

Challenor, J. & Watts, J. (2013). 'It seemed churlish not to': How living non-directed kidney donors construct their altruism. *Health*, 18(4), pp. 388-405. doi: 10.1177/1363459313501358



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Original citation: Challenor, J. & Watts, J. (2013). 'It seemed churlish not to': How living non-directed kidney donors construct their altruism. *Health*, 18(4), pp. 388-405. doi: 10.1177/1363459313501358

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'It seemed churlish not to': How living non-directed kidney donors construct their altruism

Health
0(0) 1–18

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DOI: 10.1177/1363459313501358

hea.sagepub.com



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Abstract

Our objective was to explore how prospective altruistic kidney donors construct their decision to donate. Using a qualitative design and biographical-narrative semi-structured interviews, we aimed to produce text for analysis on two levels: the social implications for subjectivity and practice and a tentative psychodynamic explanation of the participants' psychological investment in the discourses they used. A total of six prospective altruistic kidney donors were interviewed. A psychosocial approach to the analysis was taken. In-depth discourse analysis integrated Foucauldian with psycho-discursive approaches and psychodynamic theory was applied to sections of text in which participants seemed to have particular emotional investment. Analysis generated three major discursive themes: other-oriented, rational and self-oriented discourses. The desire to donate was experienced as compelling by participants. Participants used discourses to position themselves as concerned with the needs of the recipient, to resist questioning and criticism, and to manage difficult feelings around mortality. Participants tended to reject personal motivations for altruistic donation, positioning relatives' disapproval as selfish and illogical. These results suggest that the term 'altruistic' for living non-directed organ donation constrains available discourses, severely limiting what can be said, felt, thought and done by donors, clinicians and the public. A more useful approach would acknowledge potential psychological motives and gains for the donor.

Keywords

altruistic kidney donation, discourse analysis, organ donation, psychosocial method

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Introduction

'Altruistic' kidney donation is the term used in the United Kingdom to describe the practice of transplantation of a living, anonymous donor's kidney to the next compatible patient on the national waiting list. It has been permitted in the United Kingdom since 2006. When an organ is taken from a living individual to improve the health or save the life of another, the donor is put at risk, which means that this practice makes ethical demands on health professionals and regulatory bodies tasked with governing organ donation. Although the risk is described as 'very small', with risk of death given as 1 in 3000, and the risk of major complications from surgery considered to be 2–4 per cent (Human Tissue Authority (HTA), 2013), the ethical principles of a patient's 'best interests' and right of autonomy applies as equally to the altruistic kidney donor as to the potential recipient of the kidney (Hope et al., 2008: 34).

Transplants from living donors function better than those from deceased donors, and patients on long-term haemodialysis and peritoneal dialysis have an increased risk of mortality from side effects of the treatment (Himmelfarb, 2005). Increasing the number of living kidney donors is therefore a current goal of the National Health Service (NHS) in the United Kingdom. NHS Blood & Transplant (NHSBT) is the body responsible for all transplantation. In order to meet an increasing demand for kidney transplants, NHSBT actively recruits living kidney donors through its website (www.nhsbt.nhs.uk).

The term 'altruistic' in non-directed donation implies that the anonymous donor does not receive the same direct emotional benefits as a parent donating to their child. Although altruism as an ethical value is the recommended basis for all blood and organ donation in the United Kingdom (Nuffield Council on Bioethics, 2011), it is paradoxically the assumed lack of availability of emotional benefit for the 'altruistic' kidney donor that leads to their motives at times being constructed by clinicians as potentially rooted in mental illness (Henderson et al., 2003). The Human Tissue Authority (HTA, 2012) instructs clinicians to conduct a psychiatric assessment of potential donors to assure informed consent. We argue that once mental capacity to make the decision has been established, potentially more complex ideas around why people give and act are effectively shut down.

There is currently limited empirical literature for what motivates the altruistic donor. Most articles provide descriptions of assessment practice (Adams et al., 2002; Jacobs et al., 2004). One exception is a recent grounded theory study undertaken in the United Kingdom with donors, which found that two major categories emerged: 'connectedness to others' and 'un-easy negotiations with others', in addition to highlighting donors' descriptions of the resistance they experienced both from family and some health professionals, and their awareness that some constructed 'their motives as pathological' (Clarke et al., 2013: 6).

