An analysis of factors which influence cadaveric renal organ donation

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GLOSSARY AND ABBREVIATIONS

ACCORD :The Australian Coordinating Committee for Organ Registries and Donation, established in 1990 to promote public awareness of organ donation.

ADAPT : Australasian Donor Awareness Program for Transplantation, established to improve donor awareness among health professionals.

Brain death : Total and irreversible loss of all brain function.

Cadaveric organ donation : The donation of organs by an individual certified as brain dead.

CAPD : Continuous ambulatory peritoneal dialysis. Form of renal replacement therapy, which requires surgical insertion of a long term peritoneal catheter. The peritoneum acts as the kidney filter. Two litre exchanges of fluid are instilled and drained out of the peritoneum four times daily, seven days a week. The procedure is performed at home.

End Stage Renal Disease (ESRD) : Total and irreversible loss of kidney function which necessitates renal replacement therapy.

Haemodialysis : Form of renal replacement therapy, necessitating surgical creation of a permanent venous access. An artificial dialyser performs the basic functions of the kidney. Haemodialysis is necessary three times a week, for three to five hour sessions. Haemodialysis is based in hospitals, community dialysis centres, and less commonly, at home.

Opting in : The Australian system of cadaveric organ donation which necessitates permission for organ donation from the next of kin. The potential donor's wishes are not necessarily followed.

Opting out : A system for cadaveric organ donation requiring that an individual registers the intent not to donate any or all organs.

Renal transplantation : Surgical implantation of a kidney from one person into the body of a person with ESRD.

Xenograft : Transplantation of organs between different species, for example pig and human, or monkey and human.

ABSTRACT

Transplantation is dependent on organ donation! The major source of organs in Australia is from cadavers.

Cadaveric organ donation of kidneys has one potential outcome - renal transplantation for someone who needs that organ. In Australia, the lack of cadaveric organ donors has resulted in a need to foster awareness at both public and health professional levels, to promote cadaveric organ donation. Lack of health resources, individual, family and social difficulties, and spiralling health costs are all concerns related to the low organ donation rate. The trend of increasing expenditure for dialysis therapies will continue if the organ donor rate does not improve. Strategies set in place to date include the development of the Australian Coordinating Committee on Organ Registries and Donation (ACCORD), and the Australasian Donor Awareness Programme for Transplantation (ADAPT) to improve public and health professional awareness of organ donation.

The Australasian Transplant Co-ordinators Association (ATCA) and the Australian Health Minister's Advisory Council (AHMAC) have recognised the magnitude of the dilemma, and intend to promote organ donation and transplantation and the positive outcomes. This project explores the factors identified within a group of articles in relation to organ donation and transplantation. Textual discourse of the articles highlights the power of medical discourse, and the lack of publication by nurses.

Recommendations include organ donation and transplantation education for public and health professionals; the importance of not automatically excluding marginal donors without due consideration; and that the rights of the donor should be acknowledged. It is suggested that further transplant coordinator positions be established to facilitate and promote organ donation, and to reduce the number of missed potential donors. Finally, it is recommended that nurses utilise opportunities to publish and present papers, so they can share their knowledge, to achieve both personal and professional advancements.

I certify that this project does not incorporate without acknowledgment any material previously submitted for a degree or diploma in any university, and that to the best of my knowledge and belief it does not contain any material previously published or written by another person except where due reference is made in the text.

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Introduction

This project focuses on factors influencing cadaveric renal transplantation, which is one renal replacement therapy option for a person with end stage renal disease. End stage renal disease (ESRD) is the term given when a person's kidneys no longer function at a viable level, and if not augmented by some form of renal replacement therapy, the person dies. ESRD is non-discriminatory. It can be hereditary, pathological, trauma related or of unknown cause. Glomerulonephritis, analgesic nephropathy, polycystic kidney disease, reflux nephropathy, hypertension and diabetic nephropathy are the most common diseases which result in ESRD requiring renal replacement therapy (Disney,1994).

Human kidneys are viable with as little as one third of a functioning kidney. This means that a kidney recipient needs only one transplanted kidney to maintain sufficient renal function to discontinue other forms of renal treatment. In Australia, renal transplantation results from the donation of a kidney primarily from a cadaveric organ donor, and less commonly from a living related donor; the donation of living unrelated kidneys is rare (Tiller,1990; Disney,1994). Cadaveric renal transplantations accounted for over 8500 renal transplants performed to June 1995 across Australia (ACCORD,1995b).

Transplantation is not the sole method of renal replacement therapy (Allen and Chapman,1994; Stewart, Spencer and Appel,1995). For the person with ESRD, there are a number of alternatives, the most prevalent in Australia being haemodialysis and continuous ambulatory peritoneal dialysis (CAPD). Haemodialysis is a three to five hour procedure carried out three times a week, and which requires the surgical creation of a permanent venous access, and connection to a haemodialysis machine. CAPD requires the surgical insertion of a long term peritoneal catheter prior to two litre exchanges of fluid being instilled into, then drained from the peritoneum four times a day. If renal replacement therapy is not instigated for a person with ESRD, death results. The renal replacement therapy option chosen takes into consideration factors including lifestyle changes, the individual's age, family support, living arrangements, availability of facilities, travelling distance from health services, and other medical conditions, amongst others (Disney,1994; Chugh and Jha,1995; Stewart et al,1995).

Identification and treatment of people with ESRD continues to rise as diagnostic techniques are improved, along with a gradual decline in the number of cadaveric organ donors, necessitating higher utilisation of haemodialysis and CAPD, which has resulted in increased cost at personal, family, local and national levels. Individuals in elderly age groups (65 years and over) are also increasingly accepted for renal replacement therapy (Disney, 1994; Port,1995, Stewart et al,1995), along with a concurrent need for increased health services.

Australia has over 3500 people using dialysis (Disney,1994; ACCORD,1995c). In July 1995, there were 1575 people with ESRD waiting for a renal transplant (ACCORD, 1995b), and only 196 cadaveric renal transplantations had been performed in the previous six months (ACCORD,1995c). Over 1100 people had commenced dialysis in 1994 (Disney,1994). This discrepancy in demand and supply is of great concern, and is not solely an Australian problem. Internationally, the demand for human kidneys has resulted in extensive research and trialling of xenografts, for example using genetically engineered pigs (Mandel, 1993b; Port,1995) which has serious ethical and moral implications.

There have been numerous surveys to discover the reasons why people do not donate their organs (Spital,1991; Evans, Orians and Ascher,1992; ACCORD,1995c), which have led to publicity campaigns to promote the 'gift of life' and changes in legislation. It is suggested that donation of cadaveric organs is the only positive outcome from sudden death of a relative (NHMRC,1990; Spital,1991; Pearson, 1993; Chapman,1993). Increased donation has occurred in some countries following organ donation law provisions (de Chesser,1986; Chugh and Jha,1995), and in other countries it is argued that new legislation would not improve the donor rate (Evans, Orians and Ascher,1992; Stewart,1994). Spain has developed a transplant coordinator network (ACCORD,1995c), which has increased its organ donation rate from 14.3 to 25 pmp over a five year period (per million of population). Organ selling for profit is practised in some developing countries, and prohibited in Western countries as it has serious ethical, legal and medical implications (Bramlett,1989; Kreis,1992; Chapman,1994; Chugh and Jha,1995).

The major consequences of this low donor rate fact are that in the last ten years there has been an 80% increase in the number of people staying on dialysis (de Wachter,1995). Quality of life at both personal and community levels are severely restricted by dialysis regimens, and health care costs have risen (Rotary,1994; Woodbridge,1995). The emphasis on transplantation as an alternative therapy is therefore threefold; dialysis is not required, quality of life improves and the cost of transplantation is far less than the cost of any form of dialysis (Mandel,1993a; Mitchell, Smallwood, Angus and Lapsley,1993; ACCORD,1995b).

Against this background, the Australian government has undertaken specific initiatives to raise the long term cadaveric donation rate for organs. One of these initiatives resulted in the establishment of the Australian Coordinating Committee for Organ Registries and Donation (ACCORD) in 1989. The aims of ACCORD were to 'identify and overcome impediments to donor organ acquisition in Australia through wide ranging education and awareness programs targeting both the general public and the health professions' (McBride, personal communication,1995). Increased organ donation has not yet been demonstrated, however strategies initiated by ACCORD are underway (ACCORD,1995c).

In the meantime, the low donation rate continues to be a focus of ongoing policy discussion. This lack of cadaveric organs in Australia prompted the SA Health Minister to voice that 'the demand for organs far exceeds supply' at the Australian Health Ministers' Conference (AHMAC) in June 1995, and Ministers agreed that the 'issue of organ donation was of national concern' (AHMAC,1995).

The Australian average waiting time for cadaveric renal transplantation is one to three years (Mohacsi, Herbertt and Thompson,1993; NSW Transplant Coordinators,1993; AKF,1994; ACCORD,1994; Disney, 1994), and data about the increasing population waiting for a transplant for more than three years is not readily available. The lack of cadaveric organs offered within the ACT coupled with the increasing numbers of people with end stage renal disease indicates a need for identification of the factors which either enhance or inhibit organ donation. Organ donation in the ACT is lower than the majority of states in Australia at 6.8 pmp (ACCORD, 1995). Other states with low cadaveric organ donation rates are Victoria and Northern Territory at 6.3 pmp (ACCORD,1995a). The Northern Territory's low donor rate is attributed to the high indigenous population mortality rate and associated cultural beliefs about organ donation; in Victoria, the current emphasis is on promoting living related organ donation (ACCORD, 1995a;Jager and Gleeson,1995), and the low road traffic accident rate.

Purpose of the project

The purpose of this project is to identify and describe themes arising from the literature which influence cadaveric organ donation in Australia. This research arose from a professional and personal knowledge that in the ACT in December 1994, ten (45%) of the twenty-two adults using in centre or home haemodialysis, and who were on the renal transplant list had dialysed for more than three years and had not been offered a transplant. All were young at onset of ESRD (17 - 44 years old), and all remained on the active transplant list.

