"Keeping Her Whole"

Bereaved Families' Accounts of Declining a Request for Organ Donation

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Introduction

Organ transplantation remains the only treatment choice for thousands of individuals with end-stage organ failure. Currently in the United Kingdom (UK) 10,000 individuals could benefit from an organ transplant, but the shortage of available organs means that 1,000 people die each year while waiting.[1] Relatives of potential organ donors are the most critical link in maintaining organ availability for transplantation, as they must give their explicit consent[2] before organ donation can take place.[3] UK refusal rates of 40 percent, which rise to 70 percent in nonwhite groups, are therefore of concern.[4] Sque and colleagues[5] in a UK-based study challenged the notion that the most important reason that relatives agreed or declined donation was knowledge of the deceased person's wishes, as most families reported a need to protect the integrity of the deceased person's body, even if it meant the deceased's wish to be an organ donor was not fulfilled. This decision made by participants to decline organ or tissue donation appeared to be made in the context of deeply distressing concerns related to the "cutting up" of the body. Concerns about surgical intervention on the deceased may have some value in explaining why, in populations in which there is broad awareness of the benefits of organ transplantation, refusal rates remain high.

Any successful organ donation and transplant system must begin with an effective workforce that is knowledgeable about all aspects of the donation process and the benefits of transplantation. Nurses and doctors are the people charged with the crucial responsibility of identifying and caring for potential donors, a key area in increasing donation rates.[6] Failure to approach the family members at the death of their relative to offer the choice of organ donation, where appropriate, could be regarded as contravention of best practice guidelines as outlined in the *End of Life Care Strategy*.[7] Organ donation is perceived to form part of high-quality end-of-life or bereavement care, coordinated with other health initiatives. The challenge then for health professionals is how to help families make the best decision for themselves, which, however, may mean having to reconcile their repugnance for dissection[8] with the benefit of donation to the

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waiting recipient. Clearly, a deeper understanding of what motivates families to agree or decline donation is therefore essential to maximizing organ availability.

The aim of this article is therefore to explore the accounts of negative organ donation decisions. More specifically, we are interested in how family members who had been approached with a request to allow the organs of their deceased relative to be donated for organ transplantation account for their refusal. In particular, we are interested in how they discursively located themselves, their deceased relative, and the body of the deceased in the decisionmaking process.

Methodology Approach

Glaser[9] suggested that secondary analysis of data can lend new strength to the body of social knowledge, resulting in new perspectives or a new conceptual focus on the original research.[10] Furthermore, secondary analysis can be useful in situations in which sensitive topics are discussed or the population is elusive and difficult to access.[11] Both these preceding criteria apply to the population under study: bereaved family members who declined donation of organs from a deceased relative. Using the prior rationale, we used secondary analysis to examine a primary dataset of transcripts of qualitative interviews that explored the end-of-life decisionmaking and hospital experiences of a total study sample of 25 bereaved family members who declined organ and tissue donation from 22 deceased relatives.[12]

The original study, carried out in 2005–2006, was ethically approved by the South East Multicentre Research Ethics Committee and by local research ethics committees and research and development departments of participating hospital trusts. Participants all gave consent for their data to be used in secondary analysis. To provide a broad spectrum of experience, participants were recruited via three staged media campaigns in targeted, large urban areas of the UK, and from four NHS (National Health Service) Hospital Trust intensive care units.

The research was firmly grounded in the worldview of the participants, giving full representation to their experiences and concerns, and sought to present the widest view of the phenomena under study. Data were collected via retrospective, cross-sectional, qualitative, face-to-face or telephone interviews. In this article we focus solely on exemplars from the interviews in which the participants talk about their decision and account for it.

