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Organs and organisations: Situating ethics in organ donation after circulatory death in the UK

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ABSTRACT

Controlled organ donation after circulatory death (DCD) has recently been revived in the UK, as part of attempts to increase organ donation rates. The re-introduction of DCD has subsequently become the focus of bioethical controversy, since it necessitates intervening in the care of dying patients to obtain quality donor organs. Transplant policy responses to these concerns have generated new legal and ethical guidelines to address uncertainties around DCD, producing claims that the UK has overcome' the ethical challenge of DCD. In contrast, by drawing on Lynch's call to 'respecify' ethics, this paper argues that ethics in DCD cannot be reduced to abstract directives for practice, but, instead, are composed and dealt with as an organisational problem. To do this, I utilise data from an ethnographic study examining the production of the 'minority ethnic organ donor' within UK organ donation settings; in particular, the data pertains to a case hospital which was in the process of developing a DCD programme during the period of fieldwork. Findings show that the ethics of DCD are encountered as practical sets of problems, constructed in relation to particular institutional locales. I describe how these issues are worked-around by creating conditions to make DCD organisationally possible, and through the animation of standard procedures into acceptable forms of practice. I argue that ethics in DCD go far beyond normative bioethical principles, to encompass concerns around: the reputation of hospital Trusts, public perceptions of organ donation, the welfare of potential donor families, and challenges to the work of health professionals caring for dying patients. The paper enriches understanding of ethics in science and medicine by showing how ethics are assembled and negotiated as a practical-organisational concern, and calls for further examination of how DCD gets constructed as a potential problem and is made to happen in practice.

1. Introduction

In 2008 the UK Organ Donor Taskforce (ODT) introduced a series of recommendations designed to increase the UK's historically low rates of organ donation and tackle its large waiting lists for transplantation. Among the recommendations was the requirement to urgently resolve the "outstanding legal, ethical and professional issues" around controlled organ donation after circulatory death (DCD) in order to "ensure that all clinicians are supported and are able to work within a clear framework of good practice" (Department of Health, 2008: 9). At this time, there was no clear legal position or standardised protocols for DCD in the UK, and the practice was rare (Gardiner, 2016). Controlled DCD involves retrieving organs from donors who are declared dead on the basis of cardio-respiratory criteria. Whilst DCD was used in early experiments of transplant medicine in the 1950s and 60s, it became largely obsolete after the establishment of brain death in the 1970s, enabling the recovery of oxygenated organs from brain dead donors (De Vita, Snyder & Grenvik, 1993). However, declines in rates of brain death over the last two decades have led to the focus on reviving DCD as a way of expanding the availability of transplantable organs (Academy of Medical Royal Colleges & UK Donation Ethics Committee, 2011). Since the 2008 recommendations, the UK's DCD programme has rapidly expanded, with DCD donors now constituting 41% of all deceased donors in the UK (NHS Blood and Transplant, 2017).

Yet, despite its ability to increase rates of donor organs, DCD has long been the subject of ethical controversy, since it necessitates intervening in the care of dying patients in order to obtain quality organs for transplantation (e.g. Bell, 2003; Fox, 1993). The resurgence of DCD has subsequently led to debates in the clinical and bioethics literature regarding the tension between the drive to optimise the potential for organ donation and the role of medicine at the end-of-life (Bell, 2008; Gardiner and Riley, 2007; Gardiner and Sparrow, 2010). In response to these concerns, and following the ODT's recommendations, the policy response to DCD has rapidly developed, with the production of new clinical, legal, and ethical guidelines. These policies attempt to clarify ambiguities relating to DCD and act as guides to best practice for health

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professionals, for example, by outlining how to assess the 'overall benefit' of organ donation for a dying patient (e.g. Academy of Medical Royal Colleges & UK Donation Ethics Committee, 2011; British Transplant Society, 2013; Department of Health, 2009). The generation of these policies has led the National Deputy Clinical Lead for Organ Donation to claim that the UK has 'overcome' the ethical challenges involved in DCD, positioning the nation as a 'world-leader' in the practice (Gardiner, 2016).

The official discourse around the ethics of DCD therefore gives the impression that the problem of DCD has been defined, and, in turn, has been resolved through the provision of abstract directives for the (ethical) practice of DCD. In contrast, in this paper, I draw on Michael Lynch's (2001, 2013) call to respecify ethics in order to show how ethics in DCD are not simply universal moral issues, but become locally composed within specific circumstances, at particular times. Lynch's respecification draws on the tradition of ethnomethodology, which seeks to examine how taken-for-granted issues, concepts and topics, like ethics, can be understood "in-and-as-of-the-workings-of-ordinary-society" (Button, 1991: 6) and are made "locally and practically relevant" (Lynch, 1993: xii). In taking this approach I will show that ethics in DCD can be understood as practical sets of problems, which get constructed and resolved within specific healthcare settings. In so doing, this paper engages with social science work which contextually situates ethical issues in science and medicine (e.g. Brodwin, 2008; Hoeyer and Jensen, 2012; Smith-Doerr and Vardi, 2015), by highlighting how ethics are assembled as a practical-organisational problem. It also advances an alternative perspective to the clinical and bioethical debates around DCD, by arguing that we cannot fully understand the ethical conundrum of DCD without examining the organisational milieu within which DCD is constructed as a potential concern, and is made to happen in practice.

