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Healthcare Professionals' Decisions to Facilitate Organ Donation in the Intensive Care Unit: A Matter of Conscience?

Dr Laura Machin, Lancaster University
Dr Heather Dixon, Lancashire Teaching Hospitals
Dr Mark Wilkinson, University Hospital Morecambe Bay Trust

Background: Organ Donation

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- Recognise that organ donation is a community good (Caplan, 1984), 'social good' (Shafer et al., 1999)
  - Intensivists are supportive of transplantation and organ donation (Pearson & Zurynski, 1995)
- Organ donation has been described as a process involving a series of decisions (Gardiner & Riley, 2007)
  – The process of 'donation' does not involve the donor, and the donation is made by others i.e. families (Morton & Leonard, 1979)
- The interpersonal reality of the situation (Streat, 2004)
  – Family and the need for respect and compassion
- "Organ transplantation is a very complex area, because the human body evokes various beliefs, symbols, sentiments, and emotions as well as various rituals and social practices" (Childress, 2001)

Background: Deceased Organ Donation

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- Recent UK strategies to increase organ supply
  - Introduction of Specialist Nurses for Organ Donation (SNODs) within Intensive Care Units
    - Identify potential donors, gain consent, make organs available nationally, support bereaved families
  - Reintroduction of donation after circulatory death
    - Both newer and more common than donation after brainstem death, significant increase in organ donations, heavily criticised (Fenner et al, 2014)
  - An opt-out system for organ donation
    - People are presumed to consent to donating their organs unless they register their decision to opt-out on the NHS organ donation register.

Background: Conscience

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- Much debated concept
  - Fundamental commitment or intention to be moral, make decisions about right and wrong, good and evil, and what it means to be a good person (Lamb et al., 2017; Sulmasy, 2008)
- A vague, and unhelpful concept (Sulmasy, 2008)
- Linked to personal and moral integrity (Sulmasy, 2008)
- Related to, but different from, broad concepts such as 'moral distress', and 'best interests'
  - More than merely a difference of opinion between patient and doctor when evaluating what is best (Price et al., 2007)
  - Encompasses medical, emotional, and other welfare issues (Price et al., 2007)
  - Objections proposed as a response to moral distress (Catin et al., 2008)

Background: Conscience

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- Objections based on conscience set to increase (Sulmasy, 2008)
  - Medicine concerns questions of life and death = great moral significance
  - Advances in technology expanding medical possibilities
  - Cultural, religious and moral pluralism within society
- Doctors considered as 'public servants' (Savulescu, 2006), 'free agents' (Kantymir & McLeod, 2014)
- Shift in culture of medicine from paternalism to patient autonomy (Clarke, 2017)
- Calls for respect for conscience within medical practice e.g. tolerance (Sulmasy, 2008), epistemic modesty (Clarke, 2017)
  - Conscience not infallible, and is subjective

Background: Conscientious Objection (CO)

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- In the UK, healthcare staff have rights to opt out of some lawful procedures e.g. reproduction, and end of life care based on personal moral and/or religious beliefs (Lamb et al., 2017)
- Widening the scope of CO to organ donation?
  - Recent debates within intensive care community, acknowledged by GMC, US healthcare systems e.g. Dignity Health (Bramstedt, 2016); Children's Hospital Boston (Shaw et al., 2018)
  - Studies show organ donation can be a cause of moral distress, trauma and tribulation (Elpern et al., 2005; Regehr et al., 2004)
  - Professional and patient (legitimate) objection to death determination and (non) heart beating donors (Nair-Collins, 2015; Moschella, 2016)
  - Unprofessional? Uninformed? Morally complicit in letting patients die? (Shaw et al., 2018; Schuklesk & Smalling, 2017; Levi, 2015)

Today

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- Emerging findings
  - 24 in-depth, semi-structured interviews
  - Conducted in 2013
  - Clinicians and nurses across three wards (intensive care, theatre, and emergency) in one NHS Trust in the North West of England.
- Initial thematic coding of the interview transcripts
  - When are participants emotionally, morally, ethically, professionally torn or challenged?
  - What decisions are participants making? How are they making these decisions? And what is taking priority when making decisions?
  - When are participants justifying their decisions, actions? When is it a matter of conscience (resulting in either action or inaction)
- Research Ethics Committee and Research and Development approved

Deciding to Facilitate Donation

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- *Raising the topic with relatives*
- *Referring to the SNOD*
  - *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* *(A1 – 1 ICU Consultant Anaesthetist)*
- *Allocating resources*
  - *…we were dealing with one patient that we were looking at for organ donation. We had somebody down in A & E and we were full and there was nobody else to move anywhere and it's do you carry on with that person for the good of somebody else or do you move somebody into the safe environment where they need to be treated? I think that is a big dilemma* *(A4 – 2 ICU Ward Manager)*

