Journal of Applied Philosophy, Vol. 15, No. 1, 1998

Organ Donation After Death — Should I Decide, or Should My Family?

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ABSTRACT *Who should decide about organ donation after death, the individual or the family? This paper examines why this practical question can be difficult to resolve. A comparison is made between standard decision-making in medicine and decision-making about organ donation. The questions are raised of the connection of the dead body to the person, and of who properly has autonomous control over the dead body. To understand the issues, an exploration of autonomy is needed, but at the same time this shows that a resolution depends on addressing complex spiritual and cultural issues, and questions about the autonomy of the individual versus that of the group.*

Introduction

Who has the right to decide about organ donation after death, the individual concerned, or his or her family, and why? This question raises practical issues of policy, especially where that policy has to operate in a context where there are many different views about death and donation. As we shall see, it is also a question that raises difficult issues about the nature of autonomy and about how to mediate between the claims of the individual and those of others.

The problem at hand can be seen as part of a more general question of who has a proper claim on how the dead body is treated. Organ donation is examined because firstly, there actually is a current practical question, not adequately answered in many countries, of who should be able to choose; and secondly, because the nature of organ donation, an often difficult question arising at times of trauma and which involves quite significant intervention into the body, highlights some of these issues very dramatically.

It could also be said that a third party who may have a say is the state. For organ donation, this is indeed so in many countries, and the state frequently has a say in other aspects of death, for example in where burial may take place or in coronial autopsies. But rather than further complicate the question by examining the claims of the state as well, here I examine only the claims of individuals versus those of families. For this still highlights the important general question that I pose: how to resolve the claims of the individual person whose body it was, versus the claims of a group of people who survive that person.

This question arises both in 'opting-in' and in 'opting-out' systems of organ donation, as these two models of organ donation can each take different forms. In an opting-in system, express consent to organ donation must be obtained; in an opting-out system, consent to donation is presumed unless there is an explicit objection to it. But in an opting-in system, the individual before death could be the person to consent to organ donation, or the family after his or her death could give their permission; in an opting-out system, the individual

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alone may register an objection to donation, or this may also be done by the family after death. So all systems of organ donation have to face the question of who has a right to decide.

Different countries have produced different answers to this question. In some, it is the individual alone whose decision counts. In others, prime emphasis is on the wishes of the family. There are also more mixed systems, where for example an individual can express consent or objection to donation before death, and a family can also do this if the individual had not registered any wishes. For example, the law in Austria allows that organs may be taken unless the deceased had objected during life, and the family has no legal say in the matter[1]. In contrast, the current system of donation in Spain has deliberately focused its main efforts on the process of obtaining consent to donation from the family, rather than at efforts to get individuals to express their wishes prior to death[2]. In Belgium, a two tier system operates, where organs can be taken unless the individual objects within his or her lifetime, or if the family objects after his or her death; but additionally, if an individual registers a positive, explicit consent to organ donation, the family cannot overturn this decision[3].

That there may be some confusion over the issue is evidenced in many countries where there is disparity between law and practice. For example, the law in Australia holds that where a person has given consent to organ donation before death, that decision 'legally overrides any decision the next of kin may make'[4]. Yet, in practice, the wishes of the senior next of kin are considered and may be followed even if they differ from those of the deceased if 'it appears that to proceed with the donation would cause extreme distress'[5]. This appears to be an anomaly: are the wishes of the deceased paramount or not?

There is genuine tension between the two opposing positions here, which can be illustrated practically by considering the situation from the two different viewpoints, that of the individual and that of the family. On the one hand, one may be inclined to say, 'How outrageous that my family — other people — should be able to decide what happens to *my* body after I am dead!' On the other hand, a family may well feel justified in saying, 'How appalling that the authorities disregarded our grief and our deep feelings to the extent of insisting on taking organs from our deceased relative!' Informal discussions may show that individuals frequently feel that the decision should be theirs alone. Experience also shows, again and again, that families have to be treated very sensitively when confronted with the very traumatic situation under which the question of organ donation generally arises[6].

