Rational rejection? The ethical complications of assessing organ transplant candidates in the United Kingdom and the United States

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The practice of allocating scarce organs in medicine is an ethical minefield. Due to the organ shortage, organ procurement agencies in both the United Kingdom and the United States are placed in the unenviable position of having to choose a limited number of patients to compete equally for life-saving treatment. They do this by composing multidisciplinary transplant teams, which must evaluate transplant candidates and their complex range of personal, medical, environmental, psychiatric and financial characteristics. During the candidate assessment process, such teams may often be torn between their moral duty to save those who are most in need, considerations of efficiency, and the battle against forming moral judgments about particular candidates. Several ethical approaches can be adopted by transplant teams during the decision-making process, but do these ideologies provide adequate justification for their sometimes controversial decisions? This article provides a detailed examination of the ethical principles available to transplant teams in the United Kingdom and the United States, and the effect that these principles have on assessment procedures, organ allocation protocols, transplant candidates and their prospects.

INTRODUCTION: HOW IMPORTANT ARE ETHICS IN THE PROCESS OF TRANSPLANT CANDIDATE ASSESSMENT?

The allocation of health resources has always been a contentious issue in the study of medicine. The high costs of life-saving treatments combined with the lack of available resources have meant that difficult ethical decisions continue to plague the deepest fears of every working medical professional. If anything, the advance of medicine has exacerbated the problem: who is entitled to the best, most advanced care when there are not enough resources to treat everybody? On what basis can these decisions be formed?

The field of transplantation is the most contentious of all. Human organs cannot yet be man-made. Animal organs and mechanical organs have only shown limited success. This inevitably means that only certain candidates get to receive this precious commodity. In both the United Kingdom and the United States, multidisciplinary transplant teams (transplant teams) decide which patients should proceed onto the transplant waiting list, thus playing a fundamental role in deciding who receives an organ. Because such a decision can mean the difference between life or death, the assessment process undertaken by transplant teams when "accepting" or "rejecting" particular transplant candidates should be taken extremely seriously. Are we, as individuals who may one day need to tap into such a precious resource, aware of the moral and ethical factors considered by transplant teams when assessing whether a candidate should be put forward for a scarce organ? Public opinion regarding organ allocation has always been divided, sometimes provoking strong feelings of disbelief and anger. How do transplant teams decide whether one candidate is more deserving of an organ than another? Are national assessment guidelines objective and balanced, or can transplant teams employ controversial moral and ethical teachings during the decision-making process? Are the resulting decisions universally impartial, or do some groups of citizens inevitably experience discrimination?

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These are only some of the difficult ethical questions raised by the transplant candidate assessment process in the United Kingdom and the United States, which largely remains hidden from view.

What follows is a detailed examination of the ethical approaches available to transplant teams in the United Kingdom and the United States when assessing transplant candidates, and the effects of these principles on candidate assessment procedures and candidate prospects.

THE UNITED KINGDOM AND THE UNITED STATES ORGAN PROCUREMENT AGENCIES

In the United Kingdom, NHS Blood and Transplant (NHSBT) is the leading organ procurement agency.¹ All transplant candidates are registered on the National Transplant Database once they have been assessed by a multidisciplinary transplant team. Such teams in the United Kingdom are a collection of medical professionals made up of surgeons, psychiatrists, doctors and counsellors, who must ensure that the candidate can "handle" the physical and emotional traumas of transplantation. If the candidate has caused her or his own organ failure, the transplant team must ensure that there will not be a return to the person's harmful ways. NHSBT has developed some general transplant candidate assessment guidelines.² Transplant teams may examine the primary reason for liver failure; past non-compliance with *any* medical care; a history of illegal drug use or of self-inflicted ailments; medical or psychiatric conditions; family and doctor views; the patient's age; and social support.³ To encourage transparency and to maintain public trust, NHSBT has also published assessment guidelines relating to the assessment of alcoholic and illicit-substance-using candidates,⁴ which briefly outline the medical and social factors that transplant teams will consider when assessing these rather more "difficult" cases (which include social environment and criminal justice issues).

In the United States, the United Network for Organ Sharing (UNOS) administers the Organ Procurement and Transplantation Network (OPTN).⁵ Together they oversee the procurement and transplantation of all donor organs nationwide. The organ transplant process for candidates in the United States is similar to that of the United Kingdom: patients must undergo a rigorous medical and personal assessment by a transplant team before being listed on the National Database (UNet) to await a donor organ. Unfortunately, UNOS and the OPTN have not published any protocols or guidelines relating to the assessment of transplant candidates, suggesting that transplant teams in the United States is that they consist of surgeons, financial advisers, physicians, nurses and social workers, and they must assess the patient's medical and psychiatric history, social support and commitment.

In both countries, transplant teams have the unenviable task of deciding, after a rigorous candidate assessment, who is suitable for a donor organ and whereabouts on the waiting list he or she should be placed. The later process of organ allocation employs strictly medical considerations in both countries, and thus questions of morality rarely occur once a candidate has been listed. It is therefore during the candidate assessment process in both countries that the difficult medical, social and moral dilemmas originate. Making moral judgments about certain candidates during the assessment process may be inevitable in light of the shortage of organs. Even though NHSBT in the United Kingdom has previously published national guidelines outlining the ways in which particularly vulnerable

³ See Guidelines (2009), n 2, p 4 at [3.2].

⁴ Liver Advisory Group, Alcohol Guidelines, UK Liver Transplant Group Recommendations for Liver Transplant Assessment in the Context of Alcohol-related Disease (November 2005); and Liver Advisory Group, Recommendations for Liver Transplant Assessment in the Context of Illicit Drug Use (NHSBT, May 2007), <u>http://www.organdonation.nhs.uk/ukt/about_transplants/organ_allocation/liver/liver.jsp</u> viewed 16 August 2010.

⁵ See UNOS, <u>http://www.unos.org</u>; and Transplant Living, <u>http://www.transplantliving.org</u> viewed 16 August 2010.

