**Of medicine and monsters: Rationing and an ethics of care**

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This paper argues that an ethics of care can and should provide guidance for thinking about limits. In the case of health care in particular, the almost unlimited capacity to develop newer and costlier technologies produces a serious crisis for both funding and providing care to all in a fair and reasonable manner. An ethics of care can provide a basic framework for decisions about limits, but only if distinctions are drawn between the requirements of personal relationships of care and institutionalized, professional care. Professional care relationships need principled boundaries and procedural standards for determining where those boundaries are; the paper uses the recent case of a controversial lung transplant to illustrate the need for structural accounts of care in professional settings.

**I. Introduction**

An ethics of care is focused on care for vulnerable others, and on meeting the needs of those who need care. In the context of health care, this rather obviously leads to a patient-centered focus, and provides a perspective from which a number of health-care related issues can be analyzed. But when it comes to making decisions about the limits imposed by economic structures, and about either rationing resources or developing reasonable limits to care, it might seem that an ethics of care has little to say. Both rationing and drawing limits to care have been difficult issues for care theorists because they seem more like failures of care than concepts that can properly be included in an ethics grounded in care. But my argument in this chapter will be that an ethics of care does have the resources to address the question of rationing, and that developing those resources adds an important dimension to care as an ethical theory.

 One of the tasks of any ethical theory is to delimit the realm of the morally required from the morally permissible. Placing limits on the amount of health care provided to those who need it requires us to have some sense of when, as a community, we are required to offer care, and when it is permissible to either fail to provide it, or to refuse to provide it. While different theories will locate these limits in different places, with (for example), Utilitarians placing limits when the benefits of care are outweighed by total costs of providing care, or Social Contract Theorists limiting care when it infringes on either the autonomy of the care-recipient or the care giver, the basic finitude of human resources and energy require that any reasonable theory have some way of making these distinctions.

 This paper argues that an ethics of care can and should provide guidance for thinking about limits. And in particular this paper focuses on questions of the quantity of care rather than the delivery of care or the quality of the care given, both of which have received more attention from care theorists[[1]](#footnote-1). In the case of health care, in particular, the almost unlimited capacity to develop newer and costlier technologies has produced a serious crisis for both funding and for providing care in a reasonably equitable manner to all who need it. The sheer expense of medical technologies produces spiraling cost increases as professionals try to provide the best care possible for all their patients, and those increases in costs make it harder and harder to provide even basic care for many who need it. Obviously there are factors beyond technological changes that drive increases in health care costs, but newer technologies in particular generate a serious problem for the provision of health care[[2]](#footnote-2).

Clearly there must be limits to the provision of medical care. Resources are not unlimited, and as a society we need to be able to spend the resources we have on a wide variety of needs—education, infrastructure, environmental protection—other than health care. Limits to what can be provided clearly need to be drawn, but the problem is determining where those limits lie. And that determination is particularly difficult from a perspective of care because of the nature of medical needs.

I have already indicated why limits are needed. The argument of this paper begins by identifying why medical care poses a particularly difficult issue for care theory. I then adopt a distinction developed by Tove Petersen between care in interpersonal relationships and professional care relationships to argue that the expression of care in institutionalized settings needs to be conceptualized in ways that set limits to the care that can and should be provided. I add to Petersen’s account of these differences the need for a procedural structure for developing guidelines for the provision of care. The points I will make in this section are then used to analyze the recent case of Sarah Murnaghan, a 10-year-old girl in need of a lung transplant. Her case is used to illustrate both the need to adopt a perspective informed by care when making decisions about access to scarce resources, but also to argue that care theory needs to adopt a procedural framework for this type of case in order to set ethically responsible limits in health care.

**II. Limiting care: Medicine as monster**

Health care is an arena that poses a serious problem for care theory precisely because of the fact that care theory begins with the moral imperative to care. As I reflected on the topic of this chapter, in fact, it has occurred to me that health care generates a situation much like the utility monster[[3]](#footnote-3) generates for Utilitarian ethical theory. The utility monster identifies a central problematic with any theory that defines the right in terms of maximizing utility, and just as utilitarianism, to be a theory worth considering, needs to be able to respond to the problem of a being whose utility-claims swamp every other consideration. In a sense, the utility monster identifies a key weakness in utilitarianism; so too, I argue, does contemporary health care identify a key weakness in care theory. To the extent that the theory can address the problem without ad hoc or arbitrary emendations, to that extent it proves itself a worthwhile account of ethics, (and, of course, to the extent that it cannot, to that extent it is shown to be problematic.)

