

# Messiahs, Pariahs, and Donors: The Development of Social Representations of Organ Transplants

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On December 3rd 1967, Dr. Christian Barnard performed the world's first heart transplant. The years since this medical milestone have seen a situation develop in westernised countries where the procedure of transplantation now relies heavily on the availability of donor organs which are constantly in short supply. This is especially true in Western Australia, where the present study was conducted. The issue of low donation rates can be addressed from different perspectives, such as medical procedures in the procurement of organs, mandatory versus voluntary donation, rights of the next-of-kin, and so on. But, a pre-requisite to understanding donation issues must be an investigation of how organ donation and transplantation is understood by the non-medical world. Inherent in this is the social construction of organ transplantation by the mass media, which have been the main disseminators of such information into the public sphere. The theory of social representations provides an account of "social thinking", and forms the basis of the present study.

## SOCIAL REPRESENTATIONS

Once formed, a social representation comprises certain patterns of thinking, action and interaction which, when collectively concerted, create and construct a social object (Wagner, Jose & Elejabarrieta, 1996, p. 332).

Social representations theory is based on two assumptions. Firstly, that the social world is constructed through the thoughts and concerted interactions of a group, society or culture; and secondly, that discursive practices are paramount in the construction of this social world (Wagner, 1998). A social representation is a mental construct that is socially determined through discursive processes, and whose essence is shared by other members of the group, culture or society (Wagner, 1996). It is an interpretive frame whose function is to render the unfamiliar

familiar. Two processes are involved in the formation of a social representation, anchoring and objectification. Briefly, anchoring integrates a new idea, an incomprehensible phenomenon, into an already established network of meanings, generating a system of interpretation. Objectification gives a concrete form to the phenomenon turning abstract notions into reality—a statement of fact. This involves the discovery of an image or an iconic aspect of the phenomenon which then becomes the focal point of the representation, and a frame of interpretation and categorisation for new information (Moscovici, 1984; Wagner, 1995, 1996).

#### SOCIAL REPRESENTATIONS AND THE MASS MEDIA

The discursive processes essential to the formation and functioning of social representations occur at both the inter-individual level and the level of the mass media. (Farr, 1998; Wagner, 1998). The mass media rapidly disseminates scientific and medically related (and other) information to the public, creating homogeneous images in a relatively short time period when compared to inter-individual communications. Also, the mass media are, arguably, the most prolific means of information dissemination, a mediator between scientific and social knowledge, and more often than not the first to communicate new information to the public thereby setting the agenda for further discursive processes in society (Rougnette, 1996; Wagner, 1998). Having said this, not all phenomena communicated by the mass media are social representations.

It is not clear why some phenomena become social representations and others do not, but several factors have been suggested. The phenomenon must firstly engage the “social mind”. Wagner (1998) suggests that such phenomena must have aesthetic appeal. The phenomenon must also appeal to existing social knowledge either by complementing it, or threatening present understandings. And, the appropriation must have genuine social implications (Moliner & Tafani, 1993a, as cited in Moliner & Tafani, 1997).

Social representations analyses of the mass media have typically focused on describing the content, and not the structure, of social representations (see Farr, 1995; Herzlich, 1989; Markova, 1987; Rose, 1998, for an exception see Petrillo, 1996). There are, however, insights to be gained from a structural analysis that cannot be gained from content analysis alone, such as verification that what is thought to be a social representation is in fact a social representation (by the identification of a well-structured body of knowledge: Wagner, Jose, Elejabarrieta, 1996), and comparisons of such representations over time (Rougnette, 1996).

#### STRUCTURAL PROPERTIES OF A SOCIAL REPRESENTATION

A substantial body of research in social representations has demonstrated that structurally a representation is made up of two categories of elements—core and

peripheral—which play different roles in maintaining the representation. The core elements are stable, non-negotiable and immutable (Abric, 1996). They generate the overall meaning of the representation and determine the representation's organisation. The other elements are peripheral and far more sensitive than the core elements to the immediate context. These elements give concrete form to the core elements by serving as an interface between the core elements and the actuality of the world (see Abric, 1993, 1996 for a more comprehensive discussion). We develop this type of analysis further by the inclusion here of a relatively new notion of Moscovici's (1993), that of the canonic themata, because we feel it has important implications for understanding the formation of social knowledge, and longitudinal analyses of mass media communications in general.

Moscovici's (1993) premise is that the origin of a social representation can be linked back to central notions of knowledge, canonic themata, that exist in the collective memory of a society. Although, socially discursive processes within a society construct and create a representation, the shape and direction of that construction is determined by the themata on which the representation is grafted around. Examples are the theme of contagion, the mind/body duality, the binary theme of man/woman, such themata allow a phenomenon to become socially represented, and are the stable cognitive units that constrain how we will understand, and hence exchange, new information (Moscovici, 1993).

Themata are given form in the representation through the anchoring process. They are contextualised in the core of the representation when anchored to a network of meanings. Any one themata may give rise to many diverse representations depending on the contextualisation of the representation in a particular network of meanings, for example the theme of contagion has been shown to underpin social representations of AIDS and of madness (Moscovici, 1993).

Any social representation comes back therefore in expression repeated in the discourses to these exchanges of argument negotiating locally or more universally some themata (Moscovici & Georges 1994, p. 67).

In discourse they take form as oppositional systems (Moscovici, 1993, Moscovici & Vigneaux, 1995). For example, the binary theme of man/woman is seen in the oppositional categories of feminism versus masculinity, housewife versus working woman, strength vs. grace, and so on (Moscovici, 1993).

Consequently, a structural analysis inclusive of both the core elements and the themata has implications for any longitudinal study of a social representation. One of the structural properties of the core of a representation is its invariance to context. If a stable core can be identified across different categories, this would indicate the same representation is operating across those contexts. If, however, different core elements are found across contexts, then there are likely different representations in those contexts. This core invariance is ultimately linked through

the anchoring process to the historical and social epoch of the representation, and while the properties of invariance enable the determination of a representation, it is the identification of the themata which would allow commonalities between representations to be established over time.

In accordance with this, any structural analysis must be descriptive in nature. Mass media communications are systems that operate within historical and social constraints that encompass both the producers and receivers of the media; they are not stimuli received by passive individuals (Rouquette, 1996). Hence any analysis that isolates words from their context would violate this understanding.