In this article, we draw on Foucault's notion of discourse as constituting subjective experience of both the social and the psychological (Parker, 2005; Wetherell, 2008; Willig, 2008). Altruistic donation is problematised in the clinical literature and altruism itself argued to be at odds with contemporary western individualism, often viewed in the past as indicative of possible mental illness (Clarke et al., 2013; Lamanna, 1997; Roff, 2007; Sadler et al., 1971). There is anecdotal evidence that this may be changing however, as increasing numbers of individuals come forward to donate. From a social

psychological perspective, Batson (2011) proposes that altruistic motivation is produced by 'empathic concern', defined as follows: '... other-oriented emotion elicited by and congruent with the perceived welfare of someone in need' (p. 11).

Massey et al. (2010) found that people in the immediate social environment of altruistic donors are more likely to react with scepticism compared with the general public, whose views can be found represented in media accounts that construct altruistic donors as heroic, selfless individuals saving the lives of otherwise helpless victims who face imminent death or the prospect of years of painful treatment 'hooked up' to a machine. Here, donation is described as 'close to the ultimate selfless act', and 'making the difference between life and death' (*The Observer*, 2011). There is little or no space for a public discourse that questions this assumption.

Much of the clinical literature focusses on the requirement for clinicians to rule out the possibility of psychological disorders, citing psychopathology measures and with reference to Diagnostic and Statistical Manual of Mental Disorders (DSM) Axis I and II criteria (e.g. Jendrisak et al., 2006). In fact, research into altruistic donor outcomes suggests positive psychosocial results such as a self-satisfaction, empowerment and connectedness (Clarke et al., 2013; Jendrisak et al., 2006), and increased self-esteem 2 years after donating in 24 altruistic donors in the Netherlands (Massey et al., 2010). Massey et al. (2010) also suggest that scepticism and lack of understanding from people in the donor's immediate social environment was a reason for those who did not report positive psychological outcomes. The altruistic donor has accordingly been positioned in the clinical literature as something of a psychological oddity, their desire to donate a possible indicator of psychopathology and therefore in need of mental health assessment. The pathologization of the altruistic donor has also been highlighted by Clarke et al. (2013), who argue that this presumption drives the psychiatric assessment recommended for this type of donor. While these discourses of psychopathology are benign in intention, and ethical in respect of medicine's first principle not to harm, we suggest that one unintended consequence is the suppression of a discussion of the morality and ethics of organ donation itself.

Modern medical practices construct organs as commodities. As kidney transplants between unrelated individuals have become increasingly viable with the development of effective anti-rejection drugs, and even more deaths from kidney disease can be postponed, the moral rights of a patient to an organ from another body has become something of an uncontested discourse. If the organ comes from a deceased person, the body is constructed as a communal resource. Following Lock (2002), we ask whether certain discourses about the social repercussions of living organ donation are being avoided or suppressed through prevailing discourses of altruistic donation.

This study is the first to use a psychosocial methodological framework to explore how altruistic kidney donation is constructed in its social and individual contexts. Furthermore, this study focussed on donors who were pre-donation, to explore their motivations unaffected by the experience of the donation itself. Our aim was to analyse participants' discursive constructions of altruistic kidney donation and to critically explore the complex interaction of social and intra-psychic factors that arises when an individual engages with the discursive tools available to them. Finally, we aimed to explore the subject positions these discourses allow donors and others to develop a more useful understanding of altruistic donation.

Methods

Methodological approach

The qualitative methodology of this study draws on a psychosocial research paradigm that posits that social and psychological accounts are treated as separate and equally privileged entities (Clarke, 2008; Frosh and Saville Young, 2008). A total of two analytic frameworks were employed. Discourse analysis was used to examine the way that altruistic kidney donors use language to construct the ways that they can think, speak about and conduct themselves in relation to clinicians, their families and the wider world.

A discourse analytic approach to research assumes that individuals construct subject positions for themselves and others when they use the discourses or discursive repertoires that are culturally and historically available to them. Within this, positioning theory argues that individuals use different and sometimes contradictory discursive practices, actively choosing whether to engage or not with them depending on the subject positions they can provide (Davies and Harré, 1990). According to positioning theory, when individuals use discourses in social situations others are also positioned, intentionally or otherwise and may resist the positions they are placed in, requiring negotiation until both parties are satisfied with the positions available to them (Burr, 2003).

In addition to a discursive reading, an understanding of subject, self or mind as a dynamically unconscious one, existing in fantasy, as well as an embodied one (in which the body includes the brain and conscious experience) was drawn on in order to provide a psychological account. A psychoanalytically informed reading of subject positions for three of the participant's accounts was carried out to deepen thinking about the psychological and inter-subjective aspects of altruistic donation. This integrated methodology can be argued to address the failure of a purely discursive approach to give an account of subjective experience and events (Burr, 2003; Parker, 1999). Wetherell (2003) suggests that in applying psychodynamic analysis alongside a discursive one, the person is treated as an additional site of meaning-making. The epistemological tension that exists between psychoanalysis and social constructionism (Billig, 1997) is addressed here by drawing on a relational psychoanalytic theory, in which the subjective experience of an individual is always co-constructed in relation to the subjectivity of another (Layton, 2008).

