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Organ donation, ethnicity and the negotiation of death: ethnographic insights from the UK

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Abstract

The introduction of end-of-life care criteria in the UK aim at standardising the processes of care at the end of life, including how medical decisions on death are communicated to the families of dying and (brain) dead patients. In the setting of the Intensive Care Unit, these activities are routinely complicated by the imperative to secure donor organs for transplantation: where recent changes to donation services have seen the accommodation of organ donation procedures into end-of-life care routines. This has ramifications for understanding how medical decisions around death and dying are brokered with the families of potential organ donors. Drawing on an ethnographic study in England, this paper will document how communications around death get turned into a particular matter of concern for the practice of requesting organ donation from minority ethnic families. It shows how attempts to resolve differences of opinion between health professionals and families about a diagnosis of brain stem death or dying are mediated by sets of brokering practices: specifically, those termed technological, authoritative, and religious brokering. These practices, we argue, not only facilitate a family's acceptance of their relative's death, but also serve to make possible a decision on organ donation.

(196 words)

Keywords: Death; organ donation; medical technologies; death brokering; decision-making; ethnicity

Introduction: the organisation of death and organ donation

In many late-capitalist countries, the processes of death and dying are largely constituted by, and regulated through the organisational practices of bio-medicine and its institutions (Glaser & Strauss, 1965; Sudnow, 1967). In the domain of critical care, this 'disciplining' of death (Kaufman, 2005) has been made possible by advancements in the technologies and techniques designed to extend the lives of seriously ill patients. The introduction of Intensive Care Units (ICUs) in the 1950s, and developments in mechanical ventilation made possible the prolongation of life, alongside a greater capacity to control the dying process (Kaufman & Morgan, 2005; Seymour, 2001). Today, the procedures of withholding and withdrawing care from dying and brain dead patients have become routine ways of managing death in Intensive Care, while also preventing the costly continuation of futile treatments (Seymour, 2001). However, greater flexibility to organise death has also made more visible the practices of health professionals at the end of life, and the importance of having clear modes of communicating the process of death and dying to families (Kaufman & Morgan, 2005).

In countries like the US and UK, concerns about how to humanely manage dying patients have resulted in the creation of end-of-life care standards and pathways (Department of Health, 2008a; GMC, 2010; Seymour, 2012). These standards deal with the delivery of care in the last days of life and post mortem, as well as how decisions on care are discussed with family members (Seymour, 2012). In the setting of the ICU, however, communications around end-of-life care can be complicated by the imperative to secure donor organs for transplantation, as we detail below (Hadders & Alnaes, 2013).

In the UK, the procedures for requesting organ donation have recently been integrated into end-of-life care planning in ICUs. This is, in part, to ensure greater access to donor organs, due to the country's high demand for transplantation and relatively low rates of deceased organ donation[i] (Department of Health, 2008b; NICE, 2011). The process involved, in doing so, is two-fold. Firstly, a policy of 'minimum notification' means ICU staff must refer to the organ donation service[ii] patients in whom there is a plan to diagnose brain stem death, *or* who are to have treatment withdrawn on the grounds that continuing care would be futile, and that the patient would die following the cessation of circulatory function[iii] (Bleakley, 2010). Secondly, in the event of a potential donor, health professionals are expected to explore the possibility of donation with the relatives of the dying/deceased (GMC, 2010). Nevertheless, it is important to add that any communication to impart a diagnosis of death or dying to families is kept completely separate from efforts to request organs for donation (AMRC, 2008; NICE, 2011). The main reason for doing so is to ensure that families have accepted the certainty of their relative's death before they are engaged in any discussions about donation. However, despite efforts to ensure that communications about death are kept separate, this presents complex challenges for clinical practice.

One context in which these concerns are especially pronounced is in relation to potential organ donors from minority ethnic backgrounds. Conventionally referred to as 'Black and Minority Ethnic' ('BME', denoting South Asian, Black Caribbean and Black African) groups within medical and healthcare discourses, they have been presented as a problematic constituency of organ givers, the main issues of which are as follows: Firstly, in aggregate terms, minority ethnic populations are characterised as having higher need for kidney transplantation than – what are presented by transplant policy and the research literature as