This issue will turn out to be a very complex one. I am not concerned here so much with trying to argue that a particular answer to the question is correct, as with attempting to analyse its complexity, and with suggesting why it may be an especially intractable problem. Where there are differing or competing opinions on questions of value, it is often useful to appeal to respect for individual autonomy as a solution. But whose autonomy? And does the domain of autonomy properly extend to the treatment of the dead body? I shall be arguing that while we need to examine autonomy to understand the issues, doing so will show how difficult it may be to form policy that resolves the problem satisfactorily.

The issue of course concerns decision making. In terms of methodology, it could be seen as a decision about the execution of the deceased's estate and so as similar to a decision concerning the disposal of property. Alternatively, it could be seen as parallel in some way to medical decisions about how the body is treated. Although I shall argue that there are significant limits to the extent to which it can be seen as a kind of medical decision, I shall explore this avenue, because what's vital is the treatment of the person and of the body;

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notions of mere property miss an entire dimension. I firstly consider the nature of medical decision making in general. Then I discuss how decision making in organ donation may resemble and differ from medical decision making, focusing on the notion of autonomy and on the significance of the dead body and examining the relative claims of the individual whose body it is, and of his or her family.

Decision-making in medicine

In medicine, it is widely recognised that a patient's decisions about treatment should be informed, and should be made freely. This is often known as the doctrine of informed consent. There are many well rehearsed difficulties with this notion, but here, we need not trouble ourselves with these. For our major concern is with what lies behind the call for free and informed decision making in medicine. In other words, why are medical decisions important, and what values are safeguarded by protecting patient decisions and attempting to enhance the decision making process?

It is generally recognised that there are two main types of ethical justification for protecting patient decision-making in medicine. One is based on utilitarian reasons, which attempt to maximise benefit and minimise harm, to the patient and to all others concerned. Medical decisions are important decisions because they are so crucial to a person's welfare, and have the potential to involve great harm and great benefit. Roughly speaking, the reasoning is that allowing informed consent will enhance patient trust in the treatment and in the medical staff, and encourage such goods as effective compliance with treatment and allaying public fears about abuse[7].

If the justifying ground for informed consent to organ donation is utilitarianism, broad reasons for respecting the wishes of the individual may focus on the benefit to individuals whilst still alive, for example on how they may feel in the prospect of having their posthumous wishes acted on or not. It may also look at possible benefits to others. But if utilitarianism is appealed to, then of its nature, it can be overruled if there are sufficiently strong countervailing reasons, such as distress that may be caused to the family of potential donors if their wishes are overruled or not considered; this distress may be both burdensome and lasting.

On a utilitarian stance, the welfare of others may be appealed to only in exceptional cases for medical treatment, but more often in cases of organ donation, and there is an obvious reason for this difference: the organ donor is dead. On a straightforward utilitarian position, the dead person can experience no happiness or unhappiness, and has no welfare needs. So, although there may be utilitarian reasons for respecting the wishes of individuals regarding organ donation, the interests of others may outweigh this consideration relatively commonly; in any case, assessing these interests will *always* be relevant to a complete assessment of what to do.

The second main justifying ground for informed consent in medicine is based upon the notion of respect for persons and the accompanying notion of autonomy[8]. Ensuring that important decisions are based upon free and informed consent is one major way of ensuring autonomy and in return, respect for persons. In particular, autonomy in medical decision making is vital because medical decisions are decisions important to the health and lifestyle of the individual. They may even be decisions of life or death. Additionally, the ability to make autonomous decisions over one's own person, that is, to maintain bodily

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integrity, is also considered of crucial significance and so lends particular importance to medical decisions.

It is this second justification, of respect for persons and for autonomy, that is focused on here. Although questions of benefit and harm are of course relevant considerations in organ donation, a key issue again and again in debate on organ donation is how respect for persons — respect for the dead organ donor — is maintained[9]. Utilitarianism, in itself, has little of great interest to say on the matter of persons, and indeed one of its major, justified, criticisms, is that it fails to give any adequate account of how and why individual persons should be respected[10]. The question of who should make the decision is, of course, essentially a question of autonomy, and cashing autonomy simply in utilitarian terms will omit much necessary richness. Utilitarianism may be called upon to help with a practical solution where an examination of autonomy and respect for persons fails to show us a clear way; but it is inadequate as a full analysis of the issue. I therefore leave aside utilitarian considerations to focus on respect for persons, via examining further the notion of autonomy.

Individual autonomy and the importance of its protection.

