

LIFE & DEATH: THE DIALECTICAL NATURE OF THE SOCIAL REPRESENTATIONS OF ORGAN DONATION AND TRANSPLANTATION

Gail Moloney
Murdoch University (Perth, Western Australia)
moloney@socs.murdoch.edu.au

Iain Walker
Murdoch University (Perth, Western Australia)

On December 3rd 1967 in South Africa, Dr Christian Barnard performed the “inconceivable” by transplanting Miss Denise Darvall’s heart into Mr Louis Washkansky. This was the world’s first human heart transplant. The years since then have seen amazing advances in the technology of transplantation, but paradoxically little advance in encouraging the donation of organs. This has seen a situation develop where the procedure of transplantation now relies heavily on the availability of donated organs, and, because organs are constantly in short supply, the emergence of organ waiting lists. Australia now has one of the lowest donation rates in the Westernised world, and a trend in donation that has seen rates drop over the past five years. For example, the number of organ donors in Australia has dropped from 183 in 1994, to 164 in 1999, resulting in a current donation rate of 8.6 donors per million population. This is against a national waiting list where 59 people are currently waiting for a heart transplant, 73 a lung transplant and 1,531 a kidney transplant. The scenario in the state of Western Australia is no better. It has the lowest donation rate in Australia with only 13 organ donors in both 1998 and 1999 (population 1.7 million).

In contrast to these figures is the finding that the majority of Australians say they support organ donation. The central construct here has been the attitude, bringing with it the assumption that this high support should be able to be translated into correspondingly high donation rates. This has clearly not been the case. While other perspectives have been used, such as different measures of intention, the manner in which donation is requested, relationships between socio-economic variables and the donation question, the underlying conceptualisation has, for the most part, been within an individualistic framework; one that separates the individual from society, and the decision from the wider context of

understanding. This suggests that this conceptualisation may be tapping into only one aspect of what is, in fact, a much broader issue.

An alternative, and the basis of the current research, is to conceptualise organ donation within the context of social representations theory. This asserts that our understandings about a social issue, such as organ donation and transplantation, are social in origin “as certain patterns of thinking, action and interaction which when collectively constructed, create and construct a social object (Wagner, Valencia, & Elejabarrieta, 1996, p.332; Moscovici, 1984). Such understandings are dynamic, both in their construction and in their continual evolution through the processes of interaction and debate, and are never free of their socio-historical context (Moloney & Walker, 2001; Purkhardt, 1993). Within this conceptualisation, organ donation and transplantation become more than an individual’s attitude or decision; they involve a shared dynamic understanding, constructed and shaped by the interplay of past understandings with present discourse and interaction processes in society.

Thus, the aim of this research was to identify whether there was, and, if so, what was the social representation of organ donation and transplantation. Three studies were conducted, each addressing this question from a different methodological perspective. In investigating the existence of a representational field, our initial theoretical perspective drew from core theory (Abric, 1993, 1996), and the identification and distinction between core and peripheral elements in a representation. Core elements are considered to generate the overall meaning of the representation and are characterized by a high degree of stability, inflexibility and resistance to change. They also largely constitute the area of consensus in the representation (Guimelli, 1998).

