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Organ donation agency: A discourse analysis of correspondence between donor and organ recipient families

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Abstract

Studies about the psychosocial issues concerning organ donation and transplantation tend to focus on the experiences of donor or recipient families. Little is therefore known about the part played by correspondence exchanged between these two groups; in particular how they perceive the agency of organ donation. This is the first analysis to address the representation of the act of donation from the viewpoint of both donor and recipient families through interrogation of archived correspondence data, using linguistic techniques. The data was drawn from a collection of letters, from four USA Organ Procurement Organisations, exchanged between donor and transplant recipient families. Donor families consistently linguistically ascribed agency and accountability for donation to the person who died, the donor. For the recipient families, on the other hand, the 'giver' was mainly implied, ambiguous or ascribed to the donor family.

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Background

Human organ transplantation is a preferred therapeutic option for certain severe medical conditions and for individuals with irreversible organ failure, and was undoubtedly one of the outstanding medico-surgical advances of the 20th century. Improved surgical techniques, immunosuppressive agents and organ preservation, have made it possible to transplant a large variety of organs and tissues. Every year, thousands of lives (world-wide) are saved by transplantation; or enhanced, by health, sight, mobility, and a reduction in psychological morbidity. The exponential growth in the demand for viable organs over the 62 years since the inception of transplantation is testament to its therapeutic value (Farrell et al. 2011; Youngner et al. 2004). In the UK over 7,000 individuals are awaiting transplants (NHS Blood and Transplant 2016); whilst 70,000 people in the European Union are waiting for lifesaving transplant operations (European Day for Organ Donation and Transplantation (EODD) - 2015). In the USA the transplant waiting list stands at 121,473 (United Network for Organ Sharing (UNOS) 2016), with similar numbers echoed in most countries worldwide.

The process of organ donation is acknowledged to be complex and emotive for all concerned, encompassing most often the sudden, unexpected death of a relatively young person and the decision that must be made (usually by the next of kin) to posthumously allow the surgical removal of organs and/or tissues from the body of the deceased (Bellali and Papadatou 2007; Cleiren and Van Zoelen, 2002; Haddow 2005; Monogoven 2003; Pelletier 1992, 1993; Rodrigue et al. 2006; Sque and Long-

Sutehall 2011; Sque and Payne 1996; Sque et al. 2013; Sque et al. 2008; Sque et al. 2005; Wolf 1991). Sque and Payne (1996) suggested that the experience of organ donation for bereaved next of kin could be explained through a theory of Dissonant Loss; a bereavement characterised by a series of complex decisions and a sense of uncertainty and psychological inconsistency that created conflicts for the families involved. Some of these conflicts, substantiated by more recent work (Sque et al. 2008; Sque et al. 2005) were: coming to terms with the death of a relatively young person who was robbed of a future; deciding about giving consent for organs to be removed from a deceased person, that, because the body remained on cardiopulmonary support, still appeared to be alive; saying goodbye to someone who did not appear to be dead; and disposing of a body when their relative's organs were responsible for improving the quality of a recipient's life.

These studies suggested that decisions about donation may have consequences that affect the rest of donor families' lives. For instance, even as time went by the effects of the donation were perpetuated in the desire for continuing information about the organ recipients. The impact of information about recipients and the importance of contact with them have received scant attention in the context of studies about donor families' bereavement and is a contentious issue for many in the donation and transplant community (Albert 1999; La Spina et al. 1993; Sharp 2006; Sque 2013). Therefore a need existed for further exploration of this phenomenon.

One source of insight was correspondence exchanged between donor families and recipients. Only two sources of published work exist in this field. Vajentic (1997) reported patterns of correspondence of exchange, based on 542 letters between donor

and recipient families, from one USA Organ Procurement Organisation (OPO), between the years 1992-1995. She found a correspondence increase over time, from 58 items in 1992 to 202 by 1995, commenting however, that communication appeared important only for some donor and recipient families. Vajentic's work, however, was limited to one OPO and no exploration of the content of the letters or suggestions as to their importance was attempted. More recently, Sque (2002) analysed letters for their pattern of interaction, and thematically for content, looking for evidence of literal, symbolic, or metaphorical representations related to the discourses of 'gift of life' or 'sacrifice', which were potentially relevant to donor families' decision-making about organ donation. In contrast, our study focuses on discursive patterns in the letters between donor and recipient families. That is to say, we are less interested in the content of the letters and more how content was rendered by the socially significant linguistic form. Such an analysis has not hitherto been attempted.