Methodologically, our analysis is rooted in the constructionist view of discourse underpinned by the assumptions of critically oriented discourse analysis. We assume that social reality is constructed through and within language and that every language use designed to represent reality necessarily entails decisions as to which aspects of that reality to include, and decisions as to how to arrange them. Each of these selections, both in content and according to the lexico-grammatical form, made in the construction of a message, carries its share of implicit assumptions, so that the reality represented is ideologically constructed.[13] It is also through discourse (i.e., practices of representation) that language users constitute social realities: their knowledge of social situations, the interpersonal roles they play, and their identities and relations with other interacting social groups.[14] No text, spoken or written, represents reality in a neutral or objective way, and representation is never of reality as it really is; rather, reality is always viewed through the tinted lens of ideological assumptions.[15,16,17,18]

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We take a textually oriented approach.[19] Thus, we focus on the form of stretches of discourse, with an interest in both the semantics and syntax of an utterance, as well as the functions of what is said within the local context, and the social actions thus accomplished. The analysis draws on the developments of Halliday's[20] functional linguistics. Its main tenet is that the analysis of the lexico-grammatical form of utterances should be foregrounded as a resource for constructing meaning.[21] Elements of grammar and lexis are analyzed predominantly as having a particular function when used by speakers. Here we focus primarily on the ideational function of what the informants said; that is to say, we are predominantly interested in how they represent extralinguistic reality. But we also focus on the content of what is said, relating it to the larger sociopolitical context in which it is used. Using both the systemic-linguistic analysis[22] and a hermeneutic-like interpretation of discourses, in terms of the context in which they were submerged, we attempt to reach the ideological underpinnings of the participants' experiences.

We are therefore interested in the discourses our participants draw on when they speak to us. Language users are not isolated individuals, but they are engaged in communicative activities as members of social groups, organizations, institutions, cultures, and in the present study, families who were asked for consent to organ donation. We are therefore interested in discovering the "discourses of refusal," the ways in which the concept is made social through the process of narrating it. In such a way we set aside the issue of representativeness of the corpus. We are not trying to make a claim as to the extent to which the study is representative of families in a similar situation. Rather, we are interested in uncovering the discourse underpinning the negative decision to donate and, thus, in shedding light on it.

We are also aware that the data we have come from interviews. Not only were the interviewees more than likely to be in such a communicative situation for the first time, but also the interview topic was potentially very difficult, and explored a very personal sphere of the participants' lives. What we have, then, are stories in which the foci and relevancies are chosen by the participants in the particular context of the interview, a semiformal and semipublic communicative event. Realizing that our data are contextual, we are not making claims as to their universality. It is, however, worth bearing in mind that language users can, but rarely do, control the linguistic form of what they say, largely speaking "as one speaks." And, particularly by focusing on the form of what our informants said, we begin to explore what we earlier tentatively called a discourse of refusal.

Participants' Perspectives

One of the most striking characteristics of our corpus is that the main reason given by participants for declining the donation request was the wish to keep the deceased person "whole," not to cut up their body. Indeed, one of the informants explicitly states:

> Extract 1: *It was more the thought of keeping her whole*, keeping her as she was and I guess that was the only thing.[23]

As we noted earlier, this is indeed what the literature focusing on the narratives of the families declining a request for organs for transplantation suggests. However, here we would like to draw attention to the complexity and nuance of these

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findings, as a closer linguistic analysis indicates a more complicated picture. The speakers almost invariably mediated their wish to leave the body of their deceased relative untouched through their own perspective, mostly using what Halliday[24] and Halliday and Hasan[25] refer to as "mental processes," that is to say, all those linguistic tools (predominantly verbs) that refer to feeling, thinking, or seeing. In other words, there is a very clear personal perspective in the accounts of the decisions given by the participants. To put it plainly, the participants construct their accounts not so much as ones in which the body will be cut up but, rather, as ones in which they "fear," "can't imagine," or "can't bear" that the body will be cut up.

Consider the following extracts:

