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‘You have to die first’: exploring the thoughts and feelings on organ donation of English women who have not signed up to be donors

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Abstract

Four white British women who had not signed up to be organ donors were interviewed in depth to investigate their feelings on organ donation. Transcripts were analysed using Interpretative Phenomenological Analysis to reveal how the ability to detach from the body affects the acceptance of organ donation, how organ donation can trigger difficult thoughts and how the family can be used to explain not having signed up. The findings confirm previous empirical evidence but also offer original insight on the discrepancy between attitudes and behaviours, how fears can inhibit action and the importance of communicating organ donation wishes to family.

Keywords: interpretative phenomenological analysis; organ donation; transplantation; lived experience; attitudes

Introduction

Transplantation is a medical practice that enables patients with damaged or missing organs to acquire a new quality of life or greatly improve their chances of survival. Eyes, tissue and organs, such as kidneys, heart, liver, lungs and pancreas, can be transplanted from live donors or deceased donors. According to the NHS Blood and Transplant (NHSBT) Special Health Authority (www.organdonation.nhs.uk), in 2011/2012 there were more than 18 million registered posthumous donors in the UK, which represent 30% of the population. Though increasing, this number is still low, because in the same period only 3,962 organs were transplanted, while 1,000 patients died waiting for a transplant and 7,613 patients remained on a waiting list.

England currently adopts an opt-in system, meaning that consent is a necessary condition for a posthumous donation to occur. A donor should express consent by signing up to the NHS donor register, however, in case of suspected or imminent death, consent will also be sought in hospital from the next of kin. A person who had not previously signed up to the register can still become a donor through the consent of their family, but if a person has signed up and their family do not provide consent, the donation will not be followed through (www.organdonation.nhs.uk).

According to the NHSBT Potential Donor Audit (2012), family discussion and consent are the most critical factors to increase donation rates in the UK: they estimate that when donation wishes are known to the family, family consent rates jump from 37% to 79%. Due to how the system functions and the delicate moment in which the family are usually asked for

consent, to discuss one's wishes with family members is the best way to ensure that donation actually occurs.

A variety of positive and negative factors have been found to influence attitudes towards organ donation. A meta-synthesis of 24 qualitative studies (Newton, 2011) identified six main areas that negatively affect participant's willingness to become donors:

- religion, for a perceived opposition of religion to donation and for the need to maintain bodily integrity for afterlife,
- death, because of the difficulty of talking and thinking about it and the risk of tempting fate (jinxing),
- the body and how donation dehumanizes it,
- the family and their attitude towards donation,
- the lack of faith in the medical profession, and
- the choice of recipients.

Factors that positively affect a decision to donate include the altruism associated with donation and a utilitarian view of the body. Sanner (2006) proposed a model in which the attitude towards donation results from balancing anti-donation discomforts and fears, such as the body being cut up or disrespecting the dead, against pro-donation motives, such as solidarity and facticity.

In the UK, 66% of people declare themselves in favour of organ donation (Dyer, 2007), but only half of these are signed up, which suggests that for a third of the population there is a discrepancy between attitude and behaviour. What exactly is the cause of this discrepancy is

still an open point, though much research has tried to identify how cognitive and non-cognitive factors combine to influence the choices of donors and non-donors.

From a cognitive perspective, compared to non-donors, registered donors have been found to be more aware of the organ donation system and of the strong need for donations. Their attitude is more positive and they are more conscious of the incorrectness of negative myths that surround donation (D'Alessandro et al., 2012). Non-cognitive factors, such as emotional barriers and affective attitudes, are believed to be much stronger than cognitive factors in predicting signing up for donation (Morgan et al., 2008) and also affect the decision of next-of-kin to donate the organs of a deceased loved one (Shepherd and O'Carroll, 2013b). Barriers such as the belief that body integrity should be maintained, the fear of jinxing, the general disgust provoked by the thought of organ transplant (also known as the 'ick' factor) and medical mistrust have been found to negatively predict likelihood of carrying a donor card (Morgan et al., 2008), even though, in a recent prospective study (Shepherd and O'Carroll, 2013a), only bodily integrity significantly reduced the likelihood of registering as an organ donor. Some non-donors are ambivalent: they support donation and have positive cognitive beliefs about it, but they also have negative non-cognitive resistances to signing up. This ambivalence has been found to be the result of affective evaluations rather than cognitive ones (van den Berg et al., 2005).