Ethical considerations

Approval for this research was granted by City University London ethics committee and by an NHS ethics committee. All participants names used in the article are pseudonyms.

Recruitment

A purposive sample was used. The recruitment procedure was to write to all prospective altruistic donors who had been assessed as suitable for donation over the previous 12 months by a clinical psychologist in the renal department of a large teaching hospital in the United Kingdom, inviting them to take part in the research. A total of seven letters were sent in the first mailing and six responded positively, an 87.5 per cent response rate.

This small sample generates a large amount of text for analysis and is considered acceptable for in-depth qualitative research and discourse analysis (Willig, 2008). Prospective participants were told that the aim of the research was to look at the way prospective altruistic donors think and talk about their decision, how they explain it and their personal reasons for wanting to donate. The initial invitation had been to take part in two interviews, but after the first one, it was decided that a second would not provide further useful text for analysis and could risk shifting the research relationship to something more like a therapeutic relationship. As it had been in the initial consent process, participants were offered a second meeting and asked whether they would like to say more about the topic but that no further interview was required if they did not want to. All responded that they were satisfied with the single interview.

Participant characteristics

A total of 5 men and 1 woman were interviewed. Their ages ranged from 41 to 63 years. All were British: 5 White and 1 Asian.

Data collection

J.C. carried out the interviews, which lasted between 45 and 75 minutes. The interview guide was developed following a review of the literature and addressed the overall study aim – to understand how individuals construct their decision to become an ‘altruistic’ kidney donor and their emotional investment in the discourses they used. Before the interview started, participants gave their consent to being interviewed and the interview being recorded for the purpose of research. Interview practice was informed by Hollway and Jefferson’s (2000) biographical-narrative approach while remaining mindful of the ethical differences between a therapeutic analytic interview and a research analytic interview (Kvale, 2003), and the suggestion by Frosh et al. (2003) that the interview produce an ‘illustrative narrative account’ (p. 43). The first question was as follows: ‘I am interested in your decision to become an altruistic kidney donor, please tell me about it’. This was intended to both orient the participant to the subject matter of the interview and be open to the participant’s own interpretation. Although including the term ‘altruistic’ in the question meant that a ‘pre-set theoretical concept’ (Frosh and Emerson, 2005: 309) was being used, this decision was taken because it is used in the NHS literature. Follow-up questions asked about the participant’s attitude to their own health and physical body, and the response of family and friends to their decision. In line with Kvale (2003), some questions were psychoanalytically informed, such as ‘Would you tell me something about your family?’ and ‘What was life like for you when you were growing up?’ A relational psychoanalytic focus on subjective experience is compatible with a social constructionist approach to research.

Field notes were made immediately after the interview recording. Transcription strategy was informed by social constructionist perspectives that emphasise co-construction in interviews and included the interviewer’s questions and responses, false starts, pauses, laughs or evidence of sadness or distress (Frosh and Saville Young, 2008).

Analysis

Data analysis was informed by qualitative methodology. The discursive coding frame was grounded in the data and drew on a six-stage Foucauldian-inspired analytic strategy (Willig, 2008), together with a psycho-discursive approach to discourse analysis (Edley and Wetherell, 2001; Wetherell, 1998; Wetherell and Potter, 1992). For each interview, all references to altruistic donation were highlighted and given descriptions that aimed to exhaustively incorporate all examples of discursive constructions for each participant. This was stopped when all references to altruistic donation made by a participant could be described by a discourse. Examples of these included helping, mechanical, medical, risk and self discourses. The process was cyclical and exhaustive; if a reference did not fit within an existing discourse, a new one was created to describe it (Wetherell and Potter, 1992). Analysis involved consideration of what was being achieved by a participant using a particular discourse, both in the context of the research interview and outside it, and of all possible subject positions allowed for by each discourse. For example, a medical discourse might be drawn to demonstrate to an interviewer that the participant is knowledgeable, and to shore up a less 'rational' discourse that is emotional in content. It positions clinicians as experts and the participant in accord with this expertise. If a participant chooses not to draw on a medical discourse, he or she positions himself or herself outside existing knowledge and power structures, and the likelihood that they will be allowed to donate is potentially reduced.