A phenomenon whose introduction to the public mind was heralded by the mass media was that of organ transplants. This phenomenon that would have, at the time, both fascinated and threatened social thinking, sparking the genesis of a social representation. The idea of transplanting organs from one human to another was once inconceivable and incredible. Now it is commonplace; an everyday occurrence. For these reasons, an analysis of the development of representations of organ transplants provides an ideal case study of social representations generally. Moreover, if we are to fully understand the representations of today we need to be aware of the representations of yesterday (de Rosa, 1987). And so, the aim of this present study is to trace historically in one particular form of the mass media the development of the social representations of organ transplants.

## Method

Crucial to the theoretical perspective of the study was a media source that had been consistently available to the people of Western Australia since December 1954 (the date of the first successful kidney transplant, a natural starting point in tracing the chronological development of the social representations of organ transplants). This criterion resulted in only one suitable local media source—The West Australian newspaper. This is a daily morning paper that has been in circulation since 1833, and is accessible both in literacy levels and availability to the majority of Western Australians (penetration rate per head of population in 1967 and 1995 was 1:4.58 and 1:6.45 respectively). The newspaper is independently owned by WA Newspapers Ltd., and is generally conservative in its outlook. It could be argued that the newspaper operates under the auspices of diffusion, seeking to minimise social and ideological differences while uniting the majority in an unspecified manner of thinking (see Rouquette, 1996).

Acknowledging that there are limitations in using just one newspaper as a source, we stress that a longitudinal, as opposed to cross-sectional, analysis, was crucial to investigating the genesis and functioning of the social representations of organ transplants. And, while a longitudinal cross-sectional analysis would have been the most comprehensive approach, it was simply not feasible due to

the number of newspaper articles that would have been generated, which itself would have necessitated far more stringent time sampling than that used in the present study. Moreover, the *West Australian* is the only daily local newspaper, the only paper continuously available since 1954, the paper with the highest circulation rate in Western Australia, and the paper that is most accessible in literacy levels to all Western Australians.

We recognise the influence that one particular newspaper's reporting and editorial style may have, and accept these as limitations to the study. We believe any such effect is minimal, though, because there was a wide use of international news agencies (e.g., Reuters) in the reportage of this topic, and because, as Brauer (1998) argues, the reporting of biomedical news is quite homogenised with similar expert mobilisation in the quality and the popular press.

The time-span of the research (41 years from October 1954 to June 1995) was such that only selected years could be searched. Years containing significant events in transplant surgery were selected, and at least two years were selected from each decade. Two years were selected randomly for inclusion, and the most recent year at the time of data collection (1995) was also included. This resulted in the selection of 11 years (Oct-Dec 1954, 1965, 1967, 1968, 1972, 1974, 1981, 1984, 1985, 1994, Jan-June 1995; see Appendix 1 for events that relate to each year).

The search involved the use of microfilmed copies of the *West Australian*. The above years were manually searched for all articles pertaining to organ transplants and organ donation issues. Once identified, these articles were photocopied and transcribed onto disk, and then analysed with the aid of the NUD.IST qualitative software programme (Richards & Richards, 1995).

#### DATA ANALYSES

The aim of the analyses was to find out how the idea of organ transplants has been transmitted to the public by the newspaper over the 41 years in question. One method used to handle large amounts of qualitative data is content analysis. However, according to Lupton (1992), content analysis in its original form [e.g., Berelson, 1952] is primarily a systematic quantitative technique used on qualitative data; items are read for their content and coded into categories for a collation of relative frequencies. When used to analyse media messages, however, it results in an emphasis on manifest content at the expense of the significance of the media messages to the reader or, as Rouquette (1996) discusses, conceptualises the media as stimuli and the reader as passive individual. An alternative is to use the basic principles of content analysis to identify the issues which received the greatest amount of press attention (Lupton, 1992), followed by an inductive analysis (as in Glaser, 1967) of how these issues were portrayed to the reader.

Hence, two separate but interrelated analyses were conducted concurrently. The first was descriptive and was based on the principles of content analysis. Each article was coded in the first instance by year, and then clustered into four time frames on the basis of a frequency count. Each time frame was then coded into descriptive categories such as information given about the transplants, the surgeons and medical fraternity, the recipients, and the donors. These categories were determined prior to analyses. Further categories emerged as the analysis progressed that were specific to each time frame, such as information about brain death, and the use of animal organs. This analysis was concerned with what the reader was being told about organ transplants.

The second analysis was concerned with how this "information" had been portrayed to the reader. This analysis was inductive, the categories emerged as the analysis progressed and, consequently, differed within each time frame. This allowed "the important analysis dimensions to emerge from patterns found in the cases under study without presupposing in advance what the important dimensions will be" (Patton, 1990, p. 44). For example, data coding concerned the focus of each article, how the donor, the recipient, and the surgeon were described, what type of language was used, how the transplant successes and failures were described, what ethical issues were discussed, etc.

These two analyses were then synthesised to construct a "picture" of how organ transplant and donation issues were portrayed in the *West Australian* newspaper from time December 1954 to June 1995.

## Results

The search of the *West Australian* produced 672 articles pertaining to organ transplant and donation issues in the selected years. On the basis of media attention, three distinct periods are noticeable; Dec 1967 to Dec 1968, 1984 & 1985, and 1994 (see Figure 1). Although all articles were analysed, these three time periods form the basis of the results and discussion that follow.

The results of the analyses are presented in two ways. Firstly, as a narrative that describes how information about organ transplants has been conveyed to the public by the *West Australian* newspaper, and secondly, as a discussion of how the social representations of organ transplants originated and evolved from 1967 until 1995. Regarding both, we acknowledge that our focus on these three time periods has led to the exclusion of other events in transplant history, such as the first artificial heart. However, the sheer volume of newspaper articles necessitated some type of selection be made. To ensure years selected were genuinely significant events in transplant history, numerous texts were consulted (e.g., Chapman, 1993; Karpf, 1988; Lamb, 1990; Nelkin, 1987)

The following narrative is accompanied by extracts from the *West Australian*. In the majority of cases, only one extract is given to illustrate each point (for

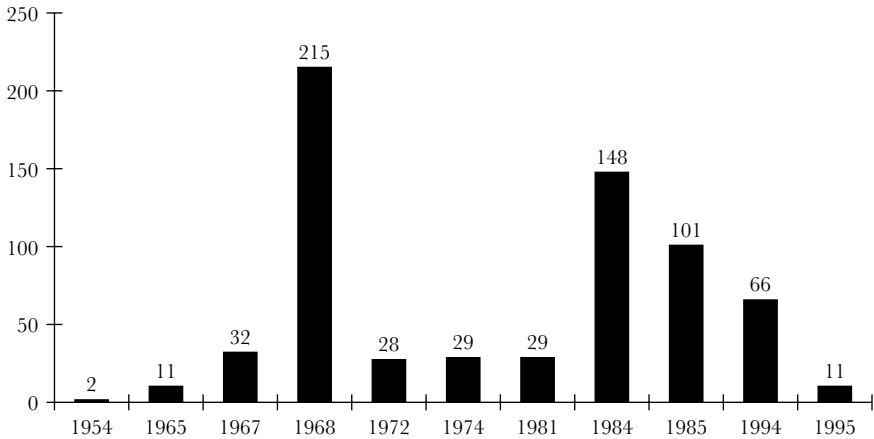


Figure 1. Number of articles pertaining to organ transplant and donation issues in the years sampled.

reasons of space and readability), but the point itself was derived from a synthesis of such extracts.