The primary objectives for this research are:

a) to identify and analyse factors identified from the literature which influence cadaveric organ donation,

b) to develop recommendations for increasing the rate of cadaveric organ donation in the ACT.

In 1964, the first successful renal transplant was performed in Australia. Thirty years later, cadaveric renal transplantation is the most widely practised form of renal transplantation in Australia, accounting for nearly nine thousand renal transplants (Mandel,1993a; Chapman,1993). The Australian Kidney Foundation (AKF) initiated national media campaigns directed at promoting the 'Gift of Life' in 1992, and 'Don't take your organs to heaven. Heaven knows they're needed here'. In union with ACCORD, the AKF promoted 'Give and Let Live' in 1994; 'Talk about it' was the 1995 campaign encouraging family discussion about organ donation. While television has been the most wide-ranging educational medium, it needs to be supplemented by an ongoing circulation of information pamphlets. The general aim of the campaigns are to encourage gradual changes in beliefs and ideals about organ donation in order to improve cadaveric transplantation (Sholle,1988; Dye,1993; ACCORD,1995b).

Elsewhere, this lack of cadaver organ donation is being actively addressed. European countries, the UK and US are all experiencing the shortage of cadaver donors (Prottas and Batten,1988; Bramlett, 1989; Spital,1991; Smith, Brumm and Crim,1991; Evans, Orians and Ascher,1992; Hibberd, McCosker et al,1992). Improvement in the efficiency of dialysis therapies, biocompatible dialysers and new medications has also increased the numbers of people with end stage renal disease (ESRD) living long term on dialysis (Chugh and Jha,1995; Port,1995). For cultural reasons, Japan has a very low rate of renal transplantation, and correspondingly has a high rate of people using haemodialysis.

Strategies

The use of media campaigns as strategies to promote awareness of organ donation have been encouraged world wide (de Chesser,1986; Herbertt,1990; Garrison, Bently, Raque et al,1991). Raising community awareness about donation through advertising and community education programs are ongoing (ACCORD,1995c; AKF,1995; Port,1995). Other strategies considered have been opting out or opting in campaigns - which are different systems for organ donation described later. Required request and presumed consent options are both considered in relation to Australia's needs.

One strategy sought to overcome the deficiency of human organs is xenografting, which is presently under extensive laboratory trialling in the US and Australia. Genetically engineered pigs are being developed to provide kidneys and other organs for humans (Mandel,1993; de Wachter,1995; Port,1995); purely synthetic kidneys have not reached this stage of trial (Mandel,1993b). Port (1995) reports a renewed emphasis on seeking living related donors.

A campaign funded by Rotary International and developed by the Science Teachers of Victoria (STAV) and the AKF produced 'Transplantation: the issues' (AKF and STAV,1992), comprising a workbook and video package is aimed at heightening the awareness of organ donation and transplantation to high school students. The effectiveness of the package on actual organ donation has not been assessed, although its purchase has become widespread in NSW and Victoria (NSW Transplant Coordinators, 1993).

Problems

The failure of physicians to identify potential donors has been identified as a major medical problem (Youngner, Landefeld, Coulton et al, 1989; Garrison et al,1991; Spital,1991; Hibberd et al,1992). It is argued that Australia's specific problems associated with the low organ donor rate revolve around lack in: 'government support in funding and coordination for organ donation; donor identification in hospitals, and community knowledge and confidence in brain death' (ACCORD,1995b:1).

Lembit and Sutcliffe (1995) found that a significant number of people surveyed did not understand brain death, the criteria for which must be established before commencing the process of cadaveric organ transplantation (Appendix 1). One strategy which proposes to increase the rate of organ donation has been to develop and implement a transplant coordinator network system, currently under trial in South Australia (ACCORD,1995b; AHMAC,1995). Additionally, research being explored is that of early detection, and primary and secondary prevention of end stage renal disease (AKF,1995; Mandel,1993a; Port,1995).

The donor

The decision of the donor does not appear to count. In Australia, the rule is that a senior family member makes the final decision about cadaveric organ donation, regardless of the donor's written or verbal permission (Pearson,1993; Chapman,1993). The 1994 AKF campaign was 'Talk to your family' in an attempt to address the issue of discussing organ donation with the family. It is conceded by ACCORD, AKF, intensive care physicians and transplant coordinators that it is better to forego a donor than to cause negative publicity, which may have dramatic effects on lowering future organ donation (ACCORD, 1993; AKF,1994; Allen and Chapman,1994; de Chesser,1986).

Negative attitudes experienced by donor families, including perceived lack of communication with health professionals, or lack of concern for the donor family, or uncertainty that the health professionals are doing their best for the potential donor has a reaching impact on future donations (Allen and Chapman, 1994; Chapman,1993; de Chesser,1986). Health professionals in intensive care, operating theatre and emergency departments have traditionally not been given the counselling, education and support

needed to cope with caring for both the donor, donor's family and their own feelings (ADAPT,1993; Armstrong,1993b; Hibberd et al,1992; Jager and Gleeson,1995; Veatch,1991; Youngner et al, 1989). The transplant coordinator can allay fears and negativity for health personnel and family alike (Herbertt,1989; Woodbridge, 1995). Emotional discomfort of staff about approaching requests for organ donation is acknowledged in the absence of a transplant coordinator (de Chesser,1986; NHMRC,1990; Tiller,1990; Youngner et al,1989).

The Australian perspective

In 1984 the median waiting time for cadaveric renal transplantation in Australia was 9 months, which increased to 22 months in 1994. The NSW/ACT median waiting time is over 24 months, higher than any of the other states (Disney,1994). The lack of cadaveric organs offered within the ACT coupled with the increasing numbers of people with end stage renal failure (ACCORD,1995a; Disney,1994; Piccone and Neville,1995), indicates a need for identification of the factors which either enhance or inhibit organ donation. In 1994, the rate of donors per million of population (pmp) in the ACT was 6.8 (ACCORD, 1995a), contrasting significantly with the Australian average rate of 10.6 pmp. The reasons for the low donor rate in the ACT are not as immediately recognisable. Australia has a low donor (12.7 pmp) rate in comparison with similar countries, for example UK, US, Austria, Sweden, Spain (ACCORD, 1995a; Dye,1993). The primary consequence of this low donor rate fact is that increasing numbers of people with ESRF continue with chronic maintenance dialysis for years. Improved quality of life post-transplantation has been reported, with release from dialysis regimens for the individual, and from the restrictions previously placed on family life (Chapman,1993; Woodbridge,1995). Improved work opportunities and sense of worth are beneficial for both family and community (AKF,1994; Chugh and Jha,1995; Disney,1994; Lovell,1990; Mandel, 1993a;Tiller,1990).

- Costing issues

Haemodialysis costs in 1993 ranged from $20,000-$40,000 per person annually in Australia. The lowest cost was for home haemodialysis at $20,000, with community based dialysis about $27,000, and hospital dialysis the most expensive. The cost of renal transplantation was $25,000 for the first year, and $5000 for subsequent years, and CAPD at $27,000 annually (Mitchell et al,1993). The effect of transplantation at the economic level is to reduce health care costs (AKF,1994; Chapman,1993; Chisholm,1988; Chugh and Jha,1995; Lovell,1990; Mitchell et al,1993; Rotary,1994; Woodbridge,1995).

Piccone and Neville (1995) predicted a 20% rise in the number of people requiring dialysis, which will force expenditure in both material and human resources. Over the last five years, 32 community haemodialysis centres have been opened, in order to promote cost-effectiveness of dialysis outside

hospital environments (Stewart et al,1995). Material needs include machines, artificial dialysers, designated water and electricity supplies, and equipment to carry out the time consuming procedures. Although the primary aims promote independence of the person with ESRD, there is renewed emphasis on also providing limited care settings, as cost-saving measures (Stewart et al,1995). Lack of availability of nephrology courses has resulted in dwindling nursing resources to manage the centres (Piccone and Neville,1995; Stewart et al,1995).

Transplantation - the outcome from organ donation

Transplantation is recognised as an effective therapy in the management of ESRD (ACCORD,1993; Chapman,1993; Chugh and Jha,1995; Drukker,1986; Hibberd et al,1992; Mandel,1993a; Tiller,1990). It is however important to understand that transplantation is not a panacea. The transplant operation itself is not always successful, as the transplanted kidney may not function, or may be rejected by the recipient. The survival rates of kidney transplants ranges from immediate failure to thirty years. Tiller (1990) reports that 50% of transplanted kidneys are functioning after ten years, with 30% still working at twenty years (Disney,1994). Some people choose not to undergo transplantation (Disney,1994), while others have had two or more transplants.

Knowledge and education

A major barrier to cadaveric organ donation is lack of knowledge within health professions and the community (Armstrong,1993a; de Chesser,1986; Gaber, Hall, Phillips et al,1990; Hodgeman,1995; NHMRC,1990). Knowledge deficit has a negative effect on organ donation. With the potential supply of organs available, strategies need to be developed. Woodbridge (1995) suggests that nurses 'are usually the first health professionals to recognise changing conditions of the potential donor', citing a 1985 Detroit study which found that transplant education for all staff in intensive care and emergency departments led to the tripling of donation requests. Education is part of the answer (ACCORD,1993; Woodbridge,1995; Youngner et al,1989), who predict that education and further development of the 'opting in' opting in will increase the supply of cadaver organs required. Others argue that the marginal donor criteria should be more flexible, rather than automatically discounting as donors those over the age of sixty (AKF,1994; Evans, Orlan and Ascher,1992;Youngner et al,1989).

There is a cadaver donation law in many countries, with some states in the US requiring doctors to routinely request donor status on admission to hospital (Armstrong,1993a; Woodbridge,1995). Over ten European countries have a presumed consent law, whereby at death each individual is presumed to have consented to donate organs (de Chesser,1986; Spital,1991). This law actually removes the personal, ethical and moral difficulties of approaching the relatives of a potential donor for permission (Prottas and Batten,1988; Tiller,1990; Youngner,1989).