– their 'white' counterparts: they represent 29% of the kidney transplant waiting list, yet only 11% of the general population. Secondly, there is a shortfall in the supply of donor organs from these same groups, who make up just 6% of deceased organ donors, with reported refusal rates of 67% (NHSBT, 2014). And, thirdly, the practices of transplantation have historically favoured close tissue matching between donor and recipient, culminating in a preference for sharing organs between individuals from similar ethnic backgrounds. Taken together, this restricts the supply of suitable organs for minority ethnic populations. In turn, this has generated attention on the relationship between organ donation and ethnicity, evidenced within transplant policy, research, and health promotion initiatives, which generally attribute the reasons for low donor rates to broader 'cultural' and social issues (see Kierans & Cooper, 2011 for critical discussion). Faith-led beliefs about bodily integrity after death and funerary practices have been particularly highlighted as potentially inhibiting organ donation from 'BME' groups (Alkhawari et al., 2005; Davis & Randhawa, 2004; Randhawa, 2012), despite the fact that such concerns have also been expressed within 'white' populations (Haddow, 2005, Sque et al., 2008).

In past work, we have drawn attention to the constructed character of this issue, and its reliance on an assumption that the category of ethnicity can be homogenised, and made to act as an explanatory framework for understanding the issue of low donor rates. In particular, we have shown that a concentration upon ethnicity within transplant medicine and across health services research often serves to render invisible the institutional processes and activities involved in securing organs for transplantation (see Kierans & Cooper, 2011, 2013). In previous work, we have argued that the problems of organ donation should not be reduced to the beliefs and practices of minority ethnic groups alone, but need to be seen within the

context of the encounters between various healthcare professionals, families, patients, policies, and technologies within particular Intensive Care and clinical settings (Kierans & Cooper, 2011, 2013). In focusing attention on the particularities of the organ donation encounter within our own ethnographic research, the problems associated with discussing death with 'BME' potential donor families emerged as an important concern for organ donation, and therefore warranted further attention.

In this light, this paper aims to examine the institutional activities involved in communicating a diagnosis of death and dying to the families of 'BME' potential donors, in order to provide greater understanding of the complex processes and problems which underpin organ donation more specifically. To begin, we discuss the social science literature informing our analysis, which examines how a diagnosis of death is managed with families in acute medical settings, including in the context of potential donors; after which we turn to our ethnographic research, to describe the particular manner in which communications around death with 'BME' families become a matter of concern (Latour, 1987) for the work of organ donation. We then document the brokering arrangements which get drawn upon, in attempts to negotiate an acceptance of death with potential donor families and facilitate a decision on organ donation.

Negotiating death in medical settings

The idea of death as an institutional and organisational process was first highlighted in the seminal ethnographies of Glaser and Strauss (1965) and Sudnow (1967), both of which examined how dying patients were managed in US hospitals. These studies showed death and dying to have a specific trajectory, which was actively structured and socially produced by the

work of medical actors within their institutional milieu. In more recent years, developments in technological medicine – such as life-support and monitoring techniques – have driven a range of studies to examine their socio-cultural, political, economic, and ethical implications for the processes of death and dying (Chapple, 2010; Hadders, 2007; Illich, 1976; Kaufman, 2005; Kitzinger & Kitzinger, 2012, 2014; Timmermans, 1998). Specifically, research within Intensive Care settings, where most patients are unconscious and unable to express their wishes, has examined how a consensus on the diagnosis of death or the decision to withdraw care is negotiated – managed and brought about – with families (Hadders, 2009; Johnson, Cook, Giacomini, & Willms, 2000; Seymour, 2000, 2001). In the context of Intensive Care medicine, death can be understood as a tightly scripted process (Page & Komaromy, 2006), in which the needs of relatives, who come to act as proxy decision-makers, are paramount.

Timmermans (2005) has labelled the practices by which death gets negotiated with families, as a form of 'death brokering'. This refers to the 'flexible scripts' employed by health professionals which 'rationalise the inevitability' of death's occurrence, ensuring that it is rendered 'culturally meaningful': understandable and acceptable for the families of the deceased (2005: 993). Crucially, these practices are an outcome of, and are shaped by the political, economic and historical contexts within which they occur (Timmermans, 2010): the routinised brokering of death not only confers its cultural acceptability, but also mitigates concerns of litigation and wider economic costs of keeping dying patients alive (Cassell, 2005; Kaufman, 2005). In addition to financial considerations, the organisation of death in high technology medical settings also exhibits a biopolitics[iv], since it plays a vital part in the administration of body parts for the purposes of transplantation (Timmermans, 2010).

