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Problematising the ethics of organ donation after circulatory death in the UK

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Abstract

This commentary addresses the ethics of controlled organ donation after circulatory death (DCD) in the UK, a practice which has recently been revived as part of attempts to increase rates of organ donation. Despite being linked to growth in donor rates, bioethics and clinical scholars have drawn attention to the ethical issues which DCD poses for health professionals, particularly around the requirement to alter the end-of-life care of potential donors. In this commentary, the UK policy response to the ethics of DCD is examined by drawing on Foucault's problematisation approach. This analyses the broader contexts within which the policy version of ethics for DCD has been created, and examines the potential implications of this form of ethics for the work of health professionals. It is argued that the policy version of ethics for DCD has a specific normalising role, which acts as an integral part of the efficiency drive by transplant medicine to optimise the potential for donation. In turn, this form of ethics is premised upon providing the right tools for health professionals to make ethical decisions around DCD. In so doing, it fails to account for the everyday practices of health professionals involved in end-of-life care. In conclusion, the commentary advocates bringing the social science perspective into debates on DCD, to ensure that the terms and practice of this technology, and its policies, are adequately problematised.

Keywords: ethics, organ donation, end-of-life care, United Kingdom, transplant policy

Introduction

In the United Kingdom (UK), rising rates of conditions such as chronic kidney disease, alongside relatively low rates of organ donation, have led to systematic attempts by transplant medicine to increase the scope for retrieving donor organs. The expansion of controlled organ donation after circulatory death (DCD) programmes within UK hospitals has formed a major part of this process.

Controlled DCDⁱ constitutes the original form of organ donation: it was used in experimental transplant procedures during the 1950s and 60s, before being replaced by the use of oxygenated organs from brain

dead donors in the 1970s (DeVita, Snyder, & Grenvik, 1993). In this context, the UK has, historically, relied upon obtaining transplantable organs from brain-stem dead donors. However, in the last fifteen years, falls in rates of traumatic deaths, alongside developments in neurocritical care have contributed to declines in diagnoses of brain-stem death (AMRC/UKDEC, 2011). This has led to efforts to renew the practice of DCD in the UK, with the establishment of a national DCD programme. In turn, recent increases in donor rates have been attributed to the development of DCD, with NHS Blood and Transplant (NHSBT) calling for further growth of DCD, to tackle what is presented as the UK's organ shortage (NHSBT, 2013).

However, the revival of DCD has raised new problems for transplantation around the wider legal and bioethical conundrums which it engenders (Manara, Murphy & O'Callaghan, 2012). These include: first, to preserve the quality of organs for transplantation, clinicians may need to intervene in a patient's end-of-life care such as adjusting drug therapies and altering the timing and location of withdrawal of care; these interventions have no medical benefit for dying patients and may cause them harm (Department of Health, 2009). Second, such interventions may alter the course of a person's death, thereby violating an interpretation of the dead donor rule, which refers to a prohibition on treating living patients 'as though they were dead' for the purpose of obtaining organs (Gardiner & Sparrow, 2010, p.17). Taken together, these interventions pose conflicts of interest for health professionals, since they can be interpreted as acting in the interests of transplant recipients, rather than the dying patient.

A number of policy documents address the ethical dilemmas involved in DCD, most notably, the UK Donation Ethics Committee's (UKDEC) *An Ethical Framework for Controlled Donation after Circulatory Death* (AMRC/UKDEC, 2011). This makes recommendations for how health professionals should make decisions around potential DCD donors, thereby acting as a guide to best practice. By recommending how to tackle the ethics of DCD in practice, the ethical framework can be viewed as seeking to overcome the issues engendered by DCD. In so doing, the ethics of DCD have been reduced to an implicit focus upon the utility of increasing donor rates for the health of the population.

In contrast, in this commentary I will challenge the policy version of ethics for DCD using Foucault's (1984, 1988, 1997) 'problematization' approach to: first, analyse the broader contexts within which the ethics policy for DCD has been created, and second, examine the implications of this form of ethics for the work of health professionals. In a problematisation approach, the interest is not in debating the problems inherent to the practice of DCD, or in finding the 'right' solutions to these issues. Instead, it seeks to understand, for example, how 'the ethics of DCD', which Foucault (1988, p. 257) would call an 'object for thought', is classified, constituted and created as an issue within particular times, under particular circumstances (Bacci, 2012; Foucault, 1997; Pallson & Rabinow, 2005). To do this, a problematisation analysis examines the social conditions under which the range of responses to DCD – in the form of policy documents, guidelines, practices etc – are made possible (Foucault, 1997; Hoeyer, 2005). In turn, it seeks to know the (lived) effects of the particular framing of an issue (Bacci, 2012; Foucault, 1988), such as how health professionals respond to 'the ethics of DCD' in their everyday practice.