By making donation routine, the decision of whether to donate organs is outside the family's jurisdiction (de Chesser,1986; Spital,1991). Religious reasons are often cited as impediments to organ donation, however all major religions agree in principle to cadaver donation (ACCORD,1994b; Chapman,1993; Chugh and Jha,1995; Tiller,1990; Veatch,1991).

The importance of identifying the factors which influence cadaveric organ donation is clear. Without organ donation, transplantation cannot occur. The ramifications of not seeking to improve the organ donation rate in Australia are enormous in terms of individual and family, community and national costs. The major themes identified from the literature were decided by their frequency, and were restricted in number only due to the limited scope of the proposed study, and included the following:

- An acknowledged shortage of cadaveric organs;
- The donor's decision is not binding;
- Haemodialysis costs exceed transplantation costs as a renal replacement therapy;
- Transplantation is an effective therapy;
- Lack of knowledge and education about organ donation amongst health professionals has a negative impact on organ donation.
- The presence of dedicated transplant coordinators is perceived as enhancing organ donation.

Methodology

The primary research method chosen for this exploratory project is content analysis, described as enabling the exploration of data by using numbers and words together to strengthen and enrich understanding and facilitate research findings (Bryman and Burgess,1994; Krippendorff,1980; Weber, 1990). The following outlines the characteristics of content analysis, its advantages and limitations, and also outlines the rationale for utilising discourse analysis, which is conducted as an integral element of the overall analysis. It is acknowledged that the dominance of the male (medical) discourse exerts influence over the publishing of, and information released to, the health care community, and by extension, the community at large (Doering,1992; Dzurec,1989; Gillon,1986). Other methods which were considered for the project are also briefly deliberated.

Content Analysis

Fundamentally, content analysis is a research design using a quantitative approach. Research utilising content analysis has gained favour with sociologists, behaviourists, anthropologists and psychologists (Gottschalk,1979; Gottschalk, Lolas and Vinex,1986; Hodder,1991; Holsti,1969; Krippendorff,1980; Naisbitt,1982). Qualitative approaches of content analysis have also been successfully used, confirming applicability and multidisciplinary acceptance of the approach (Fairclough,1994; Holsti,1969). Content analysis is 'a multipurpose research developed specifically for investigating any problem in which the content of communication serves as the basis of inference' (Holsti,1969:14).

The use of both qualitative and quantitative approaches to explore factors influencing cadaveric organ donation for this project was considered essential to discover relationships and disparities amongst and between both identified and non-identified factors (Hodder,1991; Holsti,1969; Lobo,1986). Literature relating to content analysis methods emphasised the potential of utilising numerical and interpretive data together to enhance findings (Burns and Grove,1987; Krippendorff,1980; Roberts and Burke,1989; Weber,1990).

Diverse characteristics within content analysis have been identified: a) semantic - identifying language, b) thematic - identifying themes, and c) latent - content analyses as qualitative, referring to hidden themes or meanings; d) static - identifying elements at a specified time, e) phase - identifying elements over a period, and f) manifest - coding of data by subject or by the number of times a key term appears, as content analyses, quantitative in essence (Dane,1990; Field and Morse,1985). Elements of content analysis deliberated within this project included identification of the themes of the written text, and exploration of unwritten themes, respectively considered as manifest and latent content analysis, which in itself resulted in an ongoing analysis of theme redefinition.

The researcher perceived that a combination of manifest and latent content analyses would facilitate the project's findings. The manifest content analysis explored the literature by applying statistical methods to code categories and themes by checking for specific words in the articles (Catanzaro,1988; Holsti,1969; Roberts and Burke, 1989). This process was essential to identify both common and dissimilar themes, represented in terms of frequency; and subsequently enabled factors to be prioritised within the data. Latent analysis was utilised to extrapolate unwritten themes and meanings (Holsti,1969; Krippendorff, 1980; Fairclough, 1994). The primary emphasis of latent content analysis was based on discovering threads within the texts which, although not written, were inferred (Holsti,1969). There are '*two kinds of reality*, the reality of the data and the reality of what the researcher wants to know about. In content analysis these two realities do not overlap' (Krippendorff,1980:170). The researcher utilised a conceptual framework for content analysis developed by Krippendorff (1980:26):

the *data* as communicated to the analyst
the *context* of the data
how the *analyst's knowledge* partitions his reality
the *target* of a content analysis
inference as the basic intellectual task
validity as ultimate criteria of success.

Kellehear (1993) and Woods and Catanzaro (1988) recommended using existing data for research, citing advantages in its unobstrusiveness, accessibility of data, time saving, ability to strengthen the validity of previous studies, cost-saving and availability (Weber,1980). Weber also provided a succinct overview of the advantages of content analysis, suggesting that the 'best content-analytic studies use both qualitative and quantitative operations on texts. Thus content analysis methods combine what are usually thought to be antithetical modes of analysis' (Weber,1980:10).

Initial limitations of this content analysis included a non-representative sample, and a recognised bias to medically oriented articles. The length of time required to analyse qualitative data, the possibility of researcher bias in interpretation of data within latent content analysis, and narrowness of the study were also limitations recognised. Krippendorff (1980:177) believed that if only a non-representative sample was available, for sound reasons 'little can be done other than limiting the inferences that were intended to be drawn from the data to those that can be drawn with some degree of validity'. It is acknowledged that data had the potential to be taken out of context or misinterpreted (Roberts and Burke,1989; Krippendorff,1980).

Discourse analysis

Analysis of the discourse of the texts was pursued primarily out of concern of the predominance of medical articles, and their potential influence on articles written by health professionals other than medical. The dominant discourse within the health parameters is the scientific/medical discourse, which

has traditionally meant that nurses and other health professionals are restricted by the limits of the medical (male) discourse, which also incorporates the elements of power and knowledge. The researcher did not suggest that a purposive influence was exerted on non-medical articles, however was interested in identifying any themes from within the articles which could illustrate bias. The potential for researcher bias is acknowledged, because of perceived differences in interpretation of the articles, and also because the researcher is not a medical professional. The themes identified were verified by an independent researcher - experienced in content analysis design and methodology and not otherwise involved in the project - who cross-coded the themes. This step was considered essential to reduce researcher bias, and assisted in the reliability and validity of the data analysed (Krippendorff, 1980; Weber,1990).

Consideration of other methods

There are advantages and limitations to all research methods, and some limitations will be outlined to explain the reason for their inappropriateness for this project. A number of research designs, both quantitative and qualitative, were considered . Each was considered and rejected according to difficulties envisaged by the researcher based on their methods, focus, and other factors. The researcher concluded that an exploratory analysis of articles identified through specific key words was feasible. An empirical approach analysing quantitative data was considered to be inappropriate due to its inability to incorporate social, behavioural and psychosocial factors. Content analysis was perceived to be able to address each of those factors to some extent. Possible approaches which were contemplated are outlined below.

Exploratory interpretive approaches of ethnography (and ethnonursing) - developed by anthropologists as a means of studying cultures; grounded theory - an inductive approach in relatively unexplored areas involving collection of data without a framework were each considered. Historical research, examining past events (Burns and Grove,1987) was also rejected due to inappropriateness of design or samples, need for ethics committee approval, and time constraints. Overall, these approaches were perceived unable to adequately identify and explore - for the researcher - factors relating to organ donation. The ability of content analysis to meet the conjoint demands of quantitative and qualitative approaches, its flexibility in subject and design, relative ease in accessing the sample, variable methodology, exploration of variables assisted by computer, and opportunity to change directions were factors which identified content analysis as an appropriate method for this project. Critical analysis of text was not adequately deliberated at the time of the development of the final research proposal. In the progress of this project, the researcher acknowledges that discourse analysis of the articles utilised provided further relevant and substantial material in conjunction with the content analysis.

Population and sample

Written information about renal transplantation and the factors influencing its continuation within society is restricted to a small number of health journals, both international and national. As the intent for this project was to discuss the Australian perspective of factors influencing organ donation, information was limited to Australian articles. The Medical Journal of Australia, the Transplant Nurses' Journal, the Transplant Coordinators' division of the Australian Red Cross Society and ACCORD were the only journals in the preliminary literature review which highlighted concerns about transplantation. Informal verbal communication with nephrology physicians, transplant coordinators, members of ACCORD and AKF, and medical/nursing and allied health professionals enabled extensive anecdotal discussion, and allowed the release of another article for analysis.

An initial literature search of CINAHL, HealthROM and MEDLINE using the terms 'transplantation' and 'organ donation' identified 35 articles published in Australia between 1989 and 1995. Personal communication between the researcher and members of ACCORD, ADAPT, transplant coordinators, nurses, and physicians uncovered additional articles, both published and unpublished, refereed and non-refereed. The researcher reduced the search to articles written, published or presented in 1993 and 1994, resulting in twelve articles for analysis. The rationale was due to the establishment of ACCORD and ADAPT which were expected to play major roles in the improvement of the organ donation rate in Australia.

In the initial stage of analysis, two articles were found to be very similar in theme and wording, necessitating the rejection of one article on the basis of possible skew of themes because of the replication of findings, and key words. Additionally, both articles were written by the same author. A final eleven articles were analysed (Appendix 2). Weber (1990:42) suggested that 'sampling is used primarily for the sake of economy'. Justification for the inclusion of articles both published and unpublished was based on the premise that traditionally nurses, primarily females, have had few works published (Irigiray,1985; Dzurec,1989; Doering,1992), and finally that *'anything connected with the phenomena of interest qualifies as data for content analysis'* [sic] (Krippendorff,1980:171).