> Extract 2: Anyway, as it came Saturday morning time and we were back round the bed then this Sister, the one we had seen when we first came, came down and said the consultant wanted to see us [. . .] he just said to us your son didn't carry a donor card and well straight away I knew what he was going to ask me and I had never even thought about it up until that point but as soon as he said that I knew I wouldn't do it. I just knew I couldn't do it. [. . .] I just couldn't do it. I couldn't do it. I just said to my husband at time *I said I don't know how I'm going to live with this and I can't live with thinking of him being cut up* that was you know, and it was probably irrational. I know it is probably irrational. I mean I know his organs were no good to him. I know all of that, but all I could think was for the rest of me life I would have a picture of my son cut up.
>
> Extract 3: They did and it was ahhh but I knew. I looked at her and I knew I couldn't do it. I knew that the doctors thought that we were bad people because we wouldn't do it because S had received a kidney and I tried to explain to him, because she had cancer, because she had so many operations and so many things done that *I just couldn't bear the thought of her being touched again* and he said the only thing that they could probably take from her was her liver and her eyes. Well S had beautiful blue eyes and I knew that she would hate that so we said, no.
>
> Extract 4: I have to say I used to carry an organ donor card you know. You know because I thought, you know, it was quite oh uhm interest necessary really but I have changed my views entirely now. [. . .] *Seeing L laid there imagining her being cut up* for the sake of an eye or something like this just being kept alive on the ventilator. There seemed no dignity if you see what I mean, and uhh it's funny because when he [the doctor] first asked both my wife and I said well yeah, we would be interested.

The presence of the speaker in the narratives is quite striking. In extract 2 the account is made almost exclusively through the medium of mental processes predicated of the speaker. The moment the account tells of the reaction to the request for organ donation, it is told only with the explicit presence of the speaker in the narrative. In fact the narrator introduces the request itself through the speaker's perspective ("I knew what he was going to ask me"), and this is the moment when the narrative continues constructing what happened exclusively through the eyes of the speaker.

The story culminates in the construction of the speaker's son's body, as she says, "I said I don't know how I'm going to live with this and I can't live with thinking of him being cut up." Crucially, for our argument here, the speaker

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primarily focuses on her feelings, rather than on the body of her son. It is her and her feelings that are linguistically constructed as dominant in the rejection of the request. The core of the rejection is represented through reference to some unspecified emotional states[26] rendered by "I don't know how I am going to live" or "I can't live thinking [. . .] ." Note also that the latter expression, the actual reason for refusal of the donation request, is doubly mediated. Not only is the speaker *not able to live* but she is not able to live *thinking* about her son being "cut up."

This double mental perspective can also be seen in extract 3. The initial emotional perspective introduced by "I just couldn't bear" refers to a further mental process, thinking, although here rendered by a noun ("thought").

Extracts 2 and 3 typify the corpus and show an interesting pattern in the data on request refusals. They both establish a very clear and strong domination of the personal perspective on the decision regarding organ donation. Both speakers construct the decision process through emotional and cognitive processes (feeling and thinking), presumably emphasizing not only its difficulty but also their inability to agree to the request. But what is crucial for us here is that the speakers construct themselves as not being able to take not so much the decision but their own image of what the procedure of obtaining the organs looks like, or what the body would look like during and after the procedure. In other words, the accounts do not focus on the actual bodies, or the actual procedure. Linguistically, and hence in the meaning the speakers construct, they focus on their emotional and cognitive attitudes toward the procedure. We shall return to this point later on.

Extract 4 demonstrates a clearer reinforcement of the argument. The speaker explicitly talks about imagining his daughter "being cut up." It is the imagery that conjures up the lack of dignity and, interestingly, the father's change of mind. It is difficult to speculate to what extent his change of mind is spurred by the personalization of the choice, yet, clearly, the difference of opinion is caused by the shift from supporting a principle (to donate) to having to decide on the actual case involving his daughter. Imagining the consequences of the decision does not help.

The awareness of declining the donation request on behalf of those who are alive can be seen explicitly in the following extract:

> Extract 5: I honestly believe that what we decided was the best thing all round. Taking lots of humiliating tests in the morning, it was better for Mum and then we could get her out of the hospital because we had been there from like ten o'clock that morning. I felt that what we did was best because we were all there as a family and we made it (the decision) together and it brought us all together again, so I honestly believe it was the best thing.

Extract 5 differs from those before in that the speaker does not adopt her own perspective. Yet here, although more implicitly, it is the comfort of her mother that is at stake in the account. The speaker constructs herself as the linguistic actor (one who does things), not only executing the decision but also expediting the good consequences rendered by the decision.

It is noteworthy that even though the extract is considerably less explicit in the construction of the personal, emotional, or cognitive perspective of the decision, the decision is very firmly constructed for the good of those alive, particularly the

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wife of the deceased man. Also, this decision was made to avoid some negative emotional states (e.g., the humiliation resulting from the tests) and other unspecified discomforts.