 So why does contemporary health care represent the ‘utility monster’ of care ethics? Start with the nature of health care. Medical care[[4]](#footnote-4) is a need, not a luxury (except in certain non-paradigm cases such as cosmetic surgery) and it is needed for the most basic aspects of life. It protects from illness (in the case of vaccines), it cures sickness and damage, and it saves people who are close to death. These are vital and, frequently, urgent needs. Denying medical care, then, involves denying individuals access to treatment or care that could alleviate severe pain, prevent physical harm or even death, or treatment that could cure or ameliorate disease. I take it that the claim that most medical care is a necessity not a luxury is relatively uncontroversial[[5]](#footnote-5).

 Further, those who need medical care represent one paradigm set of cases of people toward whom care should be directed. Care theorists generally link caring responses to such things as vulnerability, physical need, and suffering, all of which are present in the case of those who need medical care. Denying care in these cases would seem to cut to the heart of any adequate account of care as the basis for ethics.

 The fact that medical care is a critically necessary resource for some of the most vulnerable and needy among us sets the context for calling medical care the ‘UM’ of care ethics, but what takes medicine into a separate realm than almost any other issue is the state of contemporary medical technology. There are medical responses available for a wide array of medical conditions, many of them very effective, and almost all of them very expensive. Organ transplants, new scanning technologies, machines that can keep a weak heart functioning while a patient waits for a transplant, bonding materials that can hold shattered bones together, pharmaceuticals that alleviate the worst symptoms of advanced cancers—all of these are available in the U.S., and all for a very hefty price, both in terms of absolute dollars and in terms of commanding the resources of health care professionals, intensive care beds, and the like (Callahan, 2009).

 Len Fleck, for example, notes that just the newly developed technologies for heart care support, specifically implantable cardiac defibrillators and left ventricular assist devices, are projected to cost the health care system around $54 billion annually (Fleck, 2009, 6). These are only two treatment technologies, and only ones that focus on heart care. Furthermore, the various treatment modalities that Fleck identifies are now several years older, and newer and even more expensive options continue to appear. Meanwhile, in countries that have, so far, been able to control health care costs to some degree, the pressure to expand access to care and the use of new technologies is enormous. Canadian provinces in close proximity to the US are especially affected by this dynamic, leading to higher costs and pressure to provide treatments that have not been approved by provincial oversight boards.

 Even when treatments have not been shown to be effective, of course, they are often demanded by patients. Again, this is not surprising, since those demanding them frequently face seriously debilitating disease or death, and can hardly be blamed for grasping at straws. But this contributes, again, to spiraling health care costs. Insofar as medicine appears to offer the only glimmer of hope that a terminal patient may have, there will be constant and persistent demands even for treatment that has not been shown effective. The main problem, however, is not ineffective treatment, but effective treatment.

 Medical costs, for the most part, are not spiraling upward because of inefficiencies (though presumably there is a good amount of that in health care, as in all human practices) but because of efficacy. Health care works, and it works well. As a result there is enormous pressure to provide it, and to develop even more of it. This produces a system, unfortunately, that is ultimately unsustainable because we cannot, collectively, afford to keep providing all the available care to as many as are currently receiving it, and yet there seems no way to set limits to the care that we feel is medically and morally required. The few attempts to limit care that have been imposed in the U.S. are inevitably portrayed (and experienced) as draconian. How can we deny a dying patient the chance to live with a transplanted liver?[[6]](#footnote-6) How can an abused woman be told that there are no funds to provide the bonding agent necessary to repair her shattered bones?[[7]](#footnote-7) How can patients dying of cancer be told that a medication that would make their last months livable is too expensive to be covered under their state sponsored health plan?[[8]](#footnote-8) In all of these cases we see the dilemma. Denying care (in the sense of treatment) seems the paradigmatic case of failing to care (in the sense used by care theory[[9]](#footnote-9))—and care is what an ethics of care says we must provide. But providing care at this level threatens to overwhelm many of the other central aspects of human life. Middle class wages have essentially been flat for two decades because the soaring costs of insurance eat up the funds that might provide salary increases. Medicare costs are one of the major drivers of the national deficit. Countries that have national health care systems have, up to this point, been able to keep their costs from rising as fast as the unregulated system in the US, but as costly technology continues to become available, pressure keeps increasing on these systems to provide US levels of care.