To investigate how these evaluations combine to determine the lack of action, Moloney and Walker (2002) used focus groups. Their aim was to identify the narrative that characterises the conflict and they found that it developed as an opposition between a strong normative push that sees donation as a 'gift of life' and a functional dimension, where fears around the body

being mistreated by the medical profession arise. The Moloney and Walker (2002) study is an analysis of social representations of donation circulating within a cultural context and points to some of the tensions or pressure points within these representations. However the study is explicitly not concerned with the way individuals experience and response to these tensions.

Our research aims to complement the existing work by investigating in depth the individual experience, motives and understandings of a small homogeneous group of non-donors. The aim is to shed more light on how cognitive and affective factors interact and relate to the experience and choices of individuals; how individuals make sense of, process and deal with the complex and tensile issues around organ donation. The selected qualitative methodology, Interpretative Phenomenological Analysis (IPA) (Smith et al., 2009), is theoretically grounded in phenomenology, hermeneutics and idiography. Its application will enable our analysis and interpretation to focus on the personal beliefs and experience of individual participants, identifying convergences and divergences between them (idiography) and providing an overall picture of how the phenomenon of not being an organ donor develops (phenomenology) and is understood (hermeneutics) by those who do not sign up. Ultimately, with this analysis we aim to provide a unique insider's view of the conflicts faced by non-donors, that can usefully inform the strategies used to target this population in organ donation campaigns.

Methods

Participants were four white British females, aged between 20-35 who had no chronic health condition that could require a transplant and who declared no affiliation with any official

religion. None of the four had ever: signed up to be an organ donor, received an organ transplant, known anyone who had received a transplant organ. IPA requires a homogeneous sample (Smith et al., 2009), White British non-religious females were chosen because previous research had shown that ethnicity and religious beliefs can greatly influence the attitude of people to donation (Organ Donation Taskforce, 2008).

Recruitment was purposive: participants were psychology students or their friends, recruited using flyers and word-of-mouth. To facilitate a high level of disclosure, participants that could be considered similar to the researchers in terms of cultural background were selected. None of the interviewed women had personally known either of the researchers prior to the interview. Participants received no compensation for taking part in the study.

A schedule was developed as a canvas for the interview, to be followed loosely so that the interview could be as participant-led as possible and unexpected or relevant subjects raised by participants could be followed up. The interview schedule was designed to progress from more generic topics, including questions such as ‘Can you tell me what you know about organ donation in the UK?’ and ‘What are your personal views about organ donation?’, towards more specific and sensitive topics, with questions such as ‘Could you talk about why, so far, you haven’t chosen to register as a donor?’, ‘Do you have fears concerning organ donation?’ and ‘How do your views about organ donation make you feel about yourself as a person?’.

Participants were interviewed individually and in depth using a semi-structured interview lasting between 45 and 60 minutes. The interviews took place in a private room in an academic institution, at the participant’s house or at their workplace.

At the start of the interview the interviewer briefly explained the study objectives to participants, encouraging them to speak freely and as in-depth as they felt they could. The interview process was intended as a conversation, in which the participant did most of the talking and the interviewer actively listened, responding to stimuli presented by the participant and allowing them time to pause and think, so that their deepest feelings could emerge. At the end of the interview, participants were debriefed, they were able to ask questions, discuss the topic of the research and how the interview had made them feel. The interviews were audio-recorded, transcribed verbatim and then anonymised.

Institutional ethical approval was obtained prior to recruitment and participants signed a consent form before the interview.