Interestingly, some participants, although still constructing the refusal from the perspective of their emotions, also set up stories that make the refusal more justified. The most striking example is in extract 6, in which the speaker is setting up a rule on taking organs; even in this case, the rule is mediated through her own perspective:

> Extract 6: [. . .] I told all of my family that if they want to give anything they better carry donor cards because as their next of kin I wouldn't give permission for anybody to take anything, [. . .] I don't believe it is right to treat a human body as if it is say a car or something so that when it is finished, when parts of it are finished, you take the moving parts and put them into a into another one, which is how it appears to me, this hmm you know this organ donation is hmm and there is just a feeling *I don't feel it I don't feel it is right and another thing in my husband's case hmm I didn't want him mutilated* he had never been mutilated and my understanding is that they do have to keep everything going until hmm and they only take what is almost a living heart though it is artificially kept and I just find that totally abhorrent hmm I have never regretted saying, no, and thought I should have said, yes, I, I would, I would do the same today and as I say with any of my family that I was asked about I would still say, no.

The speaker's perspective is introduced right at the beginning of the extract, where she constructs herself as the gatekeeper for all her family as regards organ donation. What is interesting in what she says is that the moral rules she talks about, rules of no use of organs, are linguistically introduced by mental processes. The speaker ''doesn't believe'' and ''doesn't feel'' it is right; things ''appear'' to her. But the rules she constructs are in fact quite weak: not only does she introduce relatively low epistemic modality[27] but she also very explicitly makes the rules subjective. What is striking, however, is that the weakness of the rules appears to be in conflict with the fact that they are used to prepare rhetorical ground for the strong refusal of the organ donation request.

Indeed, the account of the rules leads to the crux of the story: the refusal. Also, the mutilation that the speaker talks about is constructed via her mental state; she does not want it, and she continues the account constructing stronger feelings toward it. It is noteworthy that the speaker chooses to use the word ''mutilation,'' with a very clear negative connotation, which helps underscore her negative attitude toward donation. To put it differently, it is considerably easier to refuse a mutilation than it is to refuse an organ donation.

Similarly, in extract 7, the participant creates a rule of heroic medicine.

> Extract 7: Generally speaking I think of organ donation as heroic medicine and I don't feel that anybody ought to be required to be a hero. If they want to volunteer that's up to them. The idea that lots and lots of money is being spent on this in order to make it possible makes me feel that it's not necessarily the best use of that money. I don't feel I'm an expert and I know that there are people who have by their life-long work found out

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> how and made it possible, and I think that's wonderful, you know great scientists, very impressive. I'm even willing to admire it you know.

Once again, the account as to why people can be given leave not to donate organs is highly personalized, as if the speaker wanted to show her experience of the problem. The extract quite aptly summarizes our argument. While talking about preserving the bodies of their deceased relatives, the participants do not want to take up the burden of the decision. The decision itself, notably, is constructed as heroism. This is another way in which the speaker constructs the choice as extraordinary.

Whereas in extract 6 the speaker refused mutilation, in extract 7 the speaker rejects requirements to be a hero. Both speakers, and others, on whose lexical choices we do not comment here, represent the situation of the decision as pertaining to a realm of life that is outside the normal. One does not mutilate bodies; one normally is not a hero. Constructing their choices in such a way, the speakers prepare ground for an easier and more socially sanctioned refusal. To put it plainly, they construct a situation in which anyone would say no. It is quite clear to us that the lexical choices used to describe either the decision or the organ donation procedure complement the highly personal perspective, which we uncovered in the data. And so, although the decision is consistently conveyed as about the emotional and cognitive states of the decisionmakers, it often refers to a (highly) negative situation in which one cannot but refuse the donation. Whether it is "cutting up" the body, or mutilating it, the speakers never refuse a "donation," which is a positively valued act, carrying with it a connotation of selflessness. It is much more difficult to refuse to donate than it is to refuse a cutting up of one's child.