Computer-aided assistance

There was no identified computer package available to the researcher to provide computerised word frequency counts used to find key words within the texts (Weber, 1990). The articles were all scanned into the computer to ensure the accuracy of the word counts, and to expedite the identification of key words appearing most frequently. The selected words were chosen by the researcher because of their potential to incorporate all articles pertaining to organ donation and transplantation. The inability of the computer to understand the syntax of language necessitated researcher caution in ensuring that words

were used within context (Hodder,1991), requiring the researcher to override manually some of the words highlighted by the computer. The researcher also recognised the importance of using synonyms following the initial word counts (Weber,1990; Krippendorff,1980). A computer-based thesaurus was utilised to enhance identification of alternative words, however was limited in depth of terminology.

Categories and coding

Content analysis requires coding to enable frequency counts, development of themes and enhancement of findings. Weber proposed the following: 'a) define recording units and categories, b) test code a sample of text and assess accuracy or reliability...c) revise the coding rules and test code another sample of text, d) code all the text, and finally e) assess achieved reliability or accuracy' (Weber, 1990:21). Words, sentences or phrases can each or all be used as recording units (Dane,1990), and words were identified as appropriate recording units for this project based on an exploratory word frequency count which illustrated inconsistencies in word usage and personal interpretations. The researcher concluded that phrases or sentences would prove too diverse in range. Essential elements to be considered before embarking on the exercise included the development of definitions of the variables, able to be reviewed throughout the analysis and an outline of how the procedure developed (Garvin, Kennedy and Cissna,1988; Krippendorff,1980).

Weber (1990:15) indicated that 'a content analysis variable is valid to the extent that it measures the construct the investigator intends it to measure', and to this extent the project identifies variables pertaining to author, journal, and published status (Holsti,1969; Krippendorff,1980; Weber,1990). The strongest form of validity is predictive or semantic validity. Predictions about problems outside the project 'correspond to actual events or conditions... future, past (postdiction), or concurrent. Predictive validity is powerful because the inferences from data are generalized beyond the study to situations not under the direct control of the investigator' (Weber,1990:20). This statement is of relevance because none of the inferences can be controlled by the current researcher.

Stability, reproducibility and accuracy are the three forms of reliability necessary in content analysis (Krippendorff,1980; Weber, 1990). 'Since high reliability is a requirement for high validity but does not assure it, standards for validity are clearly more powerful and hence preferable to standards for reliability. However, the measurement of reliability is important' (Krippendorff,1980:175). The difficulty of retaining context within the text is acknowledged in using a computer to process the data. Reliability is without doubt, but semantic validity is questionable (Krippendorff,1980).

Quantitative measurement of the data within this project was conducted by means of frequency counts, classified by category, with discussion of the outcomes. Latent analysis, a qualitative approach, was explored in conjunction with the manifest analysis. Discourse of the articles followed as an extension of the original theme of the project because of the skew of the articles towards the medical profession.

Results

The results of analysis were threefold being manifest content analysis, latent content analysis and discourse analysis. Manifest content analysis indicated that the words occurring most frequently were transplant and transplantation, expected as both were identified key words determined in the literature search. Latent content analysis was undertaken to identify themes which emerged from within the texts. Discourse analysis illustrated language, terminology and differences in focus and was dependent on the author of the article analysed. Emergent themes included a lack of strategies to address the promotion of organ donation, a lack of acknowledgment of the donor and the donor's wishes, an understated reference to the spiralling costs and the lack of emphasis on improved quality of life post-transplantation. The researcher regards as significant the omission of these themes from the majority of the articles.

The charts which follow identify articles by number, which were primarily selected according to alphabetical order for ease of reading for both reader and researcher. The final two articles are not placed alphabetically, simply because they were the last articles to be included in the sample, and the researcher had already commenced collation of the other scanned articles. Complete details of the articles numbered below are provided in Appendix 2.

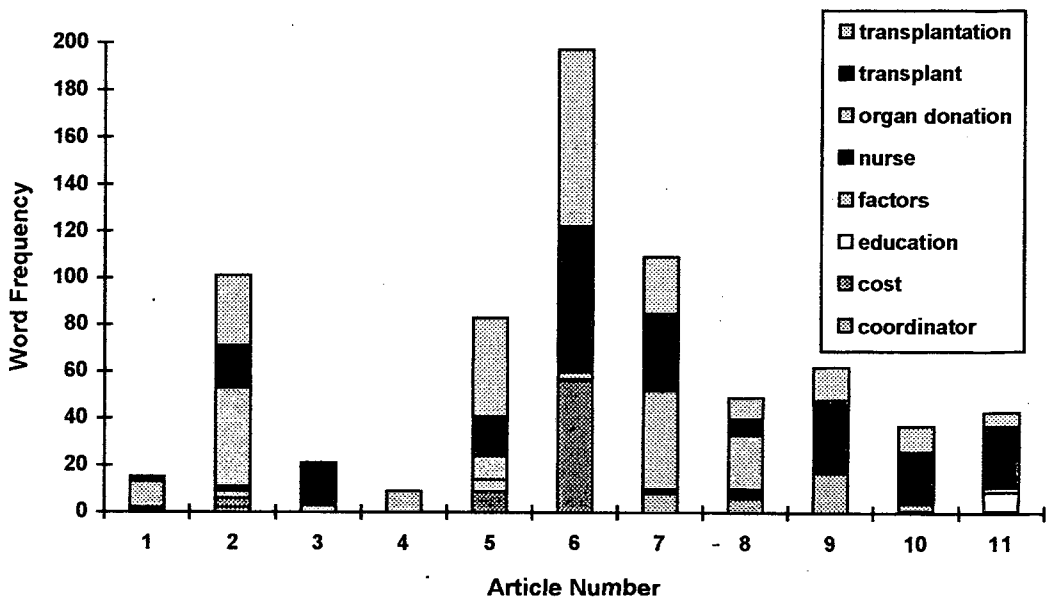
Table One: Authors of articles by number

1. ACCORD 10
2. Allen and Chapman
3. Chapman
4. Dye
5. Mandel
6. Mitchell, Smallwood et al
7. Mohacsi, Herbertt et al
8. Pearson
9. Transplant Coordinators -NSW
10. Armstrong
11. Knudson

Initial exploration of terms used within the articles included a word frequency count based on words chosen by the researcher, considered to be possible leads for further investigation (Chart 1). The first word frequency elicited very little information, due to differences in the language used between authors of different backgrounds, although it provided a baseline from which to work.

The researcher purposively included within the context of the articles words which related specifically to renal organ donation, transplant and renal transplantations, while excluding references to liver, pancreas and heart donation and transplantation.

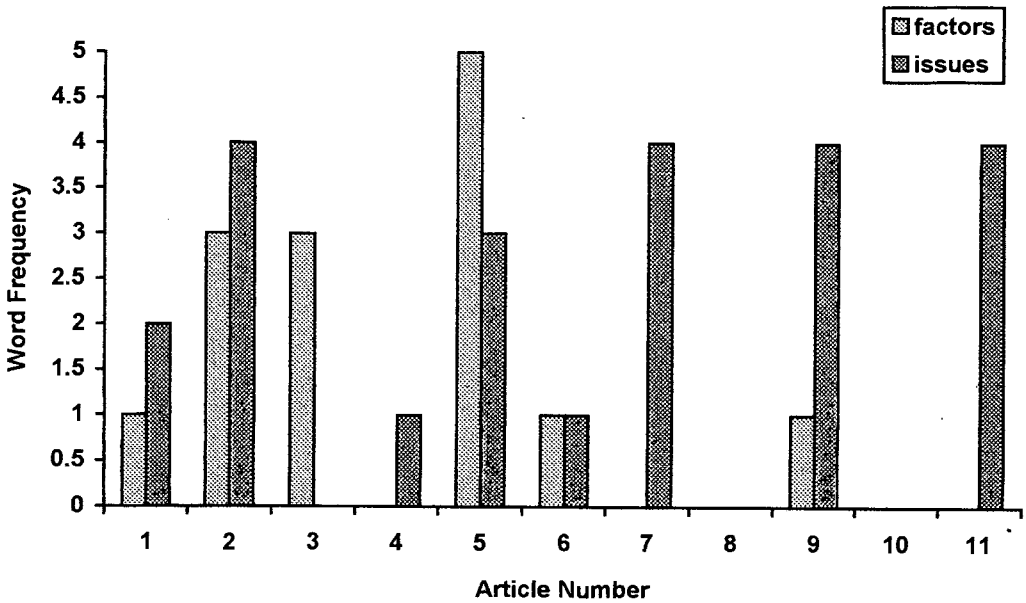
Chart 1: initial word frequency count



Identified words included transplantation, transplant and organ donation, which was expected as the preliminary literature review had tagged these words as crucial for the development of the project. Consideration of statistics, factors, nurse, education and coordinator were not well illustrated in this initial frequency. An extended word frequency was conducted to uncover the importance of each or any of those words within the articles. Terminology was extended to incorporate other words with similar meanings (Fairclough,1994). One limitation recognised was that taking words rather than phrases as the units of analysis actually presented a contextual problem, for example the word 'donation' is potentially ambiguous in meaning, and could be considered as cash donation instead of organ donation. The strategy used to minimise omission or inclusion of inappropriate words within word counts was of necessity conducted manually by the researcher.

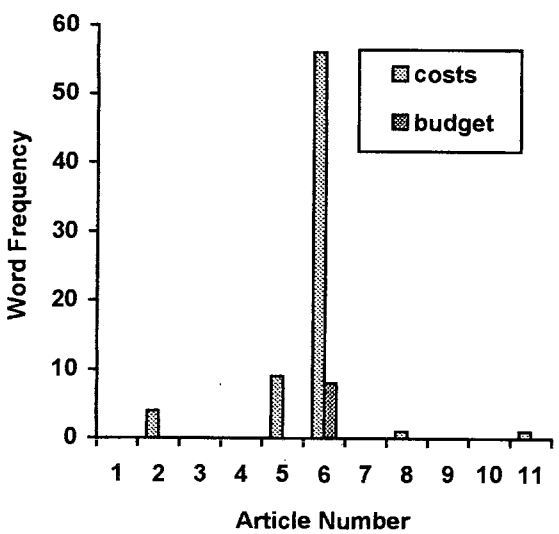
An extended word frequency count (Chart 2) divulged that the terms 'issues' and 'factors' were found to be interchangeable words, demonstrated in five articles, for example Allen and Chapman (Article 2) and Dye (Article 4). The finding demonstrated different terminologies across the articles. A mean of 1.5 was achieved for issues, and a mean of 2.1 for factors, with medians of 1 and 1 respectively.