The capacity to utilise organs for transplantation was made possible by the establishment of 'brain death', as a legitimate category of death, in the 1960s (Kaufman & Morgan, 2005). Since this time, bodies of work in the social sciences have been concerned with articulating how the nebulous boundary between life and death in medical settings is defined and patrolled, and how patients classified as brain dead are transformed into organ donors (Hogle, 1995, 1999; Lock, 2002). A critical aspect of this process for potential donor families has been to reconcile a diagnosis of brain death (known in the UK as 'brain stem death') with the fact that their family member appears to be breathing and remains warm (Haddow, 2005, Long, Sque & Addington Hall, 2008). Work in anthropology and sociology has shown how that this constitutes a profound problem of translation, which is worked through with careful communication strategies (for discussion see: Crowley, 2001; Hadders & Alnaes, 2013; Lock, 2002; Sharp, 2006). Importantly, the way in which potential organ donors are clinically managed and brain death is communicated has been shown to be far from uniform. These are highly differentiated processes across diverse healthcare systems, the culmination of which constitutes the procurement and administration of organs for transplantation (Cohen, 1999; Crowley, 2001; Crowley Matoka & Lock, 2006; Hamdy, 2013; Hogle, 1999; Sanal, 2011).

What is clear is that ways of working with death and dying are far from standardised: they need to be situated within particular local, institutional, and national settings to be understood. To date, there is no work which has examined the phenomenon of death brokering in the context of the ever-increasing imperative for organ donation in the UK. It is important, therefore, that we pay attention to the ways in which communications around both brain and circulatory death, and their associated problems, are locally structured and negotiated with potential donor families. Specifically, as detailed above, we focus our analysis

around a UK study concerned with the relationship between ethnicity and organ donation, in order to provide a greater understanding of the complex processes and problems underpinning organ donation. In the sections which follow, we outline the methodology for the research, before turning to our findings, which examine the activities involved in communicating a diagnosis of death with 'BME' potential donor families. It is important to note that the examples given in the results focus, in the main, upon brain stem death, since donation after circulatory death was in the process of becoming re-established in UK ICUs at the time of the research.

Methodology

This paper is based on data from a study which aimed to examine the issue of low rates of deceased organ donation from 'BME' groups by focusing upon the organ donation encounter in Intensive Care settings, as detailed above. An ethnographic approach was taken to enable insights into the meanings produced around organ donation, and the different practices, settings, people, and technologies which came to shape particular types of donation encounters. This approach is informed by work across the domains of medical sociology, anthropology and science and technology studies, which pays attention to the intricacies of scientific and medical practice, and their wider institutional and cultural contexts (e.g. Hogle, 1995; Latour, 1987; Mol, 2002; Timmermans & Berg, 2003).

Fieldwork, conducted between October 2009 and February 2011, focused on: 1) the work of two regional teams of Specialist Nurses in Organ Donation (SN-ODs) in England, responsible for managing the organ donation process; and 2) specific sites served by these teams, namely an ICU and Paediatric ICU (PICU) department in two acute hospital Trusts (given pseudonyms

of Hillview and Lakeland, respectively). Both sites had large minority ethnic patient populations (mainly of Pakistani Muslim and Indian heritage) and low organ donor rates. The study was granted full National Health Service (NHS) ethics approval, all participants were assigned pseudonyms, and identifying features of donation cases were anonymised.

Due to ethical and practical difficulties involved in waiting for someone to die in the 'right' way for organ donation, it was not possible to observe the donation encounter itself. Instead, insights were recorded from: observations of donation training sessions, donation committee meetings at Lakeland and Specialist Nurses in Organ Donation team meetings; gathering policy documents around organ donation; and 26 formal and narrative interviews with 22 health care professionals (these included: SN-ODs, ICU nurses, consultant intensivists and anaesthetists, and a transplant surgeon and renal consultant). We are aware that lack of direct access to the donation encounter means we could not fully draw out the subtleties of the interaction; nor could we understand the ways in which families reacted to news of death and the donation request. Narrative interviews with health professionals thus focused upon reflected accounts of experiences of donation encounters with minority ethnic families, while also eliciting more general stories about organ donation. Additional observations and ten narrative and informal interviews were conducted with a purposive sample of 'community' participants from minority ethnic backgrounds with experience of transplantation (including transplant recipients, live kidney donors, and religious representatives).