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¹ See *NHS Blood and Transplant*, <u>http://www.nhsbt.nhs.uk</u> (viewed 16 August 2010) for organ transplant regulations, protocols, guidelines and statistics.

² Liver transplantation has been used as the United Kingdom example in this article. See "About Transplants" and "Organ Allocation" in *Liver Transplant Services: Donor Organ Use – Protocols and Guidelines for Adults Undergoing Cadaveric Liver Transplantation* (November 1999, rev 2009) (Guidelines), <u>http://www.organdonation.nhs.uk/ukt/about_transplants/organ_allocation/liver/liver.jsp</u> viewed 16 August 2010.

candidates should be assessed for transplantation by transplant teams s,⁶ UNOS and the OPTN in the United States have provided no such guidelines, instead preferring each transplant hospital (there are about 200 in the United States) to create their own candidate assessment criteria.

How do NHSBT and UNOS morally justify their often controversial decisions when no significant medical, social and ethical guidelines are in place to ensure an objective and fair assessment process? Is a lack of consistency in a candidate's best interests?

A DETAILED ANALYSIS OF THE ETHICAL PRINCIPLES AVAILABLE TO UNITED KINGDOM AND UNITED STATES MULTIDISCIPLINARY TRANSPLANT TEAMS

Such a detailed analysis of medical law and policy would not be complete without the study of medical ethics, which describe the moral obligations that medical professionals have towards their patients. Any transplant candidate assessment guidelines that are implemented by NHSBT or UNOS will also be strongly underpinned by these moral obligations. Transplant teams must juggle many medical and social considerations when assessing transplant candidates, but three allocation principles in particular – the "best bet" principle, the need principle, and the moral worth principle – are considered to be particularly relevant to candidate assessment. Their influence over United Kingdom and United States transplant teams, the assessment process, the moral complications that they bring, and their effect on the candidate's prospects are now examined in detail.

The "best bet" principle

How do we measure value? Dependants, morals, age, time left, quality of life left, usefulness in society?⁷

The "best bet" principle is similar to the consequence-based theory of utilitarianism. The best-known form of utilitarianism is that of Jeremy Bentham (1748-1832), who originally submitted that actions should aim towards producing the greatest good for the greatest number by maximising pleasure and minimising pain. Efficiency and productivity are encouraged in utilitarianism by weighing the biggest gains against the least effort and cost. It looks past the needs of the individual to bring benefits to society as a whole. Morality does not play a significant role in this theory, as its main concern is the consequences of a particular action and the benefit to be derived as a result.⁸

The "best bet" principle in organ transplantation would traditionally overlook the duty to save the sickest with the need to balance benefits against burdens. Put another way, in order to allocate a scarce resource to a patient, that allocation must be efficient, practical, and it must bring about a benefit to society. Patients who are labelled as marginal, gravely ill or worthless to society will find their rights and needs sacrificed for those who belong to a larger, more resourceful group. Harris sums up the unfeeling nature of utilitarianism in regard to saving lives:

[W]hile we should favour length of life, where numbers of lives balanced against one another are equal, we should favour numbers of lives where, summed together, they yield a greater contribution to the total amount of life-time saved.⁹

When applying the "best bet" principle to the assessment of transplant candidates, candidates will be judged according to their medical utility and the benefit to be derived from that action. When the resource in question is scarce, social utility must be considered too, and this is when particularly

⁶ See Guidelines (2009), n 2; Liver Advisory Group, n 4 (2005); see also United Kingdom, Department of Health, *National Liver Transplant Standards* (August 2005), <u>http://www.organdonation.nhs.uk/ukt/about_transplants/organ_allocation/liver/liver.jsp</u> viewed 16 August 2010. These National Standards established the framework for NHSBT.

⁷ Harris J, *The Value of Life: An Introduction to Medical Ethics* (Routledge, London, 2002) pp 87-110.

⁸ For further research in relation to utilitarianism and scarce organ allocation, see Glover J, *Causing Death and Saving Lives* (Penguin, London, 1977); Beauchamp T and Childress J, *Principles of Biomedical Ethics* (5th ed, Oxford University Press, Oxford, 2001); Smith II GP, "Distributive Justice and Health Care" (2002) 18 *Journal of Contemporary Health Law and Policy* 421; Hope T, Sprigings D and Crisp R, "Not Clinically Indicated': Patients' Interests or Resource Allocation?" (6 Feb 2003) 306 BMJ 156; Benjamin M, "Transplantation for Alcoholic Liver Disease: The Ethical Issues" (1997) 3(3) *Liver Transplantation and Surgery* 148.

⁹ Harris, n 7, pp 87-110.

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complex moral problems begin to emerge. Further "best bet" considerations, in addition to medical utility, can include measuring the "value" of the candidate's life (including age), and measuring the "social worth" of the candidate (including environmental factors, criminal history and social support).

The scarcity of human organs means that they must be handled like precious resources. They must not be wasted. They must be allocated to the patient who will derive the best use out of them. It follows from this that when a transplant team comes to measuring utility, a transplant candidate must be the cream of the crop: young, fit, healthy, useful to society, and likely to survive for a long time after transplantation. The measurement of a candidate's medical statistics will therefore be paramount when deciding who should be listed for a scarce organ in line with this theory, because efficiency is at the forefront of "best bet" considerations. However, the nature of "best bet" means that a candidate's medical characteristics may not necessarily fall in the candidate's favour if they are particularly grave. For example, statistics linked to chances of survival; transplant success rate; likelihood of abstinence from dangerous substances; age; motivation and immune status will only sway in favour of the candidate if the prognosis is good. If prognosis is grave, the candidate elderly, the chances of survival slim, and the candidate's immune system poor, no matter how urgent the condition, the candidate may be deemed an "inefficient" use of scarce resources and her or his place on the transplant list may be sacrificed for another, more favourable candidate. This idea of the "best bet" seems controversial in the field of medicine, but organ transplantation is unique. There are not enough organs to go around. Why not share the organs out according who will get the best use out of them? In the United Kingdom, NHSBT has given transplant teams significant discretion when assessing particular candidates, but its collection of national transplant candidate assessment guidelines does include the following utilitarian factors: reason for liver failure; medical history; local environment; social support; psychological problems; past non-compliance; criminal record; and motivation.¹⁰ In the United States, no national protocols have been developed or published by UNOS as a way of monitoring transplant teams during the candidate assessment process. This also means that its decisions cannot be measured for objectivity and consistency. Individual State transplant centres only provide limited directions on their websites, using words such as "medical tests", "examination", "review", or "psychological evaluation".¹¹ The Final Rule (1999)¹² does promise to

standardize the criteria for determining suitable transplant candidates through the use of minimum criteria (expressed, to the extent possible, through objective and measurable medical criteria) for adding individuals to, and removing candidates from, organ transplant waiting lists...