Chart 2: frequencies of 'factors' and 'issues'



In the overall analysis, these terms were fairly insignificant, with a range of 0 - 5 occasions used for factors, and 0 - 4 occasions using issues. Nine of the eleven articles used either one or both terms, indicating common usage. The rationale for including this information is that the project's undertaking was to explore the factors which influence organ donation.

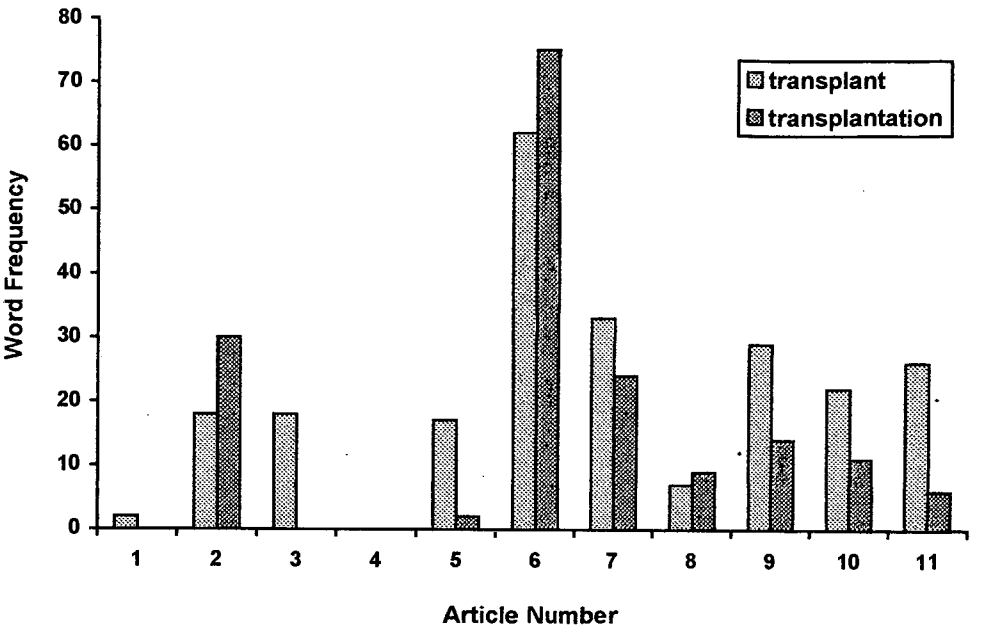
Chart 3: frequencies of 'cost' and 'budget'



Whilst authors are aware that escalating costs have marked impact on the available resources for dialysis and transplantation (Mandel,1993a; Mitchell, Smallwood et al,1993), there was little or no mention of costs involved throughout the majority of the articles. The researcher contends that an underlying latent theme of health care costs exists. Omission of the actual costs concerned with organ donation and transplantation in the articles analysed precluded discussion of alternatives for optimising health care budgets. The underlying power is related to costs, and is addressed later.

An extended word count using synonyms using the facilities of a computer-based Thesaurus was conducted (Chart 3), however 'costs' and 'budget' did not rate highly across the spread of articles. Costs were reflected primarily in article number 6 (56 occasions), and budget (8 occasions) all appearing in the same article. Costs were referred to in article 5 (9 occasions), and article 2 (4 occasions).

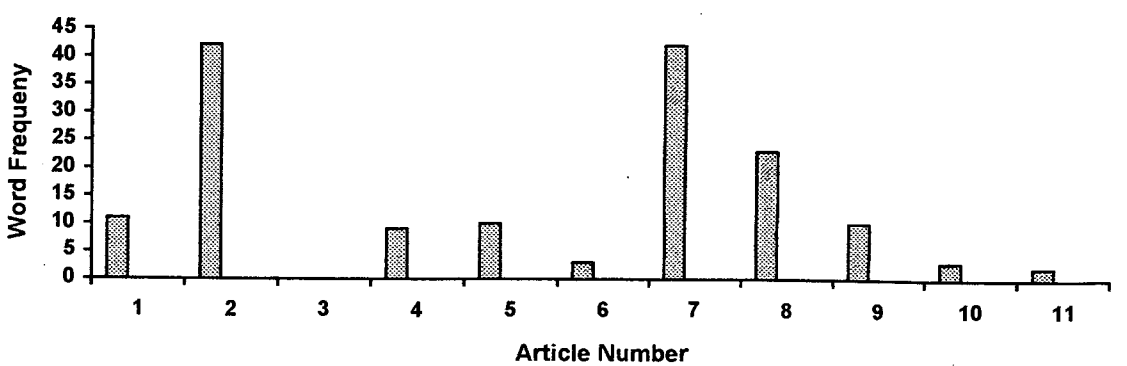
Chart 4: 'Transplant' and 'transplantation' frequencies



The mean for the word transplant was 21.27, with a median of 18, while the mean for transplantation was 15.5, with a median of 6. The low median was due to non-usage of the word transplantation in four of the articles.

Omission of the words transplant and transplantation in article 4 was presumed to be due its emphasis on organ donation. Article 1 also was directed towards organ donation rather than transplantation. The extensive usage of both key words in article 6 was considered by the researcher to relate both to the length of the article, and the authors' emphasis on the costs and transplantation. Eight articles each used the word transplant more than 12 times. Four articles used transplantation more than 12 times.

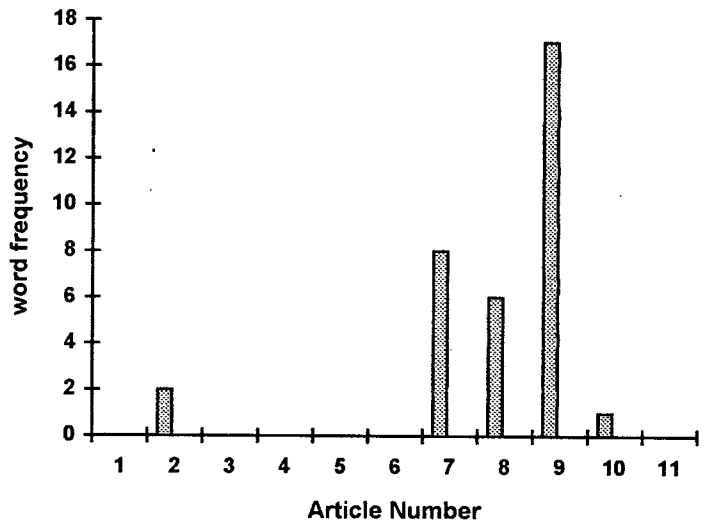
Chart 5: Frequency of 'Organ Donation'



The range of use of the term organ donation was wide, from 0 occasions in article 3 to 42 occasions in articles 2 and 7; a mean of 14, and median of 10. Total omission of organ donation in article 3 is related to the emphasis of the article on the issue of transplants and transplantation, presuming organ donation. This, though, does not elaborate on whether the organ donation is from a cadaver or living related donor.

While there were few mentions of the word transplant coordinator, the researcher notes that of those articles referring to the coordinator, three were written by transplant coordinators, and two by members of the medical profession. At the time of publication of their articles, the authors of articles 2 (Chapman) and 8 (Pearson) worked for the same health service, and were both involved in transplantation from different perspectives. Inclusion of transplant coordinator as a latent theme was extrapolated from within the articles because a number of authors inferred that transplantation was 'facilitated by dedicated personnel'.

Chart 6: Word Frequency of 'Transplant Coordinators'

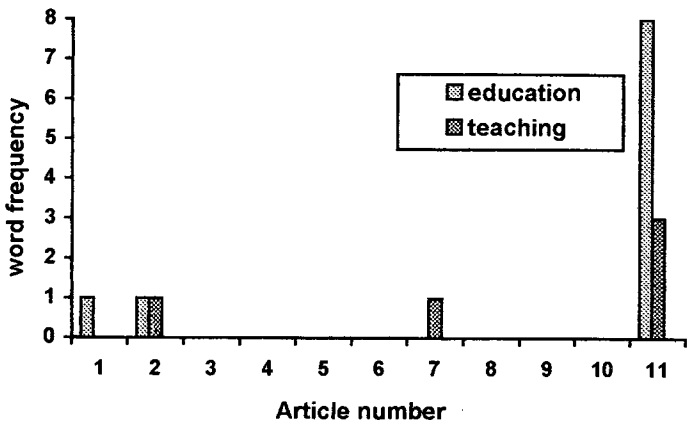


Recognition of transplant coordinators as integral members of transplant teams within those articles is significant because traditionally the primary qualification for transplant coordinators in Australia is registration as a nurse. It is noteworthy that there is relative non-acceptance amongst some medical professionals that transplant coordinators have input into the processes of organ donation and transplantation.

Power and knowledge and the medical discourse were perceived to be linked with ongoing lack of acknowledgment of transplant coordinators by some medical professionals.

