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Organ donation in principle and in practice: Tensions and healthcare professionals' troubled consciences.

Laura L. Machin, Jessie Cooper, Heather Dixon & Mark Wilkinson

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Abstract

The UK government and NHS Blood and Transplant have introduced a number of policies and organisational changes to the organ donation system following the 2008 recommendations of the Organ Donor Taskforce, which aim to increase the number of available donor organs and tackle transplant waiting lists. However, little is known about how these policy and organisational shifts influence how healthcare professionals experience delivering end of life care in the context of organ donation. In this paper, we examine ICU, Emergency Medicine, and Theatre staff's experiences of organ donation in one NHS Trust following the 2008 changes. We focus upon their decision-making when caring for patients at the end of life to highlight the tensions between health professionals' beliefs-in-principle about organ donation and their everyday moral and commonsense practices when caring for patients at the end of life. We explore how we might understand and interpret this 'troubling' of organ donation through applying the concept of 'conscience', and consider whether a conscientious objection around organ donation could exist.

Key words

Conscientious objection; Organ donation; Organ donation in principle; Organ donation in practice; Tensions; Troubled consciences

Introduction

There are currently more than 6000 people waiting for an organ transplant in the UK (NHSBT, 2019), a demand which is understood to be higher than the current supply of donor organs. This issue of the gap between the supply and demand for organs in the UK is not new, however. The UK has, historically, had low rates of deceased organ donation compared with its European counterparts, such as Spain (Department of Health, 2008). In 2008, in an attempt to close this gap, the UK adopted a widescale overhaul of organ donation services, following the seminal 2008 report ‘Organs for Transplant’ by the Organ Donor Taskforce (ODT). The report and its recommendations aimed to increase rates of organ donors in the UK by 50% by 2013 by making donation a ‘usual’ not ‘unusual’ event (Department of Health, 2008). The report focused, in the main, on making organisational and procedural changes to the system of organ donation in the UK.

Most significantly, these changes included: a) embedding Specialist Nurses for Organ Donation (SNODs) within intensive care units (ICUs), whose remit is to identify potential donors, gain consent from relatives for the donation of organs, and manage the donation process (Fenner *et al.*, 2014). Previously SNODs worked in small teams, attending hospitals only once they received a potential donor referral from ICU staff, meaning the clinical team were often involved in donation procedures, such as those around consent. The embedding of SNODs meant that the donation process was

largely removed from ICU staff post-2008 (Kierans & Cooper, 2013). The exception to this, however, was: b) the introduction of a policy of ‘minimum notification’, whereby ICU staff were given responsibility to refer to the organ donation service (i.e. the SNODs) patients in whom there is a plan to diagnose brain death, *or* who are to have treatment withdrawn on the grounds that continuing care would be futile. This policy expects 100% referral rate, meaning clinical staff are required to refer patients even when they are viewed as unsuitable for donation. The changes also included c) the re-introduction and legal and ethical standardisation of donation after circulatory death (DCD), which involves retrieving organs from donors declared dead on the basis of cardio-respiratory criteria, different from donors declared dead on the basis of neurological criteria, or donation after brain death (DBD), which made up the majority of UK deceased organ donations. DCD was originally used in early experimentation by transplant medicine in the 1950s and 60s, but became largely obsolete after the establishment of brain death as a legal diagnosis of death in the 1970s (De Vita, Snyder & Grenvik, 1993). Prior to the 2008 changes there was no clear legal position or standardised guidelines for DCD in the UK and the practice was limited to few hospitals (Gardiner, 2016). The changes meant that ICU staff would be responsible for referring a ‘new’ type of organ donor (for further insight see Cooper, 2018).

These changes to the system of organ donation in the UK following the 2008 recommendations were largely perceived as ‘successful’ since donation rates increased by the target 50% by 2013 (Department of Health, 2013). Since then, these structural approaches to improving rates of available donor organs have continued with the introduction in 2015 in Wales of a change in the law surrounding consent for

organ donation, moving from an opt-in to an opt-out system. The new opt-in legislation was also introduced in England and Scotland during the spring of 2020 (Dyer, 2019). Consequently, patients, by default, agree to donating their organs unless they have opted-out on the NHS organ donation register. However, initial analyses of the Welsh opt-out system have not shown significant change in consent and donation rates that can be attributed to the new legislation, leading to arguments that ongoing interventions are still needed around organ donation in the UK (Noyes et al., 2019). What is clear, therefore, is that the system and processes around organ donation will continue to shift in attempts to decrease the gap between the supply of, and demand for, donor organs.

Whilst policy makers and scholars have often been concerned with the ‘success’ or otherwise of these changes in policy, legislation and procedures around donation, little is known about how these shifts influence how healthcare professionals experience delivering end of life care in the context of organ donation. In this paper, we examine healthcare professionals’ experiences of organ donation following the 2008 changes, focusing upon their decision-making when caring for patients at the end of life. We do this by drawing on data from interviews with clinicians and nurses involved in organ donation in one NHS Trust in England. Findings from the data highlight tensions between health professionals’ beliefs-in-principle about organ donation and their everyday moral and commonsense practices when caring for patients at the end of life. In essence, the new processes around organ donation were presented as troubling for health professionals, who worked hard to justify and ensure their care of patients and their families was morally right, even if this meant going against organ donation procedures. We therefore explore how we might understand

and interpret this ‘troubling’ of organ donation through applying the concept of ‘conscience’. We hope our paper will generate debate over whether a conscientious objection around organ donation should exist, and what it might mean for healthcare professionals working within the new opt-out policy in England and Scotland.

