

**A SURVEY OF
MEDICAL DOCTOR'S VIEWS
ON CADAVERIC ORGAN DONATION
AND TRANSPLANTATION**

By

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the degree of
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i

Dedication.

In memory of organ donors and their families who so generously give
'The Gift of Life'
during their time of need and tragedy.

Abstract.

The views of medical doctors regarding organ donation and transplantation in the Durban Metropolitan Region were examined in an exploratory and explanatory study, which included a descriptive, convenience sampled study of 43 graduate and postgraduate professionals, practicing in the private and provincial sectors. Characteristics were obtained from a 106-item questionnaire that were later divided into component contributions according to Fazio's attitude to behavior process model (Fazio, 1989; Fazio & Roskos-Eewoldson, 1994). Variables which were analysed included personal demographics, personal views, knowledge and skills, practice-related issues, attitudes and perceptions as well as future recommendations.

Analysis of the information revealed that most medical doctors approved of organ donation practices and viewed transplantation as a significant role-player in both the community and medical sectors. However, a knowledge and skills deficit combined with religious presumptions and general uncertainty regarding issues surrounding the practical, legal and emotional concepts of brain death may be responsible for the relatively low personal dedication and practice participation rate among the sample. Medical doctors from the provincial sector appeared to have considerable concerns which included: time constraints; a perceived lack of support from colleagues, nurses and hospital administrators; a lack of medico-legal awareness relating to organ donation and brain death and a scarcity of experience and insight into the transplant process.

In order to address the paucity of awareness pertaining to brain death and organ donation activities, the findings indicate that formal and interactive education programs during the undergraduate, postgraduate and medical development phases are required in which issues surrounding death and dying can be explored by a multidisciplinary team. It appears that this team must comprise of doctors, lawyers, religious leaders, psychologists, administrators, nurses, donor families and transplant co-ordinators. This development may serve to emphasize the professional importance of holistic bereavement counseling, improve doctor and patient satisfaction, increase organ donation referrals and transplantation rates as well as diminish medico-legal concerns.

Declaration.

This work has not been submitted in whole or part to any other university.

This work has been carried out by myself, Lindy Dickson and has been supervised by Prof. M. A. Dada from the Department of Forensic Medicine, Nelson R. Mandela School of Medicine, University of Natal Durban.

Date: 04 April 2002.

Signature:

A handwritten signature in black ink, appearing to read "L. Dickson".

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Table of Contents.

	Page
Dedication	i
Abstract	ii
Preface	iv
Acknowledgements	v
Table of Contents	vii
List of Tables	
List of Figures	
List of Appendices	
 Chapter 1 Orientation to the Study	 1
1.1 Introduction to the Study	1
1.2 Background to the Study and the problem statement	2
1.2.1 Background to the Study	2
1.2.2 Problem statement	9
1.3 Research Questions	10
1.4 Research Purpose	10
1.5 Study Goal and objectives	11
1.5.1 Goal	11
1.5.2 Objectives	11
1.6 Significance of the Study	12
1.7 Conceptual Definitions	13
1.8 Research design and methodology	14
1.8.1 Exploratory design	14
1.8.2 Descriptive design	14
1.8.3 Explanatory design	15
1.9 Construction of chapters	15
1.10 Summary	16

Chapter 2	Literature Survey	17
2.1	Introduction	17
2.2	Goal of the chapter	17
2.3	Literature survey	18
2.3.1	Death & dying	18
2.3.2	The community & organ donation	22
2.3.3	The medical profession & organ donation	23
2.3.4	Death as a definition & concept	25
2.3.5	Factors contributing to organ donation referrals & consent rates	26
2.3.6	Theories & models dealing with organ donation	28
2.3.7	Obstacles & hindrances to organ donation	29
2.4	Theoretical framework guiding the research	31
2.5	Summary	34

Chapter 3	Research Design & Methodology	36
3.1 Introduction		36
3.2 Goal of the Chapter		36
3.3 Research design and Methodology		37
3.3.1 Exploratory research		37
3.3.2 Descriptive research		38
3.3.3 Explanatory research		39
3.4 Sample number and population		39
3.5 Research setting		40
3.6 Questionnaires		40
3.7 Pilot Study		43
3.8 Method of data collection		45
3.9 Variables		46
3.10 Validity & Reliability		46
3.11 Limitations		47
3.12 Data capture & analysis		48
3.13 Ethical considerations		48
3.14 Summary		49
Chapter 4	Results of the study	50
4.1 Introduction		50
4.2 Goal of the chapter		50
4.3 Results		50
4.3.1 Personal Demographics		51
4.3.2 Personal views on organ donation		54
4.3.3 Knowledge and skills on brain death and organ donation		55
4.3.4 Practice related issues on brain death and organ donation		63
4.3.5 Attitudes and perceptions related to issues on brain death and organ donation.		66
4.3.6 Recommendations related to issues on brain death and organ donation		77
4.4 Summary		80

Chapter 5	Analysis, conclusions and recommendations from the results.	81
5.1 Introduction		81
5.2 Goal of the chapter		81
5.3 Analysis		82
5.3.1 Personal Demographics		82
5.4 Discussion framework		84
5.4.1 Previous behavior		85
5.4.1.1) Knowledge and skills with regards to previous behavior		85
5.4.1.2) Practice related issues with regards to previous behavior		89
5.4.2 Social images of what people / places who engage or are associated in engaging in certain types of behaviour (eg: prototypes)		92
5.4.3 Attitude		93
5.4.3.a) Personal views on organ donation		93
5.4.3.b) Personal views on brain stem death		94
5.4.4 Whether others engage in this behavior (Subjective norms)		96
5.4.5 The extent to which a person is willing to perform these actions under a variety of different circumstances (Behavioral willingness)		98
5.4.6 What individuals plan to do in the future (Behavioral intentions)		100
5.5 Conclusions		100
5.6 Limitations		104
5.7 Recommendations		105
5.8 Implications of finding		106
5.9 Recommendations for further research		107
5.10 Final summary		108
References		110
Appendices		119

List of Tables.

1.1	Construction of the chapters of the research.	15
	4.3.1 Personal Demographic responses.	51
4.1	Country of upbringing	51
4.2	Medical school attended for undergraduate studies	52
4.3	Years practised as a medical doctor	52
4.4	Presence of postgraduate qualifications	52
4.5	Medical school attended for postgraduate studies	52
4.6	Field of current specialisation	52
4.7	Classification of current practise	53
4.8	Hospitals currently most frequented for medical practise	53
4.9	Gender group classified as	53
4.10	Age in years classified as	53
4.11	Population group classified as	53
4.12	Faith or religion followed	53
4.13	Degree of personal religious importance	54
	4.3.2. Personal views on organ donation.	54
4.14	Classification of self as an organ donor	54
4.15	Organ donor card carrying status	54
4.16	Family discussion regarding organ donor wishes	54
4.17	Acceptance of brain death diagnosis, if made on close relative	54
4.18	Preparedness to donate organs of brain dead close relative	54
4.19	Organs and tissues most inclined to donate	55
4.20	Organs and tissues least inclined to donate	55
4.21	Preparedness to personally receive organs of donor, should organ failure occur	55

