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Discussion

Legal solutions to medical problems: understanding ownership of bodily property and end-of-life issues using a rights terminology

DISCUSSION

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ABSTRACT

Summary:

This essay takes two contentious issues of contemporary society – end-of-life and ownership of bodily material and examines them through a legal lens.

Relevance:

In today's litigation culture, the spheres of medicine and law increasingly overlap, sparking a need to leave the dichotomies behind and explore the symbiosis between these fields.

Take Home Messages:

On the basis of (1) consistency, (2) coherency and (3) control, it is argued that a rights terminology would helpfully organise the way we approach medical decision-making in these two contexts.

From Ethics to the Law

In the field of medical law wherein ethical and legal issues jostle against each other, a rights terminology can prove a valuable mechanism in balancing both legal and ethical concerns. Inherent in the notion of rights is acknowledgement of ethical issues, such as equal worth and dignity, and integral to the application of rights are legal duties. Therefore, a rights-based approach has the advantage of engaging, albeit not resolving, this insistent conflict between ethics and the law.

There are three components to a rights-based approach: the subject holder, the object (the person against whom the right is held), and the content. The content of the right provides the substantive basis for the right, grounding the approach in a clear ethical principle. The subject holder and object exist in a correlative relationship with each other as the object holds a duty to the subject holder. This relationship structure of rights and duties sets up a clear response mechanism, spurring definitive action if rights are to be upheld. Whilst other ethical approaches may have the advantage of nuance and subtlety, they can prove too vague to be practically useful. These alternative approaches include utilitarianism, the ethics of care and deontology. According to utilitarianism, we should choose the course of action that has the best overall consequences for everyone concerned. Yet, with this we encounter the impossible matter of defining '*good*'. The ethics of care approach is focussed on care and empathy, but it prioritises these above choices and does not account for the fact that we all think and feel differently. Deontology is a rule-orientated theory and decisions are governed by whatever the rule demands, irrespective of the consequence of an action. This has the disadvantage of treating people as ends rather than means and can therefore be seen as a blunt tool for decision-making in this area.

Bodily Material and End of Life

This essay advocates for a rights-based approach in two specific contexts: bodily material and end-of-life. For the purpose of this essay, human bodily material is defined as any material which consists of or includes human cells, other than hair or nail from the body of a living person. The Human Tissue Act 2004 is the main guidance for the law in this area.

Euthanasia or assisted dying is the act of deliberately ending a person's life to relieve suffering. This includes a range of actions which are sometimes separated into '*active*' and '*passive*'. Active euthanasia refers to deliberate intervention to end someone's life by, for example, the administration of large doses of drugs that are not otherwise needed for treatment. Passive euthanasia refers to the withholding or withdrawing of treatment that is needed to maintain life. Whilst both active and passive euthanasia are illegal under English law, this distinction is often used in the theoretical discourse on end-of-life and sometimes seems to slip into judicial reasoning. Moreover, withdrawing life-sustaining treatment if this is in the person's best interests can be part of palliative care and is not considered euthanasia, but this is a tricky line to draw. Suicide is not a criminal act and refusal of treatment is permitted - even if it would result in death - so long as the decision is voluntary and informed, and the patient has

the requisite capacity.

Consistency and Coherency

Significant inconsistencies can be identified in the bodies of law pertaining to both end-of-life and ownership of bodily material; a rights-based approach would aid reconciliation between the conflicting legal and ethical issues at play in these contexts.

The first controversy is the active-passive distinction which is used to rationalise withdrawal of life-sustaining treatment as an omission rather than an action. An omission is a failure to act and in other legal contexts attracts different legal consequences from positive conduct. This "*semantic sleight of hand*" allows a distinction to be made between '*killing*' and '*letting die*'; the latter undoubtedly holds more intuitive appeal; however this distinction is logically incoherent. (1) In stopping treatment, a positive act still takes place. For example, in the case of Airedale NHS Trust v Bland the patient only passed away because "*a hand grasped the naso-gastric tube and pulled it out*". (2) Driving this linguistic artifice appears to be the "*moral bias*" that it is wrong to kill. (3) Whilst this is undoubtedly true in a general sense, the unnecessary commitment to it in refusal of treatment, wherein the individual seeks death, has forced the judiciary to reason creatively to avoid the conclusion that doctors are murderers. (4) However, flipping this bias to positively recognise a right-to-die would eradicate the reprehensibility associated with these actions, and thus the need to defend them. Consequently, the need for this legal fiction dissolves, restoring coherency in the law.