An autonomous person is one who can make rational decisions, based on his or her own values, which are truly his or her own. An autonomous person is thus truly to this extent in charge of his or her own life[11]. To respect a person's autonomous decisions then, it is necessary to allow, or more strongly to enable, that person to reach such decisions in the best possible way. That is, adequate relevant information must be given to arrive at a rational decision; and elements of coercion or deception must be absent.

Individuals live with and interact with each other; some things that are part of my life are part of your life and there will be disputes at the borders. These borders may be very wide, and construed in different ways. A major question of this paper is how to draw these borders to resolve disputes between individual and family. One way of addressing the question of the proper extent of autonomy is to say that an individual should be allowed autonomous control over those aspects of his or her life which are most closely connected with his or her person. It's another question how close is close enough; and, indeed, exactly how the person is conceptualised. One thing which is closely connected with the person of course, is his or her body; hence the explicit call for control over bodily integrity. So, another major question of this paper asks how closely connected to the person is his or her dead body, and how strong are any claims for autonomous control over that dead body.

It is necessary to consider exactly why autonomy is considered to be an important value. Two main reasons can be sketched. Firstly, respect for individual autonomy can be seen to be a device of political liberalism used to protect individual liberty, prevent cultural imperialism and the 'tyranny of the majority'. Hence respect for autonomy can protect different cultural, religious and moral values; it may sometimes be presented as a sort of 'neutral' arbitrator between these values. Its importance is highlighted in a multicultural situation. One of the earliest and most influential expressions of this is contained in John Stuart Mill's famous 'harm' principle whereby it is claimed that the only justification for interfering in another's liberty is to prevent harm to others[12].

Secondly, respect for individual autonomy can also be seen, not just as a device for

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respecting different value systems, but as the expression of a particular value system (or set of value systems) which values the individual, and individual choices, beliefs, and actions, very highly. Such value systems, broadly common in much of the Western world, typically give priority, or at least high value, to the individual as opposed to the community. For instance, such value systems would tend to wish to protect the individual from what are viewed as excessive demands on him or her from the community.

In addressing the question at hand, both of these aspects of autonomy must be considered. In the ethical literature, most attention has been given to autonomy as a value attaching to individuals. I shall discuss the idea that we need also to consider that the notion of autonomy may also apply to groups of people — in this case, to families. We also need to consider the question of how, if at all, notions of autonomy and of respect for persons could be translated to the case of the deceased potential organ donor. I turn to these last questions first.

How do the notions of informed consent, respect for persons and autonomy apply to the potential deceased donor?

Is it appropriate to see consent to organ donation for the deceased potential donor purely on the same model as informed consent to medical procedures? In this section I will show how organ donation is both something *less* than a standard medical treatment; and something *more* than a standard medical treatment. The discussion will help us to understand what kind of issues are at stake in the case of organ donation. We must consider here the significance of the dead body. The importance of informed consent cannot simply be transposed from the case of the living to the case of the dead person. Complex cultural, religious and value issues are inextricably involved.

It may be assumed that organ donation is simply one type of medical procedure. This assumption would lend great weight to any opinion that it must be the individual who is consulted on organ donation and who decides the matter, as is generally appropriate in standard medical cases. It may seem superficially obvious that the same justifications and the same standards must apply to organ donation as to general medical treatment. The procedure of donation takes place in a hospital and involves medical intervention in the sense that the same types of procedure are carried out on the deceased donor as on live patients, such as surgery, or ventilation.

Consider, however, that it has been shown above that the significance of free and informed consent in the medical case derives from two main sources. Firstly, that medical decisions are lifestyle decisions. At first sight, organ donation is obviously not a medical procedure in precisely this sense. But there is an important proviso here, that an answer to this question hangs on how the *person* is conceptualised. On one way of looking at persons and at organ donation, donation can be seen as one of the last acts of the person, and so in a way, to choose to donate or not to donate can be an expression of how that person wanted to live his or her life, and how he or she wished his or her death to be handled, and so in this sense, a 'lifestyle' decision. Philosophically, the moment of physical demise is not always taken to be the last moment of personhood or the last chance for any assessment of that person's life, although it may be. There is a range of views here[13].

