Health care, human worth and the limits of the particular

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Abstract

An ethics concerned with health care developments and systems must be historically continuous, especially as it concerns the application to managed structures of key moral-epistemic concepts such as care, love and empathy. These concepts are traditionally most at home in the personal, individual domain.

Human beings have non-instrumental worth just because they are human beings and not by virtue of their capacities. Managed health care systems tend to abstract from this worth in respect of both individuals’ distinctness and individual identity. The first, a common feature of quantitative approaches to health care assessment and delivery, is avoidable. The second, by contrast, is necessarily sacrificed in impersonally managed structures. Failure to distinguish the two encourages confusion and distress, and the demand for impossible medico-moral relationships.

Any ethics which concerns itself with medical practice and structures must be continuous with its own past: its concerns must be an extension of – even, perhaps, a postscript to – that past. This I take to be a philosophical truth. After all, for a very long time now people have been born, led lives, fallen sick, suffered, grown old and died. And for a good stretch of that time they have thought and written about these matters in a variety of moral tones we have no difficulty responding to and may sometimes make our own. The problem is to get clear about the extension and coherence of the postscript we have to write.

There is a specific continuity to which I want to draw particular attention. Moral-epistemic notions like love and compassion, care and concern, sympathy and empathy have a long history. They are not the inventions (or discoveries) of nurses and doctors and writers on health care ethics, but their borrowings. Of course they are given new – and sometimes startling – analyses and novel moral inflexions; but even so they remain embedded in the realm of morals, and ultimately of ethics, which tends towards the personal as opposed to the impersonal, the individual as opposed to the collective, the partial as opposed to the impartial, and the unmanaged as opposed to the managed. That there is such a realm, that it is supremely important to very many people, and that it generates a characteristic moral phenomenology and, even more, a vision of what really matters in life and death – all this is undeniable. What is far less certain is how much space can be made for it within structures whose very logic seems calculated to bypass such concerns and to marginalize them. One such structure is any impersonally and centrally managed arrangement for maximizing health care benefits in the face of scarcity.

Nothing I have to say is meant to suggest that we are not immeasurably better off with arrangements of this sort than we would be without them. Nor do I want to argue that we should seek ways in which to make room for the domain I have identified. Indeed, a central theme will be that no such argument can intelligibly be made. For I shall suggest that many of the objections people make against systematized health care and resource allocation can be understood only as demands for the impossible: for the partial and particular and personal to co-exist with and soften the impartial and the impersonal. And it is this that is in the end inconceivable.

II

Our health and welfare matter because we matter. Suppose someone now asks what makes human beings matter, some more than others perhaps, and some conceivably not at all. Are there not here two intimately linked – questions, one about humankind and its worth and the other about individual members of that kind and their several worths? The first question strikes many as perfectly intelligible. They set about making a short-list of properties characteristic of and arguably peculiar to human beings. In its possession of these properties (whichever they may be) lies the value of the kind. The trouble with adducing value-conferring properties is that the original question promptly puts itself...
once again, this time in relation to the properties themselves: why do they matter? If we feel it necessary to provide a foundation for the value we attach to humankind we shall find that whatever we offer is no more firm and secure than what it is introduced to serve as foundation for. For this reason it is hopeless to draw attention to features like rationality and autonomy, language use and moral competence in order to ground, justify, the value we attach to being human. Such features play a different rôle in our thought: to specify and describe more fully the mattering kind we belong to. Had we to choose, it would be better to say that the features we take as uniquely characteristic of humankind matter just because they are characteristic of things that matter anyway, rather than the other way round. But we do not have to choose.