Common to ethnographic research, the data were analysed iteratively. Initial concepts were established during fieldwork and shaped the data collection process – e.g. questions about death communications were incorporated into interviews after this topic was raised by

participants. An ethnographic approach to analysis looks for commonalities in meaning-making and practices around death and donation, alongside their understanding within institutional, social, and political contexts (Hammersley & Atkinson, 2007). Complementing this approach, formal interviews were also subjected to narrative analysis, to understand how the donation encounter was constructed within participants' accounts (Reissman, 2008). This combination allowed for insight into the 'structure' of donation cases, while retaining the richness of individual accounts (Kierans et al., 2013).

Before turning to our data, it is important to note that, while we utilise terms like 'BME', 'the minority ethnic family', and 'white families', these are not taken as unproblematic labels for heterogeneous populations. Rather, they are used to draw attention to how these terms get deployed as classificatory devices within transplant policy, research, and in healthcare settings, categories which enact and produce the world of which they speak (Bowker & Star, 1999). In what follows we provide a background to the organisational context in which death operates within deceased donation in the UK. We then turn to the data to show, firstly, how communications around death are turned into a particular matter of concern for requesting organ donation from minority ethnic families. Secondly, we document the brokering practices which are employed, in attempts to ensure that both death and donation are made into an acceptable outcome for families.

Background: organising death and organ donation

Fundamental to the management of death in UK Intensive Care settings are the use of end-of-life care criteria. These were established in 2008, with the aim of achieving a 'whole systems approach' to the care of dying patients (see Department of Health, 2008a; GMC, 2010;

Seymour, 2012). Key to this approach is the recognition of the central role played by family members and carers in end-of-life decision-making, such as considerations over whether to continue with, or withdraw treatment on dying patients. The care of dead and dying patients and their families becomes further complicated in situations where the patient is also a potential organ donor: intensifying the necessity to fully accommodate a clinical diagnosis of death into a family's decision making.

The incorporation of organ donation processes into end-of-life care procedures has gone hand-in-hand with efforts to increase the UK's organ donor rates over the past two decades[v], in particular, where transplant policy and health promotion campaigns have intensified efforts to foster public willingness to donate[vi]. In conjunction, there have been changes to the organisation of donation services, which were instituted by the national *Organs for Transplants* strategy in 2008, its aim: to increase organ donation rates by 50% by 2013 by making donation a 'usual not unusual' event. This was to be done by introducing standardised procedures around potential donor referral and management (Department of Health, 2008b), including the integration of the organ donation process into end-of-life care routines through 'minimum notification' policies for potential donor referral, detailed previously.

Acts of referring a 'patient' as a potential donor set in motion what is known as the organ donation 'pathway'. The pathway is currently organised by two different classifications of death. The first, donation after brain stem death (DBD), arises from individuals who have been pronounced dead by neurological criteria. The second, donation after circulatory death (DCD), involves removing organs from donors who have had clinical care withdrawn on the grounds that continuing treatment would be futile (commonly termed 'medical futility'), and are

declared dead on the basis of cardio-respiratory criteria. For both DBD and DCD, the family will firstly be informed by the medical team about the diagnosis of brain stem death (BSD) or the decision to withdraw care. Following this, a SN-OD will approach the family about their 'options', one of these being organ donation. If the family agree to donate, they will be taken through a series of consent and patient assessment forms (see Kierans & Cooper, 2013).

According to donation guidelines, families should be given news of a diagnosis of BSD or the dying status of their relative, and show their understanding of this diagnosis *prior to* the donation request (NICE, 2011, UK Transplant, 2004). As a result, the process of discussing death has acquired procedural importance for the donation pathway, in that a family's engagement with the donation request is understood to be dependent upon staff successfully communicating a diagnosis of death. This was a salient concern in fieldwork observations of organ donation education days. These were delivered by SN-ODs as part of ICU staff training in the new donation procedures. In these sessions, ICU staff were provided with a toolkit of the most appropriate vocabulary to use when telling a family about the death or impending death of their relative. The importance of describing death in unambiguous terms, such as 'your relative is going to die' were contrasted with examples of 'bad' practice, where families had been left confused by doctors telling them things like: 'your relative is very deep in the woods'. During these sessions SN-ODs would explain that it was critical, before requesting donation, to *first* check that the family had understood the news of their relative's death. If they thought a family had failed to grasp the situation, they would re-explain what a diagnosis of BSD meant or why the decision had been made to stop treatment, thereby reinforcing the significance of certainty.

While emphasis was placed upon the importance of proceduralising and routinising (Koenig, 1998) communications around death, little could prevent the interactions between staff and potential donor families from being shaped by a range of institutionally and socially mediated concerns. This was particularly the case in relation to families who were differentiated by their ethnicity, and who, as we show below, became routinely constructed in problematic terms.