 Medical care, thus, functions as the UM of care ethics because medical needs threaten to swallow up every other moral consideration. Like the Utility Monster, medical needs are almost unlimited, and are, for the most part, seriously important. Attempting to limit access to medical care in order to preserve space for other concerns (education, libraries, etc.) is problematic because these other concerns are not life and death matters. While it seems obvious that health care cannot be the only good that is morally important, attempts to limit care in order to keep taxation levels reasonable, or attempts to define basic care while treating more expensive care as something people need to pay for out of pocket or through private insurance are regularly described as immoral refusals of care because the people who are denied care are so obviously vulnerable, desperate, and in need of those resources. In the context of an account of ethics that makes care the heart of ethics, and ties care to vulnerability, medical needs seem to have turned into a monster ready to gobble up all the available caring resources, leaving none for anyone or anything else.

**III. Limits and an ethics of care**

Limits need to be set in medicine. That, I think, is uncontroversial. The question we need to focus on here, then, is how those limits get set. In the case of structuring fair limits to medical care there are a number of considerations that (arguably) any ethical theory needs to accommodate, which I will mention briefly, and then some specific considerations that arise from an ethic of care. The general considerations are recognition of the degree of an individual’s need, and the urgency of that need; fairness; and attentiveness to pain and suffering. Two other sets of considerations that are central for care theory, I will argue, have to do with ensuring that structures and policies are properly developed and that challenges to them are properly targeted. In both cases, I argue, there are important reasons from within care to adopt a certain version of fairness and procedural development of principles, and without such structures the demands of medicine cannot avoid becoming overwhelming for any system of care.

Fairness to all individuals involved in a situation, degree of need, and attentiveness to pain and suffering seem to me to be sufficiently central to any account of ethics that one should expect (and generally will find) that any adequate account of ethics (utilitarian, deontological, virtue or otherwise) will have some way of addressing the issue. As mentioned above, for example, Utilitarian theory sets limits by weighing costs and benefits, Social Contract theories set limits by consideration of what agents would (perhaps) rationally consent to, and so on. Rather than deontological principles of autonomy and basic respect for the dignity of all individuals, however, a care theorist might instead draw on the sorts of considerations that healthy families go through when deliberating about how to provide care to all members of the family, especially when some have exceptional levels of need. I will begin, rather sketchily, with fairness and degree of need. Imagine, for example, that I am a parent with several children. One of my children has a serious learning disability and requires more of my attention and support than the others. It is, certainly, appropriate that I spend more time with that child than another, given the need to work with these learning challenges, but I would fail to be a caring parent if I devoted all my time and energy to just this one child. Although my other kids may not need the same level of support, I still need to spend time with them, make sure they are thriving in school, and simply be with them as a good parent would.

In other words, when there are multiple others toward whom I have duties of care, the fact that one has serious and demanding needs does not mean that as a caring person I automatically deny the others. Instead, as a caring parent, I need to balance the greater needs of the one against the legitimate needs of the others. Fairness requires that all my children be treated as much loved members of the family, and while they will not all be treated the same, and one will get more of my attention and resources, that does not mean that the one’s greater need entitles him or her to all my resources.

More generally, while it is certainly true that care needs to take account of the level of neediness and vulnerability of those who need care, this does not entail that any single sort of neediness can legitimately claim all the resources. Instead, like any other moral system, a caring system will need to make decisions about what level of resource allocation is compatible with both a caring response to the more vulnerable party and a fair response to others who also have some claim on those resources. As just mentioned, this is an issue that any adequate account of ethics needs to deal with, and while different theories may draw the line in slightly different places (Rawls links differential access to resources to the effects on the least well off, Utilitiarianism to maximizing total utility, Kantians to a system that could rationally be accepted by all agents, and so on) all will need some account of how to balance the clear need for more resources on the part of some against the reasonable expectations of others.

From the perspective of care, there is no single formula that can identify exactly where the line must be drawn, but like Rawlsian and Kantian theories, care theorists should advocate limits that can be justified to the various individuals involved.[[10]](#footnote-10) That is, it must at least be the case that both parties, the more needy or the more average individual, see the system of distribution as relatively reasonable, rather than as irretrievably stacked against them. As is often the case, in systems where there is a great deal of local control and ownership, and where the administrators are generally acknowledged to be fair and looking out for the good of all, it is easier (though never automatic) to achieve something like such a sense of equity. But as systems get bigger, administrators more distant, rules more abstract and absolute, people’s willingness to accept differential levels of access to resources becomes weaker.