#### HISTORY OF TRANSPLANTS AS REPORTED BY THE WEST AUSTRALIAN PRE-BARNARD NEWSPAPER

Prior to Barnard's famous heart transplant, there were few reports about organ transplants, and those that were reported were overseas in origin. This was despite the fact that Australia performed its first successful kidney transplant in 1965<sup>1</sup>. The 11 articles that did appear in 1965 reflected the reality of the medical world. For example, on 19 October 1965, the following article was carried:

##### HEART CUT OUT, KEPT BEATING SIX HOURS

Surgeons had removed the heart from a dead man, revived it and kept it alive and beating outside the body for more than six hours, . . . a member of the surgical team, said that by 8 o'clock that morning, the workers were more tired than the heart, and the experiment was terminated.

The lead up to Barnard's transplant on 3 December 1967, was very quiet—prior to Barnard's transplant only four articles were found in 1967 with any reference to transplant surgery. The only hint that an explosion in transplant surgery might be imminent came in a medical report from the First International Transplant conference in Paris:

It now appeared feasible not only to transplant the kidney but . . . the lung, liver, heart and endocrine organs . . . Of these organs the heart appeared to be the least difficult.<sup>2</sup>

## BARNARD'S ERA

The article carried on 4 December 1967 was unassuming in rhetoric. There was no reference to the historic significance of the event other than it was the "world's first human heart transplant"<sup>3</sup>. What followed was a different story.

The paper reported avidly on every imaginable aspect of the Louis Washkansky<sup>4</sup> heart transplant—29 articles were carried in December 1967 alone, amounting to virtually an article every day. The stories that ran gave detailed accounts of Washkansky's progress, reporting particulars such as how many sips of water he drank, his diet, and the first words he spoke after the operation. From the onset, the operation was described as "a miracle". Vicarious associations with God, such as "A miracle has taken place"<sup>5</sup> "I think God would approve of this heart transplant"<sup>6</sup> and "If he lives to a ripe old age his reprieve will have come from human creation itself"<sup>7</sup>, cast a spiritual dimension on the transplant procedure. Barnard was also cast in the same light, and attributed God-like status for having performed this "miracle".

During the period December 1967 to June 1968, Barnard's name was mentioned 109 times in a total of 49 articles, even though he carried out only 2 of the 16 heart transplants in the same period. This veneration of Barnard was reinforced by a variety of reporting styles. Accolades to him<sup>8</sup> were sprinkled through the reporting, biographical information was given about his family and career, his movements were tracked, and his opinions on transplant matters reported. Quotes involving his patients reinforced this "Messianic" image:

Yesterday Mr Washkansky . . . spoke his first words . . .

He said to the surgeon, Professor Chris Barnard, who stood by his bedside: "What kind of operation did I have? You promised me a new heart." "You have a new heart," the surgeon told him.<sup>9</sup>

The lack of clarity over the definition of death also fed the messianic image as Barnard, himself, was reported as having to decide when the donor's heart should be removed.

Professor Christopher Barnard and his brother Marius, a surgeon-member of his team which performed the world's first heart transplant, held widely conflicting views before the historic operation. Their views differed on the exact point when Miss Denise Darvall's heart should be removed. (Barnard's view was followed)<sup>10</sup>.

Barnard gave voice to the messianic image when he explained that the first transplant occurred in the garden of Eden, "Adam was the donor, God the surgeon and He made Eve out of Adam's rib"<sup>11</sup>. Perhaps indicative of this, the transplant surgeon appeared to have an authority or right that was over and above those normally associated with the medical profession,



South African heart surgeon Dr Christian Barnard yesterday said surgeons must have the right to stop treating dying patients whose organs were destined for transplant.<sup>12</sup>

which may have served to legitimise the experimental nature of the early heart transplants. When the following article was reported 31 transplants had already been carried out:

Doctors at the Edinburgh Royal Infirmary yesterday published evidence that the test for death, which has been used in all heart transplants so far, was unreliable.<sup>13</sup>

The procedure also appeared to come before the patient. The adage “the operation was a success but the patient died” (Karpf, 1988) was arguably valid:

A two-month-old Negro girl, the world’s first heart-lung transplant recipient, died yesterday in Houston’s St. Luke’s Hospital without regaining consciousness 14 hours after the operation. The operation was called a medical milestone.<sup>14</sup>

And more subtly, the focus on the transplant surgeon’s prowess emphasised the recipient before the donor, those who could be saved over those whose could not.

Before surgeons can take the desperate measure of giving Dr Blaiberg a second heart a donor has to be found. While crowds of reporters and onlookers gathered last night and today at the hospital, the surgical team waited for an accident victim whose tissues would prove suitable for Dr Blaiberg.<sup>15</sup>

Canadian surgeons admitted yesterday that they had stopped the still beating heart of a traffic accident victim so they could transplant it to another person.<sup>16</sup>

The veneration of the transplant surgeon was also one of national pride. Reports were carried of countries appearing to vie for what was perceived to be the esteemed position of having conducted a heart transplant, paradoxically coupled with warnings about the dangers of doing so.

The British Sunday newspaper, the *Observer*, . . . said there could be nothing but admiration for the tremendous technical virtuosity of the medical team at the National Heart Hospital who had now repeated the feat of their colleagues in South Africa, the US and France. But there is an obvious danger in the general pattern. . . . This is that doctors may become infected by a spirit of international competition—a kind of rivalry in medical athletics. . . . The Sunday Telegraph asked in an editorial: “Are we now engaged in a gruesome kind of medical Olympic Games?”<sup>17</sup>.

In the early days, transplants were perceived as a medical triumph that would benefit mankind<sup>18</sup>. They enabled human beings to defy death, to transcend the diseases that plagued mankind.