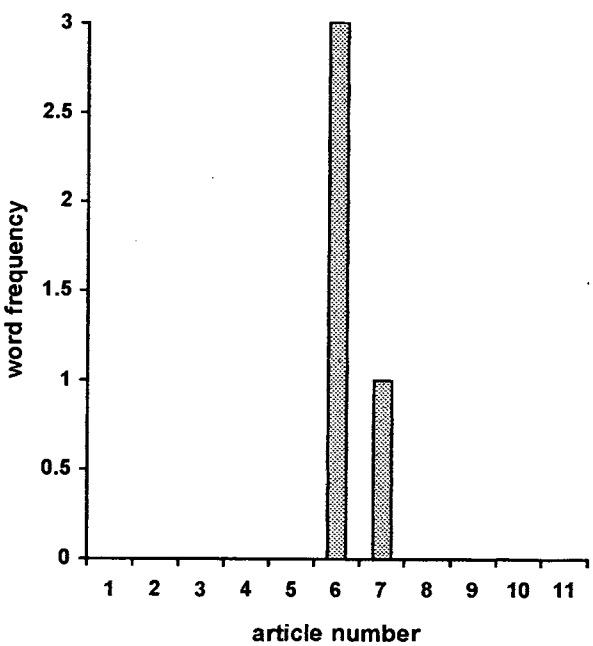
Education and teaching were considered little used across the breadth of the articles, with a total of 9 occasions for the word teaching and 11 occasions for the word education. The researcher deemed that further exploration of these terms was not appropriate for manifest content analysis. As education had been emphasised as a major strategy in increasing organ donation in the literature review, it was deemed to be a latent theme.

Chart 7: Education and Teaching



Literature earlier reviewed indicated that transplantation improved the quality of life for people who had previously used dialysis. The rationale for exploring quality of life was to ascertain the absence or presence within the articles of previously identified relationship between transplantation and quality of life.

Chart 8: frequency of quality of life



As indicated above, the articles made little mention of the significance of transplantation on the quality of life; in fact, only two articles (Mitchell et al,1993; Mohacsi et al,1993) actually used the term. Improved quality of life following transplantation was inferred within the context of the articles, however was essentially an unwritten topic, and was considered to be a latent theme.

Following comprehensive analysis, the researcher identified a number of factors which emerged across the spread of the articles. The following categories are classified in descending order of their appearance according to the researcher's classifications: health professional, social - including quality of life, family, medical and transplant coordinator, publicity, ethical, economic, legal and donor.

Discriminating between the categories of health professional, medical professional and transplant coordinator became necessary to enable clarity of understanding as the analysis progressed, because of the unique roles and responsibilities of the medical professional and transplant coordinator. As the transplant coordinators act as liaison personnel, it was considered appropriate to separate them from the health professionals. Senior medical professionals, whilst integral members of the health professional team, had the sole duty to establish brain death, denoting a unique role. The health professionals group designated by the researcher incorporated nurses, doctors and social workers within the hospital environment (Lovell,1990; Youngner et al,1989). As some issues identified within the articles were not applicable to a single identified category, there was some overlap in the findings.

Health Professional

Within the health professional category, thirty one factors were highlighted, however few were addressed on more than one occasion. Donors were missed due to non-identification of potential donors by medical personnel (2 entries), reiterated by Byth (ACCORD,1995c). There was an identified need for bereavement understanding of donor families (2), and concern for varying donor criteria for medical acceptance of donors (2). Problems were associated with the lack of progress of xenografting and immunosuppressants (2), and new and untested immunosuppressants (2). The efficiency of transplants (2), permission for donation not sought (2), and the need for supportive, compassionate and caring health professionals (2) were other issues noted more than once.

Social

The category identified as social (20 entries) indicated that donor supply was the primary problem (5). Waiting lists are rapidly growing (3), and acknowledged improvement in the quality of life post-transplant (3), were factors expressed most frequently, although the latter was identified in only two articles. Also established were that community expectations and values were recognised (3), and professional and public acceptance of organ donation and brain death are essential for enhancement of the cadaver donor campaigns (2).

More transplanted people work full time than those on dialysis (2), good quality extended survival (2,) and acceptance of transplantation as a beneficial procedure (2) were positive factors. Doubt about brain death criteria was expressed (2), and the fact that donors were missed (2) were regarded as important aspects for future strategies. The outcome that potential donors increase following education (2) was also considered significant.

Family

Fourteen issues emerged within the category of family. The importance of donor family follow up and feedback rated most highly (4). NSW Red Cross appointed a bereavement coordinator in 1993 to work with donor families, and the incumbent has recently been awarded a Churchill Fellowship to study with bereavement coordinators in Europe. Concern was placed on the negative effects of neglecting potential donor families in the intensive care unit (3), as well as the benefit of family discussion (3). Refusal by next of kin (2) to donate organs was addressed to a lesser degree.

Medical

The category described as medical referred to fourteen factors. The sole concern mentioned more than once was the lack of recognition of suitability of potential donors (2). A 1993 survey in NSW cited this concern, concluding that accuracy in identification of donors needed to be addressed (Hibberd et al, 1992).

Transplant Coordinator

The transplant coordinator category resulted in the identification of fourteen factors, most significant of which was the emphasis placed on donor family follow up (4). This issue is highlighted because of the potentially damaging effects on the donor family, and negative publicity generated in the absence of follow up (ACCORD,1995c). A critical need for the donor family to be fully informed (3) was of major concern. The coordinator's role in liaising between medical, retrieval, donor and recipient, transplant and tissue typing teams (2) was also considered important, as was the role of the coordinator in organising information, consent, and legal requirements (2). The importance of hospital and community education (2) provided by transplant coordinators was considered significant by the authors of two articles (Mohacsi et al,1993; Pearson,1993).

Publicity

The eleven issues identified within the category of publicity were concerned with the prevalence of public relations campaigns (2), and also the negative experiences of donor families (2). The perceived need for hospital and community education (2) were important as was the impact of 'Transplantation: the issues' (2). Ethical category concerns discussed ethical and religious beliefs (2), and the consequences of withholding transplants (2) to be of most significance. The economics category related primary considerations of cost benefit analysis (3), and debated the costs of alternative therapies (2). Within the category of legal issues, of most importance was concern about the brain death legislation criteria (2), and the 'opting in' system (2) currently practised for organ donation in Australia.

Donor

The donor was barely considered across the breadth of the articles, and of the three factors which did arise, the issue that personal wishes are missed (2) was of primary significance. Overall omission of discussion about the donor was identified as a latent theme.

Organ donation

During exploration of the factors influencing organ donation within the articles analysed, strategies recommended were suggested by the authors. A total of thirty seven different strategies were offered which may assist in increasing organ donation. Significantly, the emphasis was on promoting public awareness campaigns (4), that transplantation is cost-effective so money should be spent on education of people for cadaveric donation (2). Continued improvement in the referrals system is needed (2), and xenografts should be considered as a potential source of organs (2).

Discourse analysis

The analysis is strengthened through the augmentation of discourse analysis, identifying within the articles commonalities and differences in terminology, use of language, and projected audiences. This step was undertaken to ensure an awareness of reader and researcher that resultant findings from the content analysis had the potential to demonstrate bias towards the articles written by members of the medical profession. Details taken into account included the length of the articles and their publishers, as well as their projected audiences. Articles which appeared in the Medical Journal of Australia (MJA) in 1993 were in the majority (five articles), three of which were written solely by medical professionals. One article was a combined medical/researcher report, with the principal author a researcher. The final MJA article was written by a transplant coordinator as principal author, and medical professional as co-author.

The projected audience for the majority of articles is primarily medical, as is the language. MJA journals are available in all hospital libraries. Other articles varied in style and audience, from an unpublished paper (Armstrong,1993b) presented by a transplant coordinator at an international transplant conference in 1993; a paper (Knudson,1993) presented by the AKF Education officer to the Australian Transplant Coordinators Conference, then revised and published in the Transplant Nurses Journal, also in 1993. Articles by Dye and ACCORD 10 were both published by ACCORD in 1994. Allen and Chapman's 1994 publication was from a published text, written for health professionals. The researcher raises concern about the traditional power and knowledge control of medical discourse, primarily because of the lack of articles published by other health professionals. The Transplant Nurses' Journal commenced publication in 1992, because of the paucity of relevant articles for transplant nurses, according to its first editorial (Kildey,1992).

In summary, the word count frequencies demonstrated that consideration needed to be given to differences in terminology, words in context, and the use of synonyms and homonyms. Although the computer proved beneficial in displaying charts, it was unable to comprehend syntax of language, necessitating manual input to ensure validity of inclusion of terms (Hodder,1991). As Weber (1990) suggested, the original data collected did not prove to be as beneficial as first hoped, and the importance of revisiting the material was stressed.

Discussion

Discussion of the articles is addressed with manifest and latent content analysis of the articles, followed by discourse analysis of the language used. The majority of articles identified within the literature search were written by medical professionals, which may have presented a bias within the context of the project findings. To maximise the findings from the combined quantitative and qualitative approaches, the researcher revisited both manifest and latent content analyses throughout the analysis.

Initial emphasis of this discussion is placed on the latent themes identified in the results, including the lack of consideration of the donor's wishes, lack of identification of potential donors, the role of the transplant coordinator, quality of life after transplantation, omission of consideration for the cost-effectiveness of transplantation, and the need for education about organ donation at community and health professional levels. Other issues necessitating discussion include strategies to address growing waiting lists, the shortage of donor supply, the importance of donor family follow up, the significance of public awareness campaigns, and the potential for changes in religious and ethical beliefs and legislation following education about organ donation. Strategies that are proposed or which have been utilised to improve organ donation which will be discussed include the improvement in referrals which has increased organ utilisation, the importance of transplant education, publicity campaigns, and xenografting.

The Donor

The donor is the single most important factor in the cadaveric transplantation equation. No donors means no cadaveric transplants leading to more people on dialysis. Identification of potential donors can be addressed in several ways. Organ donation cards, registration of intent to donate on a national register, presumed consent, opting out, opting in, intent on driver's licence, and required request have all been considered at national and international levels. Each option has advantages and disadvantages, with wide availability but poor usage of organ donation cards in Australia (Allen and Chapman,1994). Over 12,000 people have registered on a computerised state donor registry established in Victoria in 1995, the results of which are yet to be seen.