In line with IPA's idiographic approach, a complete data analysis was conducted for each transcript before making any comparison across participants. Analysis began with a thorough reading of the transcript, to get an overall feeling of how the interview had developed and to get 'immersed' in it. This was followed by multiple analytic readings, taking notes on points of interest, key words, and elicited thoughts, from a descriptive, linguistic and conceptual point of view (Smith et al., 2009). The comments were then reviewed and potential themes were identified, ensuring the link to the actual transcript words remained. The themes were recursively reviewed, reordered, renamed and clustered to create a draft table of super-ordinate and sub-themes. Finally, the four individual tables of themes were jointly reviewed, major common themes, points of strong convergence and divergence were identified, and the master table of themes was agreed. In each stage of the analysis, work on each transcript was

conducted in parallel by the first two authors, who compared notes and acted as auditors of each other's work (Smith et al., 2009), while the third author audited the overall process.

Results

From the analysis of the four interview transcripts, five themes emerged: (1) Ability to detach from the dead body; (2) Seeing organs as something of value; (3) Avoiding thinking about death; (4) Having irrational thoughts; (5) Using the family to explain not signing up. What follows is a detailed analytic description of each theme, supported by quotes from participants.

Ability to detach from the dead body

All of the women seemed to assume that a person is made up of a body and a soul, but there were differences in how the moment of death was perceived: some saw death as the moment in which the body loses its function as container for the soul, while others seemed to continue to associate the body with the whole person, even after death.

Jennifer and Nadine described the body as holding the soul only temporarily, for as long as the person is alive. Once the person is dead, the body becomes an empty vessel or is 'evacuated' and can be made available for other practical uses such as organ donation.

I think that actually, after I die, my body is kind of irrelevant, for me it's just my little shell that just holds me in place [...] there is nothing particularly special about the physical form as such [Jennifer]

What you remember of a person, what was the person [...] has been evacuated, it has gone from the vessel and that's all that's left, [...] it might as well be a side of beef [Nadine]

They show no feeling of attachment to the dead body, to the point that Nadine equates it to a 'side of beef', suggesting she has a very matter-of-fact and realistic approach to death. In comparison, Ruth and Clara had more difficulty at seeing death as the moment in which body and soul could separate. For Clara the most disconcerting aspect of organ donation was the potential loss of wholeness it entailed. Not knowing what lies ahead after death and being open to the possibility of an afterlife, she took what felt as a prudent view, expressing a desire to remain intact just in case the wholeness of the body could affect the wholeness of the soul, which could turn out to be a requirement for afterlife.

You are somehow not the whole person, and it's kind of like, you don't know what happens after you die [laughs] and somehow wanting to remain intact or something, however irrational that is [Clara]

Ruth had no doubts. For her, the dead body was definitely still the person and, at a time when the body has already been violated by death and sickness, extracting organs could extend the violation to the memory of the deceased. Her focus was on the family: the body must be preserved because that corpse is still the person they are mourning and they are not prepared to let the deceased go yet.

Even if the person is a corpse, you know, at the time, that is still a person that you've loved and to kind of, chop them up, seems wrong. Seems like you're kind of, damaging their memory in some way [Ruth]

In fact, Ruth found it difficult to come to terms and accept death overall, and to accept that the body should be 'chopped up' implied accepting death, which she felt unable to do.

It's quite a difficult thing to accept that it's, you know, you're alive and then you're dead, and the only thing that makes you what you are is impulses in your body and biology, a scary thought [Ruth]

Interestingly, both Nadine and Jennifer described having had the experience of the death of close friends. Perhaps these experiences helped them to come to terms with the finality of death and to develop a view in which the physical body is detached from the metaphysical body. For Clara and Ruth this seemed to be more of an unresolved point. Ruth did not mention anything during the interview, but, at the end, she revealed – quite casually – that her grandmother had died the day before. This event is bound to have affected her emotionally and possibly influenced her ability to accept death, since she was probably still in a state of shock.

