Ethics- death the final taboo

Dr. Les Gemmell
FRCA MA
TITLE

Is organ procurement for transplantation hindered by the ethical and legal framework in the UK?

HYPOTHESIS

Organ donation requires an altruistic “gift” from society; do ethical and legal issues act as a barrier to organ procurement in the UK?
Death is certain, since it is inevitable, but also uncertain, since its diagnosis is sometimes fallible.

Jacques-Benigne Winslow, 
Danish Anatomist: 
*Morte incertae signa*, 1740
Number of deceased donors and transplants in the UK, 1 April 1997 - 31 March 2008, and patients on the active transplant lists at 31 March
The prime goal is to alleviate suffering, and not to prolong life. And if your treatment does not alleviate suffering, but only prolongs life, that treatment should be stopped.

Christiaan Barnard
Introduction

• We have a real problem to face up to:

  ❖ 100s die each year on a transplant waiting list, many more do not even make it onto the list.

  ❖ The number of people needing a transplant is expected to rise steeply over next decade.

  ❖ The pool of heart beating organ donors is shrinking
Donation after Cardiac Death

- NHBD or DCD now offers a viable alternative source for some organs.
- Strong utilitarian argument (good outweighs the harm)
- DCD is the answer to increasing donor organ pool

- But there are some concerns:
  - DCD poses serious **ethical** questions which are yet to be adequately answered
  - Could DCD create more harm than the perceived good.
Consequences

• UK transplant program relies on society’s assent.

• It relies on public good will and confidence in the processes involved.

• We cannot ignore public sensibilities purely on grounds of medical utility.

• Loss of support can lead to devastating consequences.
“What is truly distinctive about transplantation is not technology or cost, but ethics.”

“If there were no gift of organs or tissue, transplantation would come to a grinding halt.”

Arthur Caplan---testifying to US Congress 1990

Emanuel and Robert Hart
Professor of Bioethics
University of Pennsylvania
Ethical issues
- Planning for independent Ethics group completed
- Home established
- High profile chair

Legal issues
- QC opinion received
- Being translated into policy statement
The courts have established that best interests are wider than simply treating a person’s medical condition and include a person’s social, emotional, cultural and religious interests.

Take full account of the person’s previously expressed wishes, general preferences and beliefs.
Benefits of transplantation:

• To the individual:
  – cessation of dialysis
  – improved quality of life
  – Saving lives
  – ability to ...
    • Work
    • sport
    • have / bring up family
    • holiday
"To bridge the gap between the need for an organ transplant and the hundreds of thousands of people who die around the world each year, because no transplant is available to them.

A minimum 30% increase in organ donation has been reported by each country that has played host to the World Transplant Games"
Legal Issues

This in part reflects concerns about non-heartbeating donation, and recognises that a possible conflict of interest may be felt between the responsibilities of the doctor to the dying patient, who is a potential donor after death, and uncertainty as to whether the steps taken to facilitate donation are lawful.
Dilemmas

- Decisions on withdrawal of care
- Mode of withdrawal of care
- Pre-mortem intervention
- Location of withdrawal of therapy
- Manner of certification of death
- ‘Quality’ of NHBOD vs. certainty of death
“urgent attention is required to resolve outstanding legal, ethical and professional issues in order to ensure that all clinicians are supported and are able to work within a clear and unambiguous framework of good practice”.

The Organ Donation Taskforce report of January 2008,
Ethical Principles

Conflict is inevitable.
Ethical principles provide the framework/ tools which may facilitate individuals and society to resolve conflict in a fair, just and moral manner.
Ethical Dilemma:

Situations necessitating a choice between two equal (usually undesirable) alternatives.
**Consequentialist/ Utilitarian Arguments**
– ethical argument underpinning donation

**Consequentialism** bases our duties on consequences

• We ought to do whatever maximizes good consequences

**Utilitarianism**
• The good consequence to be maximised is human happiness.
• It doesn’t matter what we do as long as the net effect is increased happiness.
• In medical ethics happiness is equated to physical and mental well being.

**Consequentialists** have argued it is a moral requirement that organs from cadavers be ‘recycled’ to prolong life of the desperately ill.