Secondly, medical decisions are important because of the importance of bodily integrity to the person. The issue of bodily integrity is in one obvious sense relevant to organ

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donation, since the same physical organism is involved. In another obvious sense, things are crucially different — it is now a dead body. The significance of bodily integrity for a live person may be understood in many ways, but it is closely wrapped up with the health and proper functioning of a living organism; the dead body no longer carries out the integrated functions of the living, and whatever happens, barring exceptional circumstances, it will soon not exist as a physical unity. The significance of the treatment of the physical body, living or dead, for the person is open to wide interpretation, and here, cultural and religious values must be addressed. But what is certain, is that questions of bodily integrity take on a quite different import once the person is dead.

We can begin to see why the question posed in this paper is hard to answer. It is not a straightforward matter to apply models of autonomy based on the interests of the individual over his or her living body, to the case of the dead body. Although a key issue is that of maintaining respect for persons, and through this, respect for autonomy, what it is precisely to respect autonomy in relation to the corpse is open to wide interpretation. I shall try to take the question further by analysing different positions on the relationship between the person and his or her dead body. There are such diverse positions taken on this issue that here I can only indicate some broad features of some main possible views.

One class of views sees the body after death as quite disconnected from the person who has just died, for instance, as mere waste material which might as well be recycled, or as an empty shell. Such a view is perhaps expressed here, lamenting missed occasions to donate organs, that 'the chances of a proper life and happiness . . . are being buried in graveyards and burned in crematoria daily'[14]. Of course, those holding such views might still consider that it is important to respect the autonomous wishes of the deceased person regarding the disposal of the body, just as it is important to respect a person's wishes in general regarding the disposal of his or her estate[15]. However, the dead body may be seen in an entirely 'utilitarian' way, or as not in itself having great resonance or meaning.

In stark contrast, many other views see the body as still heavily invested with the person in one way or another. Indeed, given the great significance that all human societies seem to place on funeral rites, this would seem to be the dominant, almost universal position. Such views may or may not preclude donation. What is vital about such views is that the treatment of the dead body is, in itself, imbued with value, and with cultural or religious significance. How the body is treated may, in itself, be crucial to maintaining respect for the person. Notions of respect for the dead in fact often appear more stringent than notions of respect for the living — the dead may be talked about more reverentially, and may depart this life in a coffin far more lavish than any of the comforts he or she was used to when alive. Although respect for the dead is shown via surrounding rituals and monuments, importantly it accords also to the body itself, and great importance is often placed on retrieving corpses from difficult places, as well as on reconstructing damaged corpses for viewing and for a 'decent burial'. The strength of the feelings involved should not be underestimated. Witness, for instance, the widespread abhorrence at the desecration of graves and at grave robbing, and distress when a body cannot be recovered or has been destroyed in some way.

These views may take on different forms ranging from the fairly common feeling of discomfort about donating eyes for corneal transplant on the grounds that the eyes seem to be especially closely connected to the person, that someone else will somehow literally be seeing the world through these eyes; to views that the dead body must be kept intact for a literal resurrection upon Judgement Day. It should also be noted that cross-cultural

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differences may mean that the very terms of debate and understanding are so different as to make mutual understanding problematic[16].

The respect due to the dead body on such a view may be explicitly understood in terms of upholding respect for the deceased person's autonomy, e.g. in respecting wishes to scatter ashes in a certain place, but in general, this notion of respect for the dead seems to operate rather independently of the notion of individual autonomy as such. Indeed, it could be argued that to foreground the notion of a person's autonomy is to see him or her primarily as an individual, whereas rituals of respect for the dead have culturally shared modes of expression and see a person primarily — though not exclusively — as a member of a group. The treatment of the dead body is important for the individual in prospect of one's own demise, but its symbolism and significance is mediated through others, and it is through others — through a social group — that the dead are woven into a web of meaning and respect[17].

This leaves open the question of how notions of autonomy may still be thought to apply in some way to the corpse. It was argued above that claims for autonomy are stronger where what is at stake is seen as central to an individual person's life. So, if the dead body is seen as closely connected to the person in this sense, it may be held that his or her wishes concerning what happens to his or her body deserve especial respect. This is the sense in which the treatment of the dead body has a significance that the mere disposal of a person's estate does not. On the other hand, if the body is seen as quite disconnected from the person, how it is treated may not be construed as so central to the person's life and so the strength of his or her wishes regarding it not so well grounded in the call to respect his or her autonomy. Perhaps more commonly, the dead body may be seen as having a symbolic connection to what is important to others. Hence, in both these cases, other considerations may more easily override a person's pre-death directions concerning organ donation or other aspects of the treatment of the corpse.