'Gift of life' is a metaphor long associated with organ donation (Gerrand, 1994; Holtkamp, 2002; Lauritzen, McClure, Smith and Trew, 2001; Siminoff and Chillag, 1999; Sque et al, 2006; Sque and Payne, 1994; Vernale and Packard, 1990). Sharp (2006) noted that donated organs have been described as 'gifts of life' where the bereaved family is expected to give willingly and selflessly to anonymous strangers.

In his classic work "The Gift" (1990) Marcel Mauss argued that gifts are never free but are embedded in notions of ritual and obligation. Mauss (1990) suggested that the act of giving a gift is a form of contract governed by three major concepts: *the obligation to give, the obligation to receive, and the obligation to repay*. The act of giving creates a gift-debt that must be repaid, creating a relationship between the

giver and receiver. Weiner (1992) suggested that some gifts retain a tie to their owners as 'inalienable' gifts. These gifts because of their value and significance cannot be alienated or disengaged from their relationship to those to whom they belong. She further argues that inalienable possessions gain the spirit of their possessors, and so become associated with them, assuming a subjective value that places them above ordinary exchange. These ideas tally with Mauss' notion of the *spirit of the gift*, where the gift is imbued with the spirit of the giver. Although organ donation is not obligatory, there are however subtle pressures that drive *the obligation to give, receive and repay* (Fox and Swazey, 1992; Siminoff and Chillag, 1999).

Tradition, for instance, in many societies value the conviction that to give to others is supremely good. Therefore, because of their role in facilitating *the gift of life* through donation, families are left with reciprocal needs that appear to motivate an intense interest in the recipient of the organ, with the expectation that *the gift of life* be recognised, valued and not forgotten (Sque and Payne, 1996). Such appreciation encompasses the degree of benefit and difference a transplant made to the quality of the recipient's life and could kindle essential bonds of kinship (even if complete anonymity between donor and recipient is maintained), in an ultimate concern for another person. In other words, Weiner (1992) explains that through gift-giving a social bond evolves between the giver and receiver.

Likewise, Ben-David (2005) identified through interviews with organ recipients that they often felt they had received the 'greatest of all gifts', *the gift of life*. They were indeed aware of a distinct sense of obligation and a need for reciprocity. Society had given to them, so they had an obligation to give something back. Many did this in

terms of working to raise awareness about organ donation and transplantation by giving lectures and conference presentations about their transplant experiences as well as fund raising for transplant charities. Some, as we have found, chose to fulfil this obligation through correspondence with their donor's family.

Mauss' views and its application to this work will not be without its critics as Testart (2013; see also Laidlaw, 2000), for instance, is of the conviction that Mauss overstated the magnitude of obligation created by social pressure attached to gifts, particularly if the giver and recipient do not know each other and are unlikely ever to meet. However, Testart's transactions were related to impersonal objects such as money and did not take into account the deeply felt and personal involvement of donor families with the gift of their deceased relatives' organs through donation, as well as the apparent intense impact that this gift had on the lives of recipients.

Also, a paper by Sque and Galasiński (2013) suggests that describing donation in terms of a gift does not fully explain it. Narratives of those families who declined donation were constructed in terms of the unease with the deceased relative's body being 'cut up' and, from their perspective, violated. Consent to donation in view of such accounts could probably be seen as a 'sacrifice'.

Aim

The aim of this study was to further explore correspondence for representations of donation and reception of organs for transplantation. More specifically, we were interested in how donor and recipient families accounted for the act of organ donation from the deceased. We wished to elicit how the families discursively positioned

themselves, the deceased person and their organs with regard to each other and the act of donation.

In particular, we were interested in writers' positioning of themselves in terms linguistic agency. That is to say we wanted to see how 'doing things' is represented in discourse, paying attention especially to who is positioned as doing which kind of things in relation to what or whom. Our focus lay predominantly on the lexicogrammatical form, rather than on the contents of what was written. In other words, it was more important to us whether the linguistic form renders the 'doer' as doing things.