## NEW HOPE IS BORN

Heart trouble being the menace it is in modern society, world interest centers on the unprecedented South African achievement in transplant surgery. If all goes well, it will mean the rebirth of a Lithuanian Jew who migrated to South Africa as a child.<sup>19</sup>

They offered hope for mankind in a more symbolic way. The transplanting of a coloured heart into a white man was seen to be a reminder that colour was only skin deep, racial integration could occur<sup>20</sup>.

Out of a family's tragedy has come new hope for mankind in circumstances of high drama and great expectancy. As surgeons pioneer new frontiers they are reminding us that God's creatures are brothers and sisters under the skin and that, in the long run, racial barriers and unconquered disease may not be impregnable.<sup>21</sup>

## THE HEART OF IT

In South Africa blood is not transfused from non-white to the white races, yet Dr Blaiberg is a white man who owes his continuance among us to the heart of a coloured man—and who is to say the heart is not fashioned by dominant black genes from one of its “native” progenitors? . . . And while theologians grapple with the distinction between Dr Blaiberg and Mr Haupt, whose heart he is using, Mr Vorster has decisions of his own to take. If a white man can use a coloured man's heart after death, can he sit on the same park bench with him while both are living?<sup>22</sup>

Despite all of this, the fact was that many patients were dying soon after the transplant had been conducted. For example, by 22 January 1968, 5 transplants had been performed and 4 of these patients were dead, by 17 June 1968, 21 transplants had been performed and 16 patients were dead<sup>23</sup>.

While transplant patients dying was not new, the manner in which these deaths were reported changed. In the early days (December 1967 to approximately June 1968) the deaths and the accompanying criticism of the transplant were played down by the reporting style. This was done either by reiterating the good progress that an “alive” transplant patient was making (a justification for the transplant death), or by distancing the death away from the actual transplant itself by stating that the patient would have died anyway<sup>24</sup>. As 1968 progressed, so did the number of transplants and the number of deaths. Even as early as June 1968, articles began appearing in the paper seriously questioning the transplant operation.

“Surely the time has come to call a halt to this procession of deaths,” . . . “There can be no justification for an operation that carried such a devastatingly high mortality rate and the performance of which is more or less equivalent to a death sentence.”<sup>25</sup>

With the ever increasing number of deaths, and the lack of clarity over ethical guidelines, the integrity of the transplant surgeon was also questioned.

## TRANSPLANT SURGEONS “GANG OF VULTURES”

Dr Geoffrey Spencer, head of the intensive care unit at London’s St Thomas Hospital, said yesterday that transplant surgeons were a gang of vultures. “They hang around the body waiting to snatch out organs, starting with the cornea and ranging to the heart,” he said.<sup>26</sup>

Barnard himself was criticised for his notoriety and for allegedly removing the heart of an African woman for transplant without the next-of-kin’s permission.

Some doctors feel that heart-transplant surgeon Professor Christian Barnard has indulged too eagerly in the cult of his own personality . . . He made news again a few days ago when it was revealed that he had removed the heart of an African woman without the permission of relatives.<sup>27</sup>

The tenor of these reports continued, yet the number of transplants increased, as did the attendant mortality figures. This resulted in a contradiction of reporting styles. On the one hand, articles would detail the latest transplant as a success;

Four people—all recipients in a multiple organ transplant early on Saturday morning at the Texas Heart Institute—were reported to be doing well this afternoon by a spokesman for St. Luke’s hospital<sup>28</sup>.

and, on the other, carry reports questioning the morality of the transplant practice.

Jeering demonstrators greeted Professor Christian Barnard the South African heart transplant pioneer, when he arrived to give a lecture in Dublin last night . . . Other placards read “Vulture Barnard” and “What are you drinking tonight, Barnard?—blood?”<sup>29</sup>

Two Swedish accident victims whose kidneys were removed after death for transplantation might have been saved, according to a Swedish doctor.<sup>30</sup>

Towards the end of 1968, the justifications for the early transplant deaths were now no longer apparent in the reporting. Criticisms were coming from all sectors of society, including the medical profession itself.

## TRANSPLANTS CRITICISED

An internationally famous cardiologist has suggested that heart transplants are the work of “plumber surgeons” and that research into the prevention of vascular disease is much more important.<sup>31</sup>

The mechanistic view of the body, long associated with the medical profession, underpinned much of the reporting in these early days. Descriptions of transplants often reflected the image of the body as a machine, and consequently organ transplants as spare part surgery. For example, from late 1967 until mid 1968, “spare parts” was the most frequently reported transplant phrase, and was manifest in expressions such as “Global spare parts service”<sup>32</sup>, “If spare parts are to be handed out like dentures”<sup>33</sup>, “Spare parts operations”<sup>34</sup>. This mechanistic

conceptualisation could also be seen in expressions such as replacement heart, second-hand hearts and heart swaps.

#### ORGAN TRANSPLANTS IN THE LAY WORLD

The next wave of reporting pertaining to organ transplants<sup>35</sup> coincided with Fiona Coote's heart transplant in April 1984. Prior to this, the reporting in 1972, 1974 and 1981 had been minimal even though two heart transplants had been performed in Australia during this period.

Fiona Coote was admitted to the Royal North Shore hospital on Friday 31 March 1984, and by the following Thursday had become the focus of a new wave of reporting about organ transplants. The flood of articles that followed was similar in volume to that of the first transplant in 1967, which is surprising as this was Australia's fifth heart transplant. The first three transplants in 1968 and 1974 were unsuccessful (as were most heart transplants at that time), leading to a respite in heart transplant surgery. In February 1984, Australia resumed its heart transplant programme and conducted its fourth transplant on Neville Apthorpe, a 34 year old shearer from New South Wales. Very few articles were carried about Apthorpe's transplant, but reports that were carried were similar in their unembellished style to those reports at the end of 1968 when a climate of hostility towards transplants prevailed:

##### HEART MAN IMPROVING

Heart transplant recipient and former shearer Neville Apthorpe (39) is in a stable condition and continuing to show improvement.<sup>36</sup>

This was in stark contrast to the unbridled hope conveyed in the reporting of Fiona Coote's transplant just two months later:

##### DROWSY FIONA WAKES TO A NEW BEAT

The new heart of schoolgirl Fiona Coote beat perfectly yesterday as she awoke after making medical history on the weekend. The first thing Australia's youngest heart transplant recipient saw when she opened her eyes were her parents standing beside her bed.<sup>37</sup>

One possible reason for the difference was that Fiona was a 14 year old schoolgirl. While this made her the youngest heart transplant patient in Australia, it may have been what the transplant offered children, and the families of these "sick" children, not the medical significance of her age, that led to the difference in reporting style. And, Fiona's transplant was just the first of many transplants involving children. For example in 1984, 17 transplants involving children<sup>38</sup>, some as young as ten days, were reported by the paper, in comparison to 8 involving adults. (From December 1967 to December 1968, 6 transplants involving children were reported in the paper<sup>39</sup>).

