ethics consultants could foster resource allocation decisions that are more ethically justifiable thus contributing to a better result of the decision-making process. In this sense, they would be making both the process and the outcome more ethically sound. Both kinds of help would correspond to the guildelines formulated by the American Society for Bioethics and the Humanities in 1998.³⁴ Ethics support can take different forms at different institutions, ranging from advice from an individual consultant to formal deliberation within an entire committee. A core of common understanding of what ethics support is, however, is shared across these differences. For example, ethics support is not a substitute for decision-making by those who are in charge of a clinical case discussed in an ethics consultation. The aim is to respond to requests for assistance in considering the ethical implications of a difficult situation, and in using acceptable processes for decisions when reasonable persons disagree. At no stage should stakeholders be dispossessed of their role and responsibilities in the case.

Making the process less difficult

The first kind of help can only be useful if physicians indeed perceive difficulties in facing scarcity. Thus, our findings at least partially indicate a need for a process that might make decisions less difficult in scarcity-related ethical difficulties. In addition, it is interesting to note that in describing how physicians make resource allocation decision, two common assumptions are made. First, these decisions are perceived as dichotomous choices: the resources are either given, or not given to the patient. Second, physicians are perceived as making these decisions on their own. Based on findings from our prior research, both of these assumptions may turn out to be false. In analysing case examples of ethical difficulties centred on resource allocation as given by 55 American internists, we found that most of these discussions involved negotiation with various

affected parties, and that they were not handled as dichotomous choices. Rather, they included attempts to devise additional solutions within the complex contraints of the respondents' healthcare environment.

The tasks of ethics consultation typically includes facilitation of discussion in ethically difficult situations involving different affected persons. 34-36 Devising alternative scenarios is also a frequent part of the consultation process, as are providing analytic insight, helping to sort out the underlying principles and how one might apply one's thinking into action, as well as identifying the limits of our duty in an imperfect world. 37 All this may engage more of physicians' time within the context of a single consultation, but in the long run it would serve as valuable experience that could inform similar discussions in the future. 38

In these ways, then, ethics consultation may indeed be useful in helping physicians face scarcity. However, of the two possible aims outlined above, making the process less difficult is both the easiest to attain and the less important one. Whether or not ethics consultants would help physicians make more ethically justifiable allocation decisions is a more controversial, and more important question.

Making decisions more ethically sound

By affecting the decision-making process, making an ethical decision less difficult can also make it more ethically sound. The process leading to a decision has ethical relevance, in making this decision more or less reflective, participatory, and legitimate.39 For example, rationing at the bedside can be more or less explicit. Explicit rationing entails a clinician's frank acknowledgement that some benefit is being forgone and tends to involve use of practice guidelines, waiting lists, eligibility criteria, limited formularies, and other such mechanisms. Implicit rationing avoids such an acknowledgement and tends to entail strategies such as deflection or deterrence of patients' requests, or termination of a benefit without much discussion. Arguments endorsing explicit rationing focus on fairness and trust. Rationing that is not hidden is more likely to be fair since the clinician must think about the rationale and justify it to the patient.40 Explicit rationing decisions may initially raise suspicions of discrimination but these concerns can be countered by a show of even-handedness. Implicit rationing decisions that are later discovered are likely to undermine trust.

There are several additional points on which ethics support could prove useful in reaching more ethically sound decisions: recognising a justifiable limit, bringing concerns for justice to bear on allocation decisions, recognising unjustified constraints, and participating in the prevention of these difficulties.

Ethics support can, of course, only make allocation decisions more ethically sound if there is some basic ethical justification for them in the first place. If rationing were considered not acceptable, then the involvement of ethics consultants would simply serve to rubber-stamp the practice and lend it an appearance of respectability, a clearly unacceptable approach of "alibi ethics". However, setting some limits to healthcare is increasingly recognised as inevitable.2 We believe that it can, arguably, even be desirable if conducted in a fair manner. For example, justifiable decisions could conceivably be made to sacrifice marginal healthcare benefits for other important social goods, such as education. Even if we recognise the existence of a justifiable limit, however, recognising where it should lie is not easy. Physicians are usually highly aware of the amount of benefit that can be expected from an intervention and its alternatives, as well as of the degree of uncertainty attached to