4.22	Perception of the existence of community pressure on people to be organ donors	55
	4.3.3. Knowledge and skills on brain death and organ donation.	55
4.23	Reception of any formal training on brain death and organ donation	55
4.24	Situation in which formal training was acquired	56
4.25	Standard of formal training received	56
4.26	Other sources of information acquired on brain death and organ donation	56
4.27	Personal rating of knowledge and skills regarding brain death	56
4.28	Personal rating of knowledge and skills regarding The Human Tissue Act	57
4.29	Personal rating of knowledge and skills regarding donor selection and criteria	57
4.30	Possibility of certifying brain stem death while NOT on a ventilator	57
4.31	Possibility of certifying brain stem death while having seizures	57
4.32	Possibility of certifying brain stem death by cerebral angiography, if for any reason clinical testing cannot be performed	57
4.33	Possibility of certifying brain stem death by use of an electroencephalogram in the ICU setting	58
4.34	Possibility of a person dying from unnatural causes (eg: gunshot head from a hijacking) legally being permitted to being an organ donor	58
4.35	Possibility of a five year old patient being suitable as an organ donor	58
4.36	Possibility of a patient with hyperthyroidism being suitable as an organ donor	58

4.37	Possibility of donating corneas from someone who has had no pulse for 6 hours	58
4.38	Possibility of donating kidneys from someone who has had no pulse for 6 hours	59
4.38	Possibility of pathophysiological changes resulting from brain death causing organ damage	59
4.39	Relevance of time period between brain stem death and organ recovery	59
4.40	Time on the death certificate when certification of brain stem death is completed at 08h00 and organ procurement is completed at 12h00	59
4.41	Organs and tissues currently transplanted in KwaZulu-Natal	59
4.42	Hospitals currently transplanting solid organs in KwaZulu-Natal	60
4.43	What the Human Tissue Act No 106 of 1994 specifies in relation to the personnel involved in diagnosing brain death	60
4.44	Prerequisites to be satisfied prior to one conducting the brain stem death tests	60
4.45	The clinical tests used to determine Brain Death	61
	4.3.4. Practise related issues on brain death & organ donation.	62
4.46	Number of patients attended to in a year with a GCS <7/15	62
4.47	Action taken after confirming brain death	62
4.48	Personal efforts in contacting the Transplant co-ordinators	62
4.49	Methods used in contacting the Transplant co-ordinators	63
4.50	Number of experiences with the Transplant team	63
4.51	Quality of experiences with the Transplant team	63
4.52	Greatest concerns when contacting the team or referring a patient	63
4.53	Most positive aspect of involving the transplant co-	63

	ordinators in the treating team	
4.54	Degree of support received with regards to referring a patient as a donor from medical colleagues	64
4.55	Degree of support received with regards to referring a patient as a donor from hospital administrators	64
4.56	Degree of support received with regards to referring a patient as a donor from nursing staff	64
4.57	Patients least likely to be referred to the transplant co-ordinators following brain death certification	64
4.58	Reason identified for non-referral of above stereotypes	65
4.59	Involvement in caring for transplant recipients	65
4.60	Relationship with a friend or close colleague who is a transplant recipient	65
4.61	Relationship with a friend or close colleague who belongs to the transplant team	65
4.62	Possibility of referring more brain dead patients to the co-ordinators if personal knowledge on organ and tissue donation was upgraded	65
	4.3.5. Attitudes & perceptions related to issues on brain death & organ donation.	66
4.63	Medical & Clinical guidelines for deciding if a patient is brain dead are well established	66
4.64	Transplantation is expensive, tertiary care medicine that is unacceptable in a developing country such as ours	66
4.65	Chronic dialysis treatment is <i>more</i> cost-effective than Transplantation	66
4.66	Lung Transplantation is cost effective and has excellent results	67
4.67	The Transplant team is accessible to all hospitals in KZN who have potential donors	67

4.68	Organ donor referral, organ donation and procurement in KZN is a private hospital phenomenon	67
4.69	Access to organ transplants in KZN is afforded equally to private & provincial patients	68
4.70	Doctors <i>don't</i> like to become involved in making end of life decisions	68
4.71	Doctors experience a sense of personal failure when a patient under their care becomes brain dead	68
4.72	The doctors I work with think it is important to request organ & tissue donations from the families of potential donor	69
4.73	It has <i>failed</i> to be communicated that active assistance in organ procurement is a positive professional duty	69
4.74	Organ & tissue donation is a positive option for the family at the time of death of a loved one	69
4.75	Organ donation helps families grieve and in the long-term can take the senselessness from a sudden tragedy	70
4.76	I don't personally feel at all comfortable requesting consent for organ or tissue donation from a grieving family	70
4.77	I feel it is more beneficial for the family and the health care team for the specially trained procurement co-ordinator to request consent for organ or tissue donation	70
4.78	Donor families would see somewhat of a conflict of interests for the primary doctor to approach them about organ donation	71
4.79	My medical colleagues are proficient at handling end of life decision making and breaking bad news to families	71
4.80	I find organ donor referral and management activities too time consuming	71
4.81	I have a concern as the primary doctor, regarding my legal liability in the organ donation and procurement process	72

4.82	I would rather withdraw from care in a GCS 3 patient, than continue care with the option of organ donation	72
4.83	Looking after an organ donor is part of my professional responsibility to the community, as other lives may be saved	72
4.84	Looking after an organ donor occupies an ICU bed and consumes resources, which could be used for the living	73
4.85	I see organ donation as more of a sacrifice than a gift	73
4.86	I believe that the donor should still receive an anaesthetic during procurement, even though he / she has no pain response or perception	73
4.87	Brain stem death certification is absolute and has never yielded any "survivors" in international studies	74
4.88	The organs are recovered in a very professional, respectful manner	74
4.89	The organ procurement team behave ethically and responsibly	74
4.90	The body is treated with dignity at all times	75
4.91	The procurement operation is conducted by specialist surgeons under strictly sterile conditions	75
4.92	The family has the right to be given the option of organ donation, just as they have the right to choose cremation or burial for their loved one	75
4.93	At the funeral, an open coffin is possible following organ and tissue donation	76
4.94	Organ donation is costly for the donor family or donor medical aid, who cover the costs of the organ procurement	76
4.95	It would be a good idea in South Africa, if heart beating or non-heart beating donor referrals were made mandatory by law, in order to increase the availability of organs	76

	4.3.6. Recommendations related to issues on brain death & organ donation.	77
4.96	Where should education regarding Organ Donation & Transplantation be introduced in the undergraduate Training programme?	77
4.97	Under which discipline do you see this topic most belonging to?	77
4.98	Would you like to see more in-service education / info on this topic?	77
4.99	If you answered yes to the above question, where would you like to see this incorporated?	77
4.100	In what format?	78
4.101	If there was a form at the ICU / Trauma facility in which you worked which outlined the prerequisites and each brain stem death test with its clinical details and incorporated an area for you to sign each test off as positive / negative, would you use the form?	78
4.102	If you answered 'yes' to question 102 above, which reason would most encourage you to use the Brain Stem Death Criteria form?	78
4.103	If you answered "No" to the question above, which reason would most discourage you to use the Brain Stem Death Criteria form?	79
4.104	If there was a page attached to the form mentioned with simple diagrams to assist you to explaining the concept to relatives, would you find this useful?	79
4.105	If there was a page attached to the form mentioned in question 102 which consisted of a page for the family to take home, which explained brain stem death in easy to understand terminology, would you find this useful?	79
4.106	Would you like to know the outcomes of the study?	79

List of Figures.

	Page
1. The Gift Exchange Theory, as applied to the process of cadaveric organ donation and transplantation.	29
2. Fazio's attitude to behaviour process model.	32
3. The Gift Exchange Theory, as applied to the process of cadaveric organ transplantation with the roles of gatekeeper from the referral facility clarified.	101
4. The adapted Fazio's attitude to behaviour process model for organ donation behavior by medical doctors.	103

List of Appendices.

- A The Durban Metropolitan Region
- B Research Questionnaire
- C Self reply indicator
- D Brain stem death testing

Chapter 1

*'Man has never made any material as resilient as the
human spirit.' - Bern Williams -*

CHAPTER 1.