but no such minimal, objective, measureable, medical criteria have been developed on a national level.¹³ It is therefore anticipated that, if a transplant team in the United States is faced with a particularly difficult candidate (ie an alcoholic or an illicit drug user), they would simply measure "best bet" criteria close to those seen in NHSBT assessment guidelines, and these include social as well as medical considerations (ie support systems in place to help administer post-transplant care, etc). Age is a particularly difficult "best bet" criterion for a transplant team to evaluate. It is conceded that there may be little benefit in providing a 100-year-old patient with a new liver when her old immune system could not cope with the rigorous treatment program, but when a younger and stronger patient could derive much more benefit from the donor organ, how would a transplant team ethically justify the exclusion of the elderly patient? Harris¹⁴ puts forward an extreme version of utilitarianism – the "fair innings" theory – which suggests that every citizen, when he or she reaches a certain age, is entitled to no more:

¹⁴ Harris, n 7, pp 87-110.

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¹⁰ Factors listed in Guidelines (2009), n 2; Liver Advisory Group, n 4 (2005); and United Kingdom Department of Health, n 6. ¹¹ Terms taken from the official websites of the following State medical centres in the United States: the South Texas Transplant

Center; Massachusetts General Hospital Transplant Center; and the Transplant Center at the Nebraska Medical Center. ¹² The Federal regulation which established the OPTN, published by the Department of Health and Human Services in the

United States, at Pt 121, s 121.8(b)(1).

¹³ If they have been published in individual States, no mention is made of them on official transplant centre websites and they are not available to the general public.

How can it be just that someone who has already had more than her fair share of life and its delights should be preferred or even given an equal chance of continued survival with the young person who has not been so favoured? The fair innings argument takes the view that there is some span of years that we consider a reasonable life, a fair innings ... having reached it, they have received their entitlement. The attraction of the fair innings argument is that ... it allows us to preserve our feeling that the old who have had a good run for their money should not be endlessly propped up at the expense of those who have not had the same chance.

In order to establish whether a patient has reached their fair innings, personal factors such as health, finances, lifestyle, environment, goals, dependants and attitude will need to be assessed by a transplant team, leading to judgments of "value" and "worth". Moral worth is an almost impossible faculty to measure, and by concluding that a candidate has reached her or his fair innings is to say that a candidate's life is no longer worth saving. This is not an entirely ethical way to assess transplant candidates, and it would inevitably discriminate against a large portion of society.

Unfortunately, "best bet" considerations may not stop at medical characteristics such as age. This principle also requires "risk factors" to be measured by transplant teams in order to categorise candidates as "efficient". For example, it may not be considered an efficient use of resources to give a liver to an alcoholic patient who shows no signs of motivational abstinence during her or his after-care program, or a new heart to a murderer on death row, as these allocations would not provide the "greater benefit" that is sought, or offer a very good quality of life for the organ. Many patients from all walks of life could potentially be excluded from transplantation by transplant teams under "best bet" principles if they engaged in risky recreational activities. Harris notes, however, that a life is only of any value if it is lived as the patient chooses:

To many, life is only worth living if it can be lived as they choose. And this choice might involve the risk to health of living life "to the full" with drunkenness, debauchery, and every other kind of dangerous vice.¹⁵

It may seem unfair to remove candidates from the transplant waiting list simply because they enjoy energetic pursuits, but, when it comes to preserving a scarce organ, might it be in the best interests of the other waiting candidates and society in general if low-risk patients were considered for transplantation first? This could simply be viewed as a more responsible approach to resource allocation. In the United Kingdom, different risk factors are assessed by transplant teams depending on the organ sought. For example, regarding livers, when assessing the primary reason for the candidate's liver failure, the risk factors to be measured by transplant teams must "discriminate consistently and be clinically meaningful; be objective and measureable; be fair; and cannot be (or unlikely to be) modified".¹⁶ Unfortunately, no risk factors are thereafter listed by NHSBT to enable transplant teams to accurately evaluate an alcoholic candidate's risk of relapse (which will inevitably include social, environmental and psychological factors) but we know that an objective and meaningful benchmark has been set in order to safeguard the patient's best interests. In the United States, even though nothing is known of the transplant candidate assessment process, the Final Rule provides a rather inspirational goal for the OPTN: "organ allocation policies shall be designed to avoid wasting organs, avoid futile transplants, and promote patient access^{7,17} This regulation refers to organ allocation rather than assessment, but if the OPTN is to prevent all "futile" transplants from taking place, then surely it is transplant teams which must prevent all "futile" candidates from being forwarded onto the national transplant waiting list? This suggests that transplant teams must evaluate more than merely medical criteria. The Final Rule thus implies that the OPTN must develop objective, measurable criteria to enable transplant teams to assess a wide variety of problematic candidates consistently, fairly and ethically. Since it appears that this has not happened, how is the OPTN avoiding futile transplants and rejecting futile candidates with consistency and ethical integrity? What is known about the United States system is that a psychiatrist must draft a report on the following six factors:

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¹⁵ Harris, n 7, pp 222-225.

¹⁶ See Liver Advisory Group, n 4 (2005) p 2.

¹⁷ See Final Rule, n 12, s 121.8(a)(5). No further guidance is given.