In conclusion so far, the discussion of the relationship of decision-making about organ donation to standard medical decision-making has shown that, while some important reasons for respecting autonomy that apply in an ordinary medical context are missing in organ donation, other values and considerations may move to centre stage. If autonomy applies at all to the person after death, it does not apply in the same way that it does when a person is alive. So any *straightforward* notion that, by virtue of respect for autonomy, the person's wishes must be paramount, is mistaken. However, this is not necessarily to weaken an individual's claim to autonomous control of his or her corpse. The question raised is one of where the borders of a person's autonomy lie, and of whether the treatment of a person's corpse is central enough to the 'life' and concerns of that particular individual — more strongly, that particular individual alone — to be a proper part of the domain of the individual's autonomous control. But there are others who also may stake a claim and which we must now consider.

The family's role in decision making.

There are a number of possible views on the family's role. A position which placed prime and overriding importance on the autonomy of the individual with respect to decisions about organ donation would have it that the family has no role in the decision, and may be consulted only as a possible source of information about their dead relative's wishes.

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Where these are known, they should be followed; where unknown, the default position of the relevant organ donation system will apply, be it an opt-out system where consent is presumed, or an opt-in system where explicit consent is required.

Alternatively, it may be held that the family does have a role here. On one view, the family is making a proxy decision: that is, trying to decide what the deceased would have wanted. The family is often turned to to make a proxy decision for two reasons. Firstly, they are often (but not always) in the best position to judge what the person would want. Secondly, they very often (but not always) have the best interests of the person at heart. A true proxy decision would only be appropriate where the wishes of the deceased are not known. To allow the family to decide in this way, then, may be consistent with giving primary respect to the autonomy of the individual, as the family's decision may be seen as a *substitute* for the unattainable autonomous decision of the deceased, rather than as an *alternative* to it.

On another, quite contrasting, view, the family is more simply making a decision for itself, on how it wants the body to be treated. A part of reaching this decision may include considering what the deceased would have wanted, but the aim is not to reach a proxy decision as such. For example, it may be held that decisions about organ donation are, ultimately, for those left behind to decide. It may be that organ donation is simply decided on grounds of what is culturally or emotionally appropriate for the family rather than by reference to what the deceased would have wanted. For example, a family's religious views may simply dictate how the corpse is treated. It may be held that the family as a group has overriding or primary interest in how the body of a group member is treated after death.

On such a view, we may need to consider the autonomy of the remaining family unit as in itself a value to be respected. They may be seen as a group of people (or perhaps to express this more strongly, a collective) whose autonomy is also at issue. Since the autonomy of the family is not a generally used notion, I shall need to say a little in its defence, although space here does not permit me to make a full account.

It may be clear what it is to talk of the autonomy of the individual, since although an individual's psyche may be chaotic or divided, one's physical body differentiates each as a single individual. It may also be clear what it is to talk of the autonomy of an organisation such as a state, where there are more or less clearly differentiated power structures, decision-making procedures, conditions of identity and belonging, and lines of division from other organisations with their own territory of operation. What can be meant by the autonomy of the family? I shall say at least two things in defence of such a notion, with some provisos.

Firstly, a family may be to some extent likened to a state or other organisation in consisting of a group of people, identifying themselves as such, with their own interests — both individual but also collective, and with their own power structures, which may be more or less spelled out and more or less fluid. A proviso is of course that a family may be more loosely structured than some other organisations, reasons for the continued grouping may change, boundaries and power structures may alter and be disputed. But these are differences of degree only from other organisations whose autonomy may still be recognised. When the notion of a family's autonomy may come most to the fore, as with the case for individuals and states, is when it is under some attack or threat, perhaps from a government or a majority culture. (Interestingly, at such times the family may crumble — as may a state or an individual — or may conversely strengthen its ties of identity as a family sticking together for a common purpose.)