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those assessments. They are typically less aware of the concerns regarding how to define how much benefit is *enough* to say that an intervention is necessary, or useful, or marginal. Concepts such as "effectiveness", "efficiency", "appropriateness", or "futility" all involve implicit thresholds that physicians may not be accustomed to thinking through. Ethics consultants could assist physicians in evaluating what may or may not count as marginal care in specific cases. For example, considerations of medical necessity are based on concepts of what constitutes sickness and health. Exactly where medical care ceases to aim at curing disease and starts to promote the enhancement of health, however, is a notably difficult question. This is because there are several ways in which we can think of health, such as normal functioning,41 the best attainable functioning, the lowest risk group for health-related consequences, or the absence of suffering. To the degree that ethics consultants are familiar with these debates, this is one example of how their input could complement considerations brought into these decisions by physicians.

When imposing a limit is deemed acceptable in theory, issues of justice typically arise. Physicians, however, are often ill equipped to think in terms of justice and rarely formulate such considerations in explaining how they reached resource allocation decisions. 18 With appropriate training, ethics consultants are equipped to consider questions of justice in difficult cases, and may thus help physicians come to more reflective, ethically more transparent, and ultimately better justifiable decisions. This does not necessarily mean that consultants would be bringing a straightforward rule that could be applied to resource allocation cases in any simple way. Indeed, "straightforward" application of allocative rules has a history marked by resounding failures. The Seattle dialysis committee attempted to apply rules based in part on a notion of the "social value" of patients, following contemporary recommendations. 42 Oregon's application of cost-effectiveness analysis is another famous example, as non life-saving treatments were assigned higher priority than some routinely used life-saving interventions such as acute appendectomy. 43 Rather than bringing a ready-made set of rules, ethicists' task should be to bring a different and complementary kind of consideration, to bear on allocation decisions. This would be an instance of "ethics facilitation", as described by the ASBH task force.34

In our four-country study, we were struck by the diversity of criteria reported as relevant for denying medically beneficial but expensive services. This diversity may reflect variations in the experience of respondents, or adaptation to individual patients' circumstances. Thus, it is not necessarily undesirable. Alternately, however, it may suggest insecurity or tension regarding how to address issues of scarcity. One consequence might be that this diversity results in inequitable access to these services as provided by different physicians. In order to overcome this variability, one possibility might be to attempt to unify the criteria by somehow developing explicit reasoning strategies to think through issues of justice. Bringing such elements to bear on decision-making in these cases would be helpful in fostering more ethically justifiable decisions.

A case where such assistance was helpful took place at a Swiss university hospital. A couple from an Eastern European country was referred for diagnostic procedures to eventually prepare for assisted reproduction. Their health insurance, however, only covered acute treatment necessary to restore health. Had the centre accepted the wishes of the couple, the resulting costs would have been paid by the institution. This

stimulated debate regarding the duty to offer the service or the duty to contain costs. In this case, an interdisciplinary grand round was initiated and the case discussed with two clinical ethicists. Their contribution focused on discussing possible criteria for a decision. Reflection centred on whether it was justified to make an exception to provide the expensive procedure without payment. In this case consensus was reached that arguments of justice would not justify making this exception. Rather, it seemed more just not to finance the extraordinary measures through the budget of the institution which was held to serve more the urgent needs of patients whose health was threatened. In this case, then, a limit was deemed to be ethically justifiable, and its application in this case was considered to be acceptable also.

There are instances in which the actual limit is not acceptable. As outlined above, however, identifying an unjust limit, as opposed to a merely frustrating limit, can require normative considerations of justice of the kind that ethics consultants are more accustomed to dealing with. In such situations, ethics consultants could assist in articulating the concerns, giving reasons why the option is ethically not justified, and trying to support those in charge of decisionmaking to find other solutions and to communicate the problem to the relevant bodies. In addition, even when resources are limited in an unjust or otherwise unacceptable way, physicians are still confronted with difficult situations in which declining to make a choice is not an option. Making resource allocation decisions in situations of unjust limits is not itself morally problematic. While one is pressured to deny because of scarcity, issues of efficiency and justice should inform the allocation of resources.⁴⁴ Making these decisions well in these settings may even be more important as unjust scarcity is likely to be more pressing. 45 Ethics consultants could thus assist physicians facing unjust limits by helping them to bear witness to these situations. Physicians and other healthcare professionals are in a special position to witness the effects of scarcity on daily patient care. Arguably, the very uniqueness of their perspective means that they have some degree of duty to make any problems that arise more visible to decision-makers other than themselves.