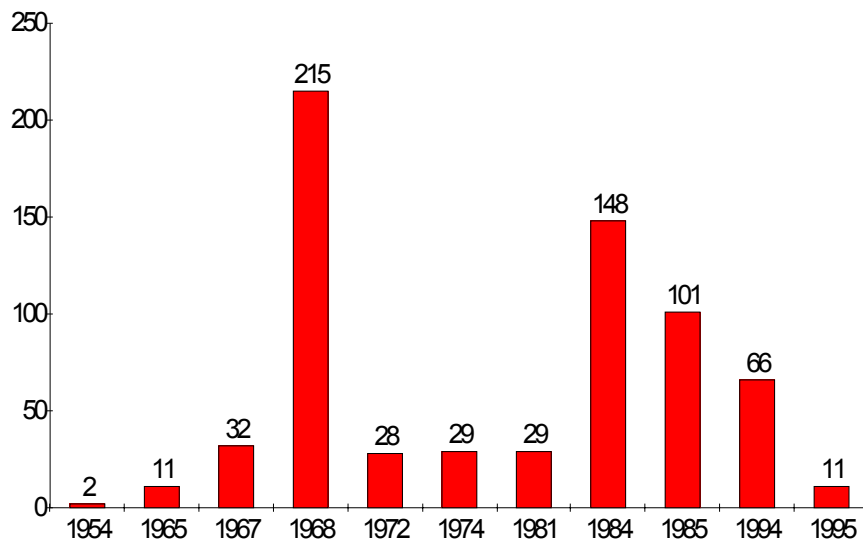
While the notion of centrality and generativity that is associated with core elements is imperative in establishing a representation, the inflexibility and coherence often associated with core elements implies a certain degree of stasis that, we feel, does not accommodate the dynamism essential to a social representation. Thus, the conceptualisation of a social representation here allowed for a fluid, negotiable understanding of the representational field that had the propensity for contradiction and tension by drawing from two theoretical

positions. The first focuses on consensual reality (Rose, Efraim, Joffe, Jovchelovitch & Morant, 1995) where there is a tacit understanding of the shared historically derived meanings that allows for differences in the manifestation of different individual or contextual shared views. The second focuses on the non-equivalent functioning of the normative and functional dimensions of the core that, in an extension of the core peripheral distinction of a representational field, would allow for differential movement within the core of the representation field (Guimelli, 1998).

Lay understandings about donation and transplantation undoubtedly had their origins in the medical world, and the media were pivotal in the dissemination of this information. Not only are the media an integral and prolific part of the discursive practices in a society, but they are also often the first to communicate new information to the public and so are implicated in setting the agenda for further discursive processes. Hence, the aim of the first study was to trace historically the development of the social representation of organ donation and transplantation through one particular form of the mass media.

The first successful kidney transplant took place in December 1954 and the only media source consistently available in Western Australia since then has been a morning paper called the West Australian. This paper was used, and 11 years between 1954 & 1995 were searched for articles pertaining to organ donation and transplantation.

Figure 1: Number of newspaper articles pertaining to organ donation and transplantation found for each year searched



As Figure 1 shows, two periods generated the majority of newspaper articles, corresponding firstly to the early years of the first heart transplants, late 1967 & 1968, and secondly in 1984 & 1985 to Australia's 5th heart transplant, a 14 year old school girl called Fiona Cootes, and the ensuing interest that developed from this in Australia's renewed heart transplant programme. An important factor in the development of the representation of organ donation and transplantation was the advent of immunosuppression drugs in the early 1980s, and the role they played in reducing organ rejection and improving transplant outcomes. Prior to the early 1980s, the majority of transplant patients died, and transplant programmes were cut back until the advent of these drugs in the early eighties.

In the early years of 1967 & 1968, the reporting of organ donation and transplantation appeared to be organised around the transplant surgeon, predominately Dr Christian Barnard. It focused on the new life that the transplant surgeon could give, and defined transplants within a "mechanistic" view of the body. The image was of a body as a machine, which equated organs to that of a spare part that could be removed and replaced by the transplant surgeon. This conceptualisation elevated the status of the transplant surgeon to that of a messiah or an alchemist, and conferred a passive state to the donor.

Before surgeons can give Dr Blaiberg a second heart a donor must be found. While crowds of onlookers and reporters gathered last night, the surgical team waited for an accident victim whose tissue would prove suitable (West Australian, 8.7.68).

Similarly, phrases such as “*If spare parts are to be handed out like dentures*” “*Global spare parts service*”, “*a replacement heart*”, “*second hand heart*” were used liberally in the reporting. Barnard himself mirrored this conceptualisation when he was reported to have explained that the first transplant occurred in the Garden of Eden and that “*Adam was the donor, God the surgeon and He made Eve out of Adam’s rib* (West Australian, 11.12.68).