Let me illustrate. John Harris believes that unless we can come up with morally relevant features in terms of which “to justify our preference for ourselves and our belief that it is right to treat people as . . . the superiors of other creatures”, this “belief” about the greater value of our kind will be “merely a form of prejudice.” Mary Warnock thinks differently: “I do not regard a preference for humanity as . . . standing in need of further justification than that we ourselves are human.” However, there is a third view, that a demand for justification is all wrong, whether in terms of “morally relevant” features or of just being human. Being human, and just that, quite irrespective of things like rationality, moral competence and language mastery, is at the centre of our determination of what most matters. And its centrality is masked and misrepresented when it is forced to play some sort of justificatory part.

Individual human beings

Where does this leave non-human kinds? The quick answer is that they fare no worse, and conceivably better, than before. For just being human is on my account no more a justification for what Harris calls “our preferences for ourselves”, “our belief that we are the superiors of other creatures”, than are the properties he and others adduce. Justification does not come into the matter.

The second question was about the worth of individual human beings. The answer to this question cannot be merely an application to particulars of the one given to the first, although they are connected. For although it may not always have been so, it is standard nowadays to distinguish two species of worth, each with its own historical continuities and territory. One is variously called “extrinsic” or “instrumental” or “relative”, the other “ultimate” or “absolute”. Value of the first kind we assign to each other in familiar ways, on the basis of features – skills and competences, intellect and creativity, looks and amiability – we possess and utilise to hugely different degrees. By contrast, absolute value is assigned, by those who believe in it, to all individual human beings. It is neither conditional nor scalar, and is attributed alongside, yet quite irrespective of, whatever instrumental values are accorded them. The attribution commonly serves to set limits of a sort to instrumental enterprises – not simply to our judgments but also to our attitudes and the interpersonal dealings we have.

More importantly, it brings into focus the idea already touched on of seeing worth in just being human. Now, just being human must of course include being just human, lacking not merely the characteristics which ground instrumental values but most or all of the properties which, I argued, fail as justifications for our valuing humankind as we do. Here is an instance of being just human:

“For about a minute, Thomas and I are alone as he weeps in his chair. Hot tears are rolling down his face as his open eyes stare blankly towards me. He appears to be inconsolable in his misery and it is impossible not to feel pain and sorrow for this frightened little human being. Like his parents, I could not tell if Thomas was aware of my presence. He is blind, deaf, brain-damaged, his limbs are useless from his cerebral palsy, and he is an epileptic. It is hard to envisage Thomas’s world.”

It is abundantly clear that Thomas, and many very like him, are valued. What is valued, when he is valued, is his just being human. After all, there is little, if anything else, about him to dilute that valuation. I want now to make some points, partly in order to forestall objections. The first is that his still being a human being is not offered as a justification for the valuing of Thomas. It is its object. As such, it is not idiosyncratic, or arbitrary, or mere prejudice. In particular, it cannot be replaced with whatever object-description takes one’s fancy, like the more determinate “being a baby”, “being a woman”, “being a psychogeriatric” and so on. For one thing, descriptions of this sort introduce a level of specific featural concern which overlays the significance of just being human.

Secondly, just being human cannot be adduced as a justification for “giving the preference” to Thomas over other kinds of creatures. This would indeed be speciesist. Were it a matter of justifying “a preference” for Thomas over some horse or dog which had lots more going for it Thomas’s humanity would be of no help. For it would be made to play the rôle of a singularly important feature of his outweighing those of the horse or dog – rather in the way that we might be tempted to cast being alive as a specially important property, giving live things the edge on lifeless ones. But being human, like being alive, cannot be put in the balance in this way. What we can do is say more about the awful deprivation in Thomas’s life, at the same time reflecting on what we do and, especially, do not, account deprivations and deficits in
non-human animals. Nothing we have to say, however, should be understood as justification or defence but as elaboration of what, in cases like Thomas’s, surrounds being human – as further descriptions of what is valued. For Thomas, being human is being deprived of many distinctively human capacities, and so being condemned to lead the only life he has with that gross deprivation. He matters neither because of nor in spite of all this. Rather, all this serves to tell us more about one individual human being who matters.