ORIENTATION TO THE STUDY.

1.1. Introduction to the study.

Hundreds of years BC, Chinese physicians had already thought of organ transplantation. Even before the twentieth century, the patron saints of medicine, Cosmos and Damien were recorded to replace damaged or absent limbs with those from whom 'had recently succumbed' (Lerut & Roggen, 2000). Numerous physicians persisted over hundreds of years, usually in vain, to implant and replace human tissue which would offer its host at very least a few additional weeks of survival, and at best a visionary new lease on life altogether. It appears that man's quest to stay alive has resulted in numerous remarkable developments and successes occurring in the field of medicine. For the world of transplantation, the specialty has grown to the point where it has become a victim of its own success. With thousands of successful transplant operations now being performed across the world annually, many more thousand await this opportunity, while hundreds die on waiting lists, or in some countries, lack access to transplant programmes altogether (Li et al, 1997).

While chronic disease continues to present itself in increasing proportion to the world's population, many of who are disadvantaged from a variety of factors, end organ failure will continue to feature as a reality in the health

care system (Moore, 2000). Where end stage organ failure is concerned, following prevention and community development strategies, the next most financially, socially and economically beneficial intervention, where possible, is one of rapid client transplantation and community reintegration (Solomon, 1999).

A combined and committed approach from the multidisciplinary team (as outlined in the following paragraph) and community members is imperative if the impact of chronic disease to the country is to be minimised. With team members functioning together, it is also important for professionals in each of the disease intervention areas to focus on examining current practises and obtaining input into improving the contribution of each component to the chronically ill client and to his or her significant others.

1.2. Background to the study and problem statement.

1.2.1. Background to the study.

It is not within the scope of nursing research to conduct studies on medical doctors, but due to the reasons outlined in this chapter, it has become essential that both nurses and medical doctors be included in facilitating the process of organ donation and procurement. Nurses are not legally able to diagnose patients as brain dead, as the Human Tissue Act prescribes that these tests be conducted by two medical doctors, one of whom must be qualified for more than five years (Human Tissue Act No. 106 of 1984).

However, nurses work closely with doctors in the critical care setting and are usually involved in multidisciplinary team decision-making, family liaison and the assistance in performing procedures such as brain death testing. American studies published in nursing journals are found to utilise both nurses and medical doctors in the research sample and researcher team, in order to report on situations regarding organ donation in the critical care setting (DeJong, Franz, Wolfe, Nathan, Payne, Rietsma, 1998; Evanisko & Beasley, 1998).

Serving as a nurse consultant in the capacity of KwaZulu-Natal Regional Transplant Manager entails one encountering a number of interesting and pressing issues in the line of ones work. The position affords one the unique opportunity of working side by side with a dynamic team which include surgeons, technicians, intensivists, nephrologists, cardiologists, pathologists, nurses, clients, grieving families and managers from a variety of different settings and facilities. One of the main objectives of the position entails optimising and increasing quality organ procurement³. Through organ procurement efforts, transplantation of the many awaiting recipients can be realised and organ donor families are able to receive a commonly reported sense of compensation or purpose for an apparently senseless and often young loss of life (Douglas & Daly, 1991; Matten, 1991).

Currently, the Transplant team is faced with the situation of having a mere 1,3 actual organ donors per million population to save or improve the lives of some 800 patients requiring a graft or transplant⁵ in the province (Rossi,

2001) at any one time. For instance, patients in renal failure face unpredictable and debilitating waiting periods, which may range from anything from a week to 10 years. Prior to this waiting time, patients (who are often parents and bread-winners) are assessed in order to determine whether or not they have the finances or health status to afford them the life-maintaining option of dialysis while they wait for a transplant. This costly form of tertiary health care has been quoted at costing in the region of R10 000,00 or \$50 000 per patient, per month and is denied to as many as 1 in 10 patients who present for selection (Crosby & Walters, 1974, Moore, 2000).

Patients in end-stage organ failure are usually aged from 30 to 55 years, but many younger patients including children are presenting to the team. For patients turned away from dialysis, they face an agonising death over a period of days to months with seizures, confusion, headaches, breathlessness and cardiac rhythm disturbances. In addition, these patients and families face rejection and discrimination as they are prevented from obtaining access to life saving health care, which has been promised by the state to the people (Soobramoney v Minister of Health, KwaZulu-Natal 1998 [1] SA 765 [CC]). For patients afforded the option of dialysis, these people who are usually employed, need to negotiate as many as three days a week away from work, often without wages.

Due to the scarcity of dialysis centres, many patients may also have to travel in excess of 100km to reach dialysis, incurring great transport costs in the process. While waiting for a transplant, these patients struggle to cope with

the severe effects of living with a chronic, life threatening illness while trying their best to work, raise children and participate actively within the community (Rowbotham, 2001).

A transplant not only offers these families the option of regaining their quality of life, but also offers the state or privately administered medical aid schemes the chance to save an average of R4 000,00 or \$2 000,00 per patient per month, from the ninth month after transplant (Ingram, 2000; Moore, 2000). In addition, it may save the state an additional R4 500,00 per patient, per year in disability grant aid. The financial benefits of transplantation versus chronic dialysis or care for a patient with end organ failure have become so pronounced that in the United States, hospitals are penalised by the medical funding agencies, if they fail to identify and request organ donation from potential donors (Matten et al, 1991). For hospitals and dialysis centres, for every one donor and therefore two kidney transplants, two additional dialysis slots can be opened up for two more people who in the state sector would otherwise be turned away to face certain death.

According to The ANC's National Health Plan for South Africa, (1994), health services were to be made available for all South Africans, giving priority to the most vulnerable groups, which included maternal and child care, environmental protection, rural services, women's health, mental health, occupational health, chronic illness and the care of the disabled. In general, organ failure patients usually fall into at least two of the above 'vulnerable group' categories, and require health promotion and curative services in

order to reintegrate them back into the functional work and home environment.

Due to my role as a patient advocate both in my profession and in the community, it causes me great concern to see patients turned away from life-saving treatment. In addition, it is also quite obvious that in order to increase patient health and welfare and decrease the burden of end stage organ failure on the state coffers, the option of transplantation needs to be offered to an increasing number of individuals.

While the emphasis on primary health care and disease prevention by the government is commendable, this should not marginalize the health status of other sectors of equally deserving citizens. Furthermore, it is my impression that most of the patients facing end stage organ failure have possibly been failed by the government in having access to primary health care and health education in that they often have undiagnosed, untreated hypertension or diabetes, have received poor antenatal care in the face of maternal complications or have had delayed emergency care following traumatic injury. Although primary health care may be seen as the most vital aspect facing South Africa today, we should also be mindful of achieving the progressive realisation of rights as envisaged by our constitution and expanding our collective health care vision to eventually (in the not too distant future) cater for the health care needs of all South Africans (Constitution of the Republic of South Africa Act 108 of 1996 s 27 [2]).

Whilst it may not be possible for our particular team to prevent the cause of organ failure, it becomes imperative for us to strive to create opportunities in order to cater for the health care needs of all persons presenting to the transplant programme with organ failure. The only manner envisaged which will enable us to do this, is to optimise and increase our transplant programme and fast track these afflicted individuals back to the community in optimal health. In realising this ideal, it becomes important for us as nurses within our role as health care professionals to understand the strengths and weaknesses at play if one is to try to facilitate change and development in this area.

The ANC's National Health Plan for South Africa (1994) encouraged the active co-operation and team participation between the private and public sectors in the country. Transplantation is one area where both sectors strive and continue to uplift their developments and successes in this collaborative challenge. The nursing component of the team has had a major role to play in this optimal partnership, and continues to examine new ways of addressing and furthering the plight of all patients.