However, focusing on the linguistic workings of the letters under analysis, we account not only for lexical choices, grammatical forms and, potentially, larger syntactic and textual patterns, but we also offer insight into how people construct their experience and their identities, and relate them to the social reality in which they live. If Bauman (1986) was right that it is not the world which is the material of the narrative; rather, it is the narrative from which the world is abstracted, then our analysis taps into the stories from which consent, donation and its experience is derived. And as language users extremely rarely control the linguistic form of what they say, linguistic discourse analysis offers insight into the discourses that form the platform from which experience is unconsciously constructed.

Methodology

This is the first analysis to address the representation of the act of donation from the viewpoint of both donor and recipient families through interrogation of correspondence, using linguistic techniques. We have found no other study analysing families' written representations of the act of organ donation after death. The data for this study was drawn from 78 copies of letters exchanged between USA donor and transplant recipient families (Sque, 2002). The letters included 38 from donor families and 40 from recipients and their families. The letters were selected by blind randomisation from an ethically approved archive of 744 letters written by recipients to donor families and 554 letters written by donor families to recipients. Letters were written between January 1990-December 1997, about 333 donors, from four USA OPOs. Anonymity of the OPOs and involved correspondents has been strictly maintained, as agreed, to protect their identities.

Our data, from written letters, meant that we had no part in soliciting the data, or, indeed, any influence upon what was written. The letters were a result of the donor and recipient families' need to communicate with each other. What we analysed was a corpus of unsolicited communications in which organ donation was discussed between non-clinical participants of the process. In such a way, we began to gain insight into 'discourses of organ donation', which were used not for the benefit of the researcher, but the people actually involved in the procedure. Moreover, the letters were most likely to have been written and re-written a number of times (indeed their authors do explicitly say that they had written a number of previous versions of the letters). We may be able to assume therefore that the letters were 'just right' in what they say and how it is said.

However, we were mindful that the very form of the letters, written language, was also a source of complication. As written texts, our data were more than likely to be different in text organisation, vocabulary, and genre from any spoken account (Linell 2005). Yet, noting it, we were not going to explore this avenue. As we have no spoken data, we could not compare them with the written data. Also, although potentially very interesting linguistically, our aim was to focus on the ways organ donation was constructed.

Methodologically, our analyses were underpinned by the constructionist view of discourse, with a particular focus of critically oriented discourse analysis. For us social reality is constructed through and within language. Every language use designed to represent reality necessarily entails decisions as to which fragments of reality to include, and how to arrange and represent them. Each of these selections, both in content and 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 (Hodge and Kress 1993). Moreover, language users constitute social realities through discourse (i.e. practices of representation), and in particular their knowledge of social situations, the interpersonal roles they play, their identities and relations with other interacting social groups (van Leeuwen and Wodak 1999). No text, spoken or written, represents reality in a neutral or objective way, representation is never of reality 'as it really is', rather reality is always viewed through the tinted lens of ideological assumptions (Fairclough 1992; Halliday 1994; Van Dijk 1993; Barker and Galasiński 2001).

Data Analysis

We took a textually-oriented approach (Fairclough 1992). We were interested in the form of stretches of discourse, with an interest both in the semantics and syntax of the script, as well as the functions of what was said or written within the local context, and the social actions thus accomplished. We were particularly indebted to the developments of Halliday's (1994) functional linguistics, with its main proposition that the analysis of lexico-grammatical form of language should be foregrounded as a resource for constructing meaning (Halliday 1994). Elements of grammar and lexis were analysed predominantly as having a particular function when used by authors. In what follows we focus primarily upon the ideational function of what the informants wrote, that is to say, we were predominantly interested in how they represented extralinguistic reality. But we also focus on the content of what is written, relating it to the larger socio-political context in which it is used. Using both the systemic-linguistic analysis (Halliday 1994), as well as 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 were therefore interested in the discourses our participants draw upon when they write letters. Language users are not isolated individuals, but they are engaged in communicative activities as members of social groups, organisations, institutions, cultures, in the present analysis: families who agreed to organ donation from their deceased relative and families who have a recipient of those organs amongst them. We wanted to discover parts of the 'discourses of organ donation', ways in which the concept was made social through the process of narrating it. And so, we bracket off the issue of representativeness of the corpus. We do not wish to make claims as to the

extent the study is representative of families in a similar situation. Rather, we were interested in uncovering the discourse underpinning the donation and thus, shed light upon it. We do realise that our data were contextual and cannot be thought of in terms of universality. It is, however, worth bearing in mind that language users can, but rarely do control the linguistic form of what they say or write. In such a way focusing upon the form of what our correspondents wrote we began to explore what we earlier tentatively called ‘discourses of donation’.