When thinking and discussing organ donation, the ability to detach the soul or identity of the dead person from the dead body would seem to be tightly connected with the ability to deeply accept the finality of death, which is a necessary condition to accept organ donation.

Seeing organs as something of value

The women in the study acknowledged the importance and usefulness of organs for donation, especially in the light of scientific progress. Thinking in terms of transplants changed the function of the body, it was no longer a home for the soul, it became a ‘provider’ of valuable organs, from which, if you were ‘fresh’ enough, organs could be ‘harvested’:

From a scientific perspective, I think it's amazing what they can do now and, you know, what you could actually provide [Jennifer]

(If) you're relatively fresh, then they will ask your next of kin whether it's OK to harvest your organs, if you haven't signed up [Nadine]

In acquiring its new function, the body is no longer viewed as a whole, it is converted into parts and develops a new value by becoming an ensemble of organs.

If my eyes get used for somebody, or my heart, [...] or my, what else do they use? Livers?
[Nadine]

Organs themselves have a value for the community, which lies in the potential they have to save lives. Signing up to become an organ donor is a way of ensuring this potential is not wasted.

There were millions of people probably out there who could help in that situation and unfortunately, via their own passing, I just think it is wasteful [Jennifer]

At the same time, organs continue to have a value for the families of donors, who are taking a risk by transferring this value to the organ receivers:

Although I suppose it might be rejected, so it might seem a shame to the family if, you know, your loved one donates an organ and then it didn't work [Ruth]

From the last two quotes, two completely different concepts of 'waste' emerge: a healthy organ that is not transplanted is a waste, but so is an organ that is transplanted and rejected. Are these simply two different concerns or is there a deeper difference in how value is assigned to organs?

In Jennifer's view, a non-transplanted healthy organ is a waste for the people who will never receive the transplant, who are usually unknown, so the waste is for society as a whole. On the other hand, Ruth seems to imply that when the organ is rejected, it is the close family who suffer, having gone through the pain of uselessly separating themselves from parts of the body of their beloved.

These two almost opposed dimensions, loss for the world and loss for the family, could be connected to who is felt to have ownership of a newly dead body and the organs that could be taken from it: society or the deceased's family. This, in turn, links back to how participants expressed attachment to the body. A view that emphasises the value organs can have for society is based on the ability to detach from the body and assumes that, once the person has died, the body can be felt to belong to the community, no longer to the dead person or their family. A view that emphasises the loss of value for the family, assumes a strong attachment to the body on the part of the family, as it is their beloved, and they are the ultimate owners who can, with a sacrifice, donate. So the varying degrees of acceptance of the new function that a body acquires through donation can be associated to varying degrees of acceptance of death.

Avoiding thinking about death

When describing discussions they had with family and friends about organ donation, most participants acknowledged that death was the elephant in the room, the 'taboo' topic that made the discussion difficult, so probably the difficulty of discussing death was the reason why organ donation had not been discussed in depth within the family context.

It's always a bit difficult talking about death, isn't it? It's not easy, it's not pleasant [Ruth]

The underlying taboo is that you have to be dead, potentially, well, you have to be dead [...] nobody really wants to think about that [Jennifer]

Thinking about death is so difficult that participants adopted strategies such as displacement, i.e. shifting the discussion to a relevant but less uncomfortable subject, like the death of somebody else, and avoidance, i.e. trying to dispel the difficult thought by thinking of something else completely or putting it to the back of one's mind.