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Secondly, the notion of the autonomy of the family may seem most inappropriate if one considers the primary case of autonomy as being the individual person, and perhaps especially if one considers that recourse to individual autonomy is often needed precisely to protect a person from the claims of others, including social groups. But the primacy or even exclusivity of individual autonomy can be, and often has been, questioned via questioning the 'atomistic' individual on which such a notion may be based. Instead, it can be argued that a person's identity can be seen as made up of group identities *as well as* individual identity. On such a view, people function and think as group members as well as individuals. It can be argued that social groups are real, their behaviour irreducible to the behaviour of individuals, and that group life can be an authentic expression of the self, and so in harmony with individuals' autonomy rather than necessarily at odds with it[18]. Hence, we can both question the notion of atomistic, isolated individuals which might try to claim that autonomy can only properly belong to such individuals, and suggest that if a social group — perhaps a family — has its own reality, it may properly be said to have its own autonomy. Indeed, if a person's identity is partly constructed in relation to social groups, a true understanding of their autonomy needs to make reference to these groups. Although the notion of a family's autonomy will doubtless be controversial and in need of further expansion, I hope I have said enough here to grant it some initial plausibility.

The decision about donation then may be seen as a decision about how a group of people handle the death of one of their members — seeing the whole process of the death of a member of a collective as being something appropriately handled in a collective manner. *One* way, but only one, such a collective may make the decision may be by considering what that person's wishes were. In terms of the earlier discussion of the nature of autonomy, the death rites of a group member may be seen as central to the life of the group, and for these reasons a proper part of the group's autonomous domain.

So much does the death of a group member affect those still alive, and so heavily imbued with spiritual, religious and cultural significance are the rituals of death in human societies, that there are good grounds for respecting claims of the group for autonomy over these matters. But, there may also be good grounds for respecting the claims of individuals for autonomy over the treatment of their dead bodies. Moreover, not only may these different views lead to a clash on the practical matter of who has final say, but they may be supported by quite diverse theoretical and ethical considerations.

We can deduce from the argument two broad divisions, and in summary it may be helpful to analyse how these interact. On the one hand, there is the division between whether the claims of the individual for autonomy, or those of the group (in this case the family) have greater hold; on the other hand, there is the division between views which see the dead body as closely connected with the person, in whatever way, and those that see the dead body as disconnected from the person. The following fourfold grouping, although slightly artificial, may be helpful in clarifying the argument.

1. Claims of individual autonomy are in general stronger than those of the group, and the dead body is closely connected with the person. This would mean that there are strong grounds to say that the individual's autonomous wishes about what happens to his or her body after death should be followed, since the dead body is construed as part of the domain, close to the person, over which the person properly has the right of autonomous control.

2. Claims of individual autonomy are in general stronger than those of the group, but the body is not closely connected with the person. This weakens the individual's

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claims for autonomy over the dead body, and the claims of others hence may override them.

3. Claims of others are in general stronger than those of the individual, and the dead body is closely connected with the person. This is a complex scenario. The claims of others may be overriding as the group may have a strong interest in what happens to their deceased group member. How dead group members are treated — and so in this case, how also their bodies are treated — may be closely connected with the identity of the group — the 'personhood' of the group if you like — and so the autonomy of the group. However, the perceived close connection with the person that was may be thought to give any claims that he or she may have had greater prominence at the same time as it underscores the group's claim for control.

4. Claims of others are in general stronger than those of the group, but the body is not closely connected with the person. Here the claims of others would generally have priority; but the issue is less loaded.

An answer to one question will interact in complex ways with an answer to the other; crucially, the question of whether claims for autonomy of the individual or of the group are stronger will depend on how closely the area of concern is to the life of the individual or the life of the group. In general, the issue is more contentious where the dead body is seen as closely connected in some way to the person who was. For example, a view that the corpse was closely connected to the person in some way, may support the claim that the individual should have autonomy over it; but it may also support the claim that the group has correspondingly strong grounds for concern about how the body of one of their members is treated.

So, how can the question be resolved?

My main aim in this paper has not been to argue for one or another solution to the problem, but to display the nature of the problem. In fact, a theoretically attractive view is that organ donation, and the treatment of the corpse in general, lies in an area of potential great dispute. There are grounds for seeing the corpse's treatment as of great importance both to the life of the individual who was, and to the life of the group of which the deceased was a member. The question of who decides about organ donation may then lie in an essentially contestable area.