The messianic image associated with the transplant surgeon appeared, initially at least, to counter criticisms and concerns over the experimental and dubious nature of transplant practices, such as lack of clarity over the criteria used to determine brain death, the removal of organs without consent, and reports that suggested that transplant surgeons had the right to stop treating dying patients whose organs may be destined for transplant. However, in the latter part of 1968, the reports began to question many of these procedures and the ethics involved, and, coupled with the increasing number of transplant deaths, a growing mistrust and air of criticism about the transplant procedure was prevalent in the reporting.

While again not exclusively, many of the articles that accompanied Fiona Coote’s transplant in 1984 defined transplants and donation quite differently. Although transplants were still about the life they could give, there was recognition that a donor and hence death was involved, and that it was the donor, not the doctor, who gave life to the recipient. Families and friends were implicated in how transplants were reported, appearing now to define the transplant procedure in a non-medicalised context. The donation of an organ was now being portrayed as a gift of life from one human being to another.

An Easter gift has given new hope of a healthy life to 2 patients. The gift, kidneys, from an anonymous donor was used for 2 transplant operations. Mrs Leigh says she is grateful to the donor and the donor’s families. (West Australian, 5. 4. 85).

While reporting of transplants in the 1990s predominantly utilised this latter *gift of life* framework, there were also articles couched in a more *mechanistic* framework reminiscent of late 1968 where mistrust in the medical profession, concern over the removal of organs, and issues about the ethics of organ removal were being expressed. What this suggested was that the initial understandings about transplants were never completely dispelled; they were instead modified with time. Organ donation and transplantation were now being

understood within two, apparently conflicting frameworks. This study suggested that there was a well-structured body of knowledge about organ donation and transplantation that could be identified as a representation, but it also posed the question of whether there was one or two representations, and, if there was one representation how the conflicting nature of these two frameworks was accommodated.

The second study focused on the meaning that organ donation and transplantation currently have within society, how people talk about donation and transplantation. Again the interest was the framework that was being used when this issue was discussed, the ideas, beliefs or values - the core elements - that could be identified as central to this understanding. Drawing from the premise that “understanding arises from social communication” (Moscovici, 1984, p.15), focus groups were used. The study was more concerned with the arguments used when discussing donation and transplantation, rather than with those who produced the arguments (Farr, 1995).

After random selection, 29 people participated in four focus groups. The procedure was the same across all groups; participants were read seven short newspaper extracts that described scenarios about donation and transplantation, followed by an unstructured discussion about organ donation and transplantation.

Three points could be drawn from the analyses. The first point was that the discussions were all conducted within a pro-donation stance. All but one member of the four groups endorsed the practice of organ donation. It was considered to be a worthwhile altruistic act, and a service to humanity. Within this stance it was considered to be a “gift of life”, a gift from one human being to another.

“I am also in favour of organ donation because it is a service to humanity and it is giving life, because you are of course dying so it is better you save someone else’s life, like a gift to society”.

The second point was that this pro-donation stance was nearly always qualified by a concern or fear about the donation process. Once the pro-donation stance had been set voluntarily by participants, these qualifiers were tossed about, their validity debated, and often in the process counterposed by the person who raised it. For example, participants were in favour of organ donation but had concerns they would be allowed to die

prematurely. They thought organ donation was a worthwhile altruistic act but didn't want to see their loved ones mutilated. They accepted the definition of brain death as long as they could be assured the person wouldn't wake up.

“They cut you open while you are still breathing - the removal of the beating heart”.

On the one hand it was a gift of life, a service to humanity, while on the other hand, phrases such as spare parts, parallels with organs being screws in a jar, hunks of meat, eyes being cut out, were used. Concerns were raised over the control of donation, the potential for trade in organs, and the frailties of the medical profession that would allow organs to be sold to the wealthy at the expense of those already on the waiting list. Many of these qualifiers appeared to imply a different understanding about donation, one where the donor was passive, no longer giving the gift of life, one where organs were parts, no longer given but removed, cut out, and one where the nature of death and organ donation was constantly questioned.