Troubling Organ Donation for, and by, Healthcare Professionals

Organ donation is generally recognised as a community and social good (Caplan, 1984; Shafer *et al.*, 1999). However, it is also acknowledged as a sensitive area, particularly because of the interpersonal nature of the process: organ donation concerns an encounter between a newly bereaved family and a healthcare professional when the matter is raised and considered (Streat, 2004). Organ donation can also be deemed a controversial area to study given the encounter involves interacting with, about, and for human bodies. For Childress (2001), “the human body evokes various beliefs, symbols, sentiments, and emotions as well as various rituals and social practices” (2001:2). For these reasons, healthcare professionals, particularly within ICU, have been tasked with ensuring that organ donation practices include humane and compassionate patient care, the avoidance of suffering, and the maintenance of dignity and respect (Streat, 2004). In practice, this equates to caring for and about the family – ensuring that they have access to their loved one during the dying process, and that they have consistent meticulous communication (Cuthbertson *et al.*, 2000). However, most research in this field has focused upon the experiences of, and decisions made by, the relatives of the potential donor (e.g. Haddow, 2005; Long *et al.*, 2008). It is rare for organ donation to be presented as an emotional experience for the healthcare professionals involved, or for their decisions when facilitating organ donation to come under scrutiny.

It is acknowledged that ICU staff in particular play a crucial role in the organ donation process (Fenner *et al.*, 2014), with research showing they are generally supportive of transplantation and donation (Fenner *et al.*, 2014; Hart *et al.*, 2012; Pearson and Zurynski, 1995). Yet, emerging insights suggest that recent developments to the processes around organ donation, discussed above, require a more nuanced understanding of the role of health professionals in the donation process (see Cooper and Kierans, 2016; Lee *et al.*, 2018; Macvean *et al.*, 2018; Walters, 2009). For example, despite the success of the UK controlled DCD programme, it has been heavily criticised and debated in terms of its ethical implications (see Cooper, 2018). It is also believed that many ICU, Emergency Medicine, and Theatre staff hold negative attitudes toward DCD (Fenner *et al.*, 2014; Marck *et al.*, 2012; Shaw *et al.*, 2018). Whilst this may have eased with the increasing routinisation of DCD in ICU, it is accepted that discussing DCD tends to evoke strong and predominately negative associations with ICU staff (Fenner *et al.*, 2014). Moreover, not all staff in ICUs have welcomed SNOD presence. Some practitioners claim that SNODs do not share the same relationship developed between ICU staff and the relatives of the dying patient and therefore should not be the one to raise the matter of organ donation with families (Fenner *et al.*, 2014; Streat, 2004).

Conscientiously Objecting to Organ Donation?

In response to some of the reported disquiet amongst health professionals around organ donation, some American healthcare systems and hospitals have restricted their practices around organ donation and/or enabled staff to opt out of DCD (Bramstedt, 2016; Shaw *et al.*, 2018). For the American Medical Association, doctors are not

defined by solely by their profession, but are viewed as moral agents in their own right, and, like patients, are understood to be informed by and committed to diverse, cultural, religious traditions and beliefs (Verheijde and Rady, 2018). Whilst there has been consideration by the UK medical regulators, the General Medical Council (GMC), and within the intensive care community to introducing conscientious objection to organ donation (see Shaw *et al.*, 2018), it is worth bearing in mind that currently conscientious objections are a limited right, meaning they can only be enacted when other doctors are available to take over patient care (General Medical Council, 2008).

Justifications for extending a conscientious objection to organ donation can be found within studies that show organ donation can be a cause of moral distress, trauma and tribulation amongst healthcare professionals (Bayley *et al.*, 2012; Elpern *et al.*, 2005; Regehr *et al.*, 2004). Furthermore, there have been professional and patient objections to how donors are declared ‘dead’ based on cardio-respiratory (in DCD) or brainstem death (in DBD) criteria (Moschella, 2016; Nair-Collins, 2015). For some, the processes involved in determining ‘death’ in DCD and DBD lacks scientific validation, prompting concerns of organs being procured from donors who might not be truly ‘dead’ (Bayley *et al.*, 2012; Nair-Collins, 2015; Olick *et al.*, 2009). For these opponents, organ donation under such circumstances goes against specific religious beliefs, and is ultimately undignified (Moschella, 2016; Nair-Collins, 2015; Olick *et al.*, 2009). The medical, legal, and religious challenges to ‘brainstem death’ in particular are thought to have increased globally (Lewis and Greer, 2017; Lewis *et al.*, 2018), and arguably undermine the sense of a broad consensus promoted by the transplant community and universal acceptance of brainstem death in a pluralistic

society (Verheijde and Rady, 2018). Yet, proponents of organ donation have queried the legitimacy of such objections, and have accused objectors of being unprofessional, uninformed, and morally complicit in letting patients die (Shaw *et al.*, 2018).