This may be attractive in theory as an analysis of the issue but may look like a nightmare for practical policy decisions. So, having rejected utilitarianism as a way of understanding the difficulty of the issue, it perhaps may now be on occasion appealed to as a way of resolving particular disputes. Hence, perhaps, policy advice to go against the wishes of the deceased where it would seem to cause too great a burden for the family.

An obvious complexity is that there is no 'mid air' position available from which different permutations of views are being held. Thus, different parties involved may take quite different stances. A deceased individual may have had views in the first category; the spouse, views in the second category; the children, views in the third category, and the parents, views in the fourth category. In other words, there may be a dispute about what the ground rules are, against which disputes regarding organ donation, or any other matter concerning the treatment of the dead body, may be resolved. This may especially be the

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case in situations where there is a mix of cultures and values, and where there is cultural change within families and between generations.

Moreover, it is far from clear that adequate ground rules for dispute resolution can be laid down by the state in accordance with a general notion of respect for autonomy, especially within a multicultural situation. Even if the autonomy of the individual is generally given priority in a particular state, there is still the question of how strong the claims of the individual are to autonomous control of his or her dead body; an answer to this question depends upon an answer to a complex and culturally loaded question of value regarding the status of the dead body and its relation to the person who was. Moreover, different cultural groups value the autonomy of the individual to vastly differing extents.

To elaborate the difficulty of the problem, recall the discussion above on the importance of protecting individual autonomy. To uphold the autonomy of the individual is often a way of respecting different cultures and allowing different value systems to live side by side. However, to grant priority to individuals on this question of organ donation can also be a way of upholding one particular cultural value system; that which values individuals over and above community or other values. It may additionally be to uphold a particular set of values about how the personhood of the individual is connected to his or her dead body. Hence, when a problem arises over whose wishes should predominate, it cannot necessarily be solved by insisting that the expressed wishes of the deceased have priority over the wishes of the family, since this is in itself to impose a culturally loaded value system.

The difference between different systems of organ donation on this question of whether the family or the individual decides, and the confusion evident in systems such as that of Australia, described above, probably stem from differences of opinion or confusions about this pervasive issue of the individual versus the collective, a point of tension which must be continually faced in a multitude of situations. Coupled with this are different views, and, very often, great uncertainties, about what the person is and how the person relates to the body. Fudges in policy may stem from a recognition of the highly contestable nature of the treatment of the dead body.

These are tensions which take on a particular poignancy in issues of death, for whilst death is always the death of the individual, it is an event of profound significance for others. On the one hand, we say 'each dies alone'; on the other, we say, 'each man's death diminishes me'. It is the individual who dies; it is others who attend his or her funeral, who mourn, who remember or forget the dead. The way in which we leave this world at once foregrounds our separation from the group, our individuality; and also our connectedness to the group, what our death will take from the group, what we need to resolve with the group, and what legacy we will leave behind. It always raises the problem of how the person relates to the body, for this of course is the time when the easy connection of the living person with his or her own body is brought into question. This again shows how deeply, thickly and inextricably the questions considered here are entangled in cultural, spiritual and religious positions on which there may be considerable diversity. The very matters at issue are where the borders of the individual lie, and how the individual is placed against others; to appeal, without further thought, to individual autonomy as a way of solving the problem, is to beg the question.

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NOTES

[1] E. Bernat (1994) Opting-in, opting-out, and necessity: The Law of organ transplantation in Germany, Austria and Switzerland, *International Journal of Bioethics*, 5, 2.

[2] R. B. Miranda Matesanz and C. Felipe (1994) Organ procurement in Spain: Impact of Transplant Coordination, *Clinical Transplantation*, 8.

[3] W. Kokkedee (1992) Kidney procurement policies in the Eurotransplant region: 'Opting in' versus 'opting out', *Social Science and Medicine*, 35, 2.

[4] National Health and Medical Research Council (1996) *Recommendations for the donation of cadaveric organs and tissues for transplantation*, 2.1, Australian Government Publishing Service, Canberra, Australia.

[5] National Health and Medical Research Council, op. cit., 2.5.