In taking up this approach, I argue that: first, the policy version of ethics for DCD has a specific normalising role, in that it forms an integral part of the efficiency drive by transplant medicine to optimise the potential for donation. Second, I show that this form of ethics has failed to account for the everyday practices of, and wider consequences for health professionals involved in end-of-life care. I conclude by advocating the importance of a critical social science perspective for understanding the issues involved in DCD. As such, this commentary will be of interest to clinicians, bioethicists and social scientists who work on the problems and practicalities of new medical technologies, like organ transplantation.

To aid my analysis I draw on bodies of social science work which examine the production and practice of ethical norms in science and medicine. In addition, the commentary is informed by previous ethnographic research conducted with a colleague in the UK, which looked at the institutional production of the 'minority ethnic organ donor' in the context of UK organ donation and allocation practices (Cooper & Kierans, 2016; Kierans & Cooper, 2011, 2013). Specifically, this research included

fieldwork in UK hospitals between 2009-2011, when UK donation services were being reorganised and the policies around DCD were produced. Whilst I do not directly draw on data from this project here, the arguments I make are informed by the analysis of national transplant policies, and interviews with health professionals about their experiences of organ donation from this study (see Cooper & Kierans, 2016 for methodological details).

Contextualising the ethics of DCD

The arguments over the ethics of DCD in the UK were precluded by fierce debates in the US over the introduction of the Pittsburgh Protocol for non-heart beating organ donation in 1992. The protocol permitted the removal of organs from the donor two minutes after asystole, alongside extensive pre-mortem interventions to preserve organ quality (De Vita et al., 1993). Debates between clinicians, ethicists and some social scientists focused on the nature and timing of death and the potential for the process to violate the dead donor ruleⁱⁱ (Arnold & Youngner, 1993; Bell 2003; Fox, 1993). In the UK context, by comparison, authorised interventions around DCD have been considered ‘subtler’ (Gardiner & Sparrow, 2010, p.20). Even so, UK clinical and bioethics literatures have drawn attention to the potential for DCD to undermine the medical principle of non-maleficence, and have questioned the timing between death and the removal of organsⁱⁱⁱ (Gardiner & Sparrow, 2010; Gardiner & Riley, 2007). In contrast, others have argued that ethical concerns around DCD should be balanced with consideration of its potential to generate more organs for transplant (Bonner & Manara, 2005; Murphy, Manara, Bell & Smith, 2008). The clinical and bioethics literatures have been polarised around understandings of DCD as a moral good which can help tackle the shortage of organs, or a worrying development in the management of death for the purposes of organ donation (Gardiner & Riley, 2007).

In turn, many have called for the creation of standardised guidelines for DCD (Bonner & Manara, 2005; Murphy et al., 2008). These calls were officially met in 2008 with the introduction of recommendations by the UK Organ Donor Taskforce (ODT), designed to increase donor rates by 50%. In the report, the ODT drew attention to the lack of a clear legal position around DCD in the UK, and

ethical questions about ‘the duty of care of the doctor to the dying patient’ (Department of Health, 2008, p.8). It duly recommended the urgent resolution of ‘outstanding legal, ethical and professional issues’ around DCD (P.9), alongside the establishment of a donation ethics body. Since then, the policy response to this request has rapidly developed. In the year following the ODT’s report, the Department of Health published *Legal Issues Relevant to Non-Heartbeating Organ Donation* (2009). In 2010, the UK Donation Ethics Committee (UKDEC) was formed, with the remit of providing ‘advice and resolution on ethical aspects of organ donation and transplantation’ (AMRC/UKDEC, 2011, p.5); this was followed by the publication of the committee’s *An Ethical Framework for Controlled Donation after Circulatory Death* (AMRC/UKDEC, 2011), and culminated in updated guidelines from the British Transplant Society for *Transplantation from Donors after Deceased Circulatory Death* (2013).