As we said at the outset, in our analyses we have focused in particular on agency constructed in the texts. We focused on how ‘doing things’ with reference to donation and reception of organs was represented in discourse. This analysis was informed particularly by the linguistics of Halliday (1994) who sees it in terms of the linguistically represented participant and the process, i.e. who was involved in a particular action. It is important to remember that the linguistic agent might not necessarily be the ‘sociological’ one (van Leeuwen, 2008), that is to say as one who is taken to be an agent in a particular social context. What we focus on, significantly, was how reality was constructed and how the authors of the letters we analysed choose to represent it.

The analytic procedure was carried out in two stages. First, the data were thematically coded with the use of qualitative data coding software (MaxQDA). We focused on fragments in which the authors of the letters referred to the organ transplanted, the act of donation and reception. In the process we created a ‘subcorpus’ of the data, which was used in the second-stage analysis. This analysis focused upon grammatical, lexical as well as narrative patterns in the data. In the paper we present the fragments

of the letters which are typical of those we identified. Importantly, while the initial stage of the data-processing involved our decision to determine which data would form the smaller corpus, the second stage of the analysis was based upon the 'objective' linguistic form which was analysed with repeatable and empirically verifiable methods of text-based discourse analysis.

Finally, while we are aware of a few attempts to apply (critical) discourse analysis to data arising in organ transplantation contexts (e.g. De Luca et al., 2014; Mercado-Martinez et al., 2013; O'Connor and Payne, 2006), we are not aware of any discourse analytic analyses of communication between donor families and recipients of their relatives' organs. Our paper therefore to a considerable extent charts new territory in the social scientific understanding of the donation process and its aftermath.

Description of the archive

All the OPOs could provide, if requested, guidance for both donor and recipients' families about writing letters to each other. There was no guidance on a preferred timescale to correspond. It was not possible, however, to know if any instruction was used to construct the letters examined. More importantly, all correspondence between donor families and recipients was read in-house at the responsible OPOs by transplant co-ordinators or donor family bereavement aftercare staff who checked it for appropriateness, and to make certain that the anonymity of the correspondent was preserved, before it was forwarded to the intended recipient.

Letters were mostly handwritten by women, who were recipients, or mothers, wives, aunts or grandmothers of donors or recipients. Letters varied in length depending on

whether they were typed or handwritten, ranging from short passages to letters of several pages. Male donors generated more correspondence from donor families, as did the under 20 age group, with 25% of families corresponding about children between the ages of three to nine years.

The age of donors ranged from 7 days to 72 years, with a mean age of 26 years (SD = 15.6); 71% (n = 238) were men and 29% (n = 95) women. Donors' deaths were mainly due to tragic, sudden circumstances and head injuries sustained from a variety of sources. The main causes of death were: motor vehicle accidents (n = 118); spontaneous cerebral bleeds or infarctions (n = 76); gunshot wounds (n = 62). Other causes were: industrial accidents; falls from ladders, trees, walls, tailgates and windows; blows to the head from being hit by a golf ball, blunt instruments, baseball bats, and having a garden rake embedded in the head; non-accidental injuries, meningitis, acute infection; cerebral anoxia following hanging, suffocation, choking, drug overdose, drowning, fire exposure, severe seizures, advanced hydrocephalous, cyanide poisoning, an airplane crash, asthma attacks, birth trauma, electrical injury, unsuccessful post-surgical cardiopulmonary resuscitation, and sudden infant death syndrome. In four rare cases donors were individuals who had primary brain tumors. The main organs donated were kidneys, hearts, livers and lungs. Many of the donors were multi-organ donors.

Both donor and recipient families' first letters were written mainly within the first year following the donation or transplant at means of seven months for two OPOs and nine and 12 months respectively for the others. Four recipients wrote letters the day following their transplant, while four others wrote to their donor families for the first

time after five years; the longest time-span being eight years post transplant. One donor family wrote to their recipient the day following the donation, while two donor families made the first contact with recipients after five years, the longest time-span being 10 years. Vajentic (1997) found that 50% of correspondence took place within the first six months after transplant and 14% after more than two years.

Findings

Families' perspectives

As we stated at the outset, what follows is an account of the ways in which the donation process was constructed in the letters i.e. the decision to donate and the actual transplantation of organs. First, we will focus on donor families' letters and second those of the recipients.