Fiona's transplant became the vehicle for the transmission of medical information about heart transplants. In contrast to the early years, medically "dry" information about the technicalities of a transplant was relayed to the public in non-medical language, or an explanation given if medical language was used.

She [Fiona] described in detail the results of the operation which saved her life eight days ago . . . "I've got all these stitches from my stomach to my neck, and I've got band-aids all over. I've got all these stitches around my belly button," she said. "I'm going to have an operation tomorrow, a biopsy, they're taking a little piece of my heart . . ." <sup>40</sup>

The reporting of ethical and legal guidelines for the determination of brain death and organ removal also followed a similar pattern.

A suitable donor heart has not been found, though there has been an overwhelming response to her [Fiona's] plight . . . Only the heart of a person who is officially brain-dead can be transplanted. The Human Tissues Transplant Act lays down strict guidelines for the diagnosis of brain death. Death must be declared by two medical practitioners, one of whom must be a specialist. <sup>41</sup>

Another difference in the reporting with that of 1967/68 was that now the surgeon was barely afforded a mention in the reporting. Dr. Chang was the leading transplant surgeon in Fiona Coote's heart transplant, yet in the 31 articles about her transplant, only one article made any reference to Dr. Chang, and this was unassuming in character:

Dr. Victor Chang, the head of the St. Vincent's transplant team, said the compatibility of the donor's heart to Fiona's tissue was excellent. Fiona's own heart was damaged by cardiomyopathy—a disease which weakens the heart muscles. Dr. Chang said the cause of this was not yet known to medical science. <sup>42</sup>

While this difference may be due to numerous other factors, such as the surgeon's own attitude towards publicity, the type of organ being transplanted, hospital policy and so forth, the role of the transplant surgeon was minimised in the reporting relative to the recipient and the donor.

#### HEART BOY IS UP, TALKING

A 4-1/2-year-old boy, believed to be the youngest recipient of a heart transplant, was up and talking today, less than a day after his six-hour operation in which a magnifying glass was used by surgeons to enable them to see his small heart. . . . The donor's name was withheld, but a spokesman said that the hospital and the boy's parents, James and Patricia Lovette, of Denver, wanted to publicise the operation to encourage more donors. "We feel we're in the presence of a miracle and the donor family is part of that miracle," the boy's mother said. <sup>43</sup>

The attribution of the transplant's success now appeared to be centred on the recipient, not the prowess of the transplant surgeon, in particular the success

of the transplants was often attributed to the personality characteristics of the recipient.

Liver-transplant baby Paul McKee has survived his third major operation in a Los Angeles hospital. The Rev. Jeff Ramsay said last night that Paul's mother said doctors had told her: "We would have lost any other baby. We don't know why, but he just continues to fight on."<sup>44</sup>

The reporting about transplants also focused on the donation of the organs from one person to another, and often, from child to child. Donated organs were often referred to as "life", and found in the same sentence as a derivation of the infinitive "to give". This engendered an image of a donated organ as a "gift of life". Similarly, the word "chance" was also used as in phrases such as "second chance", "second chance at life" "chance at life".

An Easter gift has given new hope of a healthy life to two patients at Perth's Gairdner Hospital. . . . The gift—kidneys from an anonymous donor—were used for two transplant operations. Mrs Leigh says she is grateful to the donor and the donor's relatives who gave consent for the kidneys to be removed. "I know how hard a decision it would be for the family of the donor," she said. Her husband David said that the Leigh family would never know the identity of the donor but that person's gift "will give us all a new life."<sup>45</sup>

Interestingly enough, the phrase "spare parts" or "body parts" was only found in 3 articles in this time period, but possibly of more relevance was the content and/or origin of these articles. Two had their origins in the medical world, while the other concerned a family discovery of their relative's body organs in a bag supposed to contain personal effects.

#### SPARES' SURGERY CLOSER—PIONEER

Spare-part surgery is moving closer to reality, according to a pioneer kidney-transplant surgeon, Professor Sir Michael Woodruff. Replacement surgery covers the transplanting of organs and limbs from dead people to those in need of spare parts<sup>46</sup>.

On 29 October 1984, transplant history was again made with the Baby Fae transplant. Two day old Baby Fae was given the heart of a baboon at the Loma Linda University medical centre in Los Angeles. The transplant sparked controversy in and outside medical circles around the world for its use of animal organs and its unashamedly experimental nature. While those who performed the transplant described it as "one of the biggest, overdue advances in our field"<sup>47</sup>, the criticism, for example from Australia, was fierce in its condemnation.

The controversial transplant of a baboon's heart into a baby girl in the United States would not be accepted in Australia on medical and ethical grounds, according to leading surgeons and academics. . . . A senior doctor at St. Vincent's Hospital in Sydney, said [the transplant was] "experimental in the extreme" . . . the operation required major surgery on a baby on the brink of death and he was opposed to the exploitation of animals for humans<sup>48</sup>.

A report was also carried that gave another side to this transplant. It concerned the mother, and her poignant tale of wanting to save her child at any cost. This report, which was extremely detailed and long, appeared to vindicate the experimental nature of the transplant<sup>49</sup>.

Alongside the obvious progress taking place in transplant procedures were concerns about organ removal. The genesis of these concerns may have been in late 1968 when a hostile climate towards transplants prevailed. Now it appeared to be a generic mistrust of the medical profession.

#### RELICS JAR FAMILY

A hospital in Jackson, Michigan, will pay family survivors \$9500 for the anguish they suffered when they found organs of their dead relative included in bags supposed to contain only his personal effects.<sup>50</sup>

Some British mortuary attendants sold pituitary glands from corpses for medical research, a court was told yesterday.<sup>51</sup>

#### DOCTOR RUNS OFF WITH KIDNEYS

A senior surgeon at one of Israel's major hospitals stole two kidneys in a refrigerated container to prevent another doctor from transplanting them into patients.<sup>52</sup>

The notion that "a transplanted organ was more than an organ transplanted" also began to surface in various articles on transplants. For example, an article cited a "Psychology Today" story in which a psychologist maintained that donating an organ may transmit characteristics of the donor over and above the physical properties of the transplanted organ:

Adults who undergo heart or kidney transplants often experience personality changes because they believe that the donor is living inside them, a psychiatrist contends. Dr Muslin explained that the transplanted organ often registered in their minds as being both an anatomic part and a symbol of the donor. Thus, they may believe they have acquired traits—either real or fantasised—such as artistic talent, aggressiveness or generosity, he says.<sup>53</sup>

#### CONFLICTING MESSAGES

The reporting style of the final cluster of newspaper articles (June to December 1985, 1994 and January to June 1995)<sup>54</sup>, was similar to those of 1984/1985. The main difference between the two periods was that now two disparate issues, organ donation and organ removal appeared to receive equal coverage by the paper.

