

Opting out of opting out? Organ donation in the UK and conscientious objection

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Background: Deceased Organ Donation

- 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 in England from Spring 2020
 - People will be presumed to consent to donating their organs unless they register their decision to opt-out on the NHS organ donation register.

Background: Conscientious Objection (CO)

- In the UK, healthcare staff have rights to opt out of some lawful procedures e.g. reproduction, and end of life care
- 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)
 - (Legitimate) objection to death determination and (non) heart beating donors (Nair-Collins, 2015; Moschella, 2016)
 - Recognise that organ donation is a community good (Caplan, 1984)
 - Unprofessional? Uninformed? Morally complicit in letting patients die? (Shaw et al., 2018)

Today

- 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
 - What are participants objecting to? What are the circumstances of the objection? Why do they object?
 - When are participants emotionally, morally, ethically, professionally torn? Challenged?
 - 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

Organ donation & balancing responsibilities

- To recipients
 - Yeah, I think 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 Anaesthesia Consultant)
- To patients
 - The workload for theatres I think is more significant. I think that's often overlooked with the team because it particularly in smaller hospitals can take out the capacity for emergency surgery. And particularly if you're retrieving a lot of organs, that's a long case and that's utilising anaesthetists and meaning that nobody else can have an operation for the time that that's going on. It's a big commitment, particularly when actually this patient is already dead. It can utilise theatre time and theatre staff and also it's not just that but it's the clearing up afterwards (A1-2 ICU Consultant Anaesthetist)

SNODs, DCD & conflicts of interests

- Organ donation team

 - ...I just don't like the fact that you go in and get on to the withdrawal part and you come out and then basically the organ donation team go in there next as if they were waiting and praying to go in and grab stuff. That's the bit I don't like. (A1 – 1 ICU Consultant Anaesthetist)
- Perception of patient
 - I think 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)
 - I think it's distinguishing between somebody dying and somebody for organ donation. 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. (A4 – 2 ICU Ward Manager)

Staff concerns relating to opting out

– Facilitating opting out

- How you enable people to opt-out I think would be difficult...you'd have to be very careful as to how stringently you ensured that everybody did have a proper option to opt-out...to be able to enable people who wanted to opt-out could opt-out (A1-2 ICU Consultant Anaesthetist)
- ...would there be people who if they don't opt-out but you know that they really wouldn't want it, it's very difficult. You could have had these conversations but they've just physically don't it. They might not know how to do it. It's very tricky (A2 – 1 ICU Sister)
- ...there would have to be really clear processes in making it very easy for people to be able to do that so it wouldn't be something that somebody felt they couldn't or wouldn't be able to do. (A4 – 2 ICU Ward Manager)

Staff concerns relating to opting out

- Informed consent?
 - And at what stage do you make the opt-out age? 16, 18? How many 18 year olds actually ever think about their own mortality? I certainly didn't when I was that age. (A1-2 ICU Consultant Anaesthetist)
 - I think it would be difficult to know whether patients have genuinely consented for organ donation with an opt-out system. (AB1 – 1 Anaesthesia/ICU Consultant)
 - I think the information about the heartbeating and non-heartbeating donation isn't out there...actually let[ting] them [public] know what they're buying into and the different types and actually also give them an option to choose between the two different types. Because they are different... (AB1 – 2 Anaesthesia Consultant)

Staff concerns relating to opting out

- Respecting decision
 - I think it would depend on what exactly opt-out was...I think if there was still room for consultation with family and taking into consideration families' wishes then it wouldn't actually be that different from the situation we're in currently. (A1-2 ICU Consultant Anaesthetist)
- A loss of altruism
 - I don't know if it would work because the whole thing is that it's the gift of life and it's about somebody wanting to help somebody else not making them. And I quite like that. I think there's something quite special about it being a gift. (A2-3 ICU Sister)
- National policy, local implications
 - So the time it takes a retrieval team to get here and be set up to retrieve organs is substantial. So the impact on patients that may be are waiting to have their organs retrieved is much bigger at a centre... (AB1 – 2 Anaesthesia Consultant)

Opting out of opt out

- Type of patient
 - ...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 ICU Consultant Anaesthetist)
- Raising the topic
 - I mean, some things sit easy with me and some things don't. 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)

Opting out of opt out

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- End of life practices
 - ...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)
 - ...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. (A1 – 1 ICU Consultant Anaesthetist)

Initial observations

- Strategies to increase supply of organs influencing hospital practices:
 - opting out and respecting relatives' wishes;
 - end of life experience for patient, relatives and staff, and DCD;
 - relationships with SNODs and clinical judgement, autonomy and authority.
- Acknowledge date of data, but to ignore feelings would be foolish
 - Due diligence on healthcare staff attitudes?
 - Sufficient consideration given to healthcare staff wellbeing and experience of delivering end of life care?