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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. (299 words)

Key Words

United Kingdom; Organ donation; transplantation; death and dying; ethics; ethnography; clinical guidelines; health professional practice; organisations

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 & Riley, 2007; Gardiner & 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 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 & Jensen, 2012; Smith-Doerr & 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, 2016; Kierans & 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.

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 two minutes 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 & 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 minutes 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 & 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 & 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 (AoMRC/UK DEC, 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 re-definition 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 & 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; Kleinman, 1999: 72). Writing in this journal more than two decades ago, Hoffmaster (1992: 1462) called for examination of the social and practical dimensions of ethics by investigating the "flexible ways in which human beings actually handle moral problems". These ideas have since been developed by Science and Technology Studies (STS) scholars who have articulated how knowledge and experience of ethics are co-produced in the interactions between bioethical frameworks and the daily work and informal discourses of scientific practice

(Brodwin, 2008; Pickersgill, 2012, see Jasanoff, 2004). In this vein, a growing body of social science research has demonstrated the diverse ways in which ethical norms are negotiated, transgressed and transformed within the constraints of institutions and according to the interests of different actors (Brosnan et al., 2013; Corrigan, 2003; Hedgecoe, 2014; Heimer, 2013; Hoeyer & Tutton, 2005; Hoeyer & Jensen 2012; Hoeyer, Jensen & Olejaz, 2015).

This work has therefore done much to refocus the normative programme of bioethics and offers a useful departure point for a situated analysis of the ethics of DCD. In particular, I draw on Lynch's suggestion to respecify ethics as 'ethigraphy', referring to an examination of the "circumscribed and circumstantial ways moral agents handle novel conflicts and constitute natural and social orders" (Lynch, 2001: 3, 2013). In the context of DCD, such an approach can lead us to pose questions, like: how do (ethical) concerns around DCD emerge and operate in everyday clinical settings? And, how are such issues discussed and resolved in these settings? It is these questions which this paper is concerned with addressing, in order to develop a more situated understanding of the ethics of DCD. Below, I outline the methodology for the broader study from which the data is taken, before turning to the findings.

Methodology

The data in this paper is drawn from an ethnographic study which aimed to examine the institutional production of the 'minority ethnic organ donor' in the UK, from the perspective of organ donation and allocation practices (Cooper, 2016; Kierans & Cooper, 2011, 2013). The study was developed in response to the characterisation, by transplant medicine, of UK Black and Minority Ethnic (BME) populations as a problematic constituency of organ givers, due to their high demand for transplantable organs and low rates of organ donation, in comparison to their 'white' counterparts (Kierans & Cooper, 2011). In contrast to the emphasis by health researchers on the cultural beliefs of BME groups around organ donation, the project focused on the healthcare settings and institutional processes through which potential (BME) donors are managed, and organ donation is requested. This approach to the problem was informed by work across sociology, anthropology and science and technology studies, concerned with the contexts and intricacies of scientific and medical practice (e.g. Hogle, 1999; Timmermans & Berg, 2003).

The study was granted full National Health Service (NHS) ethics approval in June 2009. Ethnographic fieldwork was conducted between October 2009 and February 2011, and concentrated on: i) the work of work of two regional English teams of Specialist Nurses in Organ Donation (SN-ODs), who are responsible for facilitating and managing the organ donation process; and ii) two hospital sites which these teams served, namely an Intensive Care Unit (ICU) and Paediatric ICU in two acute hospital Trusts. Both hospitals served large minority ethnic patient populations and had relatively low organ donor rates. The ethnographic fieldwork focused on observing activities and events which would allow insight into the processes and practices around organ donation, and included observations of: donation training sessions for health professionals, organ donation committee meetings and regional SN-OD team meetings, as well as analysing local and national policy documents around organ donation. Ethical and practical difficulties involved in waiting for someone to die in the 'right' way meant that it was not possible to observe the process of donation as it occurred. To provide detailed insight into the donation process, twenty-six narrative interviews were conducted with 22 health care professionals (these included: SN-ODs, ICU nurses, consultant intensivists and anaesthetists) who were purposively recruited on the basis of them having experience of organ donation, in particular with 'BME' families. Interviews focused on accounts of participants' experiences and practices around requesting and managing organ donation. The interviews were audio recorded and transcribed verbatim and observations were written up as fieldnotes. All participants were assigned pseudonyms, and identifying features of donation cases were anonymised.