Communicating death within the context of ethnicity

Integrating new procedures around communicating news of death in the context of organ donation had implications for the working practices of ICU staff and SN-ODs. At Lakeland and Hillview, this was also complicated by histories of low donor rates and the relatively large South Asian populations (mainly of Pakistani and Indian heritage) both hospitals served. When discussing their interactions with 'Asian' or 'Muslim' families, staff emphasised their struggles to convince them that their relative was brain dead, or to justify their wish to withdraw care on dying patients. Sandra, an ICU nurse at Hillview, explained the case of one family:

> They weren't believing what we were telling them about the brain stem death. They were pulling in everything they could think of: doctors get it wrong, and you hear about people waking up from comas [...] We were having trouble just to get them to understand brain stem death without even going down the avenue of requesting organs. [...] I mean it's difficult isn't it when they [potential donor] have got a visible heart rate and their chest is going up and down: they're pink and warm.

Resisting a diagnosis of death under these circumstances is made all the more problematic in light of the vital signs of life coming from the body of the potential donor and made visible in

attached monitors. Sandra recalled how the family became angry at the subsequent donation request, accusing staff of 'vying' for their relative's organs, who they saw as still alive, thinking that, as she put it, he 'would probably come out of his coma'. A similar case relating to a potential circulatory death donor was brought up by Sophie, an experienced SN-OD. Sophie described a situation where the medical team wanted to withdraw care on a dying Indian woman. The family refused to accept that she would not recover, and insisted that she not be taken off the ventilator. Sophie recounted how the family put an immediate stop to any attempts by staff to engage them in donation discussions. Reflecting on the negative donation outcome of this case she explained: 'so donation wasn't an option in the sense that they [family] were never *ever* going to even accept that she could be taken off the ventilator, [that] there wasn't hope for her to survive.'

Competing definitions around death, or struggles by staff to prevent what they felt to be an inevitable (non-donation) outcome as a result of these conflicts characterised discussion with many families, irrespective of their ethnicity. However, staff routinely framed their encounters with minority ethnic families around an understanding of the particular problems presented by a family's 'culture'. By way of explanation, in relation to Sandra's 'Muslim' family, tensions over death and donation were put down to: '*total* ignorance, although there was ignorance towards organ donation and brain stem death [...] I just think it was a cultural thing'. Sandra's assertion was characteristic of the reactions by health professionals to instances where they struggled to reach a consensus with minority ethnic families over the decision on death/dying. Staff would routinely justify their accounts by paying attention to religious objects brought into hospital wards, traditional dress worn by families, religious practices and beliefs, or indeed stories about the quantity of relatives wanting to participate in discussions about their

dead/dying relative. One SN-OD, Mary, introduced the case of a 'very sick' 'Asian' baby, whom doctors had wished to withdraw treatment from. She described how the doctors were having difficulty trying to persuade the family that stopping treatment was in their baby's best interests. Although Mary explained that 'there were *lots* of issues regarding actually being able to withdraw treatment', she explained these problems with reference to the family's demands for a religious leader to be brought from Pakistan, before they would participate in discussions with the medical team.

The assumption that 'culture' could hinder the procedures for engaging a family in discussions of death and facilitating a decision on organ donation was commonly articulated. 'Culture' was primarily viewed to be in competition with clinical decisions on death and, for staff, perceived to create surplus work to produce the right conditions for the donation request. Importantly, it should be understood that the particularities of these accounts emerge at the intersections between local hospital Trusts under pressure to increase donation rates and a growing bureaucracy of guidelines and procedures at a national level. The subsequent demands this placed upon the practices of ICU staff and SN-ODs required them not only to optimise opportunities for organ donation, but to draw on and create strategies for doing so, as we show in the next section.

Negotiating death in organ donation: responses to the problem

Efforts to resolve disputes with families and legitimise the medical diagnosis of BSD or the wish to withdraw care (in DCD) incorporated different brokering strategies. These we characterise as involving: (1) technological demonstrations, (2) authorising medical decisions,

and (3) religious mediation. These activities, we argue, not only facilitated a family's acceptance of death, but also served to make possible a decision on donation.