Finally, ethics consultants could help physicians by participating in the prevention of these difficulties. Resource allocation at the institutional level certainly has some impact on the frequency with which physicians encounter scarcity,24 and is value-laden to a greater extent than is sometimes realised.⁴⁶ Were they to take on a more explicit advisory role in resource allocation at the institutional level, ethics consultants could thus contribute to reducing the scarcity-related ethical difficulties encountered by physicians. This role would need to be clearly defined as the contribution of making values explicit, and bringing a different and complementary kind of consideration to bear on these decisions. The input of ethics consultants would at all these levels would necessarily be limited. Consultants have no authority to decide about allocation of resources. More importantly, the role of ethics consultants is to offer support in considering the ethical implications of a difficult situation, and in using acceptable processes for decisions when reasonable persons disagree. This role is not intended to take the decision-making role away from those whose responsibility it is. There are examples in the UK of primary care organisations establishing priorities committees specifically to bring an ethical persective to allocation decisions.⁴⁷ Some of these committees also contribute to decisions in individual cases where there is a request for treatment as an exception to the agreed limit set by the organisation for the local community.

Several obstacles currently exist to implementing the approach we propose. First, strengthening consultants' training in these aspects would thus be the first requisite for our proposal, as many currently do not have sufficient training in dealing with issues of justice. In addition, the availability of ethics consultation is much lower in Europe, than in the US.3 25 European physicians and ethics consultants, however, work within universal healthcare systems that provide better initial circumstances for fairness in resource allocation. Finally, although some aspects of the role we propose here has been proposed for organisational ethics committees,48 actual descriptions of concrete experiences, 49 50 are scarce, and data even more so.⁴⁷ Importantly, the role of ethics consultants in helping physicians face scarcity would probably vary between countries. For example, other data from this study suggests that some healthcare systems limit costs mostly by placing pressure on physicians to ration care, while others mostly rely on choices and rules affecting the availability of services.²⁶ Ethics consultants might need to furnish tools for thinking through pressure in some cases, or for applying rules in other cases. This may not be identical.

CONCLUSION

According to our findings, a significant number of European physicians encounter scarcity-related ethical difficulties, which they sometimes consider to be more difficult than other kinds of ethical difficulties. The perception that the type of help offered by ethics support services would be useful is the same for scarcity-related ethical difficulties and other kinds of ethical difficulties. Despite this, research has shown that physicians rarely refer scarcity-related ethical issues to ethics support services. This is probably a missed occasion: ethics consultants could indeed assist physicians in facing scarcity, both by making the process less difficult, more transparent, and balanced, and by contributing to decisions being more ethically justifiable. In addition, the limit placed on resources that physicians must work with is indeed sometimes unjust. However, recognising an unjust limit, as opposed to a merely frustrating limit, can be difficult. The expertise of an ethics consultant in bringing considerations of justice to bear on real cases could be useful in making these judgments also. In none of these contributions would ethics consultants be taking over decisions, as this is not a part of their role.34 Nor would they contribute the only decisive elements. Their role would be to bring a different and complementary kind of consideration to bear on the difficult decisions that physicians must face in situations of scarcity.

There are several reasons why scarcity-related ethical difficulties might not be referred to ethics support services. Firstly, physicians may feel powerless in situations of scarcity. Secondly, they may not realise that economic issues are value-laden and that ethical considerations explicitly or implicitly enter into all allocation decisions. Finally, they may expect ethics consultants to respond to scarcity-related ethical difficulties by setting impossibly ideal standards, such as giving the advice to set no limit at all. That this need not, and indeed ought not, be the case should be clear from the considerations outlined here.

Though these situations are unlikely to be among the most frequently referred to ethics support services, ethics consultants should be prepared, and trained, to address them. They should also see as part of their role a contribution to making physicians better equipped to face these difficult problems.

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