The start of fieldwork coincided with the development in one of the hospital sites (named here as 'Hillview') of a new DCD programme. As I describe below, this organisational change was viewed as an opportunity by Hillview to increase its low rates of organ donors. As a result, much of the fieldwork at

Hillview eventually focused on the introduction of the DCD programme into the Trust. The research data (fieldnotes and interview transcripts) was analysed iteratively during the course of the study. The analytical approach was broadly thematic, looking for commonalities in meaning-making and practices around organ donation, alongside situating these issues within wider institutional, social and political contexts, such as the national drive to increase organ donation. Narrative interviews were also subjected to a structured narrative analysis, to understand how participants constructed their experiences of managing and requesting organ donation (Reissman, 2008).

In what follows, I first outline how concerns around DCD were constructed as sets of practical issues, specific to the organisational setting of Hillview. In turn, I describe how these problems were worked around by creating the conditions to make DCD practically possible for the Trust, and through the animation of new DCD procedures into acceptable forms of practice for the local setting. It is important to note that, while the project was focused on understanding organ donation in relation to ethnicity, the broad ethnographic lens meant that data captured general institutional practices and processes around organ donation to contextualise the issue (see also Kierans & Cooper, 2013). This paper is therefore focused on the administrative and organisational struggles documented in relation to the development of the DCD programme at Hillview, and does not only pertain to DCD in relation to minority ethnic donors.

Organ donation at Hillview hospital: National problem, localised concerns

The year of my entry into Hillview, at the end of 2009, was a crucial time for the hospital in relation to organ donation. The creation of the 2008 *Organs for Transplant* report by the Organ Donor Taskforce (ODT) had impelled NHS Trusts into action to meet the ODT's overall aim of making organ donation a "usual not unusual event" (Department of Health, 2008: 9) at the end-of-life. To make this aim a reality, the report made a number of recommendations which were to be instituted at the local, hospital Trust level. These recommendations included: embedding Specialist Nurses in Organ Donation (SN-ODs) within hospital Trusts, with responsibility for facilitating the changes and managing the organ donation process; appointing a Clinical Lead for organ donation, usually an ICU consultant, within every Trust to promote organ donation to hospital staff and work alongside the donor nurse; and introducing minimum notification criteria for organ donation, meaning that all potential donors should be referred to a SN-OD for assessment. At the time of my fieldwork, the Trust was therefore undergoing substantial changes in the effort to drive up its rates of organ donation. These changes were being driven by the Trusts newly embedded SN-OD, Emily, who was tasked with working alongside John, a Consultant Anaesthetist and Hillview's Clinical Lead for donation, to make the necessary adjustments to increase organ donation at Hillview, with an eye to working to a 'UK-wide perspective' (DH, 2008: 6).

As part of this strategy, Emily and John were in the process of developing a new DCD programme at the Trust. In my interviews and discussions with them, Emily and John guided me to the particular conditions at Hillview which, in their opinion, made the task of implementing the DCD programme difficult: namely that the hospital serves a large South-Asian patient population, and had a reputation of rarely referring potential donors to the specialist donation nurse team. Emily described the way in which these factors interacted, to make DCD challenging at the hospital in various ways:

> Historically, the unit had always had, I think it's fair to say, a very poor donation rate. And the fact that there'd been one donor...since 2008 I think speaks for itself. So a number of problems here: no DCD programme, a large percentage of the local population are from South Asian community, and [there is a] fairly high refusal rate from this community. We'd been trying to get a DCD programme in here [Hillview] for the last 6 years, but we kept on hitting a brick wall with the [ICU] team at the hospital. The Consultants were all concerned about the legal and ethical things around it [DCD]. They seemed to believe that if they made a decision about withdrawing treatment then went forward with organ donation they would have a criminal prosecution against them. So it's been a long drawn-out thing, but as from a few months ago, we have finally got the DCD programme up and running. (Emily, SN-OD at Hillview)