**Consequentialist** arguments require the good to outweigh the harm, therefore there needs to be:
– Minimal or no harm to donor
– Minimal or no harm to others (e.g. relatives)
Medicalisation of Death

• *Ars moriendi* 1415 – 1450 “how to die well”

• Response of the RC Church to the Black Death
Death—the final taboo

Device to prevent premature burial

Patented and marketed by Count Karnice-Karnicki, chamberlain to the Tsar of Russia, in 1896.

The apparatus allowed the buried to signal that he or she was still alive by activating a flag and ringing a bell. It could be rented for a small amount of money and, after a length of time, when there was no chance of revival, the tube could be pulled up and used in another coffin.
Death is:

• Taboo, hidden away, sanitised
• Deeply personal
• Very human – in contrast to the present, target driven, impersonal era.
• Being “topicalised”, politicised
• Part of our life in community.
The Four Principles
Beauchamp & Childress

• AUTOMONY
• BENEFICENCE
• NON-MALEFICENCE
• JUSTICE

• WHAT ABOUT ADDING:-

VERACITY

http://www.ethics-network.org.uk/
Welcome to the Centre for Death and Society

The Centre for Death and Society (CDAS) is the UK's only centre devoted to the study and research of social aspects of death, dying and bereavement. Established in September 2005, CDAS is an interdisciplinary centre of regional, national and international importance. It provides a centre for the social study of death, dying and bereavement and acts as a catalyst and facilitator for research, education and training, policy development, media, and community awareness.

CDAS has four primary aims:

- To further social, policy and health research
- To provide education and training for academics and practitioners
- To enhance social policy understanding
- To encourage community outreach.

At a time of growing interest and concern for issues of mortality, CDAS is uniquely placed to pursue these aims.

Locally and nationally, research and teaching links are being forged with health professionals, local government, charities, business and the media. Internationally, we are aiming for collaborative research projects, involving visiting professors and researchers. The Centre also
"The medical diagnosis of brain death is at odds with our traditional view of when death actually occur."

Professor Allan Kellehear from the Centre for Death & Society at the University of Bath.

“There has never been a really serious national debate about whether this is socially acceptable, or just medical pragmatism.”

Dr Richard Nicholson
Bulletin of Medical Ethics
"I would argue that these should be social decisions. To better inform these decisions, we need a closer look at the social implications of brain death."

"At present, this understanding is totally lacking from the medical literature on this topic."

Professor Allan Kellehear
By moving the declaration of death as close as possible to the moment when cardiopulmonary function ceases, NHBCD risk taking organs from patients who are not yet dead.
We should not underestimate the cultural significance of heartbeat and breath, and the symbolic importance of the moment in which they cease. Neither is diminished by medical redefinitions of death.

My 16-year-old daughter’s heart saved the life of another teenage girl, and her other organs were used to save or improve the lives of six other people. I still believe in organ donation, but there are facts about the donation process that are emotionally confronting and difficult, and we should be given better information so that we are more prepared for the realities of it. These facts should be made clear to anyone considering organ donation, but especially to those who have to make the final decision. The hospital bedside is neither the place nor the time to discover these facts for the first time.
Organ donation—the role of the media and of public opinion
R. Matesanz and B. Miranda
Organization National de Trasplantes (ONT) Madrid, Spain

• PANORAMA-- OCTOBER 1980
• Organ Register errors
• Hospital Soaps
• Internet
• Other cultures
Events, seminars and symposia

Preparing for Dying –
It’s never too soon or too late!
02 February 2008
Doctor-Patient Relationship

DUTY OF CARE:
• PATIENT
• FAMILY & CARERS

FUTILITY:
• Self-fulfilling prophecy

WITHDRAWAL/WITHHOLDING:
• Timing
Time of Death

The fundamental ethical problem with NHBD

A robust, objective and independent decision has to be made that continuing therapy is futile

Problems:

• Is the situation really futile?
• Can that decision be made objectively?
• Can the decision be shown to be free and independent?
2008 Code of Practice

• Separates the diagnosis of death from organ donation

• Outlines diagnosis of death in 2 different clinical scenarios, following death of the brainstem in a comatose apnoeic patient ventilated in ITU and following cardiorespiratory arrest.
1. DCD donors are a medically and ethically acceptable source of organs.