The persistent shortages of cadaver organs have prevented transplant units from treating many patients. Surveys of hospital deaths in the local and international literature report that an average of 70% of potential organ donors are 'missed' and are never actually referred to procurement staff (Matten et al, 1991; Prottas & Batten, 1988). A lack of support, awareness and clarity among health care professionals regarding fundamental issues

surrounding potentially suitable organ donors may be a contributing factor to the existing shortage of cadaver organs (Koop, 1983).

The issues surrounding end of life decision-making involving organ donation and transplantation are complex. Little empirical evidence is available on the skills, attitudes and perceptions that underlie such decisions in local provinces and cultures. While many studies focus on the skills, attitudes and perceptions of nursing staff towards organ donation and transplantation, it has been found both in South Africa and in other studies, that the medical doctor is in fact the most critical and influential gate keeping figure in the organ procurement process (Gibson, 1986; Prottas & Batten, 1988).

While most health care professionals report a positive attitude towards organ donation and transplantation, it has been found in numerous international studies that the knowledge base of these personnel did not support or assist in practically applying donor identification, referral or management (Crosby & Walters, 1972; Matten et al, 1991; Kent & Glynn-Owens, 1995; Watkinson, 1995). Furthermore, it has been established that "Untrained staff may be struggling with their own feelings of loss or discomfort, rather than concentrating on the needs of grieving families. Trained staff understand their roles, know how to coordinate with their organ procurement organisation and endorse the idea of decoupling. They are much more likely to obtain consent from a family." (Evanisko & Beasley, 1998)

Donor organs have been identified as a scarce national resource. Every effort should be made to optimise systems surrounding their identification, nurture and recovery. An insight into the views of medical doctors in the Durban Metropolitan region may assist local procurement and health education facilities to identify strengths and weaknesses in existing programs and develop an evidence based approach to cater more effectively for the local information and communication needs of medical doctors in order to enhance the organ procurement process.

1.2.2. Problem statement.

"The medical doctor is in fact the most critical and influential gate keeping figure in the organ procurement process" (Gibson, 1996; Prottas & Batten, 1988). As the demand for donor organs continues to exceed available supplies, it becomes necessary to optimize and nurture the scarce resource. With an ever-increasing number of people recognizing this need and signing up as organ donors, the same attention does not appear to be occurring within the medical profession. At present, for every donor identified and referred to procurement specialists in the DMR², a further estimated 500 are never recognized or considered. However, the views that are expected to influence the behavior which medical doctors¹ in the DMR² display towards cadaveric organ donation⁴ and transplantation have not been investigated. In addition, nursing learning programs or curricula are based upon procedures which doctors perform. If the process of brain stem death certification and organ donation is not correctly and proficiently performed,

nurses themselves may be at increased risk for professional liability incidences.

1.3. Research questions.

From the above, the following research questions were asked:

- How do medical doctors in the DMR view issues surrounding cadaveric organ donation and transplantation?
- What variables such as experience, education and personal traits could possibly contribute to the establishment of such viewpoints?
- Which recommendations and suggestions do medical doctors make with the view to improving educational and practical resources for current and future practice?

These questions will be answered by means of the research design and methodology (see 1.9.).

1.4. Research purpose.

The purpose of this study is to describe the nature and variability of the views that medical doctors in the DMR display towards cadaveric organ donation and transplantation. The variables include characteristics surrounding personal demographics, personal views on organ donation, knowledge and

skills training, practise related issues, attitudes and perceptions and personal recommendations. It is hoped that by describing and recognising the views expressed by the local medical doctors¹, procurement personnel will be able to begin to optimally address and improve current contributions and relationships between the different disciplines. It is likely, that if knowledge, understanding, communication and cooperation is strengthened, that an increase in donor referral and organ procurement may be realised within the region.

1.5. Study Goal and objectives.

1.5.1. Goal.

- To conduct a survey of the title: Medical doctors views on cadaveric organ donation and transplantation.

1.5.2. Objectives.

- To explore the literature on organ donation, organ procurement and transplantation.
- To compile a questionnaire, based on literature findings.
- To utilise the questionnaire, in order to determine the medical doctors views on cadaveric organ donation and transplantation.

1.6. Significance of the study.

The significance of the study is that examining medical doctors views has been highlighted as an important local contribution towards furthering the donor action programme in the region. The donor action programme is the brainchild of the Spanish model of organ procurement and organ donation. The Spaniards, seen as the world leaders in organ procurement, have increased their organ donor availability from ten donors per million population to 30 donors per million population over a four year period. They have achieved this based on the following, as adopted by the United States of America (O'Connor, 1999):

- Upgrade federal regulations and policies focused on organ procurement and assist hospitals to meet the new changes.
- Build hospital commitment and view organ donation as a synergy and a quality indicator.
- Optimise and promote timely and positive family communication by facilitating a collaborative, multidisciplinary care support team.
- Offer interdisciplinary educational seminars to ambulance and emergency, intensive care and high care staff.
- *Survey clinician knowledge, attitudes and beliefs to motivate participation and serve as a base line for future comparisons.*

Currently, there is no national or local insight into what these views are, nor is there any evidence to suggest what the nature, strengths or weaknesses of

the knowledge, skills or attitudes may be. Without this feedback, it would be difficult to recommend or embark on any sound educational programmes or communication strategies without examining local needs, recommendations and conclusions that this study may yield.

1.7. Conceptual Definitions.

Conceptual definitions included concepts in the research title and are:

¹ Medical Doctors, who may include *graduate* professionals, having registered with the South African Medical and Dental Council following a programme leading to MB ChB or similar qualification or *postgraduate* professionals in possession of specialist degrees and / or postgraduate certificates or courses.

² The Durban Metropolitan Region, otherwise known as the DMR, consists of the geographical region in KwaZulu-Natal, which is bordered by Tongaat in the North, Illovo in the South and Inchanga in the West. It is divided for statistical purposes into six subregions (Department of Transport, 1999). See Appendix A.

³ Procurement, which involves the medical specialisation and activities relating to the process of organ recovery. This process centres on education and guidance of health professionals and includes donor identification,

referral, management; screening, family and state pathologist consent acquisition, theatre preparation and surgical support.

⁴ **Cadaveric Organ Donation**, which is the process by which organs and tissues donated by the next of kin following the death of a relative through the process of either brain death or cardiac death are expressly made available for surgical recovery and transplantation into a fellow human being in need of such a tissue or organ.

⁵ **Transplant**, that is the term given to the surgical procedure whereby an organ or tissue is transferred from either a live or cadaveric donor to a recipient of the same species who is genetically non-identical.

1.8. Research design and methodology.

An exploratory, descriptive and explanatory design was utilised in the research.

1.8.1. Exploratory design.

The literature was explored in order to compile the contents for the questionnaire.

1.8.2. Descriptive design.

A questionnaire was implemented which enabled the researcher to identify doctors views on organ donation.

1.8.3. Explanatory design.

The questionnaire was analysed in the format of tables and conclusions were made, which enabled the researcher to compile recommendations. (See Chapter two for a complete description.)

1.9. Construction of the chapters of the research.

TABLE 1.1.

CHAPTER:	PURPOSE:
One	Overview of the research.
Two	Literature study.
Three	Research design and methodology of the study.
Four	Description of the results.
Five	Analysis, conclusion and recommendations, based on results.

1.10. Summary.

In this chapter, an introduction and background to the study are provided and an overview of the research problem, questions, purpose, goal, objectives and significance are outlined. Operational definitions, which clarify terms utilised in the title and framework of the study, are provided.