Most of the articles in the recent period were Australian in origin. The reporting focused on both the recipient and the donor, and minimised the relative prowess of the transplant surgeon. Many of the articles involved the child as the recipient

and, as in the previous period, the success of the transplant was often attributed to the child's own personality characteristics.

Many of the reports, however, were concerned with issues surrounding the donation of organs. Children who had undergone transplants were like any other child; post-operatively, transplant recipients were "normal".

Mrs Bird said that before the transplant Sam would sit quietly and watch others play. Now he was up to mischief, digging up the garden while playing with his trucks.<sup>55</sup>

The donor's family was important in the donation process.

After two liver transplants, a period paralysed on drugs and 40 days in intensive care at the Royal Children's Hospital, the 22-month-old tot from Gingin, north of Perth, has finally started to laugh and play again. Mrs Stewart said: "We are eternally grateful to the humanity of the donor's family."<sup>56</sup>

Reports often contained information about the process of donation, such as statistics and the procedures involved. And lastly, reports conveyed the desperation of parents whose child needed a donated organ.

The Royal Children's Hospital has put out an urgent nationwide call to every intensive care unit in Australia for a heart for little Timothy Congdon of Perth . . . "The question is are we going to get a donor?" said Mr Congdon. His wife said: "It is really unfortunate a person has to lose a child but instead of losing two they can save one—they have the power to give the gift of life and save a small child."<sup>57</sup>

However, at odds with the positive ambience created by these articles toward donation were articles that appeared to convey an underlying mistrust towards the medical profession. Mortuary attendants were reported to have received payments for the removal of pituitary glands whose use in infertility treatments led to Creutzfeldt-Jacob's disease.

Mortuary attendants in WA were paid for almost 20 years to collect clandestinely pituitary glands from the skulls of corpses undergoing autopsies. The payments started at 20 cents per gland in the 1960s and later rose to 50 cents to ensure the supplies needed to develop a human growth hormone and an infertility treatment.<sup>58</sup>

Brains were removed without consent from autopsy patients.

Outrage at disclosures that doctors have been removing brains for examination from every corpse passing through Sydney's two mortuaries . . . After examination, the dissected brains were packed in steel drums with other human tissue and contaminated waste by a private contracting company which sent them to an industrial incinerator in Queensland for disposal. About 3500 bodies have been affected since 1990, although relatives were not told of the practice.<sup>59</sup>



And the possibility that “Australian” organs could be sold to overseas patients was alluded to.

Claims that organ donations were being sold to overseas patients in preference to Australian recipients were rejected yesterday as irresponsible and completely unfounded by an organ transplant organisation. His comments followed media reports last week that some Australian organs were being sold to overseas patients.<sup>60</sup>

The idea that transplants were a medical luxury was also mooted, as was the recurring theme that transplanting an organ was more than an organ transplanted.

The Ribbens brothers now share a boat, a pair of kidneys and a taste for Guinness. It is all because of a transplant operation a month ago which resulted in 34-year-old Rob Ribbens, of Kingsley, giving 33-year-old Dave Ribbens, of Mt Hawthorn, a new lease of life. In that time, Dave Ribbens realised he had suddenly developed his brother Rob’s love for Guinness.<sup>61</sup>

## DISCUSSION

The discussion section presents an interpretation of the results using the parameters of social representations theory as a framework, in particular the structural analysis of the core and peripheral elements in the representations and the role of the themata.

### *Structural analysis of core and peripheral elements*

#### *Core Elements*

*This analysis was directed by the attributes generally accepted as being characteristic of the core elements in a representation, such as stability, non-negotiability and immutability (Abric, 1993). This investigation sought to establish what underlay the main themes in the reporting—was there a belief, idea, or value that could be identified as underpinning the main themes in the reporting? An analysis across themes followed investigating the stability of this belief—was it present with any consistency (functional not numeric, consensus was used here (Wagner, 1994)—and its “negotiability”. Flament’s (1994) principle of qualitative necessity was also used here which involves calling into question the necessity of the “hypothesised” element to the representation as a whole.*

#### *Peripheral Elements*

*These are context specific, reflecting the social and historical mood of the time. They give a concrete form to the core elements. As regards the newspaper articles, peripheral elements were identified as those beliefs, ideas, values that reflected the core elements but were indicative of the social conditions or mood at the time.*

*The genesis: anchoring, objectification and the core elements.* The first heart transplant on 3 December 1967, sparked the genesis of the social representation of organ transplants. Prior to this, reporting about transplants of any sort was virtually

non-existent, and one can assume from this that public understanding was too. There can be little doubt that the idea of a heart transplant was unfamiliar to most lay people. More than unfamiliar, when the news broke that a heart transplant had actually been performed, it must have been at the same time both frightening and captivating. This captivation was spurred by Barnard, who was as much the focus as the medical technique itself.

This symbiosis between Barnard and the medical procedure of transplantation anchored the idea of a heart transplant into a network of meanings associated with doctors and the medical profession. Anchoring integrates the incomprehensible into a network of meanings marked by social values. Doctors have long held esteemed positions in society. They are authority figures who are frequently perceived to be benevolent, successful, and trustworthy (Lupton, 1991). Without doubt, a surgeon in the late nineteen-sixties would have fit a similar profile, providing the security through which the early heart transplants could begin to be understood. Barnard helped familiarise this unfamiliar world.

At the core of the representation was the unshakeable faith in the prowess of the transplant surgeon who was perceived to be an alchemist<sup>62</sup>, a miracle worker beyond repute. Possibly as a function of this, the transplant was oriented towards the recipient and life—life that the transplant surgeon gave the recipient. Death and the donor were simply necessary by-products of the procedure. The belief that transplant surgeons were alchemists elevated them above other medical professionals, and permeated reports where the success of the transplant was attributed nationally. It also permeated reports where the transplant surgeon was bestowed with rights and authority over and above those normally associated with the medical profession, the latter sanctioning the often blatant experimental nature of the early transplants, giving precedence to the procedure over the patient. Similarly, the emphasis on “life” for the recipient could be seen in reports where transplants were described as benefiting humankind, as a medical triumph that would enable human beings to defy death. And, in a more subtle form, as hope, in that the transplant symbolised humankind’s ability to transcend the diseases that plagued the world, as well as social diseases such as apartheid.