Technological demonstrations

In situations involving patients who had been declared BSD, and where families struggled to accept this diagnosis, ICU staff would engage families in a performance of brain stem death tests, in order to display the technicalities of death. One ICU nurse, Laura, described the importance she saw in showing a family these tests:

> I did a study as part of a course about allowing families to *view* the brain stem death tests, [be]cause I feel with some people it goes some way to make them understand. And we did allow one Asian family, who were not believing us about the brain death [to view the tests]. I asked the Consultant if it would be possible, especially for the apnoea test, if the family could be there. [...] And I went through what would happen and that it could become distressing for them [family], and that they could leave at any time. Which they did appreciate...and they did observe the tests, and I do think it helped them understand what we were saying. [...]But in the end they refused donation.

Showing a family the process of BSD testing was felt to help them see the technical reality of their relative's death and, as Laura explains, 'make them understand' the situation (Lock, 2002). Laura focuses particularly on the apnoea test, which involves disconnecting the 'patient' from the ventilator, to confirm the impossibility of them breathing without it. This test was regarded as potentially distressing for families, since, as one SN-OD put it: 'you almost

get a sense that they [family] are willing them [patient] to breathe, to prove us wrong that they aren't dead'.

Despite the risk of causing upset, the apnoea test was seen as effective in demonstrating the infallibility of the medical diagnosis of death. SN-ODs would sometimes use this test when they felt a family had not understood the finality of death. During one donation training day, role play was used to educate ICU and Emergency nurses as to how to approach potential donor families about organ donation. A scenario played out where a fictional family were asked to donate the organs of their brain dead relative. The 'daughter' initially objected to the request, since she could not accept her 'father' was dead, exclaiming that he was still breathing. The SN-OD, after guiding the family through an explanation of brain stem death, arranged for them to witness the apnoea test. Here, the 'patient', a mannequin attached to a simulation mechanical ventilator, surrounded by wires and machinery, was disconnected from the ventilator, and the family waited for signs of breathing, which never came. After witnessing this test, the 'daughter' finally conceded that her father must be dead, and indicated her willingness to engage in donation discussions.

This scenario produced an idealised construction of the role of the apnoea test to rescue a potentially unsuccessful donation scenario. The mechanical ventilator was thus imbued with the technical ability to bridge the gap between clinical definitions of death and a family's understanding of the situation (Hadders, 2009). By removing a 'patient' from this machine, death was made objective for families. This way of legitimising the diagnosis of BSD also acted to facilitate the choice of organ donation: in that once able to accept their non-breathing relative was dead, a family were seen as better able to engage with the donation request.

Authorising medical decisions

Legitimising medical decisions on death also involved appropriating clinical, legal, and ethical forms of authority. One consultant at Hillview, John, explained a problematic case where a 'South Asian' family refused to recognise the dying status of their relative:

> It was a very difficult experience even before we got to the topic of organ donation. It was very difficult to persuade [the family] that continuing treatment wasn't in their mother's best interests, who had developed organ failure and was failing to respond to all supportive treatments. We took several days to convince the family to limit the care we were giving. They completely refused to have care withdrawn, and I guess rather than go through the courts we negotiated a limitation [rather than complete withdrawal] of treatment. And in her particular case she eventually became brain stem dead...but...[sighs] we had a very difficult time convincing her family that that meant she was dead in terms of medical and legal authorities. So eventually she died on the ventilator. [...] But clearly we had reservations about whether we were acting in that lady's best interests. But the writing was on the wall that she was unlikely to go on and donate any organs.

John draws attention to the efforts needed to validate the unit's decision about the woman's dying status. In comparison to 'white' families, cases with minority ethnic families were storied around their need to have a firmer justification for the basis of the diagnosis of BSD or withdrawal of care. This required drawing on the authorisation of multiple medical personnel, and, as John shows, communicating the clinical inevitability of death: in this case, focusing

upon the facts of organ failure and the patient's unresponsiveness to treatment. He also mentions the possibility of negotiating the decision through the courts. In cases where there was deadlock between families and staff, hospital solicitors were occasionally consulted to advise staff who could not reach a consensus with relatives about withdrawing care on dead or dying patients[vii]. Death was thus legitimised to families as legal and medical realities, which were afforded greater value than a family's understanding of the situation.

Coupled with this, John describes the importance of convincing the family about the ethical imperative of allowing their relative to die. He frames the continuation of treatment as acting against, rather than for, the patient's 'best interests'. Instead of having the positive effect of recovery, continuing with, what one nurse termed, 'aggressive' treatment on dying patients was perceived by staff as the cause of further distress (Mohammed and Peter 2009). Ketu, a PICU consultant, described the wider demands which complicated the efforts of staff to resolve disagreements over withdrawal of care with families, explaining how: 'a lot of the decisions that we make are driven by pressures beyond that of my working environment: society's expectations, families' expectations, colleagues' expectations. All of these drive you to treatment options you don't necessarily believe in'.