Donors are largely unidentified until the prospect of being a cadaveric donor arises. Within a few short hours a family faces the imminent death of a relative or friend, and a request for permission to donate that person's organs. Sensitivity, compassion and caring are the necessary characteristics required for the professional approaching the family to seek consent for donation. Veatch (1991:1247) states that the US now 'recognizes (sic) the priority of the individual's wishes'. As previously noted, in Australia, there is a tendency not to fulfil a donor's wishes if the family objects (Allen and Chapman,1994) because of the negative publicity it may generate. A priori consent by the potential donor is not regarded as the predominant issue in the retrieval of organs (Kreis,1992), for the reason previously addressed.

A serious medical concern which emerged from the analysis was that junior medical practitioners were unable/unwilling to identify potential organ donors (Armstrong,1993b; Pearson,1993; Smith, Pearson, Tyler et al,1989). A recent NSW study of deaths in intensive care units identified that over 70% of potential donors were missed (Hibberd et al,1992), the majority of whom were not resuscitated. This outcome underpins the necessity for education of medical professionals to recognse potential donors. A transplant coordinator network trial to identify potential donors is underway in South Australia..

Transplant Coordinators

From the literature review and the analysis of the articles, it is evident that transplant coordinators provide an essential link in the liaison between the donor family, intensivists, the coroner, physicians and nurses, transplant teams and tissue laboratories. Integral components of the coordinators' role are the follow up of donor families (Norris, 1991; Woodbridge,1995), debriefs for medical and nursing staff, and provision of transplant education within the community and the health system.

Documented by some authors was a perceived lack of sensitivity by health professionals towards donor relatives (Mohacsi et al,1993; NHMRC,1990; Pearson, 1993), which may lead to fewer cadaveric donations in the future. Strategies initiated to deal with this problem have been the development of educational programs for health professionals, and the introduction of transplant coordinators. It is interesting to note that there is non-acceptance amongst some medical professionals that transplant coordinators have legitimate power and input into the processes of organ donation and transplantation. Power and knowledge and the medical discourse were perceived to be linked with ongoing lack of acknowledgment of transplant coordinators by some medical professionals.

The role of the transplant coordinator is to facilitate organ usage, and since the adoption of transplant coordinators in Australia, 91% of all organs donated have been utilised, as opposed to the 50% utilisation rate prior to transplant coordinators (Armstrong,1993a). Australia also maintains the highest organ usage per donor rate, at 7.2 organs per donor, according to McBride (ACCORD,1995b).

Thirty years ago organ donation and transplantation in Australia were practised at a state level, with the result being wasted organs if nobody in the state was deemed a suitable recipient. Problems with donors numbers was related to the lack of referral by medical professionals to transplant teams (Pearson,1993).

The referral system for organ donation now incorporates a national coordinator network, which ensures that all possible organs donated are utilised across Australia (Armstrong,1993b; Mohacsi, Gordon, Wright and Doran,1989). Coordinators are available twenty-four hours a day, and liaise with donor and recipient hospitals, tissue typing laboratories, coroner, operating theatre and intensive care unit staff to ensure optimum performance for and from all individuals. Because organ donation is not routine, the lack of familiarity with procedures is a deterrent to organ donation in hospitals outside the metropolitan areas (Hibberd et al, 1992).

Costs

The cost-effectiveness of renal transplantation was recognised within the articles analysed (Freeman, 1986; Mandel,1993a; NSW Transplant Coordinators,1993), however Commonwealth funding with the introduction of Casemix has not optimised available funds for transplantation. If more transplants were performed, overall long term health costs would be reduced because of a resultant decrease in the number of people requiring chronic dialysis (Freeman,1986; Mitchell et al,1993). Another alternative mooted is the option of offering older people transplants as a cost effective ploy, thereby reducing the numbers of people using long term dialysis (Mandel,1993b; Mathew, d'Apice and Kincaid-Smith,1986; Mitchell et al,1993).

Education

Literature abounds with studies identifying the problem of the shortage of organs, and many surveys conducted have emphasised the benefits of changing people's attitudes by education (ACCORD,1995c; Dye,1994; Hodgeman,1995; Spital,1991; Stewart,1994; Youngner et al,1989). Community and health professional education about cadaveric organ donation is essential if people are to donate or receive organs. Over the last three years, 'Transplantation: the issues' has assisted young people to develop an awareness of the importance of organ donation.

Groups in the community which need targeting according to Lembit and Sutcliffe (1995) are those 'undecided' about organ donation, those aged 16-24, males, without technical or tertiary education qualifications. Within the health sector, ACCORD (1995c) believes that medical, nursing and other health professionals need to more aware of transplantation and organ donation, their issues and effects.

The steady increase in people using dialysis has necessitated review into practices regarding transplantation, with an ongoing commitment to community and health professional education about organ donation. The majority of articles analysed presented few strategies to promote organ donation, yet all were in favour of transplantation. The 1995 ACCORD survey indicated the need for education of health professionals, as well as education to raise awareness of organ donation within the community. National campaigns are coordinated by ACCORD, ADAPT and the AKF, and their effect in improving organ donation is enhanced with availability of expert liaison personnel at the local level to provide accurate knowledge and current information about transplantation.

Public awareness campaigns are ongoing. A commitment by Rotaract to speak about organ donation to community groups, and well-publicised Organ Donation Awareness Days and Ecumenical services are some of the methods utilised to maintain the organ donation issue (ACCORD,1992; Knudson,1993; NHMRC,1990; NSW Transplant Coordinators,1993). ACCORD retains a high profile in publicising organ donation, and in December 1994 contracted consultants to undertake a national survey which sought to discover people's attitudes to organ donation. Results published in April 1995 showed that 89% of the population support transplantation in principle (ACCORD,1995b). Future campaigns plan to address those groups which have a low donation rate (ACCORD,1995b;Lembit and Sutcliffe,1995).

One strategy which has been introduced to enhance the awareness of young people towards donation has been addressed within high school curricula. Schools have access to organ donation education through use of the program using 'Transplantation: the issues' (Allen and Chapman,1994; NSW Transplant Coordinators,1993). Within hospitals and health communities, professionals from ADAPT have conducted preliminary workshops nationally (ADAPT,1993), and are currently developing programs for health professional needs based on the outcomes of the workshops.

Quality of life

Improved quality of life is emphasised to donor families as a positive outcome for the recipient. The majority of recipients believed that their quality of life was better since transplantation (Disney,1994). Previously, surveys conducted both in Australia and US have reiterated the benefits of transplantation for the recipient, with the primary outcomes being the ability to return to full time employment, feeling of worth, and improved family and social lives.

Strategies

While presumed consent may appear to be an expected solution to improve cadaveric organ donation, legislative, personal and ethical issues need to be resolved. Opting out requires that a person actually registers intent not to donate, however the senior family member may override the donor's wishes.

Driver's licences are not always available nor are they viewed by health personnel, for organ donation intentions. Opting in is the current system practised in Australia, and has the disadvantages that people do not make their wishes known to others.

Secondly, the emotional pressure exerted on the relatives of a potential donor causes discomfort to the person seeking permission for donation, resulting in fewer requests for donation. For the majority of options, the senior family member has the final word in determining whether organs may be donated. Although there is no Commonwealth law which requires the consent from that senior member, the medical profession has traditionally bypassed the wishes of the dead to follow the wishes of the survivors. As indicated earlier, it is preferable to lose a potential donor than to generate negative publicity which may prove detrimental to future organ donations.

Ethical issues relating to transplantation continue to emerge, linked firmly with legal and religious concerns (ACCORD,1995b; ACCORD,1995c; AKF,1994; Bramlett,1989; Freeman,1986). These include debate about the ethics of breeding genetically engineered pigs, and utilisation of the limited supply of the great primates. Argument about whether humans have any right to remove organs from animals for human longevity has, and will continue to frustrate the xenograft issue of supply and demand, with animal activists and ethicists decrying the practice (ACCORD,1995c; Kreis,1992; Mandel,1993; Woodbridge,1995). A recent baboon bone marrow transplantation in the USA has attracted much attention (de Wachter,1994). Future xenograft operations are dependent on the benefits of, and outcomes for both donor and recipient (Mandel,1993b).

As identified earlier, new strategies are being investigated to promote organ donation in Australia. There is a slight trend towards living related donation (Disney,1994), possibly due to the extended waiting time of the cadaveric transplant list. Research into xenografts is ongoing, and improvements in the development of immunosuppressants continues. Possible alternatives to opting out which have been considered are the opting in and presumed consent proposals, and both have been rejected for a variety of reasons, some of which are outlined above.

Discourse analysis

Language used within the majority of the articles analysed denotes a presumption of understanding of medical terminology, and is not addressed to the lay audience. Notable exceptions are the articles written by Dye, ACCORD 10 and Armstrong. Mohacsi et al (1993) use medical-oriented language as expected, for it is unlikely that the article would have been accepted otherwise for publication. Mimicry of the dominant male discourse (Irigiray,1985) is an approach which females have utilised to enable being heard and not silenced.

The written word ranks above the nonverbal word (Derrida,1978; Fairclough,1994), and nursing language is predominantly a verbal language, although contemporary practice encourages written works (Dzurec,1989; Holmes,1992). Concern has mounted for the lack of incentive for prospective non-medical authors to publish, either because of publications available, rigour of requirements, or language used (Dzurec,1989).

Avenues for publication by nurses in Australia has seen the emergence of the Australian Journal of Advanced Nursing, Contemporary Nurse, and Collegian amongst others (McConnell and Paech,1993). Power is exerted by the medical professions over other health professionals and the community (Doering,1992; Henderson,1994; Holmes,1992; Irigiray,1985; Prottas and Batten,1988; Sholle,1988). While it is acknowledged that the fields of organ donation and transplantation are historically medically based (Drukker, Parsons and Maher,1986; Fisher and Raper,1990; Prottas and Batten,1988), the impact of other health professionals has enhanced the safe and improving management and delivery of transplantation (Stewart et al,1995).