It was determined that based on the problem formulation and the research question, that the objectives of the study were to explore the literature on organ donation, organ procurement and transplantation; compile a questionnaire, based on literature findings and then utilise the questionnaire, in order to determine the medical doctors views on cadaveric organ donation and transplantation.

In chapter two, the literature study for the foundation and compilation of a reliable, valid questionnaire for the determination of medical doctors views of cadaveric organ donation and transplantation would be established.

Chapter 2

*'This is our purpose: to make as meaningful as possible
this life that has been stowed upon us,
To live in such a way that we may be proud of ourselves,
To act in such a way that part of us lives on.'* -Oswald Spengler -

CHAPTER 2.

LITERATURE SURVEY.

2.1. Introduction.

The literature survey serves to identify, analyse and synthesise independent sources of information on a subject, in order for a comprehensive overview of the current knowledge base pertaining to a particular topic to be realised (Burns & Grove, 1999). The term is used to designate a written summary of the state of the art on a research problem (Polit & Hungler, 1997). Such a search can also function to reveal methods and ideas utilised on similar studies as well as to serve as a comparison with the proposed research.

2.2. Goal of this chapter.

This literature study was structured around obtaining information from similar research and questionnaires pertaining to end of life decision making and organ donation from a medical doctors perspective, in order to structure a valid questionnaire from which doctors views on cadaveric organ donation and transplantation could be determined. In addition, it examined different models and perspectives from which viewpoints may be derived and explored frameworks through which specific contributions that may influence the doctor's behaviour can be systematically explored.

2.3. Literature survey.

2.3.1. Death and Dying.

In exploring the central issues surrounding the concepts of organ donation and transplantation, two inevitable situations arise: The end or death of one life, and the renewal or salvage of another. It is well explained that transitional life experiences, for example, birth, death and marriage prove stressful for those involved in the process (Kubler-Ross, 1997). Due to the sense of a lack of control that one has over these events, many rituals, beliefs, customs and suspicions have arisen from them over time in order for those involved to experience *perceived* control, which is of vital importance in mitigating the effects of the stressor (Baron & Byrne, 2000; Sue, Sue & Sue 1997). Most people associate these life stages with extremes of emotion, danger, uncertainty, a degree of crisis, a time for family support and a need for solace and protection.

Death itself has always been universally perceived as distasteful to people and has been associated with bad spirits, frightening happenings and something that often requires retribution and punishment (Kubler-Ross, 1997). Modern scenes of dying are often perceived as more gruesome than those experienced in previous decades, namely being attributed to increased loneliness, mechanical support, individual powerlessness and dehumanisation (Kubler-Ross, 1997). Since most transitional events now occur within a medical setting, the medical doctor is often involved in

accompanying patients and families through stages such as the end of life (McPhee, 2000). However, many doctors are reported to be strangers to the real issues of dying, because they have been taught to diagnose, treat and cure the living (Louw, 1991; Kubler-Ross, 1997).

All too often, clinicians report feeling out of place when negotiating the complexities of family dynamics, terminal symptoms and treatment goals in the dying patient (McPhee, 2000). Many doctors report feeling deeply troubled and uncomfortable around the intense emotions evoked by the family. Many also perceive death as a personal defeat or professional failure (vonGunten, Ferris & Emanuel 2000). These challenges to medical doctors should not be surprising, as several studies have documented that end-of-life care is very inadequately taught at medical school. In the United States of America, only 26% of programmes offered any training at all on communicating bad news to families or coping with death and dying (McPhee, 2000; von Gunten, Ferris & Emanuel 2000). As a result, discussions about end-of-life issues are difficult for physicians to initiate, and some even report avoiding these issues all together (McPhee, 2000).

Similarly, death in modern westernised society has also become less part of everyday life for the community, in that many sick people are restored to health, and most dying people are removed from their homes and nursed in restricted high care areas, away from family members (Louw, 1991). With death becoming an increasingly unusual and removed occurrence, people are found to speak far less of the event and issues surrounding it than in

previous generations where it was fairly common in conversation and presented itself to most families usually from an early age (Kubler-Ross, 1997; Louw, 1991). In many communities in South Africa, the situation is again changing in that many AIDS patients are currently dying at home, especially in rural areas, unfortunately not usually without stigma and denial.

In a society which appears to be bent on ignoring and avoiding death, Kubler-Ross (1997), found that in attempting to conduct seminars on death and dying within a hospital, her efforts were met with discomfort, annoyance and even overt hostility by ninety percent of doctors who were approached for their permission for the researcher to access terminally ill patients under their care. Even after these doctors listened to the proposed programme and attended the seminar personally, they then usually only referred patients as a special favour to the researcher. Over time, however, the displaced anger and hostility, although difficult to accept, was observed to be replaced with improved attitudes. Interestingly, the nursing staff attitudes changed more quickly than those of the doctors. The nurses acknowledged their conflicts more easily than the doctors and expressed a great lack of training in this area as to their role in the face of such crisis. They were also more willing to learn and attend the seminars.

Kubler-Ross (1997) also found that two subgroups of doctors were more able to listen and calmly talk about death. These were the very young in the medical profession who had either experienced a death of a person close to them and worked through this loss, or who had attended the death and dying

seminars over a period of several months. The other smaller group of older doctors were presumed to be brought up in the older generation, which used fewer defence mechanisms and faced death more often as a common holistic reality. The patients and families involved in the seminars and specialised care expressed great appreciation and worth in the experience offered. Kubler-Ross (1997) concluded that with regards to attitudes and practises on death and dying are concerned, where the obstacle and fear is great, so the need is as great.

Unfortunately, with organ donation being an end-of-life issue, the topic receives a similar avoidance and lack of attention. In addition, poor communication patterns and input from medical staff prior to the death of a loved one is often associated with a failed consent for organ donation, (if the next of kin are approached), due to decreased family understanding, fulfilment and trust. The family may also be denied the opportunity to reduce the impact that the stress has on them, by not being able to identify possible options and choose among them with the support of the treating team (Baron & Byrne, 2000). Competency and achievement in successfully managing end of life care challenges may strongly enhance the doctor's professional and personal fulfilment and may positively reinforce the essential role which this neglected area of medicine has received (vonGunten, 2000).

2.3.2. The community and organ donation.

Studies show that attitudes and beliefs of the lay public often mirror those of health care professionals (Gibson, 1996). This is not surprising, since they come from the same communities, but is interesting in that their superior medical knowledge base does not dramatically affect their choices. Many studies have focused on what factors influence donor families to consent for organ donation. Factors have been shown to vary from those of higher educational background to the degree of trust the family has for the attending hospital team and have included being of ethnic majority in a country and having had conversations with loved ones prior to death regarding ones wishes. Unfortunately, these studies have been conducted in countries outside of South Africa, where different practises, cultures and religions would prevent the findings from being generalised locally.

Professionals are found to be generally in favour of organ donation in abstract, but view it less favourably when confronted by it personally (Bidigare & Oreman, 1991). Factors that have been shown to facilitate organ procurement by medical doctors or nurses include a personal commitment to organ and tissue donation, as evidenced by signing and carrying ones own card; the perception of the health professionals own family towards organ donation, the attendance and completion of an organ and tissue donation training program and a perception of personal confidence and comfort in making a request for donation.