'She gave you life'

One of the most consistent, and probably most striking, characteristics of the donor families' letters was the construction of the donation in terms of the deceased person's agency. In other words, the family of the person whose organs were used in the transplantation consistently ascribed causality in donation to the person who had died.

Consider the following extracts¹:

(1) I am happy to hear that my son [name] was able to give life to your son...

(2) I am so happy for you to have the chance to look forward to tomorrow now. And I am so proud that it was my dear sweet husband that was able to give you that chance.

(3) As a mother it makes me proud of my precious baby boy 'G' to know that he was able to give the gift of life to someone else.

(4) This letter is mainly because I want you to know who my son is and that he gave to you out of love and that I let him give too.

In all these extracts it was the deceased person who is the 'giver'. The agency of giving appears to be constructed in two ways. On the one hand, it was represented through the action of giving ('he gave'), on the other, through the ability ('he was able to') which was effected. Still, interestingly, these typical constructions position the deceased family member as the active 'participant' in the process of giving, or, perhaps donating.

There, are however, two other notable aspects of these constructions. First, the donation was represented as giving life, rather than giving the actual organs. Second, the giving was always mediated through the writer's mental process (Halliday, 1994). That is to say, the writers expressed the giving with initial reference to those linguistic tools (predominantly verbs) that refer to feeling, thinking or seeing. In other words, there was a very clear 'personal' perspective in the accounts of the decisions given by the letter-writers. It was as if the writers claimed a stake in the process of donation. However, it was primarily the decision of the 'owner' of the organs to 'give life', but it was done with the knowledge, thinking, or approval of the surviving family.

Indeed, this personal perspective was occasionally made quite explicit, as in the following two extracts:

(5) We very willingly wanted for [name] to give what she could, as she would have wanted it.

(6) She had signed her driver's license as an organ donor, and we willingly honored her wish. (...) She certainly gave the greatest gift.

These extracts underscore our interpretation of the data. The personal perspective appeared to be used to emphasise the unison between the wishes of the deceased person and their family.

Interestingly, we have found two instances where it was the donor family who was constructed as the decision-maker. Also here, however, the agency of the deceased person was implied in attributes they possessed in life (caring, willing to help). The family acted on her/his behalf:

(7) [names] and [name] feel very strongly that donating [name]'s organs would have been perfectly acceptable to him.

(8) [name] would be thrilled and would have done what we did as he was a very caring person and always willing to help one in need.

It is difficult to offer an interpretation of the constructed agency of the deceased person. One could speculate, however, that such a narrative retrospectively makes the decision to donate easier. The position of the deceased person as the agent (even an implied one) in the process of donation relieved the family of some of the responsibility for the decision. In the same way, the inclusion of the personal perspective helped to show the decision as one which was uncontested, almost easy, regardless of the fact that it is very likely to have been anything but. The narratives the writers often seem to 'smooth over' any hardship of family debates and decisions, and, finally, life in the aftermath of the donation.

'Thank you for your gift'

The perspectives of the recipients and their families appeared quite different. In contrast to the donor families, who constructed the deceased relative in terms of agency, the recipients and their families consistently constructed the decision to donate as that of the living relatives. The agency for the donation was ascribed to the family, as in the following two extracts:

(9) God works in mysterious ways, some we may never completely understand, but your choice of a donation gave our daughter a second chance at life (...) you have given the gift to us!!

(10) I wanted to write to you once again and express my deepest thanks for sharing the gift of life. The heart you donated me has certainly given me a new life.

The clause ‘you have given the gift to us’ constructed the agency of the donor family as explicitly as it can be done. The verb ‘give’ is directly predicated in active voice of the subject of the clause ‘you’. The explicitness of this agency could also be said to be underscored by the object of the clause ‘the gift of life’. Not only do the donor family give, but also they gave a gift. Similarly, there was no ambivalence as to whose action was the donation of a heart, a very rare construction in which the organ is named explicitly in such a context.

However, what is quite remarkable in our data is that these very direct ascriptions of agency are, in fact, quite rare. What dominates in the corpus were constructions of agency, which were implied. To put it in the words of Bavelas and her associates (Bavelas et al. 1990) the writers prefer to dissolve a clear ownership of the action of giving the organ, in the letters. Typically, the recipients and their families distance themselves (on distancing, see for example Galasiński, 2004) from direct ascription of agency. The writers preferred to leave the ‘giver’ ambiguous. Consider first an extract in which the writer dwelled at some length on donation:

(11) Although the past cannot be changed and unfortunately your child cannot be here with you in body, the donation of his organs made it possible for numerous others to experience this holiday season. His organs are truly, are truly a gift of life that will live on in many others. (...) once again, let me express all of our appreciation for the organ donation that you made possible.