While discussions about conscientious objection in organ donation in the UK are still emerging, conscientious objection in healthcare more broadly is not new. In the UK, healthcare staff have rights to opt out of some lawful procedures related to reproduction (e.g. abortion) and end of life care (e.g. withdrawal of life sustaining treatment from patients lacking capacity) based on personal moral and/or religious beliefs (Lamb *et al.*, 2017). Conscientious objection can be understood as “the opposition or refusal by a healthcare professional to provide certain treatments because the individual believes that helping to provide those treatments would violate personal core ethical tenets in a way that compromises his or her moral integrity” (Harter, 2015: 224). As a concept, ‘conscience’ has therefore been associated with personal and moral integrity and been described as a fundamental commitment or intention to be moral, to make decisions about right and wrong, good and evil, and what it means to be a good person (Lamb *et al.*, 2017; Sulmasy, 2008). Research has shown that conscientious objections can emerge because of a person’s moral framework, and that such non-religious beliefs can be just as firmly held and as central to a person’s life as religious ones (Dickens, 2009; Strickland, 2012). Yet, conscientious objection cannot be based on prejudice or discrimination. The British Medical Association (BMA) are clear that doctors can conscientiously object to being involved in a particular act, but not to treating particular patients (BMA, 2018).

Contemplating objections based on conscience has generated debates surrounding the position of healthcare professionals, with doctors presented along a continuum, from “public servants” (Savulescu, 2006) to “free agents” (Kantymir and McLeod, 2014). For the GMC (2008) and the BMA (2018), doctors can conscientiously object to participating in procedures and treatments, but ultimately, they state that the care and needs of patients must take priority and cannot be compromised. Support for doctors declaring a conscientious objection is arguably wavering as it may be impossible to accommodate the number of potential objectors in the future whilst also meeting healthcare demands (Clarke, 2017; Strickland, 2012). Others show little sympathy for conscientious objectors, who are perceived as prioritising their own psychological wellbeing, and burdening their patients (Rhodes, 2006). Some argue that doctors must put patients’ interests ahead of their own integrity, and “...if this leads to feelings of guilty remorse or them dropping out of the profession, so be it” (Savulescu and Schuklenk, 2017: 164).

Yet, conscientious objection is also thought to avoid various forms of harm to the healthcare professional including moral distress that results from acting against one’s conscience, which leads to burnout, fatigue and emotional exhaustion (Grönlund, 2011). It is also understood to protect healthcare professional’s moral integrity and is considered to promote virtuous doctors with a well-developed conscience, a commitment to the moral ideals of the profession, and a reluctance to accept compromises with immorality (Crigger *et al.*, 2016; Gerrard, 2009) therefore benefitting society. In essence, conscientious objection means doctors are viewed as moral agents, informed by and committed to diverse cultural, religious, and philosophical traditions and beliefs (Verheijde and Rady, 2018), and provides

recognition of the morality, intellect, and psychology of the ‘human’ that is the healthcare professional (Pellegrino, 2002).

However, conscience as a notion in healthcare has often been criticised for being vague and therefore deemed an unhelpful concept (Sulmasy, 2008), which is perhaps reflected in its relation to, but difference from, other broad concepts such as ‘moral distress’, and ‘best interests’. Conscience has been considered more than merely a difference of opinion between patient and doctor when evaluating what is best (Price *et al.*, 2007), and is thought to encompass medical, emotional, and other welfare issues (Price *et al.*, 2007). That said, objections based on conscience are proposed as a response to moral distress experienced by healthcare professionals (Catlin *et al.*, 2008). Research has shown that healthcare professionals who cannot follow their conscience report having a troubled conscience, which has been associated with feelings of guilt (Juthberg *et al.*, 2007), and having implications for caring practices, professional relationships, and the health and wellbeing of the healthcare professional (Lamb *et al.*, 2017).

In light of these understandings and the discussions around conscientious objection in organ donation, it is vital that we explore how the changes to the system of organ donation in the UK since 2008 are experienced in practice by health professionals. In so doing, we offer further insight into the burgeoning debate around conscientious objection in the context of organ donation. In what follows we highlight the tensions for healthcare professionals between supporting organ donation in principle and facilitating organ donation in practice. We focus in particular upon healthcare professionals’ decision-making in the context of referring patients to the SNOD, and

the process of DCD to illustrate their troubled consciences when faced with organ donation in everyday practice.

Methods

The study from which the data is drawn aimed to explore the ‘ethical’ dimensions of organ donation, with a particular focus upon the decision-making of healthcare professionals. We also wished to understand better how healthcare professionals perceived the policies, processes, and practices surrounding organ donation. A social constructionist approach (Berger and Luckmann, 1966) was adopted whereby the aim was not to unearth one true objective reality, but, instead, understand the ‘reality’ of organ donation as created through various meanings and practices ascribed to the process by health professionals in the study (Kvale, 1996).

The study took place at an NHS hospital Trust in North West England over the period December 2012 to April 2013. This Trust comprises two district general hospitals each with an Emergency Department, ICU and Operating Department and a smaller hospital with some inpatient wards and an Operating Department. The Trust has an active Organ Donation Committee, with membership drawn from ICU, Emergency Medicine, Paediatrics, as well as representatives from Tissue Services, Operating Theatre, and Palliative Care. Between 2009 and 2010 the Trust introduced a newly embedded SNOD into the ICU and also introduced a programme of DCD, in line with the ODT recommendations outlined previously.