2.3.3. The medical professional and organ donation.

A major factor in the retrieval of organs is the ability to recognise potential donors, yet studies reveal that many nurses and doctors were unable to do this (Bidigare & Oreman, 1991; Sophie, 1983; Youngner & Landeveld. 1989). Griffin (1992) in a Johannesburg study cited the reason for the poor 12% referral rate of potential donors to be due to a combination of a lack of staff education on procurement issues and staff apathy in contacting the transplant coordinators. This situation appears not to have significantly improved from a 1972 Crosby and Walters study of Hospital staff attitudes to cadaveric kidney donation where it was found that apprehensions about the practical implications of organ donation and transplantation were common in doctors and nurses. These practical implications of qualified staff tend not to be related to the support for transplantation, nor the acceptance of brain stem death criteria, as found in a Doctor-based German study by Schweidtmann & Muthny in 1997. This is an interesting observation, since first year medical students in Germany *did* cite their main concerns in these two areas, suggesting a change in concerns identified, with progress in medical understanding and situational exposure (Laederach-Hofmann, 1998). Strong interest in organ donation and transplantation was identified in this early student group, with the author recommending an increase in information given to students even at this early stage of their training.

The United Kingdom Transplant Support Service Authority suggests that donation rates are dependent upon the interest of health care professionals

within the clinical areas (Kent & Glynn-Owens, 1995). There appears to be a strong hesitation towards dealing with donor families, especially among medical doctors who perhaps paradoxically appear to have the strongest influence on the attitudes of all other hospital staff towards organ donation (Douglas & Daly, 1991; Matten et al, 1991; Prottas & Batten, 1998).

In a 1991 American nursing study, less than a third of nurses agreed that the doctors they worked with thought it was important to request organ and tissue donation from the families of potential donors (Matten, Sliepcevich, et al, 1991). In addition, a national survey of public attitudes toward organ donation found that physicians were not seen to be an important source of information about organ donation in the community (AMA 2001). In a Massachusetts study in 1998, it was found that the vast majority of doctors and nurses working in critical care settings had an unexpectedly low factual knowledge about organ donation and brain death. The same findings are noted in a Portuguese study, where doctors are personally supportive of organ donation, with 82% unfamiliar on the country's laws on the subject, and 55% uncertain as to what the medical criteria were for donation (Coelho & Fontan, 1994). An Ohio survey confirmed this again by finding that 65% of respondents incorrectly identified the legal and medical criteria for determining death (Youngner & Landeveld, 1989).

2.3.4. Death as a definition and concept.

The diagnosis of death has been described as the irreversible loss of consciousness and the loss of the capacity for spontaneous respiration (The ad hoc committee of the Harvard Medical School, 1968). The introduction of mechanical ventilators that prevent respiratory arrest has transformed the natural course of terminal neurologic disorders (Wijdicks, 2001). The result of this introduction of mechanical ventilation is that brain death, (defined as complete, irreversible loss of brain stem function), can occur in the presence of residual circulatory perfusion of the deceased patient. The result is a rare opportunity presenting to a mere estimated 3% of the population of deaths in which the next of kin are able to opt for the donation of functioning solid organs (heart, lungs, liver, kidneys) from their deceased loved one in order to give the gift of life to other human beings.

In order for brain death to be diagnosed, internationally recognised brain death testing must be conducted, prior to which certain prerequisites and regulations must be strictly adhered to. These regulations are specified by The Human Tissue Act No. 106 of 1984 as well as by international consensus committees and position statements on death and brain death (Capron, 2001). To view the process and techniques conducted in brain death testing, see Appendix D. Should the family not wish to opt for the option of organ donation, active resuscitative treatment such as the administration of inotropic support, high dose oxygen and large volume fluid replacement is usually discontinued or not initiated and the body continues

the dying process in a matter of minutes to hours (Inwald, Jakobovits & Petros, 2000; Wijdicks, 2001).

2.3.5. Factors contributing to organ donation referrals and consent rates.

It has been repeatedly highlighted that staff training was the greatest independent variable when looking at the organ donation performance of a hospital (Coelho & Fontan, 1994; Evanisko & Beasley, 1998; Johnson et al 2001; Schweidtmann & Muthny, 1997). This was attributed to the fact that "untrained staff may be struggling with their own feelings of loss or discomfort, instead of concentrating on the needs of grieving families" (Evanisko & Beasley, 1998). In a Kidney foundation of Canada study, overwhelming evidence was found proving that health care professionals are not inclined to discuss organ donations with grieving families. With over 2000 health care professionals surveyed in Britain, 83% of nurses and 75% of doctors admitted their reluctance, despite over 90% of the group personally approving of organ donations (Moore, 2000). It was reported in an American public attitude's survey that medical doctors should be neither uneasy nor reluctant to discuss and initiate discussions on organ donation amongst the people (Manninen & Evans, 1985). This view is substantiated by a follow-up telephone survey of 164 consenting and non-consenting families approached for organ donation requests. All families questioned felt that it was their right to be asked, and valued being able to make the decision (Evanisko & Beasley, 1998). A Canadian questionnaire to all families approached for

organ donation in 1998 revealed that all consenting families reported that organ donation had helped with their grief and provided them with a type of coping strategy by fulfilling a loved-ones wish and turning the tragedy into something somewhat positive. Interestingly, three families reported that not being initially approached with the option was their greatest stressor during the time of their loss (Pelletier, 1992).

In South Africa, where limited studies on health care professionals and organ donation exist, it was found that even ICU nurses generally have a poor understanding of brain death and organ procurement (Crookes, 1999; Rossi, 2001). In general, nurses feel that there is often a lack of medical doctor support if and when they are involved in donation activities (Matten, Sliepcevich et al, 1991). Strategies such as orientation lectures, in-service programmes, university and training college seminars are in place to begin to try and improve this situation in the nursing fraternity. However, doctors remain the critical link and have been identified elsewhere as being the most vital in terms of hospital cue initiation and staff influence (Prottas & Batten, 1988). It is for this reason that it is necessary to ascertain the quality and the components of the local knowledge & opinions base in the DMR and utilise this vital information to initiate ventures to support and strengthen the organ donation and procurement process.

Key elements of an effective donation request include: communicating clearly and unequivocally to the family that brain death has occurred so that the family realises that brain death is death; waiting to introduce donation until

after the family has accepted the fact of death (known as decoupling, where the request for donation is separated from the explanation of brain death and the family has time to digest the information); offering donation in a quiet and private setting; and designating clear roles for hospital staff and the organ procurement co-ordinator (Evanisko & Beasley, 1998).

2.3.6. Theories and models dealing with organ donation.

The donating and receiving of organs may be equated with gift giving, as there is no barter of commodities involved (Mauss, 1993). The 'Gift Exchange Theory' was first described by Mauss with a wide reference to other societies, ancient laws and religions. Mauss suggested that in giving, one shares part of ones self and that a bond is therefore created between the giver and receiver. Such exchanges are seen as safe and good as well as being responsible for strengthening the essential bonds of kinship. In cadaveric organ donation, the donor family gives a body part, making an inestimably precious gift (Verndale & Packard, 1990). The person receiving the organ transplant accepts a priceless gift.

The concept of 'gate keeping' was introduced into the gift exchange cycle by Fox and Swazey (1974). In this study, 'Gate Keepers' of organ donation were seen as members of the health care team who control the flow of information, screen potential donors, allocate life saving organs, decide on whether or not to initiate a referral or be involved in donor identification process or whether or not to invite the procurement personnel into the treating health care team.

As a result, the health care professionals ultimately decide who can give and who can receive (Gibson, 1996). This behaviour has been suggested to possibly exhibit a detrimental display of the physician seeking to exercise a degree of control over the stress-filled dying process, in a professional capacity.