And even talking about it with my sister it was just a kind of, academic thing, you know, we weren't actually talking about donating our organs... [Ruth]

I think it's just the idea, kind of, [...] accepting that that is going to happen one day [...] I think it was perhaps more of a subconscious thing, just kind of 'Oh no, we won't go there' [Clara]

Clara reports how the undesirable thought of death was triggered whenever she was presented with the opportunity to sign up to be a donor. It made her so uncomfortable that she consciously adopted an avoidance strategy to bypass the problem:

I'm trying to think back at how I felt about it... it's kind of like I guess the idea of death sometimes [laughs], it's just that then it becomes more real perhaps to an extent ... but I don't know why I didn't just fill in the form particularly there and then, I was like, ah, yeah, another day [laughs] [Clara]

Sometimes the avoidance was enacted directly within the interview itself. In the quote below, the interviewer invites Ruth to describe her innermost feelings about the possibility of signing up to be an organ donor:

I would, I think, definitely be happy to donate my organs. I suppose, if someone I loved passed away and, you know, then I was asked about them... [Ruth]

In Ruth's response above, she briefly states that she would be happy to donate her organs and then immediately starts to talk about what would happen if somebody else died. This pattern emerged more than once in her responses: compared to the other women interviewed, she seemed to find discussing her own mortality particularly difficult and often tended to divert the discussion away from talking about herself towards talking about other people.

Inevitably having to think about one's own death produces great discomfort and would seem to be one of the major obstacles encountered by the interviewed women in signing up to be an organ donor or even in discussing their wishes about organ donation within the family.

Having irrational thoughts

Participants found it difficult to list the fears that were obstacles to signing up for organ donation. When fears did emerge, they were mostly of the type that could be classed as irrational.

I mean, sometimes, you know like, you have little worries you think, you know, what if they put me in a coffin and I'm not really dead [Ruth]

Previous literature on organ donation reports jinxing is a common fear: the idea that by doing something that relies on you dying to come to full realisation, might in fact magically accelerate or even cause you to die. When the interviewer asked whether jinxing could be a

possible fear, two participants admitted to having thought about it and, in both cases, the admission triggered a strong emotional reaction.

When I catch myself thinking it, I think 'don't be an idiot' [...] it's madness to think that just because I've signed a piece of paper, or sent an email, then I'm likely to get, you know, dragged under a bus [Nadine]

Nadine seemed ill at ease with her own irrational side, perhaps because she is a powerful woman who is proud of her ability to think rationally. In the quote above, first she describes how she dealt with the irrational thought when it occurred in the past ('don't be an idiot'), but then she goes on with what sounds like a rationalising speech that she is delivering to herself there and then. The impression is that the jinxing thought had emerged yet again and she was having to dispel it as she talked.

When Clara was asked about jinxing, she reacted like she'd had an epiphany:

That came into my mind earlier on and I was like ... mmmm (with a wailing sound). Yes, okay, there is an element of that probably [long pause] mmmm [long pause] I think there is an element of that, kind of. When I was sat in the surgery once, I think I had that thought, I remember the thought [laughs]. There was an element of that and then just going off and thinking, oh well, just do it, just do it later [Clara]

Once jinxing had been named, it became the key to Clara's fears and she referred back to it often. Later on, Clara described having to deal with the intruding jinxing thought during the interview itself:

Interviewer: Do you think you might do it (signing up)?

Clara: Yeah, I'd be happy to just fill out the form and then just like not think about it [laughs], [...] like then, when we just spoke about that... it's kind of that... jinxing kind of your destiny, that occurred to me just then as well [...] I would rather just sort it out so that I don't have that worry and I can just forget about it.

The jinxing thought and its intruding nature were dealt with differently: Nadine rationalised and Clara avoided the provoking thought all together, procrastinating her decision. The jinxing thought is sneaky and difficult to control: in the quote above Clara seemed to be looking for a way to out-trick the thought, by quickly signing up and then never having to think the triggering thought again.

The admission to having jinxing thoughts exposes the force of one's irrational side and, in general, participants seemed to find it difficult to mediate the conflict between their rational thoughts (wanting to sign up because it's right) and dealing with the irrational and magical thoughts that inhibit taking action.

Using the family to explain not signing up

The interviewed women seemed to feel a need to explain why they had not signed up to be organ donors, almost to justify themselves in the eyes of the interviewer or to resolve what they perceived to be an inner conflict between their attitude and their behaviour. The family turned out to play a very important role for how most participants related to organ donation, to the extent that you could say the family was 'used' as a reason for not signing up.