Participants were recruited from Emergency Department, ICU and Operating Departments along with members of the Trust's Organ Donation Committee as these healthcare professionals were most closely involved with organ donation at the Trust. Recruitment was via an email invitation disseminated by departmental secretaries and participation was on a voluntary basis. Ethical approval was granted by XXXX University Faculty of Health and Medicine Research Ethics Committee in November 2012 and governance approvals were gained from the Trust's Research and Development Department.

Twenty four in-depth, semi-structured interviews with clinicians and nurses were conducted between January and April 2013. Consent was taken face-to-face prior to each interview, and it was explained that participants could withdraw their consent at any point during, and up to two weeks following the interview. Interviews lasted between 30-60 minutes and were recorded on an audio device. An active interview approach was adopted which permitted the research team to draw on their background knowledge of organ donation when designing the study (Holstein and Gubrium, 1995). A semi-structured interview guide based on a literature search was used, which focused on health professionals' decision-making, their understanding of the ethical issues surrounding organ donation, and how they perceive their role and responsibilities within organ donation. The guide was used to direct the questioning, with additional open questions used to facilitate more in-depth responses and allow for investigation of new knowledge raised.

Interview recordings were transcribed by a professional transcriber, who completed a Confidentiality Agreement before gaining access to the recordings. The transcribed

data was read multiple times and coded using Nvivo software. The codes were then grouped into over-arching themes and a thematic analysis was undertaken (Braun and Clarke, 2006). Particular focus was given to when participants were emotionally, morally, ethically and professionally torn, and how participants justified their decisions and in/actions. The decision to focus on the above particular themes was influenced by literature reviews and other background research. The analysis was therefore an iterative process taking into account any “unexpected issues” (Seale and Kelly, 1998), that had not been previously considered by the research team, but emerged during the reading of the data, leading to further refinement of the codes.

Results

Tensions between donation in principle and the everyday practice of organ donation

During interviews, participants readily discussed their support in principle for organ donation. This was often framed around an explanation of their understanding of the need for organs for transplant at a societal level, i.e. that securing organs for donation would provide benefit to potential recipients on the transplant waiting list. For example, one consultant anaesthetist expressed the belief that:

Organ donation is important and ultimately there are a lot of people out there who would benefit from organ donation. I can't think of many people that would disagree with that...generally organ donation is felt to be good and of benefit to people. It's often then difficult to separate that from the individual patient that you have to put first (AB1 – 2)

The anesthetist here understands organ donation as a societal good, yet is also aware of the tensions this can create when trying to separate this belief from their responsibility towards individual (dying) patients. Similarly, an ICU consultant, who was also the Clinical Lead for Organ Donation, expressed that while the “primary obligation is to the patient”, healthcare professionals also have a further “obligation to the patient we can’t see, in other words the people that may benefit from those organs” (AE1-1). For participants then, positive beliefs surrounding organ donation created felt obligations, which had the potential to influence practices when faced with supporting a dying patient. Moreover, participants implied that tensions existed between their support for organ donation in principle and the everyday practice of donation, particularly when faced with fulfilling their professional duties for their patients. Interestingly, both participants constructed a hierarchy of felt obligations, with the patients they treated on ICU clearly taking priority over (unseen) recipients.

For some participants, tensions between organ donation in principle and practice were expressed as not being easy to reconcile, particularly when discussing making decisions relating to end of life care and the facilitation of organ donation. Some participants struggled with separating the purpose of these decisions, leaving staff feeling they were prolonging a patient’s life for the purposes of organ donation. As one ward manager explained:

I think it sits uncomfortably sometimes with people when you’re prolonging somebody’s life. Although it’s of benefit to somebody else it may be that you feel that you’re not doing justice for that particular family by keeping them

[the patient] alive or prolonging their death, if you like. And I think from listening to people's discussions that's where it sits a little bit uneasy (A4 – 2)

For staff in the study then, organ donation was far from a straightforward matter of 'believing in' organ donation and then enacting that principle in practice, particularly when contemplating the needs of patients and their relatives. In some cases, participants discussed scenarios when they would *not* actively facilitate donation as one ICU consultant anaesthetist described:

I will go with my conscience. If I think this person is suitable to do that and I feel in my own conscience that's the right thing to do then I have no problem referring to the SNOD. If there are other times when I think just let them die with a bit of dignity, a bit of peace then I will not refer. If somebody else wants to, that's fine. I think to get told off or get a reprimand for you had this patient you withdrew and you did not refer, that does irritate me (A1 – 1)

These scenarios drew on staff's understandings of what they perceived as acceptable practice at the end of a patient's life: if they felt like organ donation would undermine the dignity of the dying process for both the patient and their relatives, then, for staff, this was an acceptable reason to *not* refer a dying patient for organ donation. In turn, the decisions around delivering end of life care trumped any decisions required to facilitate organ donation.