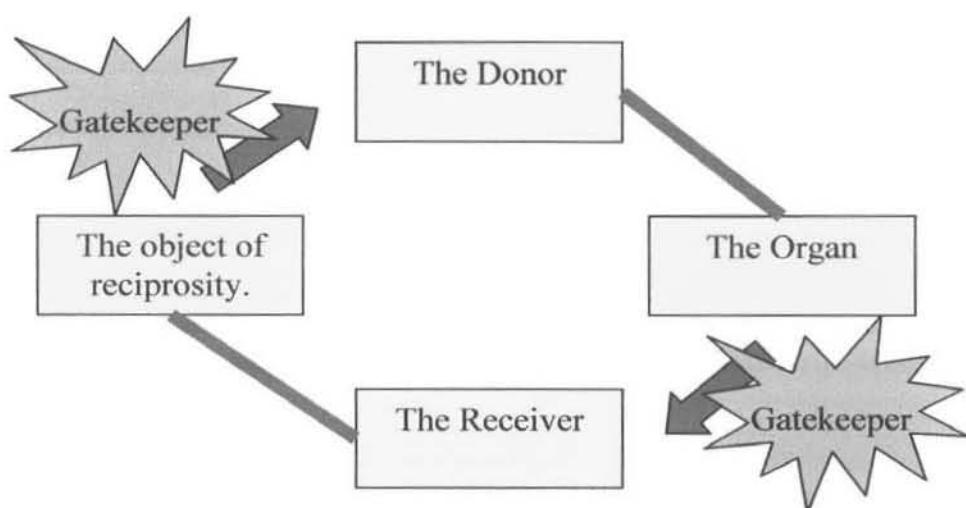


Figure 1.

The Gift Exchange Theory, as applied to the process of cadaveric organ transplantation (Sque and Payne (1994)).

2.3.7. Obstacles and hindrances to organ donation.

According to Sque and Payne (1994), the limitations in the number of available organs is exacerbated by the failure of health care professionals to identify potential donors and initiate the organ donation process. This aspect is highlighted in an Australian intensivist attitudes survey where 20% of practising physicians stated that it was their role to decide if families should be approached for organ donation consent or not. A further 20% of the

survey intensivists unfortunately withheld haemodynamic support before brain death confirmation, resulting in any organs being unnecessarily excluded for donation, due to decompensation effects (Pearson & Zurynski, 1995). Sque and Payne (1994), recommend that nurses and other staff need to take a more active role in the process of organ transplantation and explore the gift exchange theory framework for opportunities to explore their role in enhancing this vital process.

In a national Canadian study by Moore (2000), it was concluded that 'attitudes of professionals hinder organ donations'. In the study, it was found that 75% of physicians and 85% of nurses believed that organ transplants were prohibited by religious beliefs, despite the fact that in order to save the life of the individual, and occasionally with blood precautions being taken, no religion is absolutely opposed to transplantation. Over 75% participants were also unaware of recent studies that showed that organ donations actually helped grieving families' deal with the death of a loved one.

The American Medical Association (2001) noted in its May editorial that 'awareness, education and understanding are the cornerstones by which individuals become donors. Those same factors make physicians well prepared to help families work through the decision to donate'. The association is currently exploring and reporting on physician perceptions about patient organ donation, with a view to identifying and overcoming the barriers to physician participation.

2.4. Theoretical framework guiding the research.

The theoretical framework guiding the research was based on psycho-social and physical aspects and will be described accordingly.

In the literature, cultural factors such as legal and religious contexts have been found to influence medical doctors attitudes and their end-of-life practises in European neonatal studies (Rebagliato, Cuttini & Broggini, 2000).

Nursing studies in England have shown a correlation between assistance with donation, attitude and knowledge (Watkinson, 1995; Kent & Glynn-Owens, 1995).

Attitudes refer to our evaluations of virtually any aspect of the social world. Attitudes are usually generated from three general classes of information which include: cognitive information, emotional information and / or information concerning past behaviours (Wetherell, 1996). Once attitudes are established, they are usually very difficult to change and often act as cognitive frameworks, which in turn colour our perceptions and thoughts. Social psychologists widely assume that attitudes, which shape viewpoints, influence behaviour, however, this link is far more complex than what was initially thought and often remains unpredictable (Wetherell, 1996).

Most attitudes are learned, often through contact or interaction with other persons and a sizable gap often exists between what people say and do (Baron & Byrne, 2000). Scientists are now focusing on when and how

attitudes predict behaviour and what moderators come into play in influencing the extent to which attitudes affect behaviour. Attitudes acquired from direct experience have increasing effects on behaviour, as do attitudes with vested interest, intensity, specificity, relevant origin and high importance. Messages and communication do have the potential to change attitudes. Fazio's attitude to behaviour process model, otherwise captioned the "Willingness model" (Fazio, 1989, Fazio & Roskos-Eewoldson, 1994) provides us with a model, which may assist us to predict actual behaviour, based on attitudes and other factors.

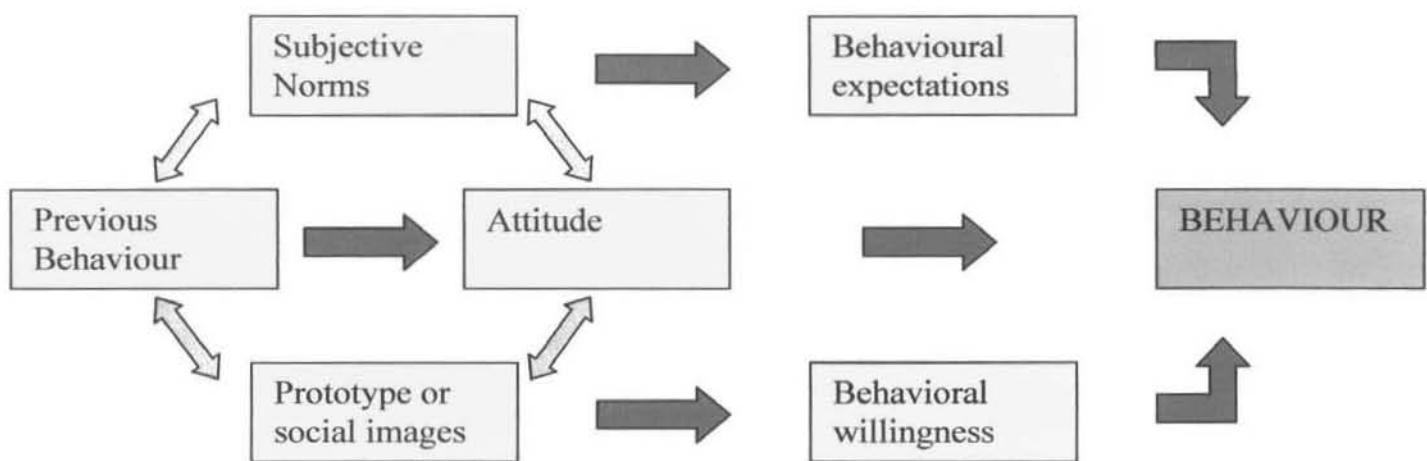


Figure 2.

Fazio's attitude to behaviour process model, otherwise captioned the "Willingness model" (Fazio, 1989, Fazio & Roskos-Eewoldson, 1994)

According to the theory proposed by the researchers, the *Willingness model* explains that behaviour is often influenced by several factors, including:

- Whether others engage in this behaviour (Subjective norms).
- What individuals plan to do in the future (Behavioural intentions)
- The extent to which a person is willing to perform these actions under a variety of circumstances (Behavioural willingness)
- Social images of what people who engage in certain forms of behaviour are like (Prototypes)

Thus the model explains that attitudes influence the intentions and the eagerness that will in turn depend on the decision on engaging in certain behaviours. In utilising attitude, subjective norm and perceived behavioural control questionnaires in potential and actual blood donors, Giles and Cairns (1995) were able to explain two thirds of a group of university students who would or would not be likely to donate. Attitudes such as "Is it going to hurt?" and "Will it help others?" combined with subjective norms such as "Do members of my family think I should donate blood?" social prototypes such as "The prime minister donates blood" and behavioural willingness "I could easily donate blood if I wanted to." (Wetherell, 1996) were assessed. Similarly, addressing questions on organ donation, as performed in this study, may yield useful information and possibly reveal viewpoints linked to participation of medical doctors in the field of cadaveric organ donation and transplantation.