2. Written protocols approved locally and open to the public.

3. Separate the responsibilities of attending physician from transplant/procurement physicians.

4. Determination of death after 5 minutes without monitored arterial pulse.

5. Families should be fully informed and offered option of attending life support withdrawal.
How does it affect your practice?

- GMC’s guidance now includes a duty to respect the wishes of patients after death.
- NMC: you must respect patients and clients’ autonomy - their right to decide.

It is clear that any decision about the futility of further treatment and whether or not such treatment should be withdrawn must be made purely in the interests of the person and independently of any consideration of possible organ donation.
Wales

Introduction of an opt out (presumed consent) system in the context of Organ Transplantation

Public Debate
2008

BMA News

Doctors praise 'bold' organ donation move

Section: News
Article date: 7 January 2010
By Felicity Waters
A move that could see Wales introducing an opt-out system for organ donation has been welcomed by doctors’ leaders.

Welsh health and social services minister Edwina Hart said this week she would pursue legislation to implement the opt-out system of presumed consent for organ donation that is favoured by the BMA.
“Presumed consent”

For:
• High correlation between “opt out” systems and high donation rates globally
• 60% of public support change in organ donation system
• No legal or ethical barriers to change to “soft opt out” system

Against:
• Potentially damaging to relationship between clinicians and families
• Comfort from gift of donation being lost to families
• “Dehumanising”, “paternalistic”
• Potential for anti-donation campaigning

Organ Donation Taskforce report, 2008
'Opt-out' organ donation plan offers hope to transplant patients in Wales
System of presumed consent could replace donor cards by spring next year

Tracy McVeigh
The Observer, Sunday 9 May 2016

Liver patient Kerrianne Phillips says she cannot imagine life as a healthy young woman. Photograph: Maria Farely/Kidney Wales Foundation

In a television advertisement to be aired in Wales this month, Kerrianne Phillips is filmed in her hospital bed as if it were on death row.

The tiny side room that she shares with piles of sweet wrappers, paperbacks and magazines – and her teddy bear pillow case "brought from home" – appears to be only a step up from a cell. "I have spent half my life in hospital," she says. "This time it's been
Sudden surge of transplants in China coincides with genocide of Falun Gong
Ethics Corner

Checklist: Passport, Plane Ticket, Organ Transplant

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Indian citizens are not permitted to be living donors for IndUShealth patients (Tom Keating, personal communication. IndUShealth, Raleigh, NC, September 2006). Hospitals with IndUShealth referral arrangements include Max Heart, which offers heart transplantation in Saket, India. MaxHeart Hospital, which offers kidney transplantation in

Economic and Health Consequences of Selling a Kidney in India

Madhav Goyal, MD, MPH
Ravindra L. Mehta, MBBS, MD
Lawrence J. Schneiderman, MD

Context: Many countries have a shortage of kidneys available for transplantation. Paying people to donate kidneys is often proposed or justified as a way to benefit recipients by increasing the supply of organs and to benefit donors by improving their economic status. However, whether individuals who sell their kidneys actually benefit

FRI DAY, APRIL 20, 2007

The Smoking Gun: Documenting the Kidney Trade

Yesterday I headed out into the field with my assistant looking for hard evidence of the organ trade. Over the last several months I’ve interviewed dozens of people who have sold their kidneys through brokers at the city’s best hospitals and yet the police have continued to do everything they can to not prosecute the case. They say that the 1994 transplantation of human organs act does not empower them to arrest kidney brokers or shut down hospitals. I’ve written on this problem in the past. As usual, the authorities that be will try anything they can not to uphold the law. More on this later.

In our search of two different slum areas Priya and I uncovered documents signed by doctors at Devaki Hospital demonstrating that they performed illegal surgeries. The documents, her health records, show that she used a forger name as well as the dates of the operation, attendants involved in the surgery, lab techs., drawings of her kidney and signatures from both doctors and hospital administrators. In other words, I have the smoking gun.