This may sound hopelessly naïve, of course. Individuals are most often not willing to accept that another has a greater claim to needed resources than they do themselves, and we are far more likely to expect people to demand more than their fair share, rather than settle for a reasonable amount, so that others can also have enough. But one of the factors that drives this dynamic is precisely the degree of distance and abstraction that characterizes so much of the contemporary world. When those denying me access to care are faceless, unknown bureaucrats, and when those who (supposedly) have a greater need for resources than I do are anonymous strangers, I am far less likely to trust the system, and far more likely to do everything I can to game it in my own favor.

This is a feature of social systems that makes sense within the framework of an ethics of care. Relationships really do matter. They are not merely abstract forces that one mentions in a philosophical treatise, but real forces that change how social systems work. And they are not simply one more factor that one inserts into a Utilitarian framework. The relationships in which people stand, both the nature of the relationship in terms of the various roles people play, and the nature of the relationship in terms of social capital that has been built up or squandered, change the structure of what sorts of systems are acceptable to participants. The more abstract, the less trust, the more the only acceptable system of distribution is equality. This suggests that the more systems of distribution of health care become large-scale, principles-based systems of distribution, to that same extent the rules will have to be the same for all concerned, the level of care to which individuals have access will need to be largely equal, and the expectation should be (if we are reasonable) that all will demand access to the same level of care when possible. This has the positive result of ensuring rules that apply equally to all, the negative result of producing a one-size fits all system that lacks the capacity to respond to particularistic circumstances.

To be fair, of course, particularistic systems have their own drawbacks. One of the more glaring is a tendency to entrench privilege. When systems have built-in flexibility to respond to particularistic needs, people who are generally privileged in society will tend to demand and receive more than their fair share of any resources, and their demands will be felt (by them and often by others) as appropriate.[[11]](#footnote-11) An ethical system that prioritizes empathetic care will be vulnerable to perpetuating this type of inequity because it responds to felt needs, and the built-in inequities of the system will correspond to inequalities in people’s sense of need and/or entitlement.[[12]](#footnote-12) So how do we resolve an issue of this sort, and how do we resolve it in the context of medical needs, which, we have noted already, have a particular force and weightiness that makes them peculiarly demanding? In order to respond to this I would like to utilize a distinction made by Tove Petersen (and others, but Petersen makes it clearly, and applies it specifically to the health care context.)

Petersen notes that an ethics of care needs to be capable of distinguishing between what she terms interpersonal relationships of care--personal relationships between family members, friends, personal connections, and the like—and professional relationships of care. In the latter camp she includes the various caring professions—nursing, medicine, and education, for example. Her focus is on nursing as a caring profession. Nursing is a profession profoundly at risk for demanding overly altruistic responses from practitioners (a variation on the UM problem I discussed above). Petersen’s analysis of how care should function in this context makes a number of important points, only one of which I am going to develop here.

Petersen notes that a central part of nursing care involves care that responds to the needs of a particular other. But the sort of particularistic care that a nurse should offer is not like the infinite responsiveness to one particular other than one finds in, for example, the thought of Levinas. Instead, the particularistic care that nurses offer is a particularism rooted in professional and theoretical knowledge. Nursing education develops skills and expertise that allow nurses to respond to patients in ways that are appropriate to that particular patient, and to do so in ways that non-professionals are unable to do. That is (at least one of) the excellences that constitutes nursing expertise. ‘Particularism’, then, in the context of nursing care, does not require that one particular patient be allowed to make unlimited demands on a nurse’s care. Instead, care is particularized for patients because of the nurse’s specialized knowledge and expertise, both with the medical issues involved and with how various types of patients respond to various types of treatment protocols.[[13]](#footnote-13) Taken in this way, professional attentiveness to particularity will be the practical expression of expert knowledge applied to particular cases and issues.

Petersen’s point can be broadened, I would argue, to include issues that go beyond the professional care offered to patients or clients. In the case of medical treatment decisions, and particularly decisions involving scarce resources and enormous expense, we can follow Petersen’s lead in arguing that attentiveness to particularity in a professional context should not be interpreted as trying to provide unlimited care. Instead, the attentiveness to particularity that is appropriate to professional caring contexts is a particularity of expertise and experience, based on theoretical knowledge of the conditions and contexts within which care needs to be given.