It is quite extraordinary to note that in this account of the present and the past, the actual agency behind the donation was only implied. First, the act of donation was consistently nominalised, that is to say that processes (for the purposes of this paper: actions), which are normally rendered by means of verbs, were represented as things and so in terms of nouns (Halliday 1994). In such a way actions become things, and things do not have those who 'do them'. And so, the author of the letter wrote about 'donation', 'gift' and donation again and, crucially, they have no 'owner'. They seem to exist on their own. It is only at the end of the extract that the author of the letter constructed an indirect 'ownership' of the donation through making it possible. The donor family was represented as enablers, those, it seems, that created a 'context' for the donation to be effected, with the agency of the donation itself removed from them. This indirectness, as we indicated earlier, was the typical construction of donor families' agency. But the most striking aspect of these constructions was that they were consistently done through the perspective of the recipient. Consider first the following:

(12) I'm a thirty-eight-year old man who was blessed with your daughter's precious lungs on March [date]. I'm deeply grateful for your courageous gift.

(13) I am sorry you had to loose someone for me to receive your wonderful gift.

(14) As the heart recipient of your loved one I would like to express my deep appreciation for your gift of life to me.

(15) I feel the need to write you to express our overwhelming gratitude for the generosity of the greatest gift of all, a new life for our son.

As in extract (11), in all the extracts above donation was nominalised into references to a 'gift'. This time, however, the gift was identified as 'your', clearly referring to the donor family. But all these constructions were done through the clauses containing verbs referring to mental processes (thinking, feeling, seeing and the like). In other words, it was the recipients' gratitude, sorrow, appreciation that invokes the gift. As in the previous section, also those receiving organs introduced the 'gift' through a personal perspective mediating the gift and, at the same time, removing the agency from the donor families.

But the mediation did not need to be done only through reference to mental processes. It was also done through other references to the recipient. Once again the 'gift' is introduced through references to the person who received it, while the 'giver' is backgrounded and only implied:

(16) Because of your kindness and generosity, I am able to live a normal life again. (...) On January [date], which I now consider my new birthday, because to me, it is the beginning of my new life, I received your gift of a new lung.

(17) I'm a 46 year old man and in the early morning hours of May [date], because of your love and generosity, I was given a new heart and a chance to live.

As in the case of the donor families, it was difficult to offer a clear interpretation of these data. But also here we would propose that it is distancing that was at stake in the narratives. The recipient families, it seems, choose to construct a reality in which no one had to give the organs. In other words, their narratives not only removed the actual person who died, but also, more generally, death as the prime reason for the organs' availability. Let us take this up below.

Discussion

First, we would like to offer some more comment on the issue of agency itself. What was surprising in the data was that the constructions of agency appeared to be counterintuitive. On the one hand, despite the fact that it was explicitly the surviving family that was asked to donate the deceased family member's organs, they still preferred to distance themselves from the decision and the act. Similarly, the recipient families, even though they wrote to who actually donated the organs that enabled their survival, in their letters they chose to background that action. To put it simply, one could say that both donor and recipient families found it too difficult to contemplate the actual act of donation and write about it directly. The very fact of being involved in donation does not seem to 'tame' it making it palatable or acceptable (Sque et al 2008).

In our paper on the ‘discourses of transplantation’ (Sque and Galasiński, 2013) an analysis of interviews carried out with families who declined donation, we noted a significant presence of references to mental processes (i.e. to representations by verb of e.g. thinking or feeling). More specifically, the families explained their inability to donate by references to their relatives’ bodies being ‘cut up’, defaced in one way or the other. What was fascinating in their accounts was that they invariably introduced the references to ‘cutting up’ through the use of mental processes. In other words, they could not ‘imagine’, ‘think’, ‘face’ the body’s defacement. The entire process was discursively managed by references to what they thought or how they felt. This is also what we observe here. Both datasets typically contained dominant references to what the surviving families thought or felt. For some reason the individuals preferred to write about thinking or feeling rather than doing. These discursive devices introduced a perspective reinforcing that of distancing correspondents from what was actually involved in donation. They allowed introduction of further indirectness into the letters. First, inserting verbs referring to mental processes as the superordinate clauses allowed the writers to describe what they thought, thereby focusing on themselves and not the donation. Second, such references potentially serve as ‘hedges’, defined by Brown and Levinson (1987) as particles, words, or phrases that modify the degree of membership of a predicate or noun phrase in a set. Phrases as ‘I think’ or ‘I feel’ and the like modify the applicability of a statement. The statement is less certain and qualified. The indirectness of writing about donation appeared complete.