- the candidate's strengths and weaknesses as indicated by the medical and psychiatric history and current symptoms;
- history of compliance;
- social support;
- coping and personality;
- cognitive status and understanding of the transplant procedure; and
- expectations, commitment and motivation.¹⁸

It appears that social utility is an important factor in candidate assessment in both countries: the most efficient candidate appears to be evaluated against her or his physical and psychological capabilities in the context of the candidate's social environment. The answers to all of these questions will reveal whether:

- the candidate will be an efficient host for the scarce organ (ie factors of abstinence, support, motivation), and
- whether the transplant has a reasonable prospect of being a success (including age, health and blood match).

Social worth is another "best bet" consideration for three simple reasons:

- it would provide a greater benefit to society to provide a scarce organ to a good citizen as opposed to a bad citizen;
- the benefit of the scarce resource can be shared out among society; and
- it maintains public support for organ donation.

The rationale behind this theory – efficiently enhancing the greater good – seems simple, but the lines are not clear. Who is a "good citizen" and how much of a contribution should they make to society in order to be eligible for a transplant? Are prostitutes and murderers actually prevented by transplant teams from progressing onto transplant waiting lists? Beauchamp and Childress support the latter idea:

Judgments of comparative social worth are acceptable in some situations. For example, in an earthquake when some injured survivors are medical personnel who suffer only minor injuries, they justifiably receive priority of treatment if they are needed to help others. A person may receive priority for treatment on grounds of social utility only if his or her contribution is indispensible to attaining a major social goal. If we limit exceptions based on social utility, they do not threaten the ordinary moral universe or imply the general acceptability of social-utilitarian calculations in distributing health care.¹⁹

It depends on public opinion as to whether this idea threatens the "moral universe". Subjectivity is a big obstacle to this proposal. Each person will feel that they are valuable in their own way, and will be repulsed to learn that they do not contribute enough to society to enable them to compete for a life-saving organ. It would also probably not be deemed as ethical to place citizens into "categories of worth" in this way. Interestingly, in the United Kingdom the Department of Health has published *National Liver Transplant Standards*, which state:

it is generally accepted that patients with alcoholic liver disease are likely to develop disease in their new liver if they continue to abuse alcohol. *Such patients are also likely to be non-compliant with medication and clinic visits* ... are *usually* regarded as *unsuitable* for liver transplantation.²⁰

This rather unfair assumption of non-compliance and negativity on the part of alcoholic candidates would be rather disappointing for a candidate who genuinely wanted to get better. Perhaps social utility should be expressly removed by NHSBT and UNOS from the ethical options available to transplant teams when assessing candidates. This would, of course, require the publication of assessment guidelines, but it would allow for objectivity and impartiality.

¹⁸ This further information was found at <u>http://www.psychiatryonline.org</u>, after a fruitless search was carried out at <u>http://www.unos.org</u>, <u>http://www.transplantliving.org</u> and <u>http://www.optn.transplant.hrsa.gov</u> viewed 16 August 2010.

¹⁹ Beauchamp and Childress, n 8, p 271.

²⁰ See United Kingdom, Department of Health, n 6 (emphasis added). A more "forgiving" approach has been taken by NHSBT, potentially through fear of bad publicity.

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If multidisciplinary transplant teams choose to apply the "best bet" principle when assessing transplant candidates, there appears to be significant room for discretion, inconsistency and subjectivity. Some highly personal assessment considerations – such as social environment, psychology, criminal record and motivation – may lead to deeply personal and discriminatory decisions by transplant teams. This in turn could lead to public criticism regarding morality-based organ allocations. Is this in the best interests of the patient? "Best bet" as a patient assessment ethic has one major factor in its favour: practicality. There is a guarantee under utilitarian-type principles that the scarce organ will be allocated efficiently (ie the transplant teams will forward the "best bet" candidates onto the waiting list). A combination of many utility factors – including age, blood type, tissue match, immune status, size of organ, social support, finances, motivation and past abstinence from medical care – will ensure a successful and long-lasting graft. However, significant ethical problems with the "best bet" principle may include:

- the forming of moral judgments about a candidate;
- excluding the weaker and minority candidates;
- giving no consideration to the feelings of individuals;
- rejecting the elderly, the gravely ill, the mentally ill, the risk-takers, the minorities, the unemployed, and the addicted from the waiting list unless it can be proven that the transplantation will be efficient and will contribute to the greater happiness; and
- the impossibility of devising regulations or benchmarks against which to measure transplant teams when assessing these criteria. Social considerations (such as past criminal convictions and social environment) play no part in calculating graft success, which is traditionally dependent on medical criteria such as blood and tissue match. Perhaps it depends on the candidate's personal circumstances as to whether such considerations are in her or his best interests.

The need principle

A critical question for an allocation system is to find an appropriate balance between urgency and efficiency. Some will argue that the urgency of patients' needs for organs should always take precedence over their likelihood of having good outcomes. To turn a dying patient away because of a lower chance of survival, it is argued, violates our duty to help the most urgently ill patients.²¹

The need principle is founded upon the Hippocratic Oath which underpins the practice of modern medicine. It states with refreshing simplicity that the patient's best interests are paramount: "I swear ... to follow the method of treatment which, according to my ability and judgment, I consider for the benefit of my patients."²² This is a universal moral duty to help those who have the shortest time left to live, or are in the bleakest of predicaments, and medical care should be provided regardless of the patient's age, ethnicity, finances, social standing, religion or behaviour. Unsurprisingly, the need principle is considered to be the "ideal" in medicine, as it abolishes discrimination and promotes charity, humanity, kindness and goodwill. Schneiderman and Jecker explain how this principle can overcome discrimination in the medical profession:

As a profession, physicians owe (even if they do not always uphold) the ideal of service to anyone in need who can benefit from medical treatments – even murderers – without regard to ethnic, racial, societal or economic factors. And although this ideal may be compromised when physicians face resource limitations, we would argue that the ideal nevertheless remains. We would still argue that the primary obligation of physicians remains to act in the best interests of their patients.²³

According to the need principle, the relationship between a doctor and a patient is based on trust. A doctor can make a medical judgment to ascertain the best treatment for a patient, but he or she is not

²² Hippocrates 460-377 BC. For the full Oath in a medical context, see Furrow BR, Greaney TL, Johnson SH, Jost TS and Schwartz RL, *Bioethics: Health Care Law and Ethics* (4th ed, West Group, 2001) p 27.