Thirdly, nothing I have said can settle what should happen to Thomas. It resolves no moral or legal issues. To give just being human the significance I have is not to suggest, for instance, that everyone – or, indeed, anyone – should be kept alive at any cost. By the same token, I suppose, it does not suggest that they should not. The idea does not determine, unaided, its own application. However, as we shall see it does not leave everything the same.

My last point is the most important. For most people there is a great distance between asssenting to the general thought (or something like it) that just being human matters and actually knowing what to do with it. It commends itself, certainly, but very much as something to be kept on hold. It seems able to get a grip only in the context of individual “hard” cases, like Thomas’s. However, just being human is not a sort of fall-back value, a net to catch even the most pared-down specimens. To suppose it is such a fall-back value would be to persist in thinking in terms of justifying properties, however minimal. Rather it is what is valued in every human creature, and extreme cases like Thomas’s merely serve to bring it into focus. To understand this is to understand how a value which can be elicited only from a particular and partial viewpoint can come to be acknowledged from an impersonal viewpoint, and ultimately to receive attention within an impartial system.

I have argued that what broadly impartial medical and caring structures like our own seek to do is accommodate the fundamental value of just being human. Cases like Thomas’s, of being just human, remind us of this by making dramatically explicit the kind of unconditioned worth which attaches to everyone, Thomas included. I say something more about how this impersonal accommodation might work in my next section. There is, however, a different kind of human value which many set great store by, but which can have no equivalent place in any impartially managed system, however much we might want it to. This I discuss in the concluding section.

III

In the presence of scarcity, resources devoted to the health care of one person will be denied some other person who might have benefited from them. A determination of clinical priorities is therefore based on a broad assessment of risks, benefits and costs. The object is to concentrate on those treatments known to be cost-effective so as to ensure that the benefits gained by treatments provided outweigh those sacrificed by sufferers denied treatment. A fiercely debated unitary measure of benefit is the Quality Adjusted Life Year (QALY), a form of health status measurement which brings together quality and length of life into a single index:

“If some health care activity would give someone an extra year of healthy life expectancy, then that would be counted as 1 QALY. But if the best we can do is provide someone with an additional year in a rather poor state of health, that would count as less than 1 QALY, and would be lower the worse the health state is. . . . The essence of the QALY concept is that effects on life expectancy and effects on quality of life are brought together in a single measure, and the bulk of the empirical work involved in making the concept operational is concerned with eliciting the values that people attach to different health states and the extent to which they regard them as better or worse than being dead.”

Even so brief a sketch as this makes apparent a variety of problems, ranging from broad-brush (and sometimes incoherent) moral objections to the very idea of managed health care rationing to methodological and technical worries about which characteristics a QALY measure can, in principle or in practice, encompass. None the less, despite much that is said I do not think people should, or commonly do, object to the notion of assigning numerical value to their health status. To be sure, they will argue about which characteristics, with which relative weightings, are to be included in the computation, but most remain perfectly capable of making refined judgments about what makes their lives worth living. Again, I do not believe that they too much mind having their health status compared with other people’s, or are reluctant to accept that their situation may compare unfavourably with another’s, even to the point of sacrificing their own interests for that other’s. Of course, even at this stage what Alan Williams would probably call “distractions” start to make themselves felt. The term “sacrifice” draws attention to one of them. If on grounds of scarcity I am to forgo some treatment or other I want this to be something I do, and something I do in favour of someone – some one – whose prospects are to be far better than my own. It is not something I want done to me, perhaps without my knowledge and involvement, in the name not of someone else but of “general welfare” (or some such thing). Connectedly, I may, if I perceive things in this “local” way, find it disturbing that I get nothing while the other gets everything instead of getting a little while the other gets a lot more. It is a matter, I
may reflect, of my ceasing to count for anything – of my nullification.

These are, perhaps, ripples only. For people are in general able to tolerate the degree of abstraction from their respective identities thus far demanded. After all, discussion has remained couched in terms of particular human beings, albeit assigned values rather than faces. And so the value attaching to just being a human being has not yet been compromised.