To do this, I utilise data from an ethnographic study on the institutional production of the 'minority ethnic organ donor' in the context of UK organ donation practices (Cooper and Kierans, 2016; Kierans and Cooper, 2011, 2013). The research was conducted between 2009 and 2011 when UK organ donation services were undergoing infrastructural change following the ODT's recommendations. Drawing on exemplars from a case hospital, which was in the process of developing its own DCD programme during the period of fieldwork, I describe the particular institutional circumstances in which DCD was both produced as a potential problem for the hospital and was made practicably workable. Before turning to the data, I further specify the bioethical and clinical debates around DCD. I then outline the social science literatures which have dealt with diverse controversies in transplant medicine, before highlighting bodies of research in the social sciences which take a situated approach to understanding ethics in science and medicine – an understanding to which this paper contributes.

2. DCD and its controversies: situating (ethical) concerns in organ transplantation

As previously commented (Cooper, 2017), the debates around DCD are not uniquely located within the UK. Arguments over the dilemmas involved in DCD were ignited in 1992 with the introduction in the US of what became known as the 'Pittsburgh Protocol for non-heartbeating organ donation', which advocated aggressive organ preservation techniques and the removal of organs 2 min after the donor's heart stopped. This prompted debate between clinicians and bioethicists about potential violations of the dead donor rule, given the short time permitted between asystole and the declaration of death (Arnold and Youngner, 1993). Commenting on the protocol, the anthropologist Renee Fox (1993: 231) went so far as to label DCD an "ignoble form of cannibalism", referring to the "morally questionable" practices it permitted.

In the UK context, death is legally declared in DCD donors 5 min after cardio-respiratory arrest, meaning organ retrieval can begin after this time (Dominguez Gil et al., 2011). While the practice of DCD in the UK involves, what are considered to be, less aggressive modes of pre-mortem intervention than in the US, such as adjusting life-sustaining treatments, and altering the timing and location of withdrawal of care (Gardiner and Sparrow, 2010), it has, nevertheless, become the subject of intense scrutiny in UK bioethics literature. Here, debates have focused upon whether DCD violates a broad interpretation of the dead donor rule (the argument that living patients should not be treated 'as though they were dead' for the purposes of organ donation) and whether potential donors receive appropriate care at the end-of-life (Bell, 2003; Gardiner and Sparrow, 2010: 17; Gardiner, 2016). In turn, the policy response to these debates has been rapid. This began with the publication by the Department of Health in 2009 of *Legal Issues Relevant to Non-Heartbeating Organ Donation,* which clarified which interventions were legally permissible in DCD. This was followed by the UK Donation Ethics Committee's (UKDEC) *An Ethical Framework for Controlled Donation after Circulatory Death* (AMRC/UKDEC, 2011), and updated guidelines from the British Transplant Society for *Transplantation from Donors after Deceased Circulatory Death* (2013). All of these policies focus on the importance of assessing the 'best' or 'overall' interest of the dying patient; they justify end-of-life interventions to facilitate DCD when it is understood that the dying patient would have wanted donation and that further life-sustaining treatment is not of overall benefit (AMRC/UKDEC, 2011; BTS, 2013). The policies therefore focus on standardising the ethical-legal frameworks around DCD, as a way of enabling the renewal of this controversial technology (Bernat, 2008; Cooper, 2017).

However, the prevailing representation of DCD as a bioethical concern which can be mitigated by the production and implementation of clinical guidelines, means that little is known about how the ethics of DCD are instantiated within everyday healthcare settings. That there is a gap in this area is surprising, given the attention which has been paid to the field of organ transplantation and its associated controversies by social scientists. This work, writ large, has been concerned with issues regarding how and when organ donation occurs, and how and by whom organs are obtained. It includes studies of: the controversy over the redefinition of death, with the introduction of brain death in the 1960s and 70s (Giacomini, 1997; Lock, 2002a); ambiguities around the boundaries between life and death in the context of the still-breathing brain dead organ donor (Hogle, 1999; Lock, 2002b; Sharp, 2006); and the commodification of organs and body parts through the trade and trafficking of organs (Cohen, 2002; Scheper-Hughes, 2000; Yea, 2010).

In particular, many scholars have moved away from conceptualising transplant technologies in relation to sets of abstract, universalised concerns (e.g. issues around bioethics, commodification, exploitation in relation to organ trafficking etc), and have concentrated on specifying the ways in which issues in organ transplantation are contextually constructed within national and local settings (e.g. Cohen, 2002; Columb, 2017; Das, 2000; Hoeyer and Jensen, 2012; Hogle, 1999; Kierans, 2011; Lock, 2002b). Of most relevance here is Veena Das' (2000) work in India, which examines the global rhetoric around organ shortages and concomitant bioethical principles of autonomy and rights in relation to the selling of kidneys by the poor. She critiques these discourses, arguing that: "a vocabulary of rights simply masks the faces of social suffering – such techniques of survival [selling kidneys] are seen by the poor not as acts of autonomy but as part of their everyday life in which all kinds of violence has to be turned into opportunity" (p.284). Das' work teaches us the importance of directing our understandings not at the level of abstract ethical principles and universal discourses, but towards the contexts and "fine texture of life" (Das, 2000: 284) through which subjects get forged and transplant technologies are (re)articulated within everyday settings.

The focus by Das on the tensions between normative bioethical principles and the everyday lives of those upon whom these categories are supposed to act, reflects early calls by social scientists to broaden bioethics beyond the domain of moral philosophy into understandings of the "social processes of moral life" (Fox, 1976; Hoffmaster, 1992;

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