In 1967 and early 1968, the transplant procedure was first and foremost a medical technique. Barnard was a doctor, transplants were carried out in hospitals, and much of the early discourse presented by the paper was medical in origin. Integral to this was a mechanistic view of the body, the image of the body as a machine. This became the focal point in understanding the procedure of organ transplantation. Body parts could be removed and replaced. The fact that the organ at the genesis of the representation was a heart must have aided this iconisation. Hearts have long been objectified, and hence frequently decontextualised, in many ways—love and life, are two such examples. As the exemplar of the transplant technique, the heart allowed the visualisation of organ removal to occur without the accompanying realism of an actual transplant. Organ transplants became understood as “spare part surgery”. Crucial to

understanding this initial representation was how the process of objectification negated the role of donor in the transplant process.

*Transformation.* Social representations are dynamic, continually evolving and transforming as they circulate and diffuse through society. Transformation occurs in a representation when other persistent beliefs about the social object contradict the core elements, creating a situation where the representation must either progressively transform to accommodate this contradiction, or become socially invalid (Guimelli 1993). In the present study, the initial representation was centred around the messianic image of the transplant surgeon and the new “life” that the transplant surgeon could give. This created the expectation that transplant recipients would live—which was not to be the case. One hundred and seven transplant recipients had died by the end of 1968.

Initially justifications, such as reiterating the progress an “alive” transplant patient was making, allowed the potential of the procedure to overshadow transplant deaths. However, by the end of 1968 the number of transplant deaths, in conjunction with the fierce criticisms of the transplant surgeon and procedure, suggest that the initial representation was not compatible with current thinking about transplantation. While time sampling did not allow any progressive changes to be followed, the next wave of articles in 1984 certainly appeared to be underpinned by a different understanding.

*A new understanding: anchoring, objectification and core elements.* In 1984, organ transplants were still a medical technique, but the reporting of them indicated that they were no longer the exclusive domain of the medical world. The transplant was now associated with lay people, in a network of meanings and, significantly, values about families and relationships. The representation was again centred around life, but now death was also an integral part of how transplants were being understood. An organ transplant involved both a donor and a recipient, and was now understood as a “gift of life”—a gift from one human being to another. New life for the recipient meant that somebody also died, and this was acknowledged. Now it was the donor who gave “life”, not the transplant surgeon. Transplants had entered the domain of the ordinary person. This could be seen in reports that decried transplants that appeared to be purely “experimental”, and in reports where the success of the transplant procedure was attributed to the characteristics of the patient (often a child) as opposed, as it had been in the late sixties, to the prowess of the surgeon.

Any discussion about the transformation of a representation is automatically inclusive of broader societal changes. Social representations do not exist independently of the social group, culture or society of which they are both a process and a product. And while, through the process of description, a social representations may inadvertently be de-contextualised, its socially constructive nature prescribes an indelible linkage to the wider context, including ‘the larger ideological

or cultural thought systems, to a state of scientific knowledges, as well as to the social condition (Jodelet, 1989, p. 35).

There are numerous plausible explanations as to why the representation in the eighties was different from that in the sixties. It may be that Fiona Coote's transplant changed the focus of the transplant from the role of the surgeon to that of the patient. By centring on the patient as a child, the representation embedded the idea of transplants into a network of meanings already established about families and relationships. This idea is given some support by the fact that Neville Anthrope's transplant, which was conducted in February of the same year, was reported quite differently, indicative more of how transplants were reported in the late sixties. This would suggest that the change in representation occurred as a function of how children and adults were perceived in the broader societal context, especially in relation to sickness and imminent death. In conjunction with this, or as a factor that stands alone, the change may be a function of time and may reflect more generic changes in social thinking in how medicine was understood. The years between the sixties and the eighties have witnessed dramatic advancements in science and medicine (see Brauer, 1998) which must have permeated social thinking about organ transplantation.

The final cluster of articles (1994 and January to June 1995) saw little change in how transplants were being represented except for one noticeable difference. Permeating many of the articles in this period was an underlying mistrust expressed towards the medical profession. While this had been alluded to in the mid-eighties, it was now marked because of the contrast it drew with the emphasis placed on the donation process.

*Themata.* Themata are contextualised in the core of the representation by the anchoring process and manifest in discourse as oppositional systems (Abric, 1996; Moscovici & Georges, 1994). Hence the reverse process of de-contextualising the core is theorised to identify the themata (Moscovici, 1993). When the cores are de-contextualised a dichotomy common to both representations emerges, the relationship of life to death, taking different forms in both representations, but in essence the same dichotomy. In the initial representation this dichotomy was contextualised, through the anchoring process, by the medical world, and as a consequence life took precedence over death. The transplant was defined in terms of life, the recipient, and the surgeon who gave the recipient life. Within this context, death and the donor were minimised. In the representation of the eighties the dichotomy took a different form, contextualised by the anchor of families and relationships, life and death became equal in the transplant process. Somebody had to die to enable someone else to have the chance to live. And life was a gift from the donor.

While we acknowledge that our analysis here is hypothetical, it raises an interesting possibility about the social representation of organ transplants. Namely, that what appears to be separate, dialectically opposed, representations may be

one representation that, through the processes of time, has formed around a conflicting core.

Two time periods generated the majority of newspaper articles; 1967–1968 and 1984–1985, and corresponding with these two periods are the two “representations” described. The impetus for the genesis and formation of a social representation is public interest in the phenomenon, otherwise the dynamics (the debate, argumentation and discussion) that spark its formation would not occur. However, it does not necessarily follow that the “second” representation occurred with the second wave of reporting, or even that it is a “second” representation. What appears to be the genesis of a second representation may also be an artifact of the time sampling; the “second” representation, instead, progressively forming over a period of time, not replacing the initial understanding but developing with it. Fiona Coote’s transplant may have highlighted one aspect of a representation that was particularly pertinent to children involved in the transplant process. What this suggests is that the initial understandings that formed about organ transplants were never completely dispelled; they were instead modified with time. While the messianic image of the transplant surgeon was invalid in the nineties, the idea of an organ transplant as spare part surgery persisted. This permeated reports that projected a mistrust of the medical profession, and in the mechanistic descriptions of organ removal. However as time progressed, and organ transplants entered the domain of the lay person, organ transplants also became understood as a gift of life. But this understanding did not replace the former, it co-existed with it.