Nadine, for instance, had discussed organ donation in the family many years earlier and had not signed up to be a donor to comply with an explicit request from her parents:

Many years ago when I said that I was going to sign up to the register [...] my parents resisted it. [...] But because my parents have expressed a feeling [...] I've not pursued it [Nadine]

It's as if by making their request more than ten years earlier, her parents had solved the problem indefinitely for Nadine. The interview then brought the subject back to her consciousness and caused her to question herself, become aware of the contradiction between her lack of action on this matter and her otherwise very strong ethical views, and decide to take the action of discussing it with her parents again, as a first step towards signing up. Other participants had not discussed the matter with their families at all, but assumed that if there ever were a decision to be made about them, the families would implicitly know that they should agree to donate their organs.

Clara: One of the reasons why perhaps I've been blasé about it, perhaps assuming, you know, if something like that did happen, my next of kin could [...] give their consent or something.

Interviewer: Have you ever discussed it with your next of kin?

Clara: No, never [laughs]

I think [...] my Mum and my family, even though we haven't talked about it, I'm fairly confident they would say yes, you know, you can, she can donate her organs ... I guess I'm kind of relying on the fact that I'm very similar to my family members, [...] I'm assuming by osmosis they will pick up my ideas [Ruth]

This strong reliance on assumptions suggests that the family are directly or indirectly used as an opportunity to put off a decision that is difficult to take.

As far as signing up as an organ donor is concerned, overall the family seems to be used as a shield to protect the person from dealing with the difficult feelings arising from the conflict between what one feels one ought to do and what one actually feels like doing.

Discussion

This research provides insight into how a group of women who had not signed up to be organ donors felt about organ donation. All women expressed an intention to sign up and judged themselves harshly for not having done so earlier, but also gave clear reasons to explain why they had not. Most of their reasons for not signing up, such as the need to maintain bodily integrity or mistrust in the medical system, have appeared in previous literature (Newton, 2011; Morgan et al., 2008; Shepherd and O'Carroll, 2013a) and align with anti-donation reaction patterns described by Sanner (2006). Discomfort with donation is an initial reaction that for most people dissolves when put against pro-donation arguments (Sanner, 2006). Our study provides additional insight on this mechanism, by focussing on the attitudes and behaviours of women who had not signed a donor card and taking an idiographic approach. The interplay between attitudes can be much more complex, particularly when the scope of the analysis is widened to include deciding and actually physically carrying out the behaviour of signing up to be an organ donor.

The adoption of a phenomenological and idiographic approach in this enquiry enabled us to provide a very deep and thick description of attitudes and how they affect donation behaviours, by using participants' own words and placing them in the context of their life experiences. What emerged is that, while various factors can influence the declared attitude to

organ donation, the factors themselves are not clear-cut and, most of all, for some people, formulating and actually carrying out the intention of signing up is much more difficult than simply expressing an attitude. As the experiences lived and described in this research suggest, for some potential donors, it is the complex interaction between rational and irrational factors that often gives rise to the inertia underlying the discrepancy between a declared pro-donation attitude and a lack of donation behaviour.

The women we interviewed had varying attitudes to bodily continuity, some expressed detachment from the body, others expressed a need for it to remain whole and intact after death. The women who were able to develop a detached view of the body seemed to have a better acceptance of death overall, and were more at ease with the idea of the inevitable dissection of the body that organ donation entails. The need to maintain bodily integrity has been found to be the strongest predictor of organ donation decisions (Shepherd and O'Carroll, 2013a) and the words of our participants who had most difficulty in expressing detachment from the body well exemplified many of the anti-donation attitudes identified by Sanner (2006) concerning body integrity. 'Issues of transcendence' are reflected in one woman's doubts on what might happen after death, while the 'illusion of lingering life' and the desire for 'protection of the individual's value', emerge from the view expressed by another participant according to which a corpse as still the loved person and agreeing to organ donation might damage their memory. These findings can also be related to work by Haddow (2005), who found that families who had immediately agreed to donation tended to associate death with disembodiment, while families who were unable to separate the self of their beloved from their organs and body found agreeing to donation more difficult. On the other hand, the ability to think of the body as a 'supply of