During later discussions with Emily and John, I was party to further uncertainties which were invoked by DCD at the Trust. John discussed his fears that NHS Blood and Transplant (NHSBT) were being overly-aggressive in their drive to increase donor rates, and that attempts to clarify the legal aspects of DCD were not as straightforward as they may seem, explaining that "it's (DCD) not like boiling an egg: you don't know what's in the patient's best interests". Emily also divulged an incident which had occurred some years previously, when an inexperienced Intensive Care clinician had tried to, in her words, "push through" a non-heart beating donation (as DCD was then called) without there being any policies at Hillview for this process. According to Emily, a number of staff were unhappy with the occurrence: it had, as she put it, "left a bad taste in peoples' mouths": a wariness about the new drive to implement DCD at Hillview.

Here we see the ways in which broader concerns around DCD – such as ethical issues involved in judging the best interest of a patient, and worries about litigation – interact with the local specificities of Hillview, as a Trust which was viewed to hold particular problems for the roll-out of a DCD programme. These issues included: the lack of an existing culture around donation at Hillview, with an ICU team little-used to managing the process of organ donation; understanding donation as being more difficult in relation to the particular locale of Hillview, with a South Asian patient population conceived of as particularly problematic for organ donation; and fears about the reality of conducting DCD, underpinned by past experiences at the Trust. Whereas national guidelines highlight abstract ethical and legal aspects of DCD, in relation to assessing the overall interest of the patient during decisions around end-of-life care and organ donation, in the context of Hillview, DCD became an emerging matter of concern specific to the locale within which it was being implemented: in the connection to existing and historical practices, and patient populations. Ethics, in this context, therefore became constructed and encountered as a practical set of problems within the organisational setting of Hillview.

However, as I show below, the particular problems encapsulated by Hillview for the roll-out of DCD were also, conversely, viewed as an opportunity for the Trust.

DCD as opportunity: practically accomplishing DCD at Hillview

As part of its attempts to overhaul the hospital's previously poor record on organ donation, Hillview went public in its campaign to drive up its donor rates. Press releases from the hospital and local media pieces reported on the new initiative to increase organ donation in the area, focusing, in particular, on the need to promote donation to the local South Asian community. These reports highlighted the potential for the initiative to save lives in the region, describing how the increased number of donors at Hillview since the changes were rolled out had helped save the lives of a number of people waiting for transplant. What was left out of the reports, however, were the exact details of what this 'initiative' involved: with DCD being a key aspect of Hillview's plan to overhaul its organ donation services.

During the course of delivering a training session presentation to ICU nurses about the roll-out of DCD, Emily highlighted to her audience the fact that there were over 100 people waiting for a kidney transplant at Hillview, and that nearly 10 people had died while waiting for a kidney in the previous year. Emily emphasised the potential for DCD to assist in the reduction of these waiting lists to her audience. This, she told them, is due to the fact that kidneys from DCD donors are usually offered to local transplant centres, because of the shortened time in which kidneys can be left outside the body in DCD. While problems in DCD were locally composed, they were also drawn on as reason for introducing DCD at Hillview. The implementation of DCD was promoted as an organisational opportunity for Hillview: it would work in the hospital's favour by providing the potential to reduce its own transplant waiting lists. Rather than simply being presented as a broader part of the realisation of the ODT's national recommendations, the implementation of DCD was thus represented as way of tackling local problems at Hillview.