Filipino men showing their scars from kidney operations, Manila, August 1999
Alternatives

- Increased promotion/education.
- Paid or compensated donor schemes.
- Priority for transplants given to those that have agreed to donate.
- Mechanical engineered organs.
- Biologically engineered organs.
- Living donors.
- Paired/pooled schemes.
- Required referral.
- Aggressive consent pursuit.
- Forced donation.
- Donation after cardiac death donation (DCD).
- Xenotransplantation.
- Presumed consent.
Donation after cardiac death

Number of non-heart beating donations per year, UK

- 1998-9
- 2003-4
- 2007-8
- 2008-9
What are the legal and ethical challenges posed by organ donation?

<table>
<thead>
<tr>
<th>Category</th>
<th>Challenge</th>
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<tbody>
<tr>
<td>Non-Heart Beating Donation</td>
<td>Can treatment be prolonged in order to give retrieval team time to get to the donating hospital</td>
</tr>
<tr>
<td>Transfer from Emergency Department</td>
<td>Is it right to admit someone to ICU, knowing that they will die, just to get their organs</td>
</tr>
<tr>
<td>Donor Stabilisation</td>
<td>Is it fair to stabilise someone’s condition, simply to be able to diagnose brain death</td>
</tr>
<tr>
<td>Early Referral to DTC</td>
<td>When should a member of an organ procurement organisation be allowed to care for the family of a potential donor</td>
</tr>
<tr>
<td>Early Consultation of ODR</td>
<td>At what point should staff be aware that their patient is on the ODR</td>
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What can be done, if anything at all, to maintain the possibility of a patient who is dying but not yet dead of donating organs after death?
What are the most common causes of death of organ donors?

Brain haemorrhage is the most common cause of death for organ donors.

![Pie chart to show most common cause of death of organ donors](image)

<table>
<thead>
<tr>
<th>Cause</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Brain Haemorrhage</td>
<td>62%</td>
</tr>
<tr>
<td>Stroke</td>
<td>6%</td>
</tr>
<tr>
<td>Trauma</td>
<td>8%</td>
</tr>
<tr>
<td>Hypoxic Brain Injury</td>
<td>9%</td>
</tr>
<tr>
<td>Meningitis</td>
<td>3%</td>
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<tr>
<td>Other</td>
<td>12%</td>
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How do you approach a patient who is dying but not yet dead?

Many of the obstacles to donation are overcome by viewing donation as part of end of life care – donation is something we do for patients, not to them.

When a patient is dying but not yet dead

- Establish donation as part of end of life care
- Discuss problematic aspects of donation in your local hospital ethics group
- Always respect unease
- Apply existing professional guidance
- Look out for guidance from Donation Ethics Committee

“These issues should not be particularly difficult, or even that costly to resolve. Overcoming them will require leadership, boldness and willingness to change established practice. The prize for doing so is considerable”

Organs for Transplants
A Report from the Organ Donation Taskforce
UKDEC Work Programme

UKDEC is constituted to provide general advice and guidance. It cannot provide advice on individual cases in real time, this should be provided locally.

UKDEC was first established in January 2010. A short consultation exercise with key stakeholders identified a number of common ethical concerns. From this, the UKDEC drew up its first work programme.

UKDEC welcomes comments and contributions from anyone with an interest in organ donation and transplantation. These can help to shape the work programme, and to ensure that guidance or comment from the Committee reflects issues of most importance to professionals and the public.

Contributions can be sent to donnaline@smrc.org.uk.

Meetings

Meetings are expected to be held four times a year. Meetings scheduled for 2010:

- 9 February
- 30 April
- 17 July
- 10 October

Work Programme

The UKDEC will be covering the following in their work programme for 2010-2011:

- Controlled Donation after Cardiac Death: conflicts of interest
- Controlled Donation after Cardiac Death: technical and organisational issues
- Consent for both donors and recipients
- Ethical issues in organ donation and transplantation research
- Faith and organ donation

Further details will be made available as work progresses. We welcome comments and contributions from anyone who may have an interest in these topics. Please contact us for further details.
ANY QUESTIONS ?