Conclusion

What we have argued in this article has put some complexity to the finding that the reluctance to allow organs to be taken from dead relatives' bodies was driven by the wish to preserve their bodies or not to let them be touched again. We have shown that although this may be so, linguistically, the refusals are constructed as focusing on those who actually make the decisions. The accounts are to do with the fact that the participants did not want to imagine what would happen to the bodies of their deceased relatives and they therefore surrendered to this imagery.

There are two points we would like to make here. The first refers to the highly personalized nature of the decision not to donate. We have shown that the decision is made solely on the basis of individual expectations as to what organ and tissue donation involves and the decisionmakers' inability to cope with this expectation. It is this image, which is likely to be contributed to by both public and semiprivate discourse, that, we think, prevents bereaved family members from agreeing to the donation request. In other words, what staff approaching families deal with, in fact, is a combination of fact and stereotype, rather than a factual image of what happens to the body. It would appear, therefore, that it is this narrative of organ donation that needs to be changed to achieve positive decisions.

Second, as we stated earlier, there is a significant hiatus between the declarations of support and the actual donation decisions. Our findings cannot explain this, yet, perhaps, they could be used to bridge the gap. If it is understood that the decisions are actually about individual expectations as to what the process of donation

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involves, a number of steps could be taken to allay such fears. To put it explicitly, any requests for organ donation should focus on the decisionmakers and the difficulty they face in making the decision, in terms of both their own attitudes and their imagery of what actually happens. How exactly to do this is of course a matter for further research.

Our study is the first to examine accounts of families who decline organ and tissue donation through a discourse analysis and as such is a much-needed addition to the body of knowledge and literature. In this respect we have demonstrated the value of secondary analysis in eliciting further meaning from a sensitive and elusive primary dataset. This technique has potentially important implications for qualitative researchers who seek to investigate sensitive health-related topics. As this was a small, qualitative study with no ambitions to be representative, the findings must be viewed within the constraints of this small sample. However, because we focused on the practices of speaking, as one speaks, we could postulate a claim to no more than a pattern in a small group of research participants. Needless to say, more research designed to further enhance the understanding of the complex processes underpinning donation decisionmaking is urgently needed to provide an evidence base for the professionals who work in this sensitive field, and who are expected to support bereaved families in their decisionmaking about organ and tissue donation.

Notes

1. NHSBT; available at http://www.uktransplant.org.uk/ukt/default.jsp (last accessed 11 Jan 2011).
2. The Human Tissue Act, which got royal assent in November 2004 and was implemented in April 2006 (for transplantation September 2006), states in part 1, section 2, that in the case of a child ''appropriate consent means the consent of a person who has parental responsibility for him (the child).'' Section 3 states that in the case of an adult ''appropriate consent'' rests with ''a nominated person'' or ''person who stood in a qualifying relationship to him immediately before he died.'' There are a number of criteria listed defining qualifying relationships.
3. Human Tissue Act, London: Her Majesty's Stationery Office; 2004.
4. Department of Health (DH). *Organs for Transplants: A Report from the Organ Donation Taskforce*. London: DH; 2008.
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6. See note 4, DH 2008.
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12. See note 5, Sque et al. 2008, at 134–44.
13. Hodge R, Kress G. *Language as Ideology*. London: Routledge; 1993.
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18. Barker C, Galasiński D. *Cultural Studies and Discourse Analysis*. London: Sage; 2001.
19. See note 15, Fairclough 1992.

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20. See note 16, Halliday 1994.
21. See note 16, Halliday 1994.
22. See note 16, Halliday 1994.
23. For more accessible reading, we decided to simplify the transcription to the absolute minimum, leaving only the basic intonation signatures (full stops) as well as noting significant pauses (dots in round brackets) and backchannel responses. Omitted text is noted in square brackets. Italicized text indicates the fragments to which we want to draw the readers' attention.
24. Halliday MAK. *Language as Social Semiotic*. London: Edward Arnold; 1978.
25. Halliday MAK, Hasan R. *Language, Context, and Text*. Oxford: Oxford University Press; 1985.
26. Galasiński D. *Men and the Language of Emotions*. Basingstoke: Palgrave; 2004.
27. Epistemic modality is the capacity of clauses to express the speaker's certainty, from very low to very high (see note 16, Halliday 1994). Modalization introduces an aspect of degree and thus makes propositions weaker or stronger.

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