Deciding to Facilitate Donation

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- *Starting (new) treatments / Optimising organs*
  - *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…But you've still got a patient (A1-2 ICU Consultant Anaesthetist)*
  - *If you've got a patient who has expressed that they want to be an organ donor…I'd still have the same issues about keeping somebody alive for a longer period of time in order that they could donate (A1 – 1 ICU Consultant Anaesthetist)*
  - *…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 Anaesthetic Consultant)*

Deciding to Facilitate Donation

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- *Policies, moral and ethical compass, sense of right and wrong, gut instinct, personal beliefs, conscience*
  - *We usually have policies and things that you have to read up on. But for me, you've obviously got that to go off but for me is it morally okay to be doing that to somebody or whatever, regardless of what it is…It's whether it's morally okay to do things like that.* (B2 – 1 Theatre Staff Nurse)
  - *Am I doing the right thing for the patient? Am I doing the right thing for actually the greater good? And also am I doing the right thing for the family as well? And it's that sort of balance between what feels comfortable is right and what actually feels very uncomfortable. 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.* (A1 – 1 ICU Consultant Anaesthetist)
  - *I do appreciate that we should be asking all patients that die on our unit about donation but sometimes it's very hard when you just don't feel it's the right time. You just don't feel that you can. You just have a gut instinct whether it's right or not.* (A2 – 1 ICU Sister)

Priorities when Making Decisions

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- Providing, experiencing, and witnessing a good death
  - *Donation after cardiac death…It did feel a little bit like body snatching and I didn't really like it…The patient was deteriorating and so we were actually starting to add treatments and you're thinking we shouldn't really be escalating…we got to 20 minutes after I'd stopped treatment and she [donor co-ordinator] 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 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* *(AB1 – 4 Consultant in Anaesthetics and Intensive Care)*

Priorities when Making Decisions

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- Providing, experiencing, and witnessing a good death
  - *…they should have been just focusing on their loved one dying really never mind what time is the [organ retrieval] team coming…What should have been a nice peaceful process, which is what we try to achieve, turned into a bit fraught and a bit up in the air* *(A4 – 1 ICU Ward Manager)*
- *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 alive or prolonging their death, if you like* *(A4 – 2 ICU Ward Manager)*
  - *…And then they die and then they've got to be rushed to theatre so quickly. You've not got time to sort of grieve and it's we've got to go now. It's an emotional time and it's really tough. I don't think whatever you do, whatever training you put in for that, it's always going to be a bit of a hard decision.* *(A2 – 2 ICU Charge Nurse)*

Priorities when Making Decisions

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- Relationships with relatives and patients
  - Raising topic
    - *…I'm going to have to have a discussion about what we do with their organs, which then sounds a bit functional…Breaking this individual down to their component parts rather than the whole person, if you see what I mean.* *(AE1 – 1 Consultant in Intensive Care Medicine & CLOD)*
  - SNOD involvement
    - *…the family might think I'm hiding something because I haven't mentioned it…I find it a really difficult part of the whole process…It feels a little bit like a betrayal to me of the family to then get an outsider in to approach them about organ donation* *(AB1 – 4 Consultant in Anaesthetics and Intensive Care)*

Priorities when Making Decisions

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- Relationships with relatives and patients
  - Perception of dying person
    - *…then there's got to be that period before. That can be a bit hard sometimes because…it is a bit vulture like really isn't it. You're waiting for somebody to die* *(B3 – 1 Operating Department Practitioner)*
    - *…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 ICU Charge Nurse)*
    - *…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* *(A4 – 1 ICU Ward Manager)*
  - Likelihood of donation
    - *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 ICU Consultant Anaesthetist)*

Conclusions

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- Organ donation policies, practices, and processes meant:
  - Healthcare professionals made a series of decisions that need to be acknowledged…and respected?
  - Healthcare professionals drew on their moral, ethical, and cultural beliefs when making decisions
  - Healthcare professionals' beliefs around how the living, dying, dead and bereaved are treated and cared for informed their decision-making
    - End of life practices; interaction and engagement with humans and their bodies; dignity and respect for the dying and the dead
  - Adopting a healthcare professional's perspective, organ donation can be viewed as a 'conscience' matter

Implications for Practice?

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- Extending the scope of CO for organ donation
  - Reflection of liberal and democratic state we live in
  - Protects doctor's moral integrity
  - Facilitates practitioners with virtuous moral characters (Gerrard, 2009)
- Emotional and mental well being of healthcare professionals
  - Studies have shown that the moral distress that results from acting against one's conscience leads to burnout, fatigue and emotional exhaustion
- Shifting to an opt-out system
  - How prepared are our healthcare workforce for the policy
  - Acknowledge the limitations of the data
  - Lessons learned elsewhere