Finally, three interviews were selected for a psychoanalytically informed reading, extracts from two of which are presented below in the analysis. These psychoanalytic accounts were concerned with suggesting possible psychological explanations for the emotional investment made by participants in particular discourses, taking care to ground the interpretations in what could be observed in the text (Frosh and Saville Young, 2008). The decision to subject three rather than all six interviews to this analytic reading was taken in order to provide an alternative, psychological understanding of the three major discursive themes that had emerged from the analysis. Selection of the three was based on the researcher's reflexive response to interview transcripts, recordings and in field notes. This required the interviewer to be acutely aware of her contribution to the jointly constructed understanding of the topic. For example, at certain points in some interviews, a reluctance to ask about a particular subject or feeling was noted, suggesting moments of what Frosh and Saville Young (2008) describe as 'unconscious processes' interacting with the research work. The interviews which contained the most biographical information and which appeared to offer the most material for a psychodynamic analysis were selected. Particular sections of interview to be subjected to a more detailed psychoanalytic reading were selected according to Gough's (2004) description of emotionally laden text and informed by an interpretive strategy that attends to what Hollway (2008) describes as the 'whole narrative' (p. 140). This included meanings that were co-constructed between researcher and participant, links in the participant's account, conflict, tension and what is not being said, as well as what is.

The two phases of analysis did not always proceed in the order described, but formed a cycle (Frosh and Saville Young, 2008). This cycle began with the responses felt by J.C. towards the participant in the interview, recorded in field notes, describing feelings and

thoughts that were evoked in the researcher by the participant and their talk in the interview and immediately afterwards. After this, the focus of analysis moved to the text and recordings, with continuous reflection on what was being evoked at the same time as what was being accomplished discursively.

Results

Participants' discourses were grouped into three broad themes. These thematic groups were given the names 'other-oriented' discourses, 'rational and risk' discourses and 'self-oriented' discourses. Participants drew on all three groups in their talk, or from just one or two, positioning themselves and others in different ways with each discursive shift. Like a game of chess in which pieces are deliberately moved when it is the player's turn or placed in certain positions by the moves of an opponent, there was both a deliberate use of certain discursive moves, for example, in order to resist something, and inadvertent effects of being positioned by another person's discourses. Here, we present a summary of the three discursive groups and suggest possible subject positions that they make available. Where it deepens understanding, an alternative, psychoanalytic reading is also presented.

Other-oriented discourses

At first, would-be donors constructed altruistic donation as *other-oriented*, drawing on notions of altruism, morality, sacrifice and ethics. These other-oriented discourses were the way into altruistic donation for all the participants in this study, and they often described an instantaneous, emotional and unmediated response to learning about the possibility of altruistic donation from a television, radio or newspaper item:

- James: I just sat there going, that's incredible, that's absolutely amazing!
 George: ... and I don't know what it was but it just hit me that ... it's such an interesting idea.
 Liz: I suppose it's quite deeply ingrained isn't it, the thing that you should try and help other people to have a better quality of life if you can.

These discourses positioned the donor as not benefitting in any way from the action, but paradoxically, through them the donor is simultaneously constructed as a life-giver, intervening to prevent the death of another individual. It was common for donors to talk of making a 'difference', invoking their unique power to save another's life:

- James: I could stop somebody being on a machine, I could give them their life back.
 Liz: ... [the kidney] could make such a big difference to someone else that desperately needs it so it's as simple as that really.

Universally, among participants, other-oriented discourses were drawn on to describe how altruistic donation was something that felt 'obvious' and 'right, unremarkable yet compelling. This discourse of obligation was difficult to contest, and discourses of

certainty and obviousness foreclose on the possibility of ambivalence. Discourses that draw on the 'obviousness' of the morality of helping reduce the listener to little more than an admiring observer, without recourse to argument or challenge.

Richard: ... It's a thing that worthwhile doing and, you know, I can do, why not do, you know if I've got two kidneys and a kidney I know can make a huge difference to a person's life, why not, it seemed churlish not to, you know, why hold on to it if I don't need it?

Richard appeared to be determined not to give himself any special status. He rejected discourses of the self and would not allow that what he was proposing to do was in any way remarkable. With his use of the word 'churlish', Richard seemed to be saying that because he could save a life, he had to do so. Understanding this compulsive quality of this discourse was one instance in which the psychoanalytic notion of the unconscious was able to deepen the analysis. Responding to the biographical focus of the interview, Richard described difficult events and relationships in his childhood and adolescence that made a psychoanalytic reading of the text possible.