A crucial aspect to making the plans for DCD a reality at Hillview was through the coordination of different people and resources at the hospital. For Emily and John, a large part of this work involved bringing together and negotiating the interests of different actors who would be involved in DCD. John explained to me the challenge of this process:

> Initially it took right until the beginning of this year to convince the 6 main Intensive Care consultants to agree to set up this programme, and the feeling was we couldn't really set it up without everybody's agreement. So having got the agreement of the 6

> main Intensivists, we then had to seek support from the rest of the team: all the nursing staff, both here and theatres, and the Emergency department, and the consultants in the Emergency department. And we've talked to an awful lot of people in the last six months, and we got to the point where we'd got a fairly good pathway defined and we're having to […]make sure that we're all happy in how it's set out.

John describes the work involved to make DCD a practical possibility. This involved, in the first instance, lengthy negotiations to secure the agreement of various staff members, including: Intensive Care consultants, nursing staff, Emergency Department consultants, and theatre staff. During this negotiation process, localised concerns about DCD were worked around and re-constructed through the initiation and alignment of various people at the Trust, who were crucial for the establishment of the DCD programme. In so doing, the spaces needed to perform DCD (the Emergency Department, ICU wards, and operating theatres) were also made available. The production of the DCD programme was therefore not simply a matter of overcoming ethical concerns about the practice itself. In order to begin to consider the ethical issues involved in DCD, John and Emily had to first create the conditions to ensure that DCD was a practical possibility, by co-opting diverse bodies of staff and resources into going forward with the process.

With the support of the ICU, Emergency and Theatre departments at the Hospital, Emily and John could begin to roll-out the DCD programme. A key element to achieving this was in the generation and dissemination of a local protocol for DCD, to provide practical certainty to the process (Hogle, 2009). One year after Emily started working at Hillview, the DCD programme was pre-launched with training sessions for ICU and Emergency Department staff to introduce them to the new procedures for conducting DCD at the Trust. These sessions took place during lunch-time slots in Emily's office, which also doubled-up as the ICU's seminar room. During one such session with some of the ICU nurses, Emily took her audience through the Trusts DCD protocol on PowerPoint slides.

Emily was concerned with emphasising the importance for her audience of developing ownership over the new procedures around DCD, so that they were able to respond to events as they unfolded in practice. She talked the nurses through each stage of DCD, encouraging their feedback at each step. She asked her audience whether they thought a dying patient should be maintained with therapies if they had not yet obtained their relative's agreement for donation. One nurse replied with "I wouldn't"; Emily assured her audience of the flexibility of this procedure, by telling them that such decisions should be made as events play out on the day. One slide, highlighted in bold stated that "***consent can be revoked at any time"***, referring to the fact that families can withdraw their consent for donation right up until the first incision is made in theatre. At this point, the nurses interjected with their concerns about family members chasing their dead relative through the hospital corridor. One nurse expressed her more general worry that families would feel under pressure to consent to donate when their relative is not yet even dead. Emily interjects: "I know what you're thinking, that's what I thought before I did it for the first time, but it's not like that at all." A discussion then ensued about the potential problems involved in transporting someone who is obviously dead to the operating theatre and how this might look to members of the public. Emily discussed likely tactics: "We'll have someone waiting by the lift and to clear the corridors. We may even cover their face with an oxygen mask for sanity reasons, so that you don't get people stopping you asking what you're doing with *that* patient".

The introduction of the new DCD programme in training sessions provoked debate and, at times, criticism from ICU staff regarding possible issues it could raise for potential donor families. At the end of a training session, one nurse became quite opinionated and, arms folded, expressed her worries about the implications of a family member giving consent for DCD if they were not aware of their relative's wishes around donation. Emily reassured her, firmly asserting that she would advise a family member against going ahead with donation if they were not comfortable with the idea of it. Dissatisfied with this answer, the nurse pressed: "I just don't agree with it (DCD), it sounds like you're pushing it on a family. I've got a donor card but you get some families who are so distressed, and then to have a team approaching them about donation is wrong". In response, Emily calmly told her that everyone was entitled to their opinion and that it was important to talk about issues like the one the nurse raised. In a later interview with Emily, I questioned her over this incident. Emily recalled how, after the session, this particular nurse had approached her with an apology: "she said: 'I'm really sorry for behaving like that in there (…) I'm really pro-donation'. I think it's difficult when you have your own views and then you see patients and families isn't it? It's just that very fine line". Here, Emily refers to the tension between health professionals being pro-DCD in theory, but the struggles some may experience with carrying this stance into practice, when faced with dying patients and distressed families.