This challenged the notion that healthcare professionals were passive service providers merely carrying out a patient's or relative's wishes around organ donation

or simply complying with organ donation policies. Instead, healthcare professionals positioned themselves as autonomous actors. Whilst staff respected a patient's or relative's decision, and/or acknowledged the benefit of organ donation guidelines and policies, it was they who had to decide to refer a patient as a potential donor, and decide or deliver on the continuation of treatment in order to facilitate the organ retrieval. Of significance was the way in which participants constructed their position based on their conscience, which enabled them to portray themselves as moral, and their decisions made with integrity. Such positive framing of themselves ultimately makes their position hard to challenge, and reasserts a (lost) power and authority in the face of organ donation policies.

Participants also discussed their awareness of different stances that existed around organ donation amongst their colleagues. Some participants were clear that they would support colleagues who did not want to participate in the organ donation process. For example, one ICU ward manager explained how, within their team, there were differences of opinion on what was considered 'ethical' regarding withdrawing treatment, *"it may be that someone's personal ethical dilemmas are different from another's. I think it's important (..) to be able to acknowledge that and for people to take on different roles of what they feel comfortable"* (A4 – 2). Here, the subjective and individualized nature of healthcare professionals' 'beliefs' surrounding practices to facilitate organ donation were emphasised. Yet, such different ethical stances created tensions for other participants: it was perceived as not always possible to accommodate their own or colleagues' objections to organ donation. For these participants, facilitating organ donation was presented as integral to their role, the

avoidance of which would undermine their responsibility as health professionals, as a theatre nurse explained:

Some people just don't agree with it. They say you're just butchering people...I don't think you should have to take part in something like this if it upsets you. I don't see why we should. But then, again, if you're working in an operating theatre I don't think it's something you can sit and refuse to do because it upsets you, what with all the stuff we see coming through. I think you've got to be a bit more hardened to it...We knew we did it when we took the job here...So I think if you choose to work in an area that does things like that then you have to accept that that's part and parcel of the job (B2 – 1)

To some extent, staff empathised with colleagues who exempted themselves from organ donation practice. The theatre nurse implicitly expressed empathy when she showed insight into how some colleagues can view organ donation as “butchering people”. The theatre nurse acknowledged the emotional challenges with organ donation practices, whilst also implicitly presenting those who did participate in organ donation as emotionally sensitive and aware, and therefore equally open to being affected by organ donation as those who opted out. In turn, this positioned those who refused to participate in organ donation practices as transferring the emotional burden to others, and unwilling to share the emotional load. For this participant, organ donation was perceived to be part of staff’s professional responsibility and therefore those who refused to participate based on individual emotions and personal beliefs were considered to be stepping away from their broader healthcare community values and duties.

It is apparent from the data then that those articulating tensions between organ donation in principle and in practice presented organ donation as troubling for both others and themselves. There was rarely a clear line between healthcare professionals' 'beliefs in' organ donation and what this meant for their practice. At times, staff were torn because of the range of responsibilities felt towards individual patients, relatives and colleagues. Staff tended to frame their position in 'professional' terms informed by guidelines and communal values, or as 'ethical' and referred to their own sense of what is 'right'. The notion of conscience implicitly ran throughout both of these positions. Participants made references to knowing what the job entailed, an understanding of the needs of transplant patients, and supporting/burdening colleagues. Participants also made explicit references to the notion of conscience and used it as a way of shielding their perspective from hospital guidelines and national policies on organ donation. The idea of troubled consciences was a prominent theme throughout the data and was most prevalent when participants discussed caring for a dying patient and specific practices to facilitate organ donation, as we discuss next.

Between 'ordinary' care and organ donation: troubled consciences

What was apparent from the data was that staff beliefs and conscience around organ donation were particularly challenged by some of the organ donation practices, introduced since the 2008 ODT recommendations. In particular, these related to: the required processes around referring all eligible patients for organ donation; introducing/continuing with interventions at the end of life for the purposes of organ donation; and the temporal demands created by the process of DCD. We outline each

of these, the particular issues they engendered for staff, and how, in some cases, staff managed these particular tensions, in turn.

The need for donors vs ‘commonsense’ patient care

Staff described their discomfort with changes to the organ donation pathway, specifically with reference to their responsibility to refer every potential eligible donor (i.e. patients who staff plan to withdraw treatment on and/or are suspected of being brainstem dead) to a SNOD. Participants described how they and/or their colleagues felt uncomfortable with this process in cases where it was clear to them that the patient was unlikely to become an organ donor. They articulated what this meant for their practice, as the following quote from a consultant anaesthetist illustrates:

Now, there might be a decision that might ethically be fine to do but my conscience doesn't feel I'm able to do that or get involved with that. So, for example, if there was a patient who I thought organ donation was actually unsuitable for that patient I personally wouldn't really want to go and get the SNOD involved early. I've no problem with another member of the team doing that if that's what they want to do. But if my view is I don't feel comfortable about it I will not get involved with it (A1 – 1)

For this participant, the policy of referral had ethically legitimised the practice of referring eligible patients to a SNOD. Yet he also implicitly questions how ‘ethical’ the policy is when referring to his conscience. In this instance, the consultant positions his conscience as trumping the ‘ethical’ policy, which enables him to justify

not adhering to the policy, whilst also accepting colleagues' compliance with the policy and presenting their actions as ethical. The consultant here positions the patient as the priority, which potentially conflicts with the positioning of organ donation and the needs of potential recipients suggested by the referral policy. The power and control over dying patients is transferred back to the clinical care team that had arguably been perceived to be lost to the SNOD with the introduction of the referral policy.