Once we press the model further, however, it becomes clear that to an abstraction from identity, which can accommodate the value of being a human being, is added an abstraction from separateness, which cannot. For what is accorded value are no longer human beings but life-years quality adjusted, no matter whose. The trouble is not that decisions are taken elsewhere but that they are taken on the basis of equations, the units of which are not individual people. It is true that it is to individuals that QALYs are assigned and re-assigned. None the less, these individuals are seen to matter only to the extent that they are bearers, or generators, of such units. If it is thought that maximising the benefit of healthcare is purchasing and providing as many QALYs as possible with what money is available there can be no reason to attend to the distinctness of human beings. Individuals will become so many particularisations of a universal concept; and where one stops and the next starts will cease to be of any moment – except, of course, to them.

Now, abstraction from distinctness, to which an unrestrained QALY programme is committed, is incompatible with the idea that someone has worth just because he or she is some one. For it seeks to attach that worth to some sort of supra-individual entity, obliterating the boundaries between them. This is why the idea can make a difference, as a constraining device. By affirming, in literal ways, the separateness of human beings it can serve to keep the agglomerative enterprise in check. But I make no detailed proposals here.

IV

I have argued that the value of just being human can, and should, set limits within health care systems to abstraction from separateness. I earlier suggested that there might also be another kind of value, dependent upon particularities of identity, which could not likewise be accommodated within such structures. If there is such a value it must be internal to particular and personal arrangements and unable to exist outside them. Many people believe that there is such a value, and hope vainly to find it retained intact in health care systems.

In an episode of Cardiac Arrest (a TV soap about life in a teaching hospital) the following exchange took place between a doctor and a patient admitted with self-induced and untreatable renal failure:

Patient: Tell me, doctor, do you really care whether I live or die?
Doctor: Of course I do. More than anything else I want my patients to get better and survive, and you’re one of them.
Patient: (Probingly) Yes, but do you care whether I live or die?
Doctor: (with commendable bluntness) No, of course I don’t.

The exchange illustrates well what it is to abstract from identity. The patient retains his particularity as one amongst those for whom the doctor cares. But just being one of her patients is not, he feels, enough. There is something more he wants, or wants restored. What?

An immediate answer is "B wants (quite inappropriately) to be special", or "He wants to be irreplaceable, not intersubstitutable with some other of Dr A’s patients." Now, “One of Dr A’s patients” is the general identifying description characterising Mr B’s relationship with his doctor. It is exhaustive in that it spans, from start to finish, the only relationship B has with A. It specifies the raison d’être of the relationship. What B would like is to see it replaced, or supplemented, with one incorporating reference to the particularities of identity – his and the doctor’s – which “one of my patients” excludes. However, something of this sort would be possible only if the actual medical relationship were merely one segment within a longer-standing relationship not itself generated in a doctor-patient context.

My point is a logical one: in certain sorts of relationships, including medical ones, a degree of abstraction from identity is not just desirable but unavailing. Why make so much of this? The answer refers us back to the moral-epistemic concepts noted at the beginning, and to the way in which they are pressed into service by medical and nursing professionals. Ideas such as love, devotion, caring for, suffering with, feeling compassion for and empathising with are most at home where there is minimal abstraction from identity, where the alleviation of misery, deprivation, sickness and suffering falls within the frame of a pre-existing relationship which has started and developed independently and of which it cannot therefore be the point. Where such issues are the sole reason for a relationship the moral epistemic concepts are significantly modified; a modification which amounts, in essence, to an abstraction from identity. Mr B was asking for something he could not intelligibly have.