If that is the way that professional particularity is understood, then, in the context of allocation decisions we will need structures of decision-making generated by expertise. What this means is that in cases where a resource is both scarce and expensive, the policies we adopt for distributing the resource need to be developed by experts on the subject. Obviously there are other considerations as well in cases of this sort. To avoid entrenching implicit bias, for example, it is also important that those who develop policies are representative of a wide range of class and privilege (and this may not always coincide with subject-area expertise) and certainly other considerations may play a role here, too. My point is not to generate a complete set of considerations for those who set policies in this type of situation, but merely to note that among their qualifications care theory would include professional expertise and experience. Care in a professional context is not best interpreted in terms of empathic responsiveness to a particular other, but is, instead, a reason for developing principles that give all potential recipients of care a fair and measured set of explicit and well-grounded principles of distribution.

Arguably, this way of understanding the attentiveness to particularity in a professional context leads to second consideration: when principles or rules are challenged, the challenge needs to be directed at the rules, not at the fact that specific individuals don’t receive the care that they want and perhaps need. Again, though this seems paradoxical in the context of care, it is not. In the same way that caring families set up rules so that every member gets their time to be treated as special and their time to do chores as well, and just as the rules are necessary to make sure that those who complain loudly don’t get away with demanding unfair treatment, in the same way, challenges to systems of distribution need to address the rules involved, not focus specifically on particular cases to the exclusion of others.

Both of these basic principles help to limit the UM features of medical care, because both start from within systems that assume limited resources. The problem with always focusing on individual cases is that it generates the assumption that surely the right resources are available somewhere (and in individual cases it often is possible to scrape together resources), leading to the assumption that any denial of care is unacceptable…and generating the UM situation. Developing caring structures requires the rejection of magical thinking in favor of a clear recognition of what is actually available. Given those resources, then, developing rules that try to be fair to all, and allowing those rules to be challenged when necessary are integral parts of a caring system.

**III. An illustrative concluding case: Sarah Muraghan’s lung transplant**

One of the most intractable arenas of limited resources and deep need in contemporary medicine is organ transplantation. Now, a fairly limited essay of this sort is clearly inadequate for resolving all the issues that the scarcity of organs raises, but a few points can be made in illustration of the issues raised above. In order to focus this discussion, I would like to consider a specific case—the recent case of Sarah Murnaghan—and use that case to focus in on some specific issues raised in the earlier discussion.

Murnaghan’s case appears to many people to be a classic tale of a little girl rescued from an evil bureaucracy.[[14]](#footnote-14) We have, on the one hand, a 10-year-old girl needing a lung transplant due to cystic fibrosis, and on the other hand the United Network for Organ Sharing, with its rules that give priority to recipients for adult lungs who are 12 and older. Her parents sue Kathleen Sebelius, the Health and Human Services Secretary, and the judge rules that Murnaghan must be placed on the registry, calling the rule discriminatory towards children, arbitrary and capricious, and an abuse of discretion.[[15]](#footnote-15) Sebelius is described as a ‘one-woman death panel’ by right-wing opinion pieces[[16]](#footnote-16). Murnaghan’s placement number on the organ recipient list is changed by direct order of the judge in the case, and she receives not one, but two lung transplants (the first is unsuccessful). Reports of the case almost universally treat it as a triumph that Murnaghan received the transplant.

From the perspective of care ethics, should we accept the framing of this issue? Is it the case that when a 10 year old who needs a lung transplant is able to jump forward on the recipient list due to a judge’s ruling, care for the individual has triumphed over rigid, legalistic principles? Based on the earlier discussion, I am going to argue that this way of framing the issue gets it deeply wrong. While there are reasons for regularly reviewing the criteria for how recipients are placed on organ lists, and while there may be reasons for changing the criteria for younger children in particular, the judge’s ruling in this case is problematic for a number of important reasons, and needs to be challenged. Both of these issues illustrate the points made in the earlier section—that an ethics of care needs a procedural account of principles and processes in the context of medicine, and that without such an account it falls prey to the ‘Utility Monster’ problem almost automatically. I will begin with this last point.