Richard's account was notable for his determination and compulsion to donate. It was as though he was compelled to make a sacrifice of himself by foreclosing on his own value. Making himself special in any way in the research interview seemed unthinkable, and he was unable to experience himself as deserving of praise. With a psychoanalytic reading, it is possible to suggest that Richard's subjective experience of wanting to be an altruistic donor might entail unconscious feelings about himself and his experience of being powerless in his own life, both as a child and later in adulthood. He was determined not to allow himself any pleasure through giving, which suggests the possibility that he may have been unconsciously compelled to repeat his earlier experience of deprivation. Altruistic donation may therefore have offered him a way to manage difficult feelings about what he described as his failure to make something more of his life.

Other-oriented discourses created an important drawback for participants in their personal relationships, and all reported that family and friends tended to suggest that the donor was 'mad', to the surprise of donors. Their decision apparently evoked a degree of anxiety and opposition in other people who in contrast with donors did not construct it as an 'obvious' thing to do. All the participants described incidents in which they had been fiercely criticised, how they had been urged to reconsider the donation:

Liz: ... the most surprising thing about the whole thing is the reaction of people when I tell them. I started telling friends and I would say 80% of friends say that I'm mad and some of them are quite vocal about it and think it's completely the wrong thing to do and you're messing with nature, and if, you wouldn't have two kidneys if you didn't need two kidneys, and what if your children need them ...

George: I was incredibly surprised, everyone, every time I saw them raised it and sort of stated their, erm, dislike for that.

J.C.: They were against you doing it?

George: Absolutely. I mean not just ‘oh that’s really stupid, you shouldn’t do that’, [but] ‘You’re mad’, they would make a very big point of it ...

Sometimes strenuous attempts by other people to prevent them from going ahead placed donors in the uncomfortable position of having to defend an action that they had constructed for themselves as obviously moral. They stressed this position, and in further support of their argument also turned to rational discourses to dispel criticism and refute accusations of being ‘mad’.

Rational and risk discourses

‘Rational’ and risk discourses such as medicine and engineering incorporate ideas about acceptable levels of risk and the commodification of body parts. They allowed participants the subjective experience of being both right and moral if questioned and all used them extensively. Physical risks and discomfort were discounted and parallels drawn that constructed altruistic donation as equivalent to other types of medical donation, such as blood or organs after death:

Liz: ‘I’ve been a blood donor and regularly, and to me it actually doesn’t seem terribly different to that’.

These discourses allowed the construction of a pragmatic stance and positioned participants as rational, highly responsible individuals, enabling them to refute both the suggestion of psychopathology from experts or of being ‘crazy’ from friends and relatives. Rational discourses were also used to construct altruistic donation as a safe, measurable, quite unremarkable procedure:

Richard: ... it seemed to me a waste to put it in the ground, if it can be used and so it just seemed an obvious natural thing to do when I, when I heard it was possible.

One participant described how he had turned to thoughts of organ donation as he considered the possibility of suicide during a period of depression. He described how he thought about how his body might be most effectively put to use, thereby rhetorically avoiding the emotional implications of the end of his life as himself:

Will: I’m going to make sure, you know, I can be broken for spares. You know, being a good engineer, you know, you reuse the bits if you can.

A psychoanalytic reading of the interview with Will leads to another possible understanding of his determined use of engineering and mechanical discourses. His description of donation after death offered him something akin to resurrection; the ‘good’ bits, his physical body, would be kept and recycled, while the ‘bad’ bits, his mind, could be disposed of. Will did not seem to have any thoughts about what he might expect to feel after having donated while still living, other than in terms of

satisfaction at getting a job done. In Will's life narrative, he recounted little experience of any good relationships other than with his father, who had died suddenly when Will was a young boy. All other relationships were experienced as rejecting, and his experience was of not being truly seen. With a psychoanalytic reading, Will's pragmatism may have been a defence from similar disappointment. The idea that the recipient might not be grateful to him is almost too painful for Will to contemplate in the interview, seen in the following extract:

- J.C.: Do you think about that person it might help?
 Will: Erm, no I try not to, I, um, in case they don't say thank you.
 J.C.: What would that be like if they didn't?
 Will: If they knew and they just um, they just um, it's like doing a favour for somebody and then, like my sister, you know ... and um I don't want to experience that. There's the kidney, I hope it goes well for you, that's all.
 J.C.: So if you think about them and try and sort of imagine them in anyway then they don't thank you, you would experience that as quite hurtful?
 Will: Well I'd be very hurt and it's um, a bit of a big thing isn't it?
 J.C.: Yes, it's a very big thing.
 Will: And er, if I knew who they were and they knew who I was and they didn't thank you mate, or just ignored it or just, I don't want to go, I don't want to experience that. They can have the kidney but I don't want to know who they are, job done and I'll never know.
 J.C.: And then you won't have to be disappointed?
 Will: And I don't get the opportunity of being disappointed, there you go.