In the case of Bland (5) a patient refused treatment and the courts used the act-omission distinction to rationalise why the doctors were not guilty of murder. However, as academic Foster has noted, "*the language of duty is more satisfactory*". (2) A right demands a correlative duty and by recognising a right-to-die, the result in this case could have been straightforwardly justified as the doctor having a resultant duty not to continue feeding.

Additionally, the law makes an incoherent distinction between lawful and unlawful life-shortening practices. Dying from starvation or suffocation (means of death permitted through refusal of treatment) can often be more protracted and distressing than the quick and painless death that would be induced by a single fatal injection that is currently prohibited. The arbitrary nature of this distinction was highlighted in the Nicklinson case. (6) After locked-in syndrome left Mr. Nicklinson unable to speak or move, he argued that the current prohibition on assisted dying is a breach of human rights because it fails to recognise his right-to-die. If a man such as Mr. Nicklinson has the right to starvation, leading to a long and painful death, surely, he should also have the right to a quick and painless death? Using and recognising rights would eliminate this discrimination between lawful and unlawful life-shortening practices, giving the law more coherency.

Moreover, there is currently disparity between offence (unlawful action) and punishment (legal consequence), giving unsatisfactory uncertainty to the law. A rights-based approach could better manage this. Despite their widely publicised illegality, assisted dying prosecutions are rare, and convictions are rarer still. As leading academic

McLean asks, "*what purpose is served by a law which technically criminalises behaviour which it then effectively ignores and forgives?*"; this does not accord with constitutional principle. (7) Contrary to academic Greasley's remarks that the "*pre-Purdy approach of wilful blindness was the best method of navigating the tricky moral territory of assisted suicide*", certainty in this area of the law is something we should be striving towards. (8) Why settle for '*wilful blindness*' when recognition of a right could give the judiciary a concrete tool on which to base end-of-life decisions? Working on a backdrop of fierce emotion, investment of certainty and coherence into the law is of the upmost importance. Clarification of policy is a step forward, but recognition of a right-to-die would standardise decision-making even further.

In the area of bodily material too, a rights-based approach would offer coherency and consistency with regard to legal consequence. Failing to recognise property rights of human bodily material significantly limits the remedies that can be sought when legal disputes arise. For example, in a Californian case, a doctor used embryos without consent. Given the reluctance to recognise embryos as property, the doctor could not be charged with theft as this is a property offence. Instead, the doctor in question was charged with mail fraud, an incongruous remedy that failed to correct the alleged harm. (9) In contrast, the case of Yearworth has proven the merit of recognising property rights. (10) In this case a remedy based on bailment was allowed where it would have been otherwise inaccessible. Whilst this was promising, the development should be taken further and extended into a comprehensive property regime. As the academic Moses has noted, "*legal categories such as property… create default rules that can be applied in diverse contexts*". (11) Therefore, rather than the default being the '*no property*' rule and forms of property rights being identified on an ad-hoc basis, the best way forward would be a rights-based approach that recognises property rights as the default.

Control

The appeal of using property rights is the strong degree of control it gives to the individual, comparable with the strong emphasis put on the protection of bodily autonomy in other areas of medical law. Property rules create an institutional structure that permits the owner to function as the supreme agenda setter for the resource. (12)

The case of Moore is a useful example of how a rights-based approach could give better effect to bodily autonomy. (13) In this case a doctor used human tissue, removed from the patient in the course of treatment, to make a '*cell line*' which was then patented for commercial use. It was ruled that a prosecution based on property rights could not be brought. In his dissent Justice Mosk made the pertinent point that the law should at least recognise Moore's right to do with his own tissue whatever the third-parties did with it. (14) The failure to recognise property rights meant that "*the person who made 'everything possible' was left with nothing*". (14) A rights-based approach could alleviate this ethical injustice by allocating the originator of this bodily material as the first owner, allowing them to share in the products and profits of their material. Further, it would mean that any subsequent transfer would have to be implemented validly, necessitating clarity as to what legally occurs when this type of material is transferred. Of course, the argument against this is that it imposes more onerous duties on third-parties, such as the procurement of valid consent, which could inhibit

medical progress. However, despite this, the stability that a rights-based approach provides sustains the case for it.

Another counter-argument to a rights-based approach is that this privileges individual control to the detriment of altruistic giving. It can be rebutted however, that if people are swayed against donation this was not true altruism in the first place. Moreover, using the language of gifting as the preferred way to conceptualise transfer of bodily material is technically incoherent without acknowledgement of rights. (15) As a matter of legal principle, gifting involves the exercise of property rights. (16) "*You must have a right to possess something to give someone else the right to…it*", and therefore a property model is not in conflict with altruistic giving, but rather facilitates it. (17) Therefore, communal interests could still be realised using gifts and charitable trusts, whereby multiple researchers can use the tissue at the same time.