Carers and writers on caring often give themselves a bad time because they mistake what is a logical impossibility for a shortfall in compassion. They do not adequately distinguish between the relief of suffering as something called for within the course of a relationship of which that suffering is just one feature and the relief of suffering as the essence of a relationship, as the only reason why it should be there at
all. With this goes a failure to distinguish between the logics of “non-abstracted” and “abstracted” caring, and hence a sense that if only they tried hard enough they could offer the first and not merely the second.

All this shows itself in much thinking and writing about caring. I give just one example:

“To be moral the good doctor must not only be just in dealing with her patients, but she must also love her patients . . . justice is the perspective of morality that, at least for humans, requires a foundation of loving friendship to be, and to produce, ethical behaviour.”

Rhodes leaves us uncertain throughout whether she is thinking on the abstracted or non-abstracted level (her paradigms pull in contrary directions), and why it should much matter which. Yet of course it must matter what patients may intelligibly hope for and what carers intelligibly provide.

Many people lay great value on arrangements in which the carer/cared-for relationship, no matter how all-enveloping it may have become, is still an episode within a broader relationship where particularities of identity are long since already and independently entrenched. So they set great store, when people fall ill, by the idea of non-abstracted love and care. This value cannot conceivably exist within a managed health care system, although it can of course co-exist – in the community, for example – with other values the system incorporates or generates. At the same time, many who believe in the centrality of this non-transferable value believe also that its unavoidable sacrifice is a price regularly (and increasingly) worth paying for the institutional goods and professional skills the system makes possible. I think they are right.

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References and notes
1 See, for instance, Empathy and the Practice of Medicine, eds Spiro H, Curnen MGM, Peschel E and St James D, Yale University Press, New Haven, 1994; and the special section on compassion in Cambridge Quarterly of Healthcare Ethics 1995; 4: 476–87.
4 My idea is very unlike Kant’s. He and others who believe in the ultimate value of persons, and talk in this connection of Respect and Dignity, believe that there are properties, such as rationality, which human beings must possess to join the person club. I have no use here for this notion of “person”.

5 Guardian Weekend 1996 Feb 3.
6 I am aware that I leave much unsaid. Some of the issues involved are examined by John Harris in his criticisms of Anne Maclean’s The elimination of morality, London: Routledge, 1993, in his The elimination of morality, Journal of Medical Ethics 1995; 21: 220–4. Both Maclean and Harris seem to me to confuse (though in different ways) questions about humankind with ones about individual human beings, justification with description, and determinacy of description with inde-
7 terminacy.
9 It is unclear how extensively or consistently QALYs are currently applied at micro- or macro-level in our own or others’ health services. Even so, they represent the most developed attempt so far to measure benefits from health care with a view to ranking them in league tables for rationing purposes. Some of the broad-brushed objections are interesting in ways which go far beyond the issues to which they are addressed. For they attach great ethical significance to the difference between moral and natural evil, between doing bad things and bad things happening. It is one thing to plan where distress shall and shall not fall, and another to let it fall where it will, as nature takes its course. Planning it should mean, of course, that there will be less of it, anyway, but this can’t have much force against anyone who makes the distinction between act and event fundamental.
10 The discussion of the last page or two raises a number of far more general points. One is that a fairly familiar distinction between caring for and caring about cannot accommodate my own which is (very crudely) one about different applications of the former and their respective conditions. Another is the extent to which many people care not just about being made better or made to feel better but also about who makes this happen, and why – about sources and agents of delivery as well as, and to a degree irrespective of, outcomes. They want, however obscurely, to know why it should be thought worthwhile to try and make things – indeed, anyone – better, and ultimately how the centralised system of care in which they find themselves can be seen to retain links with the root impulses to relieve suffering which must somehow be its original inspiration. This concern – a further and related point – is one determination of a more general Human concern with natural and artificial virtue. How or earth can the latter be grounded, as it must be, in the former? And of course the parallel does not stop there. The values that only artifice can bring, like justice and its management, are always purchased at some cost to natural partiality. (See my Nature, artifice and moral approbation. Journal of the Aristotelian Society 1996; L:265–82.)