Despite the extremely pragmatic discourses that Will drew on, a psychoanalytic reading of this interview extract suggests something far more deeply felt, a longing to be appreciated and wanted, to relate to someone through helping. This desire remains unconscious perhaps because he does not want to experience the disappointment again of being 'ignored'; it is too painful, and therefore, it is safer to resort to the engineering discourses with which he is familiar, and which perhaps importantly he identifies with the lost good object in his life, his father.

Doctors and other medical professionals were helpfully positioned by these discourses as trustworthy and benevolent, with only the donor's best interests at heart. Medical discourses allowed donors to feel safe and secure in the expert hands of clinicians:

- James: 'I really do trust the doctors, they're not going to do something that's wrong'.

Participants' emphasis on the separateness of the physical self from the psychological self, a form of Cartesian dualism, had the effect of dismissing the significance of the physical body. There was no sense of a wish to keep the body intact and the donation of organs after death appeared to be given equal status to donation while alive. In saving the life of another person, the participants might in some way have been able to rhetorically defy their own embodiment and therefore eventual physical demise.

The possibility of the donor's death is constructed as acceptable using these discourses. However, this idea runs directly counter to prevailing medical discourses in which it is ethically unacceptable for a live donor to be harmed in the process of donating:

- George: ... if I gave a kidney away tomorrow and in 12 months time I had problems with the one that I had left which ended up resulting in me dying, I know this sounds probably a little bit depressing but I did what I could with the information that I had at the time.
- Richard: ... if I were to die on the operating table, it wouldn't make any difference to me.

Again, a psychoanalytic reading of the absence of emotional investment in Richard's discourses suggests that he was unable to care about what happened to himself. In constructing altruistic donation as something that ought not to confer a special self-status, he defended against the possibility of any related personal loss, needs, importance or intrinsic value. By giving a part of himself away and refusing to concern himself with the possibility of any negative outcome, he splits himself from his physical body. It seems from this as though Richard felt that for him, living and dying were equivalent.

Self-oriented discourses

Discourses in the third group were self-oriented, and included self-esteem, self-worth and reparation. These reflected the donor's own potential emotional gains from altruism and were not used by all participants. One reason for this may be that discourses of self-interest are difficult to reconcile with constructions of altruism. However, some participants were able to acknowledge rewards to the self. For these, donation could be expected to provide them with an increase in self-esteem.

In contrast with other-oriented discourses, these call into question definitions of altruism that assume no benefit to the donor. Participants were able to describe altruistic donation as something giving them emotional gains and increasing their sense of self-worth:

- James: It's that feeling that you've done something significant so if you died tomorrow, 'he will be the guy that ... oh yeah, he gave somebody a kidney', you know that'd be important, nice, not just you haven't been nasty to people in life, but something positive.
- Liz: ... you know it sounds terribly goody-goody but God you know, if it works, it will make such a difference to someone who's really struggling, and that actually helps the probability an awful lot, but yeah, it does give me great pleasure ...

In contrast, the other participants continued to resist these discourses and the attendant construction of their own needs outright:

Richard: I hope that whoever gets it, it makes a difference to that person's life but I don't expect to ever get to have contact or recognition from that person and that's not the point of doing it, you know, it's, it's there ... if it's no loss to me and it's a gain to somebody else, why not?

Those who did use them constructed altruistic donation as a legacy, describing it as a way of giving something back in return for their own perceived good fortune in life:

James: ... other people start a business, or I've never had kids, something like that ... I'm not really interested in kids, not really that sort of person, this was something different ...

One participant drew on an atonement discourse to suggest that for him, donation was a process of reparation for damage he had inflicted on his own psyche through past behaviour:

Peter: I still believe that I'm not sort of a bad guy, but I've made a mistake and ... whether this kind of altruistic donation is some sort of internal compensation to get over that? You know ...

With a psychoanalytic reading, it could be argued that Peter's constructions of altruistic donation were not fixed during the interview, and the interview conversation took several contradictory turns as he wondered aloud about his motivation for donating. Peter was alive to the possibility that for him, kidney donation symbolised something other than 'pure' altruism, and his willingness to think symbolically may account for his openness to alternative constructions. He said, 'I can't actually get a clear answer as to what am I getting out of it'.

Parker (2005) argues that psychoanalytic discourse has become an accepted way for people to talk about psychology so that it in effect becomes 'true' for them. One of the goals of critical psychology research is therefore to remain reflexive about this possibility, and Peter's engagement with unconscious material may have been in part a response to what he perceived was being asked of him in the interview.