It was in these training sessions, therefore, that the local concerns of ICU staff, expected to participate in DCD, began to develop and become visible. These worries were largely orientated around the practical tasks involved in DCD, and included: 1) *Dealing with families: the contingencies of consent*: how to deal with difficult scenarios involving potential donor families, such as the problems involved in approaching distressed families about DCD; concerns over whether families might change their mind on their decision to donate their relative's organs, and questions about whether invasive treatments should be maintained in dying patients prior to obtaining consent for donation; 2) *The practical environment of DCD*: how to deal with the potential interaction between the public and dead bodies being transported through the hospital into theatre, usually only reserved for the treatment of the living. Ethics here are revealed as developing in relation to particular imagined/hypothetical circumstances, and embedded within specific environments in the hospital (especially spaces where the general public and deceased donors may come into contact).

These common-sense, situated concerns were, in turn, worked through by Emily, as part of her task in training staff about the new procedure. This she did using a number of strategies, namely by: reassuring her audience that the procedures they are learning are flexible: mouldable to donor scenarios as they are encountered; allaying their concerns using her own experiential knowledge of the process of DCD; reassuring them about certain practices that would absolutely not occur (such as pressurising families into consenting); and orienting the nurses to practical solutions for potential problems, such as how to conceal the dead status of a donor. In so doing, Emily translates the new procedures around DCD into "locally relevant guides-to-action" (Kierans & Cooper, 2013: 226): as having the ability to work with, rather than against, the everyday contingencies and concerns involved in clinical practice. The conceivable (ethical, practical, personal) concerns of staff, responsible for putting DCD into action, were therefore made tenable by practically orientating them to future solutions within the organisational setting in which these concerns were composed, and worked through.

These intensive preparations for the DCD programme at Hillview were a way of ensuring that everything was ready to actually *do* DCD, or, in John's words: "it was just a matter of going ahead and making sure that what we'd done [to prepare] was sufficient to get us through the process [of DCD]". However, towards the end of my fieldwork, it became apparent that preparations for the (ethical) practicalities of DCD could never fully encompass the reality of what was involved when a potential DCD donor came along. By the time the DCD programme had been up and running for a few months at the end of my fieldwork, the hospital had gone through the process of having two potential DCD donors. Neither of these had ended up proceeding to donation: one patient did not die in the allotted two hour time-slot after care was withdrawn (this ~ time period between withdrawal of care and the patient going into asystole is necessary if the organs are to be of suitable quality to donate); the other case had not gone as planned and donation did not go ahead. Interestingly, these cases were not something that Emily and John discussed in detail, due to potential sensitivities over the programme having only just been implemented and their first potential DCD cases not having been successful. This lack of transparency around the actual practice of DCD at Hillview is more telling than frustrating. It reflects the 'silencing' of certain stories about organ donation (Jensen, 2011; Sharp, 2006) which have the potential to "undermine" the "fragile system" of transplantation, reliant, as it is, on the public willingness to donate (Jensen, 2017: 121-122). In this case, these non-stories highlight the fact that DCD is not only locally constructed as an ethical issue for patients, families, health professionals and hospital Trusts. Ethics in DCD extends wider, into understandings around what kind of information about the practice of DCD is deemed (ethically) acceptable for public consumption, in the context of a perceived organ shortage and the reintroduction of DCD as a way of tackling the ever-growing demand for organs.

Discussion and conclusion

The current focus by transplant policy-makers and bioethicists relate the ethics of DCD to sets of abstract principles, which are understood as being relevant for the practice of DCD. For example, the principle of 'overall benefit' is represented as the benchmark for practitioners, in their task of making (ethical) decisions about intervening in the care of dying patients for the purposes of organ donation.