These policies all act as forms of guidelines for best practice around DCD: they specify *what* constitutes ethical decision-making in DCD and *how* these decisions should be made by practitioners. In so doing, the policies attempt to re-shape the contested process of DCD into a routine activity for health professionals (Berg, 1997). This standpoint reflects work in the social sciences which has examined the contexts in which public controversies around science and medicine emerge and, in turn, how these issues are dealt with by governance processes, such as the production of legislation and policy (Montgomery & Oliver, 2009). For example, Sperling’s (2008) work on stem cell policy in Germany documented how ethical concerns over research based on destroying embryos were underpinned by a nation’s memories of the Holocaust. Sperling showed how the debate was shifted by the introduction of legislation which transformed ethics from a model of public accountability into one formed around technical expertise. Thus, Sperling argues, the focus of ethics became less about the protection of human dignity and more about enabling scientific research. Other work has showed that, rather than problematising an issue, ethics in science and medicine operates as a form of policy-making, which recomposes previously contested issues into accepted norms of practice (Hoeyer, 2005; Hoeyer & Tutton, 2005).

We can draw connections here with the *Ethical Framework* (2011) for DCD, which makes recommendations around issues such as the risk of causing harm to a patient when facilitating donation. In particular, the policy provides an algorithm to aid clinicians in implementing its recommendations along the donation pathway, such as obtaining consent and clinically managing potential donors. By attempting to normalise the processes involved in DCD, the framework thereby assists the ODT's aim to make organ donation a 'usual not unusual' event (Department of Health, 2008, p. 9), despite UKDEC specifying that its remit is 'not to increase organ donation per se' (AMRC/UKDEC, 2011, p. 5). The ethics of DCD have therefore emerged in line with wider institutional efforts to optimise organ donation in the UK over the past two decades, which include: the introduction of the new Human Tissue Act in 2004; the establishment of a potential donor audit in intensive care units; and embedding specialist nurses in organ donation within hospital trusts (see Kierans & Cooper, 2013 for details). In turn, by focusing on providing the right tools for health professionals to tackle the ethics of DCD, the *Ethical Framework* leaves little room for understanding the implications of this version of ethics for medical practice at the end of life.

Practicing the ethics of DCD

While the ethical framework provides guidelines to aid the decision-making process in DCD, it is unclear how this version of ethics will be applied in practice. In his problematisation approach, Foucault (1984, P. 369) was interested in 'historically analysable practices': the acts or behaviours which are implicated in a particular mode of thought, such as 'the ethics of DCD'. For example, referring to the ethics of whether to intervene in the care of a potential DCD donor, the *Ethical Framework* (2011) states that interventions should be taken in the context of understanding that organ donation would be of 'overall benefit' for the patient. If organ donation *is* decided to be of overall benefit by the healthcare team, the *Framework* advises that: 'in planning and managing end of life care with the aim of donation as an outcome, the clinician is therefore acting for the overall benefit of the patient and does not have a conflict of interest' (p.41). The advice implies that if the wish for organ donation is evident, clinicians should not experience moral tension between caring for the patient at the end of life and altering this

care for the purpose of donation. The ethical actions of health professionals are therefore implicated in how well they can operationalise the ethical principle of ‘overall benefit’ in relation to organ donation and end-of-life care.

In contrast, social scientists have long critiqued the approach of bioethics^{iv} to the problems posed by medical developments as a normative enterprise, which views moral standards as ‘binding’ (Hedgecoe, 2004, p. 124; Hoffmaster, 1994). Critics of bioethics have argued that abstract ethical principles, such as ‘overall benefit’ are prescriptive, and are never straightforwardly reflected in the moral concerns and everyday decision-making of health professionals and patients (Corrigan, 2003; Hedgecoe, 2004, p. 124). In turn, scholars have documented the diverse ways in which ethical standards get worked around by health professionals, who negotiate, and even transgress, ethical norms within their organisational contexts (Hoeyer & Jensen, 2012; Smith-Doerr & Vardi, 2015). Moreover, our own research (Cooper & Kierans, 2016) showed that the recent integration of donation procedures into end-of-life care guidelines are negotiated in particular ways by health professionals, in that their conversations on death/dying with potential donor families become organised around a possible outcome of organ donation.

What is clear, therefore, is that clinical practice does not simply mirror ethical guidelines. In the context of DCD, the *Ethical Framework* provides an idealised version of how health professionals should judge the ‘overall benefit’ of organ donation in the context of managing end-of-life care. This includes assessing evidence of the patient’s wishes around donation, such as whether they had joined the donor register or communicated their wishes to a relative. If organ donation is understood to be of ‘overall benefit’, the *Framework* states that the end-of-life care plan should ‘incorporate the patient’s views on organ donation’ (AMRC/UKDEC, 2011, p.18). However, by mapping out an abstracted decision-making process, the *Ethical Framework* leaves little room for understanding how the notion of ‘overall benefit’ is made sense of and *done* in practice (Mol, 2002). For example: How is ‘overall benefit’ assessed in the context of the interactions between health professionals, potential donor

families, and dying patients? What other factors, besides the principle of ‘overall benefit’, are important when making everyday decisions about end-of-life care in the context of DCD?