Discussion

When prospective altruistic donors were asked to give an account of their desire to donate, they drew on discourses of morality and obligation to others that are in line with accepted notions of altruism. Donors positioned themselves as responding to another's need and drew on rational and scientific discourses to position themselves as ethical and 'sane' individuals capable of assessing risk. One important effect of this use of discourses of morality and obligation is that donors' claims are made difficult to contest. Those who may question the desire to donate are positioned as critics, and clinicians become 'gatekeepers' who can prevent would-be donors from achieving their goal. When behaviour is 'obvious', as participants in this study suggest altruistic donation is, the implication is that there should be no need to examine it further. In this way, assessment is made

problematical. By using both emotional and rational discursive themes, donors are able to position themselves as both ethical *and* responsible when they perceive that their motivation is being questioned.

The majority of participants rejected the possibility that some of their own psychological needs might be met through donating, and discourses of the self were used rarely. In contrast, medical, engineering and mechanical discourses were extensively drawn on, and we suggest that one important function of these is to separate mind and body, thereby preventing the experience of difficult feelings about the self, death and dying. Indeed, some participants went as far as to suggest that their own deaths would in fact be an acceptable outcome of donating. A psychoanalytic reading allowed for a deeper and more nuanced way of thinking about altruistic donation than a discursive approach alone.

There was little sense of a wish on the part of donors to keep the body intact and the donation of organs after death was given equal status to donation while alive. It is possible that this construction of altruistic donation allows for the possibility of the avoidance of mortality and loss.

To date, people who want to donate a kidney to a stranger have been lauded in the media but approached with some suspicion and as a potential risk in the professional and academic literature (e.g. Adams et al., 2002; Dew et al., 2007; Jacobs et al., 2004; Jendrisak et al., 2006; Rodrigue et al., 2007). This binary construction of altruistic donors as heroes or as potentially 'mad' reduces opportunities for a more useful understanding of what leads people to want to be altruistic donors. The reduction of the donor's motives to being either 'mad' or 'brave' has also been found by Clarke et al., (2013). There are important implications for assessment, regulation and practice. By limiting understanding of this type of donation within the bounds of altruism, not only are donors denied the opportunity for a more multi-layered explanation and understanding of their motivation, clinicians are also denied the opportunity to respond to what may be a more complex case than first presented, and this is particularly relevant if a clinician has ethical concerns about the procedure.

Most of the clinical literature to date on altruistic kidney donation has focussed on efforts by transplant assessment teams to rule out the possibility of mental illness or personality disorder in the donor (Adams et al., 2002). In contrast, the media feature only stories of heroism and self-sacrifice and tend not to question the wider implications of the practice. These public discourses of selflessness, however, are frequently either ignored or rejected by those who are closest to the participants in this study: the siblings, parents and friends who may be the only stakeholders able to talk more freely about altruistic organ donation. Participants described being accused by those closest to them of madness, leading to resentment and confusion. Relatives and friends vocalise something problematic in volunteering to have one's body opened, and risking death outside the network of social relations. This more complex understanding of the act is so difficult to vocalise that the interviewer (J.C.) also struggled not to affirm the hero discourse. This finding has been reflected in outcome studies of altruistic donations (Clarke et al., 2013; Massey et al., 2010). Participants' discourses of rationality, risk and logic might therefore be considered to be a response to the explicit suggestion of madness by people close to donors, and the implication of psychopathology that resides in psychiatric assessment.

One possible explanation for the anxiety felt by individuals closest to prospective altruistic donors is that it represents an otherwise unspoken social response to the idea of organ donation *in general*. It seems that we may not be entirely comfortable with the notion of taking bits of our bodies and putting them in another individual. Medical discourses of the desperate shortage of organs for transplant serve to further complicate this dilemma.

A degree of anxiety towards organ transplants may therefore underlie social policy and public responses to altruistic donors, contributing to a binary understanding of the practice; either the donor is mad and cannot be allowed to donate for their own good and that of an ethical society, or is sane and therefore good and should be allowed to donate. There are important implications of this for the rights and responsibilities of donors, recipients and the clinicians who are tasked with deciding who is allowed to donate. A question remains about who decides what level of risk is appropriate for a particular individual, the individual or the clinician? If it is the individual, ought a clinician be expected to carry out a procedure such as a transplant they might not feel comfortable with because a donor appears to meet the necessary criteria?