spare parts', using the machine metaphor strongly reinforced by medicine, is a key determinant of the attitude towards organ transplantation (Sanner, 2001), independent of religious beliefs (Stephenson et al., 2008). Attitudes to bodily continuity mediate donation decisions because through donation the body assumes a new function and an inability to separate the body from the self makes accepting death and the new role of the body more difficult.

Organ donation also elicited difficult thoughts for our participants, mainly because it requires one's own mortality to be taken into consideration. Strategies to avoid having to think about death, such as avoidance and displacement, were described and even enacted during the interview. According to Terror management theory (Greenberg et al., 1997), the anxiety generated by the awareness of being mortal can trigger avoidance strategies, but can also motivate prosocial behaviour. However, this does not extend to organ donation (Hirschberger et al., 2008), where the salience of death can become so overwhelming that a self-protecting instinct prevails over the altruistic impulse. This could explain why death-related thoughts, particularly jinxing, acted as concrete obstacles for our participants. One participant described having the donor slip in her hand and not being able to sign it due to the intrusion of a jinxing thought. This description of how jinxing operates in practice, by hindering the action of signing up, suggests that if the system were designed to make signing up sufficiently quick and easy it might help willing potential donors bypass their own irrational fears. This finding could usefully inform policy makers looking to improve the current methods used to sign up to the organ donor registry.

Families play a very important role in organ donation in England on account of having to ultimately give consent, even if the deceased is already on the donor register. For most of our

participants the family had been functional to not signing up: either an explicit request not to sign up had come from the parents, or the parents were being delegated with the responsibility of deciding on donation, without a prior discussion. Participants were ‘assuming’ the family would share or be sympathetic to their views, which is a very risky assumption to make. The decision to donate a loved one’s organs depends on many factors and the attributed desires of the deceased is only one of them (Radecki and Jaccard, 1997). For instance, Shepherd and O’Carroll (2013b) found that registered organ donors were more willing to donate a loved one’s organs compared to non-donors and that this decision was influenced by the affective attitudes towards organ donation of the person taking the decision. There are also differences in how parents and their offspring view organ donation (Waldrop et al., 2004) that, along with the criticality of the moment in which parents are required to make a decision (Radecki and Jaccard, 1997), can negatively affect family consent rates. Our finding suggests that public communication on the importance of discussing organ donation with one’s family should not only encourage people to have ‘the’ conversation, but also emphasise the dangers of relying on assumptions. In fact, reliance on the assumption that their family will implicitly and correctly interpret their point of view may well be a common tendency among the people who support organ donation, but do not sign up to be donors. Our in-depth description of how the assumption mechanism can subtly operate, could be a valuable input for future public communication campaigns related to communication within families.

Caution should be used in generalising the findings of this study to the entire non-donor population, for the limited size and characteristics of our sample, but also because all our participants actually declared their intention to sign up. With hindsight, it could have been

interesting to arrange for a follow-up to see whether their intentions were actually carried out. It would also be interesting to extend this research to non-donors who declare they have no intention of signing up and to non-donors with different demographics.

Thanks to the high level of disclosure by participants and the depth of analysis enabled by IPA, a rich and comprehensive understanding of the motivations and beliefs of the interviewed non-donors was achieved. Most of the emerging themes were linked to obstacles to donation that had already been identified by previous research, however probably no previous quantitative or qualitative study has been as effective in capturing the complex interplay between competing fears and needs that characterises the personal experience of not signing up to become an organ donor. All participants were well represented in the emerging themes, their attitudes converged in some areas and diverged in others, providing overall a coherent picture that measures well against the criteria for a good IPA paper defined by Smith (2011). This study also provides a good example of how Health Psychology, with its focus on the interaction between physical body and psyche, can help increase organ donation rates by providing insight on the subjective attitudes and beliefs of people who are currently non-donors but have the potential to become donors.