The requirement to refer all patients for organ donation when there was a planned withdrawal of treatment on the ICU was, in particular, perceived to undermine the autonomy and commonsense of clinical staff. One consultant anesthetist described a specific case around this:

...we get into trouble if we don't refer everybody that we withdraw treatment on. And it is a bit of a bind sometimes because we go, God, we've got to ring SNODs, and you realise the patient is 85...out of hospital cardiac arrest, prior to that bed-bound for about two years, heart failure, kidney failure, COPD. You name it she'd got it but we still had to refer her. We'd already talked to the family and they were all happy that we were going to stop...And so they [SNODs] got back to us and went, oh, we might be able to have her kidneys and I was like, no. The family were ready to come in [for the withdrawal of treatment] and we had to have a bit of a delay while they [SNODs] rang round everywhere to decide if anyone would want her kidneys. Fortunately they didn't (ABI – 4)

The anaesthetist here describes this case as a moral tale: it was presented as evident to ICU staff that the patient's organs were unsuitable for donation, but the change in policy meant staff had to refer the patient to the SNOD in order for their position to be validated. In turn, this process became seen as a barrier to staff providing what participants presented as 'commonsense care' for dying patients. Staff were positioned as 'protectors' of dying patients and their relatives, and organ donation as an imposition or threat in cases where donation was perceived as unsuitable. The procedural requirement therefore to refer every potential eligible patient to the SNOD was therefore seen by staff to undermine their professional expertise and clinical autonomy.

Providing 'care' for the dead/dying patient vs 'care' for the future donor

Participants highlighted how the need to introduce/continue with interventions at the end of life or on brain dead patients, for the purposes of organ donation, were sometimes at odds with their own understandings of what was in a dying patient's best interests. The following quotes from two consultant anaesthetists and a ward manager illustrate this:

Ethically I find it difficult when you have pronounced somebody brain dead, starting new treatments purely to optimise organs. I find that difficult. You can argue it that when you've made the decision that you are going for organ donation you need to optimise and you are now dealing with these organs for other people and so you need to keep them in as optimum a position as you can. But you've still got a patient (A1-2)

...the treatment shouldn't be overly onerous...you've got to think about whose interests are you acting in and what's an acceptable thing to do...I think there becomes a line when someone is so unstable you're having to bring in more and more treatments just to keep them alive (AB1 – 3)

I think it's a bit of a – I might be wrong – grey area or a minefield actually starting different things...it depends how invasive it would be to the patient as well. Because ultimately you've got a patient, a person, dying so that's got to be your first priority really, looking after that person and not thinking that they're not a person and they're just going on to the next thing. So that probably is the difficult thing. So it depends what's going on, how invasive and how traumatic it would be (A4 – 1)

In these quotes, participants struggled to reconcile competing perceptions of the (brain) dead/dying patient as they transition to a future donor when making decisions and taking action to facilitate donation or not. Implicit in these quotes was the sense of flexibility around staff's decision-making, particularly when determining whether it was 'un/ethical' or 'un/acceptable' to continue escalating treatment on dying or (brain) dead patients for the purposes of facilitating organ donation.

Similar to the beliefs around organ donation in principle, participants imply that they are willing to escalate treatment in order to facilitate donation, but when faced with the realities of this in practice, they established limits. They justified the setting of limits by framing the escalation of treatment as an “ethical” matter, and as such emphasized their decisions were taken according to what they believed was

“acceptable”. For these participants, it was not simply a case of following or adhering to policy: any decision or action taken needed to sit comfortably with them and therefore they set ‘ethical’ limits for themselves.

These ‘limits’ appeared to be constructed by participants according to the circumstances of the patient case at hand. They justified this flexibility in their decision-making by referring to patients’ interests. In the three quotes, a line is drawn between letting a patient die and continuing with treatment for the purposes of donation. They forefront the ‘person’ entangled in their decisions, actions and beliefs, and present themselves as respecting the humanity of the patient when making a decision regarding interventions for the purposes of organ donation. When the latter are understood to interfere with the best interests of the dying patient, health professionals asserted their responsibility to their patients first and foremost, thereby rationalising their decisions to sometimes *not* act as they are supposed to in relation to the requirements of organ donation. In this way, participants also attempted to justify and legitimise the inclusion of staff’s beliefs when making decisions surrounding organ donation, even if they went against a patient’s wish to be considered as an organ donor.

The particular ‘problem’ of DCD and caring for relatives and staff

Nearly all participants discussed the particular issues that they had with the processes around DCD. These mostly related to the strict timings required around DCD, which are necessitated to ensure the viability of DCD organs for transplant. The problem of time in DCD, and how this was felt to impact patients and families, was oriented around two issues, as we outline below.