The compelling nature of organ donation for participants in this study has also been found in existing research with directed kidney donors (Clarke et al., 2013; Franklin and Crombie, 2003; Gill and Lowes, 2008; Lennerling et al., 2003). The current research goes further in addressing the way that altruistic donors use ideas about emotions and rationality in their discursive repertoires, suggesting the possible subjective experience that each allows for.

In accounts of participants' emotional investment in their discourses, psychoanalytic ideas about the way individuals experience themselves and other people through a mixture of fantasy and reality were used to theorise possible feelings about donating. From this perspective, it is possible to suggest that for some donors, altruistic donation may be formulated in terms of the donor's unconscious experience of self and other in fantasy. Altruistic donation can also be thought of in terms of a possible response to loss in the donor's life, a way of making concrete feelings about loss that cannot be spoken about. This suggests a profound rethinking of the notion of 'altruistic' in which donation becomes an embodied and psychological response to perception of a socially and technologically constructed need. In allowing the violation of their physical integrity or boundary, a physical space is created inside the donor, and something of their unconscious experience may be communicated, as though they are saying: 'Look at what I have given of myself'. Within this actual space created in their body, an unconscious recognition of an intra-psychic or inter-subjective lack may be represented.

From this perspective, anxiety is split off for other people to feel and is represented in the tension that is created between the discourses outlined above. Concerns about altruistic donation are felt not just by the families and friends of donors, but also by health professionals who engage with altruistic donors. These concerns are never acknowledged in public, as if to do so is somehow unacceptable. We might ask ourselves what would a more complex discourse look like here?

This study has generated useful material for thinking about the discursive context for altruistic kidney donation, and this is a measure of its validity (Frosh and Saville Young,

2008). Through a detailed consideration of the social expectations placed on the individual and encoded through discourses, together with the effect of, and response to these discourses by the individual from an internal, psychological perspective, it is possible to suggest a more nuanced and useful understanding of this complex act. Another strength of this research is its topicality. Examining the language used by altruistic kidney donors to explain what motivates them offers an alternative perspective on the ways in which society and individuals think about organ donation that can usefully contribute to the current debate on increasing donor numbers.

It is important to note that recruiting participants through a hospital meant that the researchers' association with the hospital department in which the participants were being assessed may have had the effect of encouraging particularly clinical discourses and discouraging discourses that participants considered did not fit with an 'official' viewpoint or social expectations of altruism.

From both the discursive and extra-discursive themes identified, a problem, and therefore a potential solution, lies with the current official and societal designation of this type of non-directed organ donation as 'altruistic'. This discursive repertoire, encoded in policy and practice, carries with it a set of powerful and compelling social values that are both constraining and seductive. The technological nature of their altruistic action means that it is not just donors who pay the price for their benevolence, their desire to 'help' implicates the recipient, clinicians and the donor's family in the conflict between the social and psychological experience of altruism.

Separating living non-directed kidney donation from discourses of altruism would make it possible to construct the procedure in a way that could accommodate a wider range of motivations and subjective experience. If psychological benefits to the donor from altruistic donation could be permitted, as well as its wider societal benefits, this becomes a subject position available to the donor. Taking this into account would grant all parties greater freedom from the current constraints that altruism places on them, and would mean that a more valid assessment of the needs of donors, recipients and society as a whole could take place.

The construction of participants' decisions to become altruistic kidney donors is characterised by conflicting discourses and subject positions, suggesting that even when the donors seem sure of what they are doing, altruistic organ donation is far from straightforward in psychological terms for everyone involved. This study's findings might therefore be usefully incorporated into assessment protocols for living non-directed donations. This would involve taking what might be considered to be a more open stance to the donors, rather than remaining within an existing framework that is discursively bounded by society's expectations of altruism.

The voices of recipients of kidneys donated altruistically are neglected in this study. Recipients are positioned in participants' discourses as helpless, disempowered through disease and dependent on the donor for their health, maybe even their life. This subject position is an inevitable consequence of discourses that construct the donor as 'saviour'. This is in contrast with research findings that suggest patients who receive transplants from deceased or related donors can experience complex and ambivalent reactions to their donated organs (Franklin and Crombie, 2003; Lock, 2002; Sharp, 1995). Future qualitative research might usefully consider the experience of kidney

patients in relation to living anonymous donors, in order to understand what effect, if any, the nature of this type of donation has on a recipient. The methodological approach used in this study could be extended to include clinicians: the physicians, surgeons, specialist nurses and psychologists who are involved in transplant surgery. Their discursive constructions of altruistic donation are of central importance in the process. This study goes some way to expand thinking beyond it being ‘churlish to say no’, or mad to say ‘yes’.

Funding

This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

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