The multidisciplinary team which manages organ donation and transplantation issues should ensure that it is not directed by the power of the medical profession, a view shared with Drukker, Parsons and Maher (1986). Knowledge is inherent in power. The knowledge base of the medical professions has traditionally expected acceptance and little argument with medical decisions, however medical issues are not the predominant concern, and are the weak link (Prottas and Batten,1988). The silencing of others has been a primary factor in the maintenance of power by medical (male dominated) professions (Doering,1992; Dzurec,1989; Henderson,1994; Irigiray,1985). The extensive practice of other health professionals into transplantation has incorporated a true multidisciplinary approach, along with ethicists, lawyers, economists and other non-health related professionals in the promotion and participation in transplantation (Evans, Orians and Ascher,1992; Prottas and Batten,1988; Stewart et al,1995), and accordingly the power should not be controlled by any one group. The researcher suggests that a change in focus would result in substantial funding cuts from the medical research surrounding renal disease, which has the potential to reduce the power of the medical base.

Limitations

The selected articles did not encompass a true picture of cadaveric organ donation and transplantation in Australia. The recommendations sought in the proposal objectives were to be specific to the ACT community, and this was not possible, due to the paucity of both published and unpublished materials. The few articles published about organ donation and transplantation left the researcher with no option but to use primarily medical articles.

In hindsight, the use of content analysis was not the best method to gain the information sought, nor were the chosen articles appropriate for the task either in number or in diversity. The inconsistency in using one chapter from a text, articles which had been published and others which had not, meant that there were differences in language and contexts. Findings are not generalisable, because of the different interpretations and foci expressed by the different authors.

The preliminary word counts utilised key words of 'issues' and 'factors' which were the terms recognised within the literature review as those most frequently used in relation to discussion about organ donation. Alternatives identified since include the following: aspects, problem, point, topic. Further content analysis of the articles using these terms may enhance the findings. The researcher had commenced the project with a preconceived belief that transplant coordinators make a difference to the organ donation rate (Tiller,1990), and some interpretation may be skewed towards this preconception.

As ACT figures are viewed within NSW figures for tabulation purposes within ANZDATA figures, it is difficult to extract ACT findings. In the 1994 ANZDATA report (Disney,1994), one finding was that waiting times for transplantation had increased, with a mean of one hundred and five weeks for NSW / ACT, eight weeks more than the next state. The researcher contends that at the onset of the current study, the mean waiting time in the ACT for cadaveric renal transplantation exceeded all other states and territories, and was hidden within the NSW figures. Cadaveric organ donation remains the primary solution to renal transplantation. The lack of cadaveric organs offered nationally, and at a territory level, was the driving issue underpinning this project.

Conclusion and Recommendations

Factors influencing cadaveric renal organ donation from a limited Australian perspective have been addressed. Major issues which emerged were an acknowledged shortage of cadaver organs, the failure of medical professionals to identify potential donors within hospital settings, and lack of community and health professional education about transplantation. Positive factors recognised included the improved quality of life reported by transplant recipients, and the suggestion that the presence of a transplant coordinator in the ACT would contribute to an increased organ donation rate. Although the impact of transplant coordinators on the utilisation and increase of transplants has not been quantified in Australia, the presence of transplant coordinators as integral members of the multidisciplinary transplant team has been confirmed by a number of authors. Sensitivity, competence, and compassion are the essential qualities needed by transplant coordinators to facilitate relatives to make informed decisions about cadaveric organ donation (Allen and Chapman,1994; Johnson,1990; NHMRC,1990; Pearson,1993).

The Australian Health Ministers' Conference (1995) was advised to develop a more integrated approach to organ donation, improving the skills and knowledge of transplant coordinators to facilitate people to make informed decisions about organ donation (AHMAC,1995). The issue of presumed consent has been tentatively explored in Australia, however the experiences of other countries have been explored in regard to the actual and potential impacts of presumed consent on organ donation. 'Reports from countries with presumed consent policies are ambiguous about whether such a presumption produces a substantial change in transplantation' (Veatch,1991:1247). Informed community support is essential; cultural, religious and social aspects of organ donation need to be explored prior to advancing to any legislative changes.

Opting out has also been suggested as an alternative option (Veatch,1991). Opting out requires the individual to inform the health authorities that the individual does not wish to donate organs. Thoughts about opting in or opting out systems, promotion of organ donation through media campaigns, education of health professionals and community, and possible financial remuneration for the donor through assistance in funeral costs have all been considered to some extent. Although the opting out system has been a focus of serious discussion in the UK, and is successfully practised by some European countries, 'it is unlikely that any significant benefits would result' (Stewart,1994:106; Armstrong,1993b). In consultation with the AKF, ACCORD agreed that the opting in system currently used could be better developed with financial resources directed towards public awareness campaigns (ACCORD,1993).

The donor's wishes should be recognised and acted upon (NSW Transplant Coordinators,1993), and Stewart (1994) recommended a national register for individuals to indicate their wishes. Currently, national interest is directed towards the effect on organ donations by the newly formed Victorian Donor registry. The current trial of a transplant coordinator network to identify potential donors [in South Australia,1995] yet to be assessed, is based on the successful Spanish network system, which experienced an increase in the donor rate from 14pmp to 25pmp in five years (ACCORD,1995c).

Also demonstrated in this study is that languages spoken within the texts are not the same, which disallows people from understanding issues in common. The importance of cadaveric organ donation cannot be overemphasised, and increased public awareness will assist in addressing the need. The premise of this project was to identify and describe the themes from the literature which influence cadaveric renal organ donation, and to develop recommendations for increasing the rate of cadaveric organ donation in the ACT by reiterating the need for increased awareness of cadaveric organ donation, and highlighting the effectiveness of transplantation on quality of life.

Awareness of the need for organ donation starts with informed education of health professionals, prior to widening the education of the community at large. Evans, Orians and Ascher (1992) affirm that education leads to gradual rather than immediate change to personal, religious and cultural barriers. Education for both individuals and their next of kin is recommended, in order to enable the family to make decisions about organ donation consistent with the potential donor's wishes (Armstrong,1993b; Veatch,1991).

Issues which have emerged are that people must be able to make informed choices about organ donation (AHMAC,1995). The positive factor about organ donation needs to be advocated - the quality of life enjoyed by transplant recipients. People who have received transplants are better able to be productive members of society. Communities also need to understand that organ donation and transplantation reduce health care costs.

Whilst the emphasis on factors influencing organ donation has been Australian-based, it has been imperative to observe the means by which other countries have maintained or improved their organ donation rates. In the USA, many states have passed legislation requiring donor status for each person entering hospital (Armstrong,1993b; Spital,1991). Documented problems include the concern that inexperienced personnel inadvertently discourage organ donation (Veatch,1991); disbelief that the institution has done its best for the potential donor (ACCORD,1995c; Veatch,1991); or based on religious beliefs (Veatch,1991).

Recommendations

Byth (ACCORD,1995b) and Pearson (1993) recommend that people previously discounted as donors due to age, should be considered by physicians or transplant coordinators before a decision is made to cease resuscitation. The change in focus would remove the overall emphasis from the young multi-organ donors alone. Possibilities to be considered are that the ACT could set up a Donor Registry similar to the Victorian Registry, potentially easier because of the small population within the ACT. Adopting the practice of required request on admission to hospital is certainly feasible due to the one hospital concept practised in the ACT.

The importance of identifying factors which influence cadaveric organ donation is clear. Without organ donation, transplantation cannot occur. Ramifications of not seeking to improve the organ donation rate in Australia are enormous in terms of individual and family, community and national costs. It is essential to recognise the impact of these issues on potential recipients, which will form the basis for a future study.

The primary position needed in the ACT to facilitate an improved organ donor rate is a transplant coordinator. A contributory factor to the lack of donor referrals is the difficulty perceived in approaching the relatives of a potential organ donor for permission to donate. Transplant coordinators are professionals dedicated to facilitating both organ donation and transplantation, and provide a wealth of knowledge and expertise in the ongoing care of the donor, the donor family, health professionals and the transplant recipient. The establishment of a transplant education program for the community and health professionals is essential for the ACT (NHMRC,1990; Pearson,1993; Allen and Chapman,1994).

Overwhelmingly, the findings indicate a need for further education, promotion of knowledge at both medical and community levels. These Australian findings are reinforced by need for further education for health professionals (Stewart,1994; Veatch,1991), and the promotion of knowledge at both medical and community levels (Stewart,1994). Education is a major component of the transplant coordinator's role, as it is practised in Australia.

This project forms the framework for preparation of a submission to ACT Health for the establishment of a transplant coordinator position for the ACT. 'Transplantation: the issues' has not been widely distributed within the ACT college system, and the researcher recommends that the ACT Department of Education avail itself of the package, and encourages its adoption within secondary schools as part of the curriculum. Recommendations from this project will be presented to the Director, Renal Unit at Woden Valley Hospital. A copy of the report will be made available in the ACT Health library.

> We need to continue discussions about the "gift of life". This donation should never become routine. It should always be regarded as what it is - one person's gift, allowing another to continue a productive life - perhaps the most generous act one human can make for another. (Tiller, 1990:35)

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Appendix 1

Multi-organ donor criteria

1. Age 0-70 years.
2. Has suffered complete and irreversible brain stem damage, resulting in brainstem death.
3. Is maintained on a ventilator.
4. Has no malignancy except primary brain tumour.
5. Has no major systemic sepsis.
6. HCsAg/HBsAg/HIV negative.
7. ABO compatibility. (NSW Transplant Coordinators, 1993:6)

Tests for brain stem death

1. The pupils are fixed and dilated and do not respond to sharp changes in the intensity of incident light.
2. There is no corneal reflex.
3. No vestibulo-ocular reflexes.
4. No motor response within cranial nerve distribution.
5. No gag reflex or reflex response to tracheal stimulation.
6. No respiratory movements occur when respiratory centre is stimulated.

(Allen and Chapman, 1994)

Appendix 2

Articles used in the content analysis of the study

ACCORD(1995).
'The Newsletter'. *Australian Coordinating Committee on Organ Registries and Donation,* 10:1-4.

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