The Murnaghan case clearly illustrates how a caring focus on an individual in need alone generates a UM problem for care ethics in the context of medicine. The judge who decided this case was faced with a 10 year old girl who would die without a lung transplant. Her exclusion from the list of adult recipients appeared to be something close to a death sentence, given the scarcity of child donors of vital organs. Those who had excluded her from access seemingly had done so for what sound like bureaucratic reasons: Sebelius argued that it was not her place to second-guess the committee charged with setting standards for access to the registry, an argument that the seemed perverse to the judge. Faced with a deeply needy and vulnerable individual, the judge did what (it seems) a caring judge should do—he insisted that Sarah should have access to the adult organ registry immediately.

So long as our focus is on one individual’s emotional response to another in need, this case seems an open and shut case of acting in a caring way. The problem comes when we broaden our focus to all the individuals involved in a case of this sort. Sarah is not the only person desperately needing a lung transplant. There are currently just under 1600 people in the US waiting for a lung transplant, many of whom will not get one in time.[[17]](#footnote-17) When the Murnaghan case went to trial there were four other adolescents needing lung transplants in the same health center that cared for Sarah. Insisting that she be placed on the adult registry, as the judge decided to do, was a good thing for Sarah, obviously, but not so good for those patients that she jumped ahead of. The two sets of lungs that she received were a life-saver for her, but they would have been a life saver for at least one, and possibly two other people. These other people are nameless and faceless to us, both because medical confidentiality prohibits any health care system from disclosing identifying information about patients, and because it is not always possible to identify the recipient who would have suited a particular donated organ given the complexity of matching blood types and the like. But they are not nameless and faceless to their families, and certainly their hopes and fears for their own futures are meaningful in much the same way as Sarah’s. The problem is that for the judge in the case, only one person appears as an individual. Other people affected by his ruling are faceless and anonymous, persons in the abstract, perhaps, but not actual individuals needing a caring response.

When a personalized sense of care becomes the central focus for our responses, in the way that it seems to have become the central focus for this judge’s ruling, the result is an inability to recognize that even difficult limits may sometimes be justified by a concern for the fair provision of care for all the people involved in the system. Further, when decisions about providing care are made on the basis of an emotional response to the need of another, an already scarce resource may be used in ways that provide only limited assistance to those who receive it. The median survival rate for recipients of double lung transplants is 6.6 years[[18]](#footnote-18) and only about 55% of patients survive five years after a transplant.[[19]](#footnote-19) The sicker a patient is, the more unlikely she or he is to experience a long term benefit from a transplant, since co-morbidities diminish positive outcomes. But the sicker a patient is, the closer to death, the more she or he tugs at our heart strings, and the more our empathetic response is to try to provide any chance at survival that she or he might have. The result is a system that tries to provide enormously expensive treatments, using resources that are in extremely short supply, to those who may benefit very little, if at all, because their condition is already so serious. Organ recipient regulations are set up, in part, to circumvent this dynamic, and eligibility for lung transplants in particular requires that there be no other major organ damage in the recipient. But if we follow the lead of the judge in this case, and focus on a particular patient with complicating factors, but one who could, conceivably, gain a few more years of life with a lung transplant, we will find ourselves transplanting organs into those patients whose need we see most clearly, generating only marginal benefits while health care costs skyrocket.

Further, basing decisions about who is to receive organ donations on perceptions of an individual’s need can produce paradoxically problematic results in other ways as well. Regulations for listing patients on registries for organs distinguish among different classes of people in order to protect one or another group. In the case of lungs, children are separated from adults precisely because there are so many more adults in serious condition than children. If the two registries were combined, statistically the chance of children receiving a new set of lungs would diminish because more adults would qualify for the available child-sized lungs. It is precisely to protect children’s access to lungs that separate registries have been set up, and the judge’s ruling removing age constraints for listing on a registry will, if followed in the long term, be harmful to children like Sarah who need a transplant.[[20]](#footnote-20)

Both of these considerations indicate that making decisions about placement on organ recipient registries is not something that should be done by people unfamiliar with the complexities of particular transplant issues nor by people who do not have a good understanding of the various factors at issue in transplantation. A piece-meal approach to organ transplantation will result in increased costs but lower benefits, serious inequities that may harm the very types of persons we are trying to help, and (though I have not developed the point here for reasons of time) all the inequities associated with allocations decisions made on the basis of emotional appeal, including tendencies to show illegitimate preferences for already privileged classes of patients.