[6] See, for instance, P. E. Buckley (1989) The delicate question of the donor family. *Transplantation Proceedings*, 21, 1; J. M. Foy (1990) Duty to respect the dead body: A nursing perspective, *Transplantation Proceedings*, 22, 3; D. T. Savaria *et al*, (1990) Donor family surveys provide useful information for organ procurement, *Transplantation Proceedings, 22, 2;* A. Stein *et al.* (1995) Organ transplantation: Approaching the donor's family: Train doctors to approach families sensitively, *British Medical Journal*, 310.

[7] See, for instance, T. L. Beauchamp and J. F. Childress (1983) *Principles of Biomedical Ethics*, 2nd. ed. (New York, Oxford University Press).

[8] See, for instance, R. R. Faden and T. L. Beauchamp (1986) *A History and Theory of Informed Consent* (New York, Oxford University Press).

[9] See, for instance, J. M. Foy (1990) *op. cit.*; A. Lynch (1990) Respect for the dead human body: A question of body, mind, spirit and psyche, *Transplantation Proceedings*, 22, 3; M. J. Lynch (1990) Duty for respecting the dead body, *Transplantation Proceedings*, 22, 3; S. J. Youngner (1990) Organ Retrieval: Can we ignore the dark side?, *Transplantation Proceedings*, 22, 3.

[10] Much has been written on this. See, for example, Jonathan Glover (ed.) (1990) *Utilitarianism and its Critics* (New York, Macmillan).

[11] There are variations on how exactly autonomy is conceptualised but core ideas include mastery over self and freedom from interference by others. See for instance, Richard Lindley (1986) *Autonomy* (Atlantic Highlands, Humanities Press International).

[12] J. S. Mill (1975) *On Liberty*, in *Three Essays* (Oxford, Oxford University Press).

[13] For a debate on this issue, conducted in terms of whether or not a person can be harmed after his or her death, see J. Feinberg (1974) The rights of animals and unborn generations in W. Blackstone (ed.) *Philosophy and Environmental Crisis* (Athens, University of Georgia Press); J. Feinberg (1977) Harm and self-interest in P. M. S. Hacker and J. Raz (eds) *Law, Morality and Society: Essays in Honour of H. L. A. Hart* (Oxford, Clarendon Press); E. Partridge (1981) Posthumous interests and posthumous respect, *Ethics*, 91; B. B. Levenbook (1984) Harming someone after his death, *Ethics*, 94; J. C. Callahan (1987) On harming the dead, *Ethics*, 97.

[14] Elizabeth Ward (1990) A case for opting-out? *The Silver Lining Appeal of the British Kidney Patient Association*, 17th ed.

[15] For an interesting discussion of such a view and the relative importance of respect for autonomy and for the dead body, see P. J. Kalshoven (1990) A humanistic conception of the human body after death, *Transplantation Proceedings*, 22,3.

[16] Fuller consideration of these matters really deserves a separate paper. For a range of views see Rabbi R. P. Bulka (1990) Jewish perspective on organ transplantation, *Transplantation Proceedings*, 22,3; A. F. M. Ebrahim (1995) Organ transplantation: Contemporary Sunni Muslim legal and ethical perspectives, *Bioethics*, 9, 3/4; E. Namihira (1990) Shinto concept concerning the dead human body, *Transplantation Proceedings*, 22,3; A. A. Sachedina (1989) Islamic views on organ transplantation, *Transplantaton Proceedings*, 20,1, S1; S. H. J. Suganasiri (1990) The Buddhist view concerning the dead body, *Transplantation Proceedings*, 22,3; H. L. Trivedi (1990) Hindu religious view in context of transplantation of organs from cadavers, *Transplantation Proceedings*, 22,3.

[17] See for instance, Jon Davies (1994) *Ritual and Remembrance; Responses to the Dead in Human Societies* (Sheffield, Sheffield Academic Press).

[18] For a discussion of such views see P. J. Oakes, S. A. Haslam and J. C. Turner (1994) *Stereotyping and Social Reality* (Oxford, Blackwell); J. C. Turner and P. J. Oakes (1997) 'The Socially Structured Mind' in

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C. McGarty and S. A. Haslam (eds) *The Message of Social Psychology* (Oxford, Blackwell) J. C. Turner, P. J. Oakes, S. A. Haslam, C. McGarty (1994) Self and Collective: Cognition and Social Context, *Personality and Social Psychology Bulletin*, 20,5.

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