Ketu highlights how the act of stopping treatment runs counter to a family's expectation that medical practice will attempt to save a life at all costs. For clinicians, this created an ambivalent situation, meaning they would sometimes continue with treatment on dying patients that they considered inappropriate, at the behest of the family. In the case of dying patients, staff therefore also worked at drawing a family's attention to the discontinuation of care as an ethical, rather than simply a medical concern, as we saw in John's case. By utilising the broader

authorities of clinical, legal and ethical forms of knowledge and understanding, these brokering practices attempted to validate medical judgements on death and, in so doing, created further opportunities for organ donation.

Religious mediation

When medical forms of negotiation failed to work, at times, staff would try to bolster support for their decision by calling in a religious representative. This was especially the case with 'Muslim' families, a group classified by staff as typically troublesome for withdrawal of care procedures on dying patients. At Hillview, where there were regular differences of opinion between 'Muslim' families and ICU staff over decisions to withdraw care on patients whose situations were deemed hopeless, a local Imam, Aatif, was often asked to arbitrate between the two sides. Aatif described how these scenarios played out, in his role as mediator between the interests of families and those of the medical team:

> The family will say: 'no, he's still breathing.' Okay [doctors respond] 'it's not him that's breathing, he's been assisted by this machine. He's unable to do that himself.' The family will come back with: 'oh no, but he might improve'. So, somebody needs to come and bridge the gap between *their* [family] expectations and *their* [staff] expectations. So who comes along? Call in the Chaplain: I come fully armoured!

Aatif's role involved 'bridging the gap' between the understandings of the largely 'white' ICU consultant body at Hillview and 'Muslim' families. Upon arriving at the scene, Aatif explained that his first action was to question the medical team about the patient's prognosis. He would

ask what treatments had been tried, and whether there was any possibility that other treatments might work. Once he had gained the 'medical' perspective, Aatif would approach the family, who, in his words: 'will put responsibility for the decision on my shoulders. They will say "Imam, whatever you think: we are happy with the outcome of whatever God has to say"'. Aatif described how he would come to a decision in such high pressured scenarios:

> So *Islamically* I seek a second opinion from another Islamic Scholar, just like your medical staff would. [....] There are times when I have gone up to the consultants, asked leading questions and haven't agreed with their opinion. And I have actually said: 'I don't think you can be supported in this [decision to stop treatment]'. So medical staff have to win my approval for their decision. If I agree with them, then staff will say: 'Okay, now that you're with us, go and sort them lot [family] out' (laughs). When all fails, they know that I can pull it together for 'em.

Aatif describes how he has his own system of practice for approaching a case: he attempts to find out about all possible options for a patient in order to reach an understanding of the diagnosis, thereby enhancing a 'religious' decision on whether to continue or withdraw care. In seeking a second 'Islamic' opinion, Aatif shares his responsibility as decision-maker, similar to how he sees the practices of a medical team. This means that the usual constitution of death (Latour, 1993) – as a clinical, procedural, ethical, and legal reality – is potentially disrupted by religious authority. Importantly, Aatif emphasises how, when in agreement with the medical team, he has the power to mediate the situation and convince a family of the justification to withdraw care. The involvement of religious figures in withdrawal of care discussions thus illustrates how staff attempt to engage with struggles around death by

utilising a family's (religious) understanding of the situation, in an endeavour to overcome the very difficulties that religion itself was perceived to cause.

Discussion and conclusion

This paper has shown that the communications around death and dying within Intensive Care settings have become the subject of rigorous scrutiny for policy-makers, particularly in light of their critical role in facilitating decisions on organ donation. Instituting procedures around end-of-life care in the context of potential organ donors thus aims to guide the practices involved in discussing a diagnosis of death or dying. By standardising exactly how and when death is discussed with families, procedures intend to 'discipline' the work of health professionals, to ensure that practices get uniformly employed within local settings (Hogle, 1995), and to limit the potential for families to 'misunderstand' the medical decision on death. However, while procedural courses of action are emphasised as the most effective way of optimising donation opportunities, these need to be considered within the context of the clinical localities which organise and underpin their everyday peculiarities (Crowley Matoka & Lock, 2006; Lock, 2002).