The first of these three problems, the factor of increased costs and decreasing benefits is directly relevant to the UM problem. Fair rules for organ recipients balance the chance of success and the seriousness of various individual’s situation as best they can. But they necessarily also limit people’s access to needed care. Fair rules do not ensure that everyone gets an organ, unfortunately, and they cannot do so. But interventions such as the judge’s in the Murnaghan case do not ensure that everyone gets access either—they simply ensure that some people are allowed to jump the queue, rather than accepting that even with fair principles, some individuals will not receive the care they desperately need. And while principles can at least make sure than no one is denied arbitrarily, interventions and individual decisions about allocations both result in unfairness and increase the costs and inefficiencies in the system, resulting ultimately in far worse outcomes than the original system.

A second point can be made, however, about the Murnaghan case. One of the issues that generated a separate set of lists for children and adult recipients was a simple concern for making sure that transplanted organs were appropriately sized for optimal results. Children’s smaller bodies do better with smaller organs; adult bodies do better with adult-sized organs. But as commentators have pointed out, if the main concern for allocation is physical size, then age is a fairly poor proxy for actual measurements of size.[[21]](#footnote-21) If the guidelines cite age as a factor, but are actually designed to regulate body size, then there is good reason to change the regulations. Body size, after all, can be as easily measured as age, so there is no need (and a significant cost) to using age as a proxy.

I do not know how these considerations will play out in the case of guidelines for organ recipient registries in the future, but considerations of this sort are clearly worth raising. And this generates another way in which we might approach the Murnaghan case. When allocation principles are perceived to be inappropriate or unfair, they can be and should be challenged. Nothing I have said so far should be taken to indicate that I think that the Murnaghan parents were wrong in trying to change guidelines they perceived to be unfair. That sort of challenge is entirely appropriate, in fact, so long as the concern is directed at the guidelines themselves and the criteria they put in place. Guidelines can be unfair to particular demographics, due to a wide range of reasons. And from the perspective of care, it is vital that those who live with the effects of principled systems be able to challenge the system when it appears to burden them unfairly. This type of challenges is precisely what differentiates a responsive system from the sorts of absolutist, legalistic principles that many care theorists rejected in the first place.

But the point to note here is that the challenge needs to be directed at problematic aspects of the principles. Professional care, under conditions of limited resources, must always allow for appeals when the principles themselves appear to be unfair. But appeals based on the problematic nature of the principles themselves needs to be distinguished from appeals based on an individual’s need for the particular resource since all the individuals waiting for lungs have the same desperate need. Appeals go wrong precisely when the care offered ceases to be professional care and becomes particularistic care in the sense that is (sometimes) appropriate for interpersonal relationships.

Resource allocation is a particularly difficult moral issue, especially in the context of health care. For proponents of an ethics of care, that difficulty is multiplied by the fact that care theory does make the emotional response of care central to ethical analysis. But taming the utility monster is possible, I think, if we respect the particularities of specific relationships in which people stand, recognizing that professional relationships exhibit care in specifiably different ways from, say, family relationships. An ethics of care still requires attentiveness to particularity, but how that attentiveness is practiced makes an enormous difference for how care is provided to those who need it.