“Thinking of them as a hunk of meat like a sheep or something. That is how doctors think.”

“ But there is also someone there waiting for someone to die so they can have their part to save their life”.

The third point from the analyses was that these qualifiers or concerns were familiar to all of the participants. Although the participants may not have agreed with each one, they were familiar with what was being said, just as they were familiar with the counterarguments against them, suggesting again that there was a familiar body of knowledge about donation and transplantation.

These results suggested that organ donation and transplantation were being interpreted within two distinct, but dialectically opposed, frameworks of meaning that did not, however, relate exclusively to donation or transplantation. Rather, these dialectically opposed frameworks of meanings co-exist, dovetailed within one representational field. Drawing from Guimelli (1998), it appears that there are differential normative and functional dimensions to the representational field. The normative dimension is where organ donation is understood in a distant, globalised manner - intellectualised as a gift of

life, a service to humanity, and, serving as the norm in how we respond to the question of donation and transplantation. In the functional dimension, organ donation and transplantation are understood in relation to the individual's self or family, bringing with it concerns such as the nature of brain death, disfigurement, mistrust in the medical profession and so forth.

The basis for the third study was a mail-out questionnaire sent to 1500 randomly selected Perth residents, which sought to delineate the representational field of organ donation and transplantation, and the nature of the diversity within this field that had been suggested by the previous studies. The technique used was word association and the methodology was based on Wagner's (1996) research. Central to this is the premise that core elements, which give meaning to the representation, can be understood as a structurally stable unit that remains relatively unaffected by situational variation or context. These can be differentiated from peripheral elements, which do not retain their stable structure in situational variations because their role in the representation is to adapt the representation to different contexts.

Briefly, respondents were asked to freely associate what ideas, thoughts or words come to mind when they think of organ donation or organ transplantation. The context of the stimulus word (donation vs transplantation) was experimentally manipulated. If a well-structured representation could be elicited within different contexts, then sets of words should emerge across these contexts that retain their stable structure (the core) as well as sets of words that do not retain a structure (the periphery). Eight conditions were used, four where the respondents were asked to associate with organ donation, and four where they were asked to associate with organ transplantation. Each of the four conditions for each stimulus word was either preceded, or followed, by a scenario that described an event where donation or transplantation would occur. One of these used "medically mechanistic" language, the other "gift of life" language, reflecting language used in the previous two studies. No reference was made in the cover letter or instructions to organ donation or transplantation.

Stacked matrices of the co-occurrence of words were analysed by correspondence analysis. Based on dissimilarities between words, this produces a plot of the positions of the words' co-occurrence relative to each other in semantic space, interpreted within this technique as the structure of associations.

Twenty-three categories of associations (Appendix 1) were entered into the analyses and a stable structure between three words, *Life*, *Death* and *Heart*, emerged across all eight conditions (see Figure 2). While there was some movement in semantic space, the basic triangular structure between these three words was retained, suggesting that these three words were central to the representation. Analyses across "Donation" words and across "Transplant" words also showed this same structure between *Life*, *Death* and *Heart*, confirming the finding of one, not two, representations. The representational field thus pertains to both organ donation and organ transplantation.

Figure 2: Comparison between co-occurrences of the words Life, Death and Heart when the stimulus word Donation was preceded by context and followed by context.

(figure manquante)

These results suggested that there were two elements, *Life* and *Death*, at the core of the representation pertaining both to donation and transplantation. However, these two elements do not appear to have a cohesive, unitary character that is commonly associated with the core of a representation. Rather they are dialectically opposed, and generative of conflicting periphery elements. And while the co-occurrence of the third element, *Heart*, was synchronised with *Life* and *Death*, it appears to be fulfilling a different central role in the representation, in that it contextualises *Life* and *Death* within the representational field. This is all the more plausible if we consider Dec 3rd, 1967 when Dr Christian Barnard propelled the technique of transplantation into the public mind by performing the first human *Heart* transplant.