²³ Schneiderman LJ and Jecker NS, "Should a Criminal Receive a Heart Transplant? Medical Justice vs Societal Justice" in Caplan and Coehlo, n 21, pp 294-304.



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²¹ Ubel PA, Arnold RM and Caplan AL, "Rationing Failure: The Ethical Lessons of the Retransplantation of Scarce Vital Organs" in Caplan AL and Coelho DH (eds), *The Ethics of Organ Transplants: The Current Debate* (Prometheus Books, USA, 1998) pp 260-274.

qualified or entitled to make a moral judgment about a patient for any purpose. Citizens are therefore not merely treated as a means to an end, but rather, their best interests are considered to be the primary concern, showing respect, transparency and impartiality. Most health care systems around the world implement this needs-based policy. Intensive care wards, children's wards and emergency departments in hospitals are excellent examples of this.

In relation to organ transplantation, the need principle suggests that every patient who is awaiting an organ transplant should receive one, not only because it is in their best interests but because it is the moral duty of the medical profession to provide the best care for every patient.²⁴ In practice, it is not possible to do this for two reasons:

- transplant teams must consider more than a patient's medical statistics (particularly mortality rate) if they are to treat scarce resources responsibly, place efficient candidates on the national transplant waiting list, and avoid numerous re-transplants; and
- there are simply not enough organs available to transplant into all the urgent patients.

When it comes to the allocation of organs, both the United Kingdom and the United States show a strong dedication towards the "need" by transplanting urgent candidates first, but the selection process in both countries does consider other "best bet" factors, such as blood match, age and organ size. This combination of ethics opens the scope for more candidates to be eligible for transplantation. For example, in the United Kingdom, patients with only days or hours left to live are considered "super urgent", and along with a blood match, they are the primary candidates for transplantation.²⁵ UNOS in the United States has developed a mortality scoring system (particular to liver transplants) entitled "the MELD score". It is based on blood test results which measure liver and kidney function. The most gravely ill candidates are given a higher score with the aim of transplanting those individuals first. Points can also be added for blood match and waiting time.²⁶ It is encouraging to see the "need" and "best bet" principles working in harmony in practice, but how much of a role does the need principle play during the earlier process of candidate assessment? During assessment, the main aim of a multidisciplinary transplant team is to assess whether a candidate is suitable for transplantation. This rationale underpins the entire assessment process. Is it possible that needs-based considerations, such as mortality rate and appropriate treatment options, could be overshadowed by "best bet" factors (both medical and social) which could influence transplant teams to assess candidate characteristics beyond the ambit of those which are reasonable or fair?

As a starting point, transplant teams in both countries will perform medical tests on the candidate during the assessment process to ensure that any available donor organ can be matched to the candidate's physical characteristics. The candidate's mortality rate (ie level of urgency) will emerge from these test results, but the primary purpose of the tests is to ensure an efficient graft match. The candidate will also undergo a thorough personal assessment process with numerous specialists, including dieticians, surgeons, financial advisers (particularly in the United States) and psychologists. These examinations and the results derived from them go beyond considerations of "urgency" or "best treatment" and delve into the candidate's needs, goals, history, limitations (physical and psychological) and lifestyle. This thorough process may allow a transplant team to see the "bigger picture" when deciding what is in the "best interests" of the candidate, or, the assessment of a plethora of social factors may simply discriminate against the candidate on personal, social or moral grounds. It is certainly in the candidate's best interests to ensure that he or she undergoes a thorough medical

²⁵ See Liver Organ Sharing Principles (July 1999) at [B.4], <u>http://www.organdonation.nhs.uk/ukt/about_transplants/organ_allocation/liver/liver.jsp</u> viewed 16 August 2010.

²⁶ See *Policy 3.6: Allocation of Livers* (March 2010) at [3.6.2] and [3.6.3], on official UNOS and OPTN websites, n 5 above, under "Policies".

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²⁴ For further research specific to duty-based ethics and organ transplantation, see Nelson JL, *Hippocrates' Maze: Ethical Explorations of the Medical Labyrinth* (Rowman & Littlefield, New York, 2003); Harris J, "Organ Procurement: Dead Interests, Living Needs" (2003) 29 *Journal of Medical Ethics* 130; Blank R, *Rationing Medicine* (Columbia University Press, New York, 1988); Higgs R, "Human Frailty Should Not Be Penalized" (17 April 1993) 306 BMJ 1049; and Ubel PA, "Transplantation in Alcoholics: Separating Prognosis and Responsibility from Social Biases" (May 1997) 3(3) *Liver Transplantation and Surgery* 152.

assessment to enable a perfect graft match, but it is not clear whether the inclusion of some rather personal considerations in the assessment process could *support* the needs-based principle or *undermine* the candidate's best interests. It may depend on the candidate's situation (ie the organ failure may be due to the candidate's own reckless behaviour) as to whether the overshadowing of urgent medical considerations with personal or social evaluations could scupper her or his chances of treatment. A transplant team would probably think it more practical to forward onto the waiting list for transplantation a candidate who was able to stick to a post-operative care program, who was able to remove herself or himself from harmful environmental or social pressures, and who was fit, young and strong. It appears that the candidate's "urgency status" will play a significant role in where the candidate is placed on the waiting list and how soon he or she will receive an organ, but beyond these future roles, it does not play any further role in the assessment process. Perhaps only by combining ethical theories can we truly ensure that the best interests of the donated organs *and* of the waiting candidates can be met.