Anthropologists Sharp (2006) and Lock (2002) stress the ambiguity of organ donation. Sharp makes the point most explicitly stating that organ transplantation

acquired both “a wondrous and disquieting medical field” (Sharp, 2006: 40). What our data demonstrates, most notably, is that going through the procedure, whether as a donor, or as a recipient, does not actually change this ambiguity. We believe there are two aspects related to this ambiguity. The donor family as much as they were pleased to save a life, appeared uneasy about the very fact that they were responsible for the decision to allow organs to be removed from the body of their deceased relative. They had to imagine and live with the fact that their loved one’s body was ‘cut up’ (Sque and Galasiński, 2013), which raises concerns about the ownership of the organs, for example. If it was the deceased person who was perceived to be the giver, all these issues disappeared. Recipient families, as grateful as they were for the organ, were equally uneasy with the fact of donation. And so, the addressees of their letters were actually the donating families, with the organ donor backgrounded and constructed as uninvolved in the donation.

Indeed, Sque and Payne (1996) showed that donor families had two main concerns about donation; the mutilation of the body, and the possible suffering the relative might sustain as a result of the operation. The letters that we analysed complements this study in that they offered a way out for the families. Whether or not the potential donor’s wishes were known, the family decision-maker still had to give consent and authorisation to donation or not, so the final decision remained with them. If, however, they perceived the donor to be the person making the donation i.e. the giver, then the family member was relieved of having to make a possible contested decision that might have involved ‘perceived suffering’.

At the same time, information about recipients provided donor families with a sense of reassurance, referred to in this study, that comforted them in the knowledge that somehow the deceased's organs had found a purpose and there was now a sense of wholeness again that made the donation worthwhile.

Finally, the 'gift of life' was used by families in this study to communicate about what they regarded as a very precious *gift of an organ* or *the gift of life* that had the ability to transform the quality of recipients' lives; giving benefits to both recipients and donor families. This study demonstrated that reciprocity did not appear to be egotistically motivated by families but was directed at *the achievement of the donor*. It is suggested that it is from the acknowledgement and appreciation of that achievement that families received *reciprocity on behalf of the deceased*, and, thus, potentially, solace in their grief (Sque and Payne 1996, Sque et al. 2013). Donor families in this study appeared to regard themselves merely as facilitators of their relatives' donations, which helps to explain the importance given to the inalienable attributes of the donor. It appeared that if relatives perceived them to have been generous, caring people, giving their organs was viewed as something they would have been proud to do.

Conclusions

This is the first study to provide discourse elaboration of the agency of donation through correspondence between donor and recipient families. Apart from the findings we reviewed above, we have also demonstrated the importance of discursive micro-analysis in achieving deeper understanding of the experiences of organ transplantation. Discourse analysis, with its focus on both the form and the content of

what is being communicated offers an additional insight into social constructions of donation and transplantation.

The strength of this work is that it was developed from data that provided a unique perspective of families' experiences of donation and transplantation from letters written by them, reflecting their world-view. Therefore, it is expected to have relevance to other individuals in similar circumstances. However, as we bracketed off the issue of representativeness, we cannot offer comment on the commonness of the discourses we discuss here, both within the US context as well as beyond. In such a way, this study provides a springboard for further investigations. Follow-up studies are needed to provide further insights into the bereavement experiences of donor families. Moreover, further such analyses in other cultural and social contexts would offer welcome enrichment of the data and analyses we conducted here. Moreover, our study could also provide a platform for further larger-scale quantitative studies offering further perspectives on donation and transplantation experiences. These in turn, in combination with our study, could inform better clinical and social care for those involved in the processes of donation and transplantation.

Endnote

¹The extracts are the exact rendition of the letters. We deleted any personal information to preserve the anonymity of the authors and/or recipients. The deletions are flagged in square brackets. For space we occasionally shortened the extracts, indicated by (...).

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