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References

- D'Alessandro A, Peltier J and Dahl A. (2012) The impact of social, cognitive and attitudinal dimensions on college students' support for organ donation. *American Journal of Transplantation* 12: 152-161.
- Dyer C. (2007) Two thirds favour organ donation, but only one in 20 take steps to facilitate it. *BMJ: British Medical Journal* 335: 533.
- Greenberg J, Solomon S and Pyszczynski T. (1997) Terror management theory of self-esteem and cultural worldviews: Empirical assessments and conceptual refinements. *Advances in experimental social psychology* 29: 61-139.
- Haddow G. (2005) The phenomenology of death, embodiment and organ transplantation. *Sociology of Health & Illness* 27: 92-113.
- Hirschberger G, Ein-Dor T and Almakias S. (2008) The self-protective altruist: Terror management and the ambivalent nature of prosocial behavior. *Personality and Social Psychology Bulletin* 34: 666-678.
- Moloney G and Walker I. (2002) Talking about transplants: Social representations and the dialectical, dilemmatic nature of organ donation and transplantation. *British journal of social psychology* 41: 299-320.
- Morgan SE, Stephenson MT, Harrison TR, et al. (2008) Facts versus Feelings': How Rational is the Decision to Become an Organ Donor? *Journal of Health Psychology* 13: 644-658.
- Newton JD. (2011) How does the general public view posthumous organ donation? A meta-synthesis of the qualitative literature. *BMC public health* 11: 791.
- NHSBT Potential Donor Audit - Summary Report for the 12 month period 1 April 2011 - 31 March 2012, retrieved from http://www.organdonation.nhs.uk/statistics/potential_donor_audit/ on 6 March 2013, page 6.

- Organ Donation Taskforce (2008) The potential impact of an opt-out system for organ donation in the UK, retrieved from http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_090312 on 13 March 2013, page 29.
- Radecki CM and Jaccard J. (1997) Psychological Aspects of Organ Donation: A Critical Review and Synthesis of Individual and Next-of-Kin Donation Decisions. *Health Psychology* 16: 183-195.
- Sanner MA. (2001) Exchanging spare parts or becoming a new person? People's attitudes toward receiving and donating organs. *Social science & medicine* 52: 1491-1499.
- Sanner MA. (2006) People's attitudes and reactions to organ donation. *Mortality* 11: 133-150.
- Shepherd L and O'Carroll R. (2013a) Do affective attitudes predict organ donor registration? A prospective study. *Journal of Health Psychology*: 1359105313488984.
- Shepherd L and O'Carroll R. (2013b) When do Next-of-Kin Opt-In? Anticipated Regret, Affective Attitudes and Donating Deceased Family Member's Organs. *Journal of Health Psychology*: 1359105313493814.
- Smith JA. (2011) Evaluating the contribution of interpretative phenomenological analysis. *Health Psychology Review* 5: 9-27.
- Smith JA, Flowers P and Larkin M. (2009) *Interpretative phenomenological analysis: Theory, method and research*, London: Sage.
- Stephenson MT, Morgan SE, Roberts-Perez SD, et al. (2008) The role of religiosity, religious norms, subjective norms, and bodily integrity in signing an organ donor card. *Health Communication* 23: 436-447.

van den Berg H, Manstead AS, van der Pligt J, et al. (2005) The role of affect in attitudes toward organ donation and donor-relevant decisions. *Psychology and Health* 20: 789-802.

Waldrop DP, Tamburlin JA, Thompson SJ, et al. (2004) Life and death decisions: Using school-based health education to facilitate family discussion about organ and tissue donation. *Death studies* 28: 643-657.