As demonstrated in our findings, discussing the death of potential donors acquires particular form in the context of families who have been represented as problematic constituents for organ donation (Kierans & Cooper, 2011, 2013). In the local research sites, ethnicity and notions of cultural difference were employed as explanatory devices: they were assigned qualities understood to exacerbate the difficulties involved in following the rules around organ donation. We are not, however, disputing that staff also had problems with fostering understandings of death and facilitating donation with 'white' families; this is attested to in

the wider literature showing how families deal with a diagnosis of death and the request for organ donation (see Haddow, 2005; Sque et al. 2008). What is important is how the classification of families in particular ways has consequences for the everyday strategies which get employed to negotiate a diagnosis of brain stem death or dying (Bowker & Star, 1999).

In Hillview and Lakeland, understandings of death, and thus control over the dying process, were ordered through the particular brokering activities of technological demonstrations, clinical, legal and ethical forms of authorisation, and religious mediation. While these strategies demonstrate some similarities to those described by studies on both organ donation and dying in acute care (Hadders & Alnaes, 2013; Kaufman, 2005; Lock, 2002; Seymour, 2001; Sharp, 2006; Timmermans, 1998), it is important that the activities we highlight are not simply understood as abstract sets of practices, which would function regardless of their setting. As Timmermans (2005) has argued, there is the need to demonstrate the specific purposes of these brokering techniques within their local contexts – their implicit and explicit endpoints – beyond the ability to construct death as a culturally acceptable outcome for individual families.

As this study has shown, the negotiations drawn upon by staff are responsive to the conditions imposed by new donation procedures, targets to drive up rates of deceased donation, and the specific focus upon families classified by their ethnicity. This offers the potential for developing our understanding of the phenomena of death brokering: as a practice which acquires particular 'cultural' shape, and has specific end points depending on the local and national biopolitical contexts within which it occurs. In the space of the interactions with families of potential donors in the UK, the practices of death brokering become 'routinised'

and ‘ritualised’ (Koenig, 1998) around the possible outcome of organ donation, despite the best efforts of policy to keep these as procedurally (and ethically) separate domains of practice. Thus, it is not only death as the end point which is made meaningful to families, but also a death which is produced as acceptable for the purposes of organ donation.

This has implications for the practitioners responsible for imparting death and facilitating the process of organ donation, and for social scientists working with issues of death and dying in high technology settings. The task now is to conduct further research into the wider ramifications of the routinisation of organ donation in end-of-life care. For example, we did not look at how ‘minimum notification’ policies for potential donors affect the practices involved in making a diagnosis of brain stem death or reaching a decision about a patient’s dying status. Equally, our research was conducted when donation after circulatory death had just begun to be implemented as a standardised form of practice in the UK. This reflects the weight given to DBD in our data, and means there is scope for further research on the practices of donation after circulatory death, such as the ethics of continuing with aspects of treatment for the purposes of donation (Murphy & Adams, 2013). Finally, while we understand the peculiarities of death brokering in response to ethnicity, we know little of how families classified in this way make sense of these interactions and respond to these practices. In conducting continued research in these areas, we would come to a more situated understanding of the biopolitical implications of the brokering of death in the context of the ever-growing demands of transplant medicine.

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[i] As of March 2014 there were 7,026 patients on the active transplant waiting list in the UK. This represents 111.5 patients per million population (pmp), which is starkly contrasted with the deceased organ donation rate of 20.6 pmp (NHSBT, 2014).

[ii] Patients also have to be initially suitable to donate. Contraindications for organ donation include known HIV infection or neurodegenerative diseases linked to infection.

[iii] In both cases, potential donors are attached to a mechanical ventilator. In potential donors who are to have treatment withdrawn, this involves stopping ventilation and most pharmacological support and waiting for their heart to stop beating. After five minutes of the patient being in cardio-respiratory arrest, a clinician will certify death and the donor will be taken to the operating theatre for the organ retrieval. Potential donors who are declared brain stem dead will remain ventilated while their organs are removed.

[iv] We use Foucault's (2003) conception of biopolitics. This deals with the political concern with the 'life processes' of populations and the governing strategies and mechanisms which manage these processes (2003: 245).

[v] This has been driven by developments in transplant technologies, with transplantation now considered the 'gold' standard for treating chronic organ failure (DH, 2008b).

[vi] The UK currently operates an opt-in system of organ donation. As of 1st December 2015, Wales will operate an opt-out system.

[vii] If disagreements on withdrawal of care cannot be resolved, this may lead to obtaining the views of a court, as justified in medical case law (GMC, 2010).