The results from this study, while initially surprising in that the notions of "gift of life" and "spare parts" were not part of a stable core, when interpreted within the three studies go some way to explaining how organ donation and transplantation are socially represented.

The first study indicated that organ donation and transplantation were being understood within a “medically mechanistic” framework and a “gift of life” framework, reflecting possibly the formation of the representation around Dr Christian Barnard and its later integration into the non-medical world. The second study suggested organ donation and transplantation could best be understood as a representational field comprising of conflicting elements; where pro-donation was dovetailed with qualifiers about donation fulfilling normative and functional roles within the representation. The third study has taken these results to a different level, to suggest that this conflict between what appeared to be a “gift of life” and a “medically mechanistic” understanding about donation and transplantation, is generated by the dichotomous relationship between the core elements of *Life* and *Death*. This study also suggests that spare parts, second chance, mutilation, operation, cutting, saving, etc., are periphery elements, situationally variable and solicited according to the context in which the representation is elicited. However, it is important to note that this third study used a method of analysis that also assumed a certain degree of inflexibility within the core, by seeking a stable substructure within the core elements. And, while this allowed the core elements to be distinguished from peripheral elements, it did so at the expense of the dynamism that we believe is the essence of a social representation. Therefore, the data in the third study were re-analysed using a related type of semantic analysis that, we believe, accommodates more flexibility in the core (see Moloney, 2002). Together these studies suggest that the representation of organ donation and transplantation is best understood as a representational field that contains contradiction and diversity, and *not* as a representation with a unitary, cohesive character. It also suggests the social issue of organ donation and transplantation is best understood in a non-linear way, one that encompasses the possibility that social thinking can be contradictory, dialectical and dichotomous, and reflective of situational context. These results have implications for the promotion of organ donation. Currently many health campaigns work on the linear assumption that a favourable response towards donation will, with the right amount of publicity, translate into favourable donation behaviour. The results of this research suggest that we can be simultaneously both for and against the idea of organ donation and

transplantation, depending on the contexts in which our understanding are solicited. Possibly of more importance, there exists at the centre of our understandings about this social issue a fundamental tension between *Life* and *Death*.

The authors acknowledge the Medical Research Fund of Western Australia (MEDWA) who partially funded this research

References

- Abric, J. C. (1996). Specific processes of social representations. *Papers on Social Representations*, 5(1), 77-80.
- Abric, J. C. (1993). Central system, peripheral system: their functions and roles in the dynamics of social representations. *Papers on Social Representations*, 2(2), 75-128.
- Guimelli, C. (1998). Differentiation between the central core elements of social representations: Normative and functional elements. *Swiss Journal of Psychology*, 57(4), 209-224.
- Moloney, G. (2002). *Social representations and organ donation and transplantation*. Unpublished Doctoral Thesis. Murdoch University.
- Moloney, G., & Walker, I. (2000). Messiahs, pariahs, and donors: The development of social representations of organ transplants. *The Journal for the Theory of Social Behaviour*, 30, 203-227.
- Moloney, G., & Walker, I. (In Press). Talking about transplants: Social representations and the dialectical, dilemmatic nature of organ donation and transplantation. *British Journal of Social Psychology*.
- Moscovici, S. (1984). The phenomenon of social representations. In R.M. Farr & S. Moscovici (Eds.), *Social representations* (pp. 3-69), Cambridge, Paris: Cambridge University Press et Maison des Sciences de l'Homme.
- Purkhardt, S.C. (1993). *Transforming social representations*. London: Routledge.
- Rose, D., Efrain, D., Joffe, H., Jovchelovitch, S., & Morant, N. (1995). Questioning consensus in social representations theory. *Papers on Social Representations*, 4, 150-155.
- Wagner, W., Valencia, J., & Elejabarrieta, F. (1996). Relevance, discourse and the 'hot' stable core of social representations. A structural analysis of word associations. *British Journal of Social Psychology*, 35, 331-351.