This raises two possibilities: that a representation can exist that is not coherent or cohesive in the sense that a unitary representation is thought to be (see Abric, 1993); and that aspects of a representation are solicited according to context. In their discussion of consensus and representational structure, Rose et al. (1995) dispel the idea of monolithic and homogenous representations, and suggest instead the idea of a representational field which allows “contradiction, fragmentation, negotiation and debate”, and which is characterised by “incoherence, tension and ambivalence” but through which presides a *consensual reality*<sup>63</sup>. This consensual reality allows a dialectical understanding to co-exist because it does not dictate one hundred percent agreement, rather just an awareness of the antithese understanding. This may well be the case in the social representation of organ transplants.

## CONCLUSION

Within the context of the representational discourse sampled, 672 newspaper articles sampled from the years 1954 to 1995, the social representation of organ donation and transplantation emerges as a representational field organised around a dialectically opposed conflicting core. One aspect of the representation field

is medically orientated. Organised around an iconic image of spare part surgery it emphasises the recipient at the expense of the donor. The other aspect of the representational field is situated in the lay world, and organised around the image of organ transplantation as a “gift of life”. Here both the recipient and the donor are emphasised in the transplant process. However, these dialectically opposed understandings appear to originate from one common theme, the dichotomous relationship between life and death, whose relationship is given form as a consequence, as in the representational field, of its contextualisation in the social world.

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## NOTES

<sup>1</sup> This was on 21 February 1965 at the Queen Elizabeth Hospital, Adelaide. A second kidney transplant was performed in Sydney at the Prince Henry hospital in August 1965. The first recipient lived for ten years, the second recipient was still alive in 1993 (Chapman, 1993).

<sup>2</sup> p. 4, 18.7.67, the *West Australian* newspaper. Hereafter, only the date and, where possible, the page number will be given.

<sup>3</sup> p. 1, 4.12.67

<sup>4</sup> 5.12.67. The recipient was Mr. Louis Washkansky and the donor Miss Denise Devall.

<sup>5</sup> p. 1, 6.12.67

<sup>6</sup> p. 2, 6.12.67

<sup>7</sup> p. 9, 5.12.67

<sup>8</sup> For example: “Most tremendous achievement by Dr. Barnard”, “the exciting feats of Barnard”, “the great tide of pride in South African achievement that Professor Barnard provided”

<sup>9</sup> 6.12.67

<sup>10</sup> 6.12.67

<sup>11</sup> 11.12.68

<sup>12</sup> 7.3.68

<sup>13</sup> 6.8.68

<sup>14</sup> 18.9.68

<sup>15</sup> 8.7.68

<sup>16</sup> 2.10.68

<sup>17</sup> 7.4.68

<sup>18</sup> By 1997 this term would be replaced by humankind, but articles in 1967 used this term, which is why it is used here, and elsewhere in this article where we refer to articles using this term.

<sup>19</sup> 5.12.67

- <sup>20</sup> This was South Africa during the apartheid years.
- <sup>21</sup> 5.12.67
- <sup>22</sup> 9.1.68
- <sup>23</sup> Of these 21 transplants, 16 were heart transplants, and the remainder were lung and liver.
- <sup>24</sup> 8.12.67
- <sup>25</sup> 20.6.68
- <sup>26</sup> 12.9.68
- <sup>27</sup> 21.9.68
- <sup>28</sup> 10.11.68
- <sup>29</sup> 13.11.68
- <sup>30</sup> 23.9.68
- <sup>31</sup> 20.11.68
- <sup>32</sup> 6.12.67
- <sup>33</sup> 15.12.67
- <sup>34</sup> 23.12.67
- <sup>35</sup> This does not include mechanical heart transplants; according to Nelkin (1987) there was a great deal of American media coverage in relation to the first mechanical heart pump used in Barney Clark.
- <sup>36</sup> 27.2.84
- <sup>37</sup> 10.4.84
- <sup>38</sup> Some of these were prospective patients and died before a suitable donor was found. Most of these transplants involved the heart or liver.
- <sup>39</sup> These involved child recipients; child referring to persons 16 years and younger, see 8.12.67, 28.5.68, 24.7.68, 17.9.68, 27.8.68, 11.11.68. The 2 transplants performed 11.11.68 were bone marrow.
- <sup>40</sup> 17.4.84
- <sup>41</sup> 7.4.84
- <sup>42</sup> 9.4.84
- <sup>43</sup> 12.6.84
- <sup>44</sup> 16.7.84
- <sup>45</sup> 5.4.85
- <sup>46</sup> 2.9.85
- <sup>47</sup> Dr. Sandra Nehlsen-Cannarella, an immunologist on the operating team, 29.10.84.
- <sup>48</sup> 2.11.84
- <sup>49</sup> This was detailed and long by the newspaper's standards, 1043 words to be exact.
- <sup>50</sup> 8.2.84
- <sup>51</sup> 21.1.84
- <sup>52</sup> 14.12.84
- <sup>53</sup> 3.10.84
- <sup>54</sup> Which was when the data collection ended due to the microfilm only being available to this date.
- <sup>55</sup> 26.1.94
- <sup>56</sup> 12.2.94
- <sup>57</sup> 23.4.94
- <sup>58</sup> 2.7.94
- <sup>59</sup> 6.8.94
- <sup>60</sup> 20.3.95
- <sup>61</sup> 20.7.94
- <sup>62</sup> Karpf (1988) used this term
- <sup>63</sup> Our underline

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## APPENDIX 1

### 1954 (Oct-Dec)

December 23 1954, the first successful kidney transplant between identical twins. This has been identified as heralding the “modern era of transplantation”

1965: First and second successful kidney transplants performed in Australia

1967: First successful heart transplant performed in South Africa

1968: 107 heart transplants performed by 64 teams in 24 countries (Lamb, 1990)

1972: Random selection

1974: Australia’s 3rd heart transplant

1981: First successful heart-lung transplant at Stanford University in California

1984: The resumption of Australia’s transplant programme after a respite of 10 years, and Australia’s 4th heart transplant

1985: Continuation of Australia’s renewed transplant programme

1994: Random selection

### 1995: (Jan-June)

At the time of data collection, June 1995 was the last available microfilm due to the processing time needed by libraries to transpose the hard copy of the newspaper onto microfilm