In other words the notion of *what* constitutes ethics in DCD and *how* DCD should be ethically practiced has been drawn in stone by official discourse.

Whilst I am not disputing the importance of delineating what is, and is not, acceptable for clinical practice in matters around end-of-life care and organ donation, the findings presented here show that ethics in DCD are not abstracted moral issues, but present as emergent practical problems, which are deeply embedded within specific organisational settings. In the context of Hillview, general concerns around DCD – such as the legalities of withdrawing treatment and proceeding with organ donation – interacted with more concrete practicalities and fears in relation to historical practices and existing institutional culture around organ donation at the Trust. Following Lynch (2013), the ethics of DCD are therefore encountered and constructed as particular sets of problems which cannot be disentangled from the institutional (historical, practical, and political) milieu in which they emerge.

Moreover, the data from this case was documented prior to the production of the *Ethical Framework for DCD* (2011), and at a time when the legal parameters for the practice had only just been published (DH, 2009 guidelines). As such, staff at Hillview could be considered 'moral pioneers' (Rapp, 2000: 307), in that they first had to create the conditions to make DCD functionally possible at the Trust, as well as define and work through conceivable predicaments of DCD as they were encountered. As we saw in the case presented, concerns expressed around DCD were novel and often pragmatically orientated around the steps that were necessary to convert a potential DCD donor into reality. Notions of what were potentially at stake in DCD went far beyond the abstracted bioethical principles such as 'overall benefit', as laid out in the guidelines, and included understandings of: the potential for DCD to reduce local transplant waiting lists; the reputation of the hospital Trust and their staff, alongside public perceptions of organ donation; the welfare and actions of potential donor families; and changes to the everyday work of health professionals caring for dying patients. In turn, the process of working-through these locally situated concerns around DCD involved animating procedures into acceptable forms of practice for the everyday environments in which DCD would be realised and donor organs materialised. The ethics of DCD are not, therefore, something which can be wholly pre-defined outside of the contexts in which they are implemented. Instead, ethics in DCD need to be also understood in relation to how concerns about the process are organisationally and practically composed and, in turn, are dealt with *in situ*.

In documenting the emergent, practically situated ethics of DCD, this paper adds to the growing body of social science research which examines the contexts in which controversies in science and medicine emerge and are managed (e.g. Hoeyer, 2005; Sperling, 2008), and the (co-) productive relationship between ethical norms and their application within medical and scientific settings (e.g. Brosnan et al., 2013; Hoeyer & Tutton, 2005; Smith Doerr & Vardi, 2015). The findings presented here have demonstrated the ways in which ethics are assembled and dealt with as distinct sets of practical-organisational problems, thus highlighting the importance of an institutionally-nuanced analysis for understanding both the composition and management of bioethical controversies, such as that of DCD.

Whilst the study did not directly observe the clinical management of potential DCD donors, an analysis of the development of a DCD programme has demonstrated the importance of not making assumptions about the character of ethics in relation to DCD. Indeed, if we are to more fully understand what is at stake in the re-introduction of this original form of organ donation – for health professionals, patients and the public writ large – it is key that we do now turn to the study of DCD in practice, to examine *what* occurs when a potential DCD donor is identified and clinically managed for the purpose of organ donation. Having this type of situated focus on ethics is also of utmost importance given the proliferation of new techniques to increase the scope for obtaining organs from the deceased. Such interventions include: the use of 'suboptimal' organs from older donors, who would have previously been considered less than ideal candidates to donate (Callaghan et al., 2014); trials of novel procedures for preserving and resuscitating 'higher-risk' donor organs (Hosgood, Saeb-Parsy, Hamed & Nicholson, 2016); and testing protocols for uncontrolled DCD in the UK (Ortega-

Deballon, Hornby & Shemie, 2015). It is only through the study of these technologies *in situ* that we will be able to more fully consider and intervene in the issues at play in relation to the seemingly endless array of interventions to obtain organs at the end of life.

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