As long as human organs are scarce, it will always be deemed most appropriate to transplant urgent candidates first. However, the need principle may need "a little help" when the resource in question cannot reach everybody. When a life-or-death decision is made during the assessment process about who is, or who is not, to be placed on the waiting list, the need principle will not suffice on its own as an assessment ethic. With no utilitarian-style filter in place, a needs-based transplant list would simply house only *gravely* ill candidates, including those who are completely unsuitable for transplantation as a result of their lack of motivation, lack of support, or bad prognosis etc. In conclusion, the "best bet" principle and the need principle work quite well together during the patient assessment process in both countries, although transplant teams may need to find the right balance.

The moral worth principle

We might think there was something wrong in giving the only available lung to the person who has destroyed his own lung through smoking, and showed every sign and intention of doing the same to his new lung, rather than, say, giving it to the woman next door whose need for a new lung has been in no way self-inflicted.²⁷

During the candidate assessment process, the freedom and discretion bestowed upon multidisciplinary transplant teams lead to one major concern in both countries: the opportunity for inconsistent decisions. In the United Kingdom there are national guidelines available for transplant teams and the public to illustrate the general boundaries (both medical and social) of assessment,²⁸ but no protocols exist in the United States to safeguard against such inconsistencies.²⁹ Public support is vital to the field of organ transplantation, and careless organ allocations may see public support wane considerably. Should particular individuals be automatically turned away from transplantation to reflect the public mood? Can transplant teams make moral judgments behind closed doors? If so, how far do transplant teams have to go to justify their controversial decisions, if at all?

The moral worth principle is adopted from virtue-based ethics, which were conceived by St Thomas Aquinas and developed by the ancient Greek philosopher Aristotle. Good personality traits were divided into highly valued moral virtues, such as courage, patience, integrity, trust, respect, empathy, generosity and honesty.³⁰ Virtue-based ethics value the moral integrity of individuals, and support the idea that we must all behave altruistically. Those who do not behave in this manner (eg murderers) may possess a depleted moral worth and may be undeserving of certain scarce resources.³¹

³⁰ See further, Howard P and Bogle J, Medical Law and Ethics (Blackwell Publishing, Oxford, 2005) p 13.

³¹ In relation to virtuous decisions and scarce organ allocation, see Gillon R, "On Giving Preference to Prior Volunteers When Allocating Organs for Transplantation" (1995) 21 *Journal of Medical Ethics* 195; Eaton S, "The Subtle Politics of Organ

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²⁷ Harris, n 7, pp 222-225.

²⁸ Particularly for problematic patients: see Guidelines, n 2; Liver Advisory Group, n 4 (2005); and United Kingdom, Department of Health, n 6.

²⁹ State discretion appears to be preferred in the United States. The *National Organ Transplantation Act 1984* (US), s 274(b)(2)(N), states that the OPTN shall "attempt to increase transplantation among populations with special needs", but no details are given about tailored assessment procedures for these purposes.

Rational rejection? The ethical complications of assessing organ transplant candidates

The moral worth principle in the field of medicine would mean forming moral judgments about a patient's lifestyle. Happily, it is rare to see such an approach in modern medicine today, as any policies emanating from this principle would simply be deemed old-fashioned, discriminatory and harmful to a patient's best interests. However, the field of organ transplantation throws up an interesting dilemma. The scarcity of human organs means that only certain patients can receive a life-saving transplant. Someone must be selected for treatment at the expense of everybody else. Self-inflicting transplant candidates (ie those who have caused their own organs to fail through their own reckless behaviour) are not viewed as favourably under the moral worth principle as those whose organ failure has occurred out of the blue. When transplant teams move on to assess the reasons behind a candidate's organ failure, self-inflicting patients such as alcoholics, smokers and drug abusers suddenly look particularly vulnerable against the backdrop of the moral worth principle. For example, an alcoholic, "B", who has shown a lack of motivation towards abstinence, who has not complied with medical care in the past, who keeps a dangerous social circle, who is unemployed and homeless, and who is unwilling to communicate, may simply be deemed by a transplant team to be unsuitable for liver transplantation despite possessing perfectly adequate medical statistics. How would a transplant team ethically justify this decision? If we were to do a comparative analysis of ethical approaches, "best bet" considerations would include B's medical statistics, her mental state, her ability to stick to her post-transplant program, her unsupportive environment, and her prospects of success (including the benefit to the greater good). B's transplant team may conclude that her medical statistics allow for a graft match but her negative social utility may see her being excluded from listing if her new organ could be put into jeopardy. The need principle would measure B's mortality rate and conclude that it was in her best interests to transplant her as an urgent case without any further assessment. This approach turns a blind eye to B's alcoholism. All other transplant team considerations - including criminal convictions, family perspectives, doctor views, a bad attitude, and some overlapping utility considerations such as motivation and social environment – are the result of the moral worth principle. They are personal judgments that can morally distinguish B from all other candidates but hold no apparent medical relevance to the success of B's graft. In the United Kingdom, NHSBT has developed assessment guidelines specifically for illicit-drug-abusing candidates who are seeking a liver transplant, and in addition to strict contraindications to listing (such as unexplained non-compliance with past medical treatment), it also lists "potential" contraindications to "allow issues of concern to be factored in without necessarily attempting to weight issues against one another in the absence of good evidence".³² It is interesting that NHSBT would like transplant teams to consider additional potential contraindications for only illicit drug abusers. What kinds of factors could see only a drug-abusing candidate potentially excluded from transplantation? They are listed as follows: substance use in the candidate's wider social group; mental health and criminal justice issues; an insufficient social support network; an unsuitable or unacceptable social support package; a lack of motivation to move away from the drug culture; and a reluctance to agree to treatment. Although it is expressly stated that these additional social factors are included in the assessment process to simply highlight areas of concern, these considerations only reveal the candidate's community environment and social life, not her or his physical and mental ability to undergo a transplantation procedure. It is particularly curious that a transplant team in the United Kingdom can evaluate drug use in the candidate's social circle and assume that the candidate will be "reluctant" to follow treatment. Could these criteria be interpreted as assessing whether the candidate is *morally* suitable for a scarce organ? UNOS in the United States has taken the same approach (albeit informally). As mentioned above, the psychiatrist must report on several factors, including the candidate's history of compliance; social support; coping and personality; cognitive status; understanding of the transplant procedure; expectations; commitment; and motivation.³³ Although the report does contain some utility-type

³² See Liver Advisory Group, n 4 (2007) p 2 at [2.2].