Similarly, legal recognition of a right-to-die would protect control in this sensitive area. Often, the patient seeking death will have lost control of significant aspects of their life but assisted death provides an assurance that they can control these last moments in a private and peaceful manner. This is exemplified in a study conducted in Washington and Oregon wherein 90% and 89% of patients respectively, cited the decreasing ability to participate in activities that made life enjoyable as a principal reason for requesting physician-assisted suicide. (18) Control over death gives more control during life and as recognised in Lord Hope's dictum in Purdy: "*the way [one chooses] to pass the dying moments of one's life is part of the act of living, and she has a right to ask that this be accepted*". (19) In particular, using a rights-based approach better protects dignity; there is a right not to be "*forced to linger on in old age or in states of advanced physical or mental decrepitude which conflict with strongly held ideas of self and personal identity*". (19) These last few days of life are precious and people should be liberated from fear by the confidence of control. A rights-based approach affords this control, empowering the patient, at a time when they are at their most vulnerable.

Changes in attitude

In the interests of balance, some of the arguments against the recognition of rights should be considered. There is a forceful concern that accepting a right to die would result in widespread attitude changes, coarsening the way we think about life and death – a slippery slope. (20) Greasley warns that symbolic statements are sent to disabled people when assisted death is permitted and that this leads to a change in how they, and those around them, view their condition and their options. (21) However, the argument regarding signals and messages can run the other way; by failing to recognise a right to die we may also be sending a signal that those who wish for death are weak or ungrateful. It is wrong for us to impose a judgement on the worthiness of another's life (even if it is a positive one). In an article for the Medical Law Review, Ford advanced the '*person paradox*' argument against a right to die. According to this, an entity which is rational and autonomous is unreasonable in wishing for its own demise, since in wishing for this it is wishing for the destruction of something of "*ultimate value*". (22) However, as academic Harris riposted, "*if the most significant interest is that life will end*

when the person whose life it is wants it to then there is no paradox", and in discussing attitude change to life and death this is the key. (23) Failing to recognise a right to die separates the person from the life in question and arguably this does the greatest violence to our understandings of life and death.

Moreover, we can be too quick to categorise people as vulnerable. Viewing them as easily coerced or incompetent is patronising and fails to respect their agency and autonomy over their lives. As Harris argues, whilst persons should have the value of their lives respected, they are not "*doomed to have it respected. They can waive their right*". (22) Properly understood, a rights-approach provides individuals with options; they may choose to exercise a right if it is important to them, but there is no imposition to do so. In our society which champions liberty and seeks to promote freedom of action, a rights-based approach seems the only way forward.

In the purview of ownership over bodily material, there is the concern that a rights-based approach introduces a market rhetoric that distastefully objectifies and commoditises people. (24) As to the objectification concern, this attitude is already present. Human biomaterials are things which are controlled, transferred and used so applying property principles "*does not alter how we treat them, but instead gives legal protection to what we already do*". (17) Moreover, allowing matter to be the subject of property is not synonymous with making it subject to free trade; there are many examples of restrictions on the sale of things which are property, such as firearms or drugs. (15) Inappropriate use can always be limited by statute and the Human Tissue Act 2004 is an existing example of how the law can legislate against exploitation to assuage these concerns.

It has also been argued that property rights are inappropriate for protecting the spiritual values that are bound in human biomaterial. (25) However, property rules are used to protect scarce resources that have value and, as Douglas has argued, it is the very specialness of bodily material which makes it suited to being treated as property. (25) Therefore, rather than damaging personhood, the property approach engages with it.

A rights-based approach gives decision-making consistency and coherency (legal concerns) and affords individuals control, protecting their autonomy and dignity (ethical concerns). By effectively reconciling both legal and ethical issues in this way, a rights terminology is a helpful approach.

Without a recognition of rights, the law will remain forced to invent moral and legal fictions, and make arbitrary distinctions, to avoid unjust results. Despite the ethical impasses, the law must be clear and intelligible, allowing citizens to be knowable, and a rights-based approach does this. The Royal College of Physicians recently adopted a neutral stance on the subject of assisted dying, reflecting the range of members' opposing views as well as growing support for a change in the law (26). Discussion of the law surrounding assisted dying is likely to continue and medical students and junior doctors should engage plainly in the discourse that follows. It is much more

intrusive to block an action than allow an action to be available, which people can be free not to choose.

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