First, patients need to die within a three-hour window of having their treatment withdrawn in order for their organs to be viable for transplantation. For participants, this window of waiting to see whether a patient would die in the necessary timeframe created a sense of uneasiness, as the following quote from an operating department practitioner illustrates:

...then there's got to be that period before [death]. That can be a bit hard sometimes because – I don't want to use this word because that's what some of my colleagues use that are anti-donation things. But it is a bit vulture like really isn't it. You're waiting for somebody to die. I've had the [retrieval] team here for four or five hours and the patient's pressure didn't drop and they just wouldn't die. So then they can't do anything. And you've got everything organised and ready and everything is all set up (B3 – 1)

The unpredictability and potentiality that underpinned DCD in relation to the dying time was a source of tension for staff. Participants explained that they struggled with their own conscience when they were in a situation where they were waiting for a patient to die (in time) so that his/her organs could be useable, as a charge nurse explained:

The non-beating [DCD] is just difficult because people just don't die like that, do they, they go on for two or three hours and it feels like you're saying you need to die now or your organs aren't going to be any good... (A2 – 2)

Both the nurse and operating department practitioner imply a sense of uneasiness about this waiting time. Whilst being with a patient at the end of his/her life is not unusual for healthcare professionals, it is the *waiting* that is altering how healthcare professionals experience being with a dying patient. Furthermore, DCD has generated a purpose to being with a patient as s/he reaches the end of his/her life, which was not necessarily felt when organ donation was absent. For these participants, there is anticipation of the action that will take place once the patient dies. This led to feelings of impatience, which in turn generated feelings of guilt, due the understanding that these feelings were linked to wanting patients to die in time to enable donation. Participants battled with retaining the perception of the patient as a person reaching the end of his/her life, but not yet transitioned to a dead person who had agreed to donate his/her organs.

This discomfort was also expressed by participants in relation to the needs and sensitivities involved for the relatives of the dying patient. Participants reflected on how this strict timeframe for patients to die in order to facilitate DCD could also be a source of stress and pressure for family members, who are also waiting for the death, as the following quote from a consultant anaesthetist shows:

I think sometimes the timescales involved are difficult for the relatives to grasp and the unpredictability is difficult. And the fact that the staff have got to support the relatives through a withdrawal of active organ support. It's the watching and waiting....It seems a lot to put relatives through, the build-up for retrieval and then with the expectation that the patient will die within the required timeframe with the perfusion time, etc. And then it not to happen and

they end up surviving longer than anticipated, it's an awful lot to put relatives through (A1-2)

The consultant's concerns for the dying patient's relatives as well as the extra pressure this put on staff created doubt over the practice of DCD, and led her to question whether it should go ahead. To some extent, it appears she is querying whether it is morally right for DCD to take place when contemplating the emotional burden and impact on patients' relatives and her team versus the likelihood of the donation going ahead.

Second, the issue of timing as an issue of conscience in DCD also related to the speed with which potential donors are taken to the operating theatre for organ retrieval, following the certification of their death (which typically happens five minutes after death has been certified). One ICU consultant explained:

It seems like we're whisking them [donors] away to take their organs as quickly as possible...And so that whole process is less clean and less predictable and uncertain. And I think it was that that was unpleasant (AE1 – 1)

For participants, like the ICU consultant, this rapid transition from patient to an organ donor was seen as an intrusion on a 'good death'. The speed involved in the process was viewed as being undignified for the recently dead patient, as one consultant in anaesthetics and intensive care described:

we got to 20 minutes after I'd stopped treatment and she [SNOD] went that's his liver gone...Like it's really time limited and they've got to die really quickly otherwise they can't have the organs. I felt really uncomfortable...As I was certifying death she [SNOD] was wheeling him out of the room. I actually was following her down the corridor with my stethoscope on his chest so I could legally confirm death before they took him to cool him down and whip his organs out. The staff and myself that were on the unit, we were really upset about it and felt it was really messy and it felt undignified and very uncomfortable...we found it a really traumatic experience. It was horrible (ABI – 4)

The urgency involved in moving from the certification of death to surgically removing organs in DCD donors was also perceived by participants to negatively impact on the immediate grief experienced by relatives. It also disrupted what was considered to be the ordinary and usual practice of health professionals involved with dying patients, as the following from a consultant anesthetist demonstrates:

...normally if we have a death on intensive care the family is given a certain period of time with the patient when they've died. So you bring the curtains round and they have their period of time to sit with them and grieve. The staff too as well. Obviously the nursing staff will have spent a lot of time with that patient and they will also have a relationship with the family and it just gives them a bit of time as well. With the non-heartbeating donation it's difficult because as soon as the patient is asystolic they have five minutes or so to get to theatre and there is none of that. The patient's family are just told to

go...there's certainly a lot of tears...because it's just not the normal way that we'd manage the dying process in intensive care (AB1 – 2)

What is clear, then, is that health professionals perceived particular organ donation practices (those of referral, altering/continuing end-of-life care for the purposes of donation and the timings involved in DCD) to disrupt their usual or as participants portrayed 'commonsense' care practices at the end of a patient's life. This, in turn, led to participants experiencing troubled consciences over their new responsibilities around organ donation. For some, this was dealt with by particular practices to distance themselves (both psychologically and physically) from the processes of organ donation and, in some cases, even led to inaction in terms of them not fulfilling these donation responsibilities.