³³ See n 18 above.

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Donation: A Proposal" (1998) 24 Journal of Medical Ethics 166; Harris J, "Could We Hold People Responsible for Their Own Adverse Health?" (1995) 12 Journal of Contemporary Health Law and Policy 147; and McLachlan H, "Smokers, Virgins, Equity and Health Care Costs" (1995) 21 Journal of Medical Ethics 209.

factors such as past compliance, it can be argued that there are significantly more social considerations. Through assessing the candidate's personality, understanding, expectations, commitment and motivation levels, the transplant team is placing a burden on the candidate's social and emotional state to decide whether he or she is suitable for transplantation, even though these factors do not affect the person's medical ability to undergo the procedure or successfully match a graft. Is this practical, or is this simply discriminatory? How far can transplant teams go with the moral worth principle? It would seem highly inequitable of a psychiatrist or a transplant team to declare that a candidate is not suitable for transplantation simply because her or his personality, cognitive status, expectations and motivation were not up to scratch, even if the candidate was genuinely capable of coping. Further difficulties occur when drawing a line between moral and immoral candidate behaviour, making the moral worth principle almost impossible to implement in practice:

There is absolutely no agreement – and there is likely to be none – about what constitutes moral virtue and vice and what reward and penalties they deserve. The fair weighting of such a consideration would entail highly intrusive investigations into patients' moral habits – investigations universally thought repugnant. To accomplish this, we would have to make vigorous and sustained efforts to find out whose conduct has been morally weak or sinful and to what degree.³⁴

Measuring the moral behaviour of a candidate is indeed an almost impossible task. It would involve a significant invasion of privacy and a host of moralistic judgments, which most would find uncomfortable. Are there more clear-cut cases which do not prove so problematic? Can transplant teams justify excluding reckless, self-inflicting patients? Moss and Siegler put forward a bold argument in relation to alcoholic patients:

In view of the dire, absolute scarcity of donor livers, we ... believe that patients with alcohol-related end-stage liver disease are unequal in a relevant respect to others, since their liver failure was preventable. It is only fair that patients who have not assumed equal responsibility for maintaining their health or for accepting treatment for a chronic disease should be treated differently.³⁵

Would society agree with this policy? If so, would it make this policy less unethical for transplant teams to adopt as a formal assessment ethic? There may be some truth behind Moss and Siegler's theory. Alcoholics who drink over many years may show a disregard not only for themselves but for the other citizens in society who may one day need to compete directly against them for a new organ. Cohen et al also argue that the public perception of alcoholics is generally negative, and that the already low rate of organ donation could fall even lower if it becomes known that donated livers are going to alcoholics.³⁶ The last thing organ procurement agencies need is for public support in organ donation to wane as a result of "questionable" organ allocations. Can a happy medium be found? When rejecting a candidate from the transplant waiting list, might it be possible for transplant teams to disguise or justify their "moral" decisions as "best bet" ones? For example, let us assume that a transplant team must assess a policeman and a serial rapist for a heart transplant. Not only would it be *morally* suitable under the moral worth principle to allow the policeman to proceed onto the waiting list rather than the rapist (which means that during the organ allocation process they would not have to compete against each other), but the decision to forward the policeman for transplantation would also enhance the greater good. As a more contentious example, a candidate who keeps a questionable social circle, who shows a bad attitude towards his medical care, and who has been rumoured to have been involved in paedophilic activities, could, in theory, be rejected from transplantation on two grounds: he can either be deemed by the transplant team to be "unsuitable for transplantation as a result of his immoral behaviour, his unsavoury attitude, and his disrespect towards his medical care", or, he could simply be described as "at risk of not complying with his post-transplant treatment due to a lack of appropriate environmental and social support and limited prospects of graft success". The former "moral" policy is more honest, but the latter "best bet" decision is easier to justify.

³⁶ Cohen et al, n 34.

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³⁴ Cohen C, Benjamin M and the Ethics and Social Impact Committee of the Transplant and Health Policy Centre, "Alcoholics and Liver Transplantation" in Caplan and Coehlo, n 21, pp 286-293.

³⁵ Moss AH and Siegler M, "Should Alcoholics Compete Equally for Liver Transplantation?" in Caplan and Coehlo, n 21, pp 275-285.

Once placed on the waiting list by a transplant team, organs are allocated to candidates according to medical criteria (in both countries). Therefore, this sleight-of-hand during the patient assessment process could certainly give transplant teams in the United Kingdom and the United States considerable freedom to reject candidates whose selection they knew would anger the public if they made their way onto the transplant waiting list and received a scarce organ. It may be deemed unethical by some, but no strict guidelines or avenues of redress are currently in place in either country to prevent this practice from happening behind closed doors.

There has been significant public outcry in the past when high-profile offenders, alcoholics or drug abusers in the United Kingdom and the United States have received transplants at the expense of other candidates.³⁷ The use of the moral worth principle by multidisciplinary transplant teams could potentially filter out any "problematic" candidates from the transplant system, but this ethical approach may encourage a more "social" system of organ allocation. The judgmental principles underpinning any "moral" assessment policies would be incredibly difficult for an organ procurement agency to justify, particularly to the family of a rejected candidate who appears to have been excluded from transplantation for no tangible medical reason. If moral considerations do play a considerable role in the candidate assessment process in both the United Kingdom and the United States, perhaps NHSBT and UNOS could develop some clear, national transplant candidate assessment guidelines to promote objectivity, transparency and trust. Further protocols to allow for redress and formal justification could also be implemented in both countries to allow for a candidate – who feels he or she has been unfairly discriminated against – to seek a formal justification for the negative decision.