1. My thanks to Maurice Hamington for calling my attention to this distinction. Among the care theorists who have addressed questions of limits to and requirements of quality of care and care delivery are Joan Tronto, Eva Feder Kittay, and, unsurprisingly, Maurice Hamington himself. [↑](#footnote-ref-1)
2. See, for example, Daniel Callahan, *Taming the Beloved Beast: How Medical Technology Costs are Destroying our Health Care System*. (Princeton: Princeton University Press, 2009) and Len Fleck, *Just Caring* (New York: Oxford University Press, 2009). [↑](#footnote-ref-2)
3. Ref to Nozick. The utility monster is a theoretical being capable of absolute maximal happiness (or utility, or preference satisfaction, depending on the variety of utilitarianism at issue.) Because the monster is capable of experiencing the absolute maximal amount of happiness, its happiness trumps that of any other beings, and by (utilitarian definition) the right policies become those that channel all resources and all action toward the satisfaction of the UM. Diverting anything elsewhere, by definition, diminishes over-all happiness, and so is contrary to what morality demands. [↑](#footnote-ref-3)
4. I will be using health care, medicine, and medical care as largely interchangeable terms in this paper. There are reasons for separating them in many contexts, but for the purposes of this paper the differences are not salient. [↑](#footnote-ref-4)
5. Or, perhaps better, relatively uncontroversial. There is good research demonstrating that for populations as a whole, there are a number of interventions that generate far greater health benefits for lower over-all costs than many expensive medical treatments. If one were a utilitarian, this would be decisive, I take it. But from the perspective of care, the fact that there are less expensive interventions that increase the well-being of the population as a whole cannot end the discussion, since attentiveness to the particularities of individuals’s lives requires that we continue to care about, and respond to, the needs of individuals. And those needs often call out for medical intervention. [↑](#footnote-ref-5)
6. The case of Nataline Sarkisyan, a 17-year-old Leukemia patient denied a liver transplant by her insurer, Cigna Corp. (http://www.nbcnews.com/id/28393752/ns/health-health\_care/t/teens-family-sues-cigna-over-denied-transplant/#.U0a5vShOg99) [↑](#footnote-ref-6)
7. The National Institute for Health and Clinical Excellence in England first approved, and then denied access to a medication (Xtandi) that relieves the symptoms of end stage prostate cancer and on average extends the lives of patients by around five months. (http://www.telegraph.co.uk/health/healthnews/10599963/Anger-over-NHS-U-turn-on-prostate-cancer-drugs.html) [↑](#footnote-ref-7)
8. A case considered by an ethics committee, complicated by the fact that the patient was not a resident of the geographic region in which the health care system was located (and which defined the population for whom they were mandated to care.) The regional hospital in the patient’s location did not have access to the treatment in question. [↑](#footnote-ref-8)
9. And the fact that I use the same word in both cases again underlines the close connection between medical care and ethical care. [↑](#footnote-ref-9)
10. And like Kantian theorists, presumably the care theorist should emphasize that these limits can be justified, which is not the same as being accepted as justified by all involved. Reasonable and fair limits do not always feel reasonable and fair to all parties in a dispute. [↑](#footnote-ref-10)
11. I take it that some variant of this concern is one of the reasons Martha Nussbaum has been generally critical of an ethics of care. Her work with women’s groups in some Indian provinces has made her aware of the way that systems of privilege can leave some groups of people expecting far less than is their due, others expecting more…[complete this thought]. [↑](#footnote-ref-11)
12. This is not to say that an ethics of care cannot respond to systemic inequalities. Michael Slote, for example, resolves this problem by defining care in idealist terms [explain and cite]. The point I am making is that this is a problem that any care theorist should be aware of and have some response to. [↑](#footnote-ref-12)
13. This discussion summarizes several issues raised in Petersen’s discussion in *Comprehending Care*, predominantly in Chapter 8. Petersen also discusses the dangers of this type of particularism in entrenching structures of class and race privilege, an obviously important issue, but one that I set aside here to focus on her discussion of particularism and expertise. [↑](#footnote-ref-13)
14. Consider CNN’s caption, for example: “With just weeks left, Sarah fights the system for a life-saving pair of lungs” (http://www.cnn.com/2013/05/27/health/pennsylvania-girl-lungs/index.html). [↑](#footnote-ref-14)
15. http://www.politico.com/story/2013/06/sarah-murnaghan-lung-transplant-ruling-kathleen-sebelius-92299.html [↑](#footnote-ref-15)
16. See, for example, ‘A death panel of one: A dying little girl exposes a cold and callous government bureaucracy’, and Op-ed in the Washington Times, June 10, 2013. (http://www.washingtontimes.com/news/2013/jun/10/a-death-panel-of-one/). [↑](#footnote-ref-16)
17. http://optn.transplant.hrsa.gov/data/ [↑](#footnote-ref-17)
18. http://www.nhlbi.nih.gov/health/health-topics/topics/lungtxp/risks.html [↑](#footnote-ref-18)
19. http://www.sfgate.com/health/article/Lung-transplant-patients-face-tough-odds-3998899.php [↑](#footnote-ref-19)
20. Halpern, Scott D. 2013 “Turning wrong into right: The 2013 lung allocation controversy” *Annals of Internal Medicine* 159(5): 358-59 doi:10.7326/0003-4819-159-5-201309030-00684 [↑](#footnote-ref-20)
21. See, for example, Keren Ladin’s Op ed in the *New England Journal of Medicine*, ‘Rationing Lung Transplants—Procedural Fairness in Allocation and Appeals’ http://www.nejm.org/doi/full/10.1056/NEJMp1307792 [↑](#footnote-ref-21)