Discussion

Researchers have claimed that objections based on conscience have become more common and are set to increase given that medicine concerns questions of life and death and therefore decisions made by healthcare professionals are of great moral significance (Clarke, 2017; Sulmasy, 2008; Strickland, 2012). For the participants in our study, organ donation generated more than simply an uneasy feeling. Equally, the concept of moral distress, and/or notions of acting in the best interests of the dying, dead and bereaved, seem inadequate when reflecting on the experiences that were described to us. Our research has confirmed the powerful influence that any interaction with, about, and for human bodies can have on people (Childress, 2001), and creates a role for the concept of 'conscience' when considering such interactions (Catlin *et al.*, 2008; Price *et al.*, 2007; Sulmasy, 2008).

Our research has shown the tensions created for health professionals, who struggled with the responsibilities arising from organ donation procedures when they were experienced as contrasting with their moral beliefs, conscience, and what they perceived as common-sense clinical practice. Issues of dignity and respect for the dying, dead, and their families were also of concern to participants. Whilst organ donation was recognised as a social good by participants (Caplan, 1984; Shafer *et al.*, 1999), this created tensions for some when attempting to fulfill their professional obligations to the dying patient, whilst showing concern for their own and their colleagues' emotional wellbeing (Streat, 2004). Staff struggled with whether the option of organ donation should be broached with relatives, and some felt like a dying person was being kept alive when starting new treatments to optimise organs, or they witnessed the invasiveness of (new) treatments. When faced with the realities of organ donation in their everyday clinical practice, healthcare professionals drew on their conscience, their sense of what was 'right' or 'wrong' at the time (Lamb *et al.*, 2017; Sulmasy, 2008) to avoid compromising their moral integrity (Harter, 2015).

Organ donation is often presented as healthcare professionals caring for someone near and at the end of their life, and demonstrating compassion for relatives and staff (Cuthbertson *et al.*, 2000; Williams *et al.*, 2003). In our study, staff who felt uneasy with the procedures of organ donation and chose *not* to act in certain instances were able to present themselves as, ultimately, caring for and about the interests of patients and their relatives. Healthcare professionals drew on their own moral, ethical and cultural understandings around how they should treat and care for the living, dying, dead and newly bereaved. These understandings formed healthcare professionals'

moral frameworks that influenced the decisions they made and the care they delivered (Strickland, 2012). Being portrayed in this way, it is possible to view organ donation as a ‘conscience’ matter.

Our research would add support to others’ calls and actions for consideration of conscientious objection to be extended to staff involvement in organ donation practices (Bramstedt, 2016; Shaw *et al.*, 2018). It is too easy to simply categorise staff who express their reluctance, hesitance, and reticence to partake in organ donation at times as being ‘against’ organ donation or unsupportive of organ donation. Our research has shown that healthcare professionals who view organ donation as a conscience matter do not necessarily object to organ donation in principle, but, instead, are balancing the needs of the newly bereaved, the dignity of the dead, and the emotional wellbeing of colleagues and themselves (Streat, 2004). The reasoning underpinning a conscientious objection may differ between people according to specific information being prioritised over others. For this reason, ‘conscience’ itself is acknowledged to be fallible and subjective, but many argue that does not mean that conscience should be ignored or avoided (Clarke, 2017; Saad and Jackson, 2018).

Those in favour of healthcare professionals being able to express objections based on their conscience argue it is beneficial for society, patients and professionals alike. For some, the availability of conscientious objection reflects the existence of a liberal and democratic society (Schuklenk, 2018), and creates debate between policy makers, and healthcare professionals having to work within the constraints of the policies (Pruski and Saad, 2018). In the context of organ donation then, healthcare professionals are more than passive service providers and instead need to be understood as actors who

have autonomy in the process (Kantymir and McLeod, 2014; Savulescu, 2006). As others have identified (Pellegrino, 2002), healthcare professionals are human as well, and therefore extending the scope of conscientious objection for organ donation may benefit society, patients, and the healthcare professionals (Crigger *et al.*, 2016; Gerrard, 2009; Schuklenk, 2018). Whilst concerns over whether conscientious objection can be accommodated in healthcare in order to meet patient need are important (Clarke, 2017; Strickland, 2012), we should not lose sight of the possible impacts in service provision by healthcare professionals feeling no alternative but to leave the profession if their troubled consciences cannot be eased, or experience burnout, emotional fatigue and exhaustion (Juthberg *et al.*, 2007; Lamb *et al.*, 2017).

It is important to acknowledge that the data discussed in this paper was gathered before an opt-out legislation was introduced in England, although debates around the matter were ongoing at the time. It is possible that the troubled consciences identified in our data in the context of the required referral policy and DCD could indicate how healthcare professionals may experience delivering care for dying patients within the context of an opt-out donation system. Future research is needed to explore if perspectives around organ donation and care have shifted following the introduction of the opt-out system. Our research has highlighted that organ donation can be a highly emotional experience for healthcare professionals, given the decisions they are required to make. In recent years the significance of addressing the emotional needs and wellbeing of healthcare professionals have been acknowledged (Oliver, 2018; West and Coia, 2019); recognition of the emotional impact on staff resulting from the moral and ethical decisions associated with the organ donation is in keeping then with this recent focus. As such, it follows that consideration of conscientious objection to

be extended in order to show respect and compassion to *all* involved in organ donation is warranted.

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