Asking such questions opens out an understanding that the rule-based approach to the ethics of DCD has reduced a complex, socially embedded issue into a matter of finding the right solution for the job (Smith-Doerr & Vardi, 2015). As a consequence, the *Framework* also fails to question the broader implications of these standards for the work of medicine at the end of life. For example, by positioning interventions in end-of-life care as morally unproblematic in situations where donation is seen as appropriate, the *Framework* redraws the ethical boundaries of what it means for health professionals to care for people at the end-of-life: where care becomes about facilitating a wish for organ donation, and the practicalities of managing this process. At present, it remains unclear how the policy version of ethics for DCD has addressed this moral conundrum for both medicine and the public writ large.

Conclusion: resituating the ethics of DCD

In this commentary I have used Foucault’s problematisation approach as an analytical framework to examine the construction and potential implications of ‘the ethics of DCD’ in the UK. In so doing, I have moved away from bioethical and clinical debates, which are polarised around an understanding of what is ‘right’ and ‘wrong’ about DCD, to draw attention to the particular contexts in which the policy version of ethics for DCD has emerged. By tracing the production of the *Ethical Framework* to institutional changes around organ donation in the UK, I have shown that ‘ethics’ in this context is a constituent of (and constituted by) the efficiency drive by transplant medicine to make routine, and thus optimise, the potential for organ donation at the end of life. Indeed this phenomenon is not unique to the UK. In other contexts, such as the US and Netherlands, where controlled DCD is common, there have been similar policy responses involving the standardisation of ethico-legal frameworks which enable the ‘mainstreaming’ of DCD (Bernat, 2008, p. 669; Bos, 2005).

The argument made in this paper about the normalising function of the *Ethical Framework* also develops critical social science work which has examined the implications of the routinisation of

transplant medicine for processes around death and dying, healthcare practices, and social relations, among others (Fox & Swazey, 2001; Sharp, 2006; Shaw, 2015). What is unique about the problematisation perspective is that it enables an understanding of ethics as a particular ‘object for thought’ (Foucault, 1988, p. 257), with a specific mode of operation for transplant medicine, in the context of the reintroduction of the technology of DCD.

In this way, rather than questioning the terms and practice of DCD, a black-box ethics has emerged. Here the contestable nature of DCD is closed off to scrutiny, in favour of a normative interpretation of *what* constitutes ethics in DCD and *how* ethics should be practiced (and thereby overcome) in the hospital ward. This version of ethics functions as a kind of ethical toolkit: the moral concerns of health professionals can be neutralised with guidance around how to make decisions about the interventions required of DCD, in a way which is ethical. In turn, this has left little room for understanding how ‘the ethics of DCD’ will interact with the work of health professionals, or, what Pickersgill (2012) labels as the looping effect between formal ethics, scientific practice and the social world. What is certain, however, is that there will be no one-way street between the idealised *Ethical Framework* and everyday healthcare practices around DCD.

Social scientists therefore have a valuable role to play in furthering the debate around the ethics of DCD. First, by offering a more contextual perspective on the issue, and its policy response, in both the UK and other national settings, and, second, by having the ability – for example, with ethnographic research approaches – to examine the implications of these governing processes for the work of medicine at the end of life (see Hedgecoe, 2004 for a discussion on critical bioethics in this vein). It is vital, therefore, that the social science viewpoint has equal footing alongside dominant bioethical and clinical concerns around DCD, for example, by ensuring the representation of social scientists on ethical committees, such as UKDEC. It is only through such scrutiny and collaboration that we can ensure that the terms and practice of this technology, which is usually seen as an inherent good for treating organ failure, are adequately problematised.

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ⁱ Controlled DCD involves removing organs from donors who have care withdrawn on the grounds that continuing life-sustaining treatments would be of no overall benefit, and who are declared dead on the basis of cardiorespiratory criteria.

ⁱⁱ This refers to the rule that patients must be dead before their organs are removed for donation.

ⁱⁱⁱ In the UK death is declared five minutes after cardiorespiratory arrest, after which time the donor can be moved to the operating theatre.

^{iv} I use Callahan's definition of bioethics as: 'the application of ethical theory to the dilemmas raised by the practice of modern medicine' (Callahan cited in Hedgecoe, 2004, 122).