CONCLUSION

The "ideal" in medicine is that every patient has equal access to life-saving treatment. In many areas of medicine, this ideal is realised. The field of organ transplantation is different. The resource in this instance is so rare that many patients die while awaiting their treatment. It therefore makes sense to think carefully and discriminately about the allocation of organs to ensure not only that the donor organ is not wasted on a patient who, for whatever reason, cannot carry the organ successfully, but that public support for organ donation remains steady.

As highlighted above, NHSBT in the United Kingdom and UNOS in the United States allocate organs using mainly medical criteria, but their multidisciplinary transplant teams, who critically assess potential transplant candidates to ascertain their suitability for transplantation, have several ethical principles available to them when assessing candidates. First, they can assess the candidate's medical status to confirm her or his level of urgency using the need principle. The universal moral duty bestowed upon medical professionals to save those who are the most in need means that a blind eye is turned to the candidate's personal and social characteristics when calculating the candidate's best interests. This ideal is met in most areas of medicine. As an alternative view of the need principle, could *patients* have a moral duty to preserve scarce medical resources? The notion that we have a moral duty not to put our own organs at risk is not as far-fetched as it seems. Drug abusers, alcoholics, smokers and the obese are all encouraged by the United Kingdom and the United States governments to manage their health problems in order to minimise the financial and administrative strain on the national health systems. Both countries have launched a myriad of self-help programs and incentives to enable "problematic" patients to find support and counselling for their addiction.³⁸ If these patients are encouraged to take responsibility for their own actions, perhaps we would no longer burden a duty to save them at the expense of ourselves.

Secondly, multidisciplinary transplant teams may use calculations of medical and social utility to assess a potential transplant candidate under the "best bet" principle, which strives to maintain

³⁸ In the United States, see <u>http://www.smokefree.gov; http://www.drug-alcohol-rehabs.org;</u> and <u>http://www.nutrition.gov</u> viewed 16 August 2010. In the United Kingdom, see *NHS Stop Smoking Services & Nicotine Replacement Therapy; Safe, Sensible, Social: The Government's Alcohol Strategy;* and *Healthy Weight, Healthy Lives: A Cross-Government Strategy for England, <u>http://www.dh.gov.uk</u> viewed 16 August 2010.*

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³⁷ George Best was a high-profile case in the United Kingdom: see "Best Deters Organ Donations", *BBC News* (15 December 2003), <u>http://www.news.bbc.co.uk/1/hi/england/3321153.stm</u> viewed 16 August 2010. Mickey Mantle was the controversial United States case: see Munson R, *Raising the Dead* (Oxford University Press, Oxford, 2002) Chs 2 and 3.

efficiency for the greater good. This principle connects rather closely to the thought processes underpinning organ donation and transplantation. The general public, eg, who altruistically donate the scarce resource, may carry with them the expectation that their donated organs will be allocated sensibly (ie they will not be wasted). It is also logical to allocate a *scarce* resource efficiently so that it can bring about a large benefit to many recipients. However, the "best bet" principle by its very nature as a candidate assessment strategy employed by transplant teams may actually discriminate against many but benefit very few. The only real entity to benefit from the application of utilitarian-type ethics to the candidate assessment process is the organ itself, which will be forwarded to a waiting list full of "best bet" recipients. Society may also benefit from a "best bet" transplant candidate assessment policy, but the needs and values of individual candidates may be lost in the process.

Thirdly, transplant teams can assess transplant candidates based on their moral and social behaviour. The application of the moral worth principle to candidate assessment would provide NHSBT and UNOS with waiting lists full of "morally deserving" transplant candidates. In practice however, because this assessment strategy is not connected to medical criteria in any way, successful candidates may not be medically suitable for transplantation, leading to many unsuccessful grafts. Transplant teams may also acquire a reputation as "God Squads", passing moral judgment upon those who seek their precious resource.

As a fourth option, transplant teams could use a combination of ethical principles in order to select perfectly suitable candidates. This appears to be the preferred method in both countries, and this combination of ethical approaches enables transplant teams to take account of a patient's best interests while choosing efficient and deserving candidates.

NHSBT has promised on its website to allocate organs "in a fair and unbiased way".³⁹ UNOS has published the following similar pledge: "when you are on the waiting list for an organ, what really counts is the severity of your illness, time spent waiting, blood type, and other important medical information, not your financial status or celebrity status."⁴⁰ It has been shown that both countries keep to these promises when allocating scarce organs by using medical calculations, but when it comes to assessing potential candidates earlier on in the transplant process, the decisions behind closed doors may not be so objective. During organ allocation, "need" and "best bet" work well together to ensure the best graft match for the most urgently ill candidates. During candidate assessment, the decision-making process is largely unregulated, making it difficult to determine exactly which ethical, medical, moral or social considerations have influenced the transplant team's decision when a particular candidate is excluded from the transplant waiting list. It has been shown that United Kingdom transplant teams will assess much more than medical criteria. They have developed only basic national assessment guidelines which contain very limited safeguards against the use of moral, unethical or discriminatory decisions, but their guidelines do provide an insight as to what a candidate can expect. The United States has not published any national candidate assessment protocols as yet, allowing for transplant teams to assess all candidates behind closed doors using a wealth of discretion. This adds to the likelihood of subjective and inconsistent decisions. UNOS falls especially short of providing safeguards to protect "difficult" candidates such as alcoholics or illicit drug-users from discriminatory evaluations. The ultimate verdict of who lives and who dies may therefore be determined by whichever ethical principle the transplant team feels is appropriate at that particular time. We therefore appear to see a completely different ethical rationale underpinning the *allocation* of organs as opposed to the candidate *assessment* process in both countries, leaving a moral paradox in the human organ transplantation system.

Although it is difficult to find a happy medium in this area of medicine, further transparency and avenues of redress would build patient trust and would contribute to meeting the best interests of the patients.

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³⁹ See http://www.nhsbt.nhs.uk viewed 16 August 2010.

⁴⁰ For further "myths and facts" see newsroom area of <u>http://www.unos.org/news</u> viewed 16 August 2010.