Despite the existence of links between attitudes and behaviour, correlations between expressed attitudes and measures of how people will react in

different situations remains difficult to predict with any certainty (Wetherell, 1996).

It would appear that education and information may have an influence on 'previous behaviour' and 'behavioural intentions' or expectations. Increasing the exposure and acceptability of organ donation may also influence the 'subjective norm' contribution towards the attitude and possibly even the behaviour. In this manner, the views determined will provide an interesting input into furthering our understanding of this area of focus.

Furthermore, responding to the group pressure towards conformity, if an increasing number of medical doctors exhibited the behaviour of being more actively involved in organ donation activities over time, peer interest and activity in the area would predictably increase, as seen in other behavioural phenomena (Wetherell, 1996).

2.5. Summary.

It was apparent that a scarcity of information from a South African perspective on the general viewpoints of medical doctors, on end of life decision-making and on organ donation and transplantation exists. Unfortunately, the same exists for perspectives on nurses and other health care professionals on these above-mentioned aspects. Interestingly, there appears to be a fairly large degree of concern and consensus among the international literature, especially with regards to the paucity of formal

knowledge, education and co-operation found with regards to brain death determination, donor identification and confidence in dealing with families and other members of the health care team. In arriving at these conclusions, the international literature presented numerous well-presented questionnaires, focusing on different aspects and issues in the organ donor and transplant process. In addition, two interesting frameworks were identified which could assist in clarifying and explaining potential viewpoint findings.

In chapter three, the research methodology for the survey of medical doctors views on cadaveric organ donation and transplantation is described.

Chapter 3

'Embrace hard things and your mind will blossom.'
- Japanese proverb -

CHAPTER 3.

RESEARCH DESIGN AND METHODOLOGY.

3.1 Introduction

A research design has been labelled the 'blueprint' of a study (Burns & Grove, 1999). Each design is individualised and specific in order to reflect reality in what is being researched. According to Polit and Hungler (1997), a research design is developed to refine procedures for obtaining, organising and analysing data.

The methods section of a research report, according to Burns and Grove (1999), describes how the study was conducted. It is an overview that should be provided in sufficient detail as to allow the reader to critique the adequacy of the study methods in order to produce reliable findings.

3.2 Goal of this chapter

The purpose of this chapter is to briefly detail and provide information on the research design and methodology utilised in order to determine the medical doctors views on cadaveric organ donation and transplantation.

3.3. Research design and Methodology.

An exploratory, descriptive and explanatory research design was used in this study to explore and examine what the views characteristic of medical doctors in the DMR to organ donation are. It utilising these techniques it was hoped that new meaning and a greater understanding of concepts and relationships could be realised. These studies are useful in identifying problems with current practise, obtaining a picture of a situation and determining what others are doing (Burns & Grove, 1999).

The research design methods (*typed in italics*) have characteristics that will be outlined below. In addition, the utilisation of each of the three concepts as pertaining to this particular research shall be explained.

3.3.1. *Exploratory*: The goal of an exploratory study is to explore a relatively unknown field of study (Uys & Basson, 1996). The aims of such a study include:

- Gaining insight into the phenomenon.
- Initiating a pre-investigation in preparation for a more structured study into the phenomenon.
- Facilitating the construction and definition of central concepts.
- Defining new hypotheses regarding an existing phenomenon.

The methods available to construct an exploratory study include:

- Providing an overview of existing relevant literature.

- Determining a survey of expert knowledge on the research field.
- Analysing stimulating, insight invoking research matter on the topic.

In this study, the available local and international literature was explored on the psychological, social, physical and cultural aspects of cadaveric organ donation and transplantation. Chapter two can be viewed for a more detailed insight into these findings.

3.3.2. *Descriptive*: The descriptive study is said to provide a clearer picture of a situation or phenomenon as it naturally happens, in order to gain more information about characteristics within a particular field of study (Burns & Grove, 1999). According to Wolcot (1994), descriptive research addresses the question, "What is going on here?". Data consists of observations made by the researcher and reported to the researcher by others.

Descriptive studies may adopt a qualitative or quantitative approach. In quantitative research, the researcher wishes to develop techniques in order to move away from abstract ideas, to develop specific data gathering techniques and to produce more empirical data that represent ideas. In this research, the quantitative aspect was selected which relies upon a data collection instrument that is utilised for gathering and interpreting data (Denzin & Lincoln, 1998). The descriptive aspect of this research design included the method of data collection and analysis, which included the:

- Sample number and population.

- Research setting
- Questionnaires
- Method of data collection
- Variables.
- Validity and reliability.
- Limitations.
- Pilot study.
- Data capture and analysis.

3.3.3. *Explanatory*: Explanation builds on exploratory and descriptive research and attempts to identify causes and reasoning behind occurrences (Uys & Basson, 1996). The researcher has adopted an explanatory approach in order to attempt to present and determine the results of the questionnaires. In Chapter four and five, each question on the questionnaire was presented, according to the respondent's responses. The results were then analysed and summarised accordingly.

3.4. Sample number and population.

Two hundred convenience and network sampled graduate and postgraduate professionals in the Durban Metropolitan Region from eight different hospitals within the DMR were selected, with equal private and provincial distribution. (An average of 218 subjects per group expect to have a power level of .80, thought to be the minimal acceptable level) [Burns & Grove, 1999]. In addition, medical doctors attending certain

meetings and gatherings within the Nelson R Mandela Medical School who worked in the eight sample hospitals were also approached in a convenience-sampling manner to consider participating. In this manner, more doctors could be identified and numerous shifts and teams could be accessed. Respondents were divided into graduate and postgraduate medical doctor categories but were included in the study from any discipline or department.

3.5. Research setting.

The study was conducted in a setting natural to the sample population, in their normal working environment. Such a setting included doctors consulting rooms or offices in private or provincial hospital or university premises. All eight of the hospitals selected had Trauma and Intensive Care facilities, three had active transplant programmes, six had chronic haemodialysis programmes and four had neurosurgical facilities. The size of the hospitals ranged from 317 to 1 600 beds, with an average size of 860 beds.

3.6. Questionnaires.

Attitudes and opinions were explored by asking respondents agreement on a multivariate linear regression response scale from strongly agree to strongly disagree. The statements were developed after a review of the literature in which questionnaires were utilised and after in-depth,

qualitative, personal and group interviews conducted among a small sample of physicians in KwaZulu-Natal during the pilot study. The conceptual model was utilised in the development of the questionnaire and responses relevant to each factor category were included. The self-administered questionnaire was selected as it has been found in similar studies that when an interviewer is present, even over the telephone, that due to the high value placed on altruism in society, respondents may reply altruistically and adversely effect results (Manninen & Evans, 1985). This is especially relevant when examining organ donation issues where people have been found to behave inconsistently with the attitudes they express (Gibson, 1996). The medical doctor structured questionnaires were anonymous and self administered to protect confidentiality. Each questionnaire included a cover page and a request form for follow-up information (See Appendix B). They include 106 questions that included:

- 13 Questions asking participants about their personal demographics and characteristics.
- 9 Questions on personal viewpoints on organ donation.
- 24 Questions on knowledge and skills.
- 16 Questions on personal practise.
- 33 questions on attitudes and perceptions
- 10 questions on recommendations.
- *1 non-study related informal question on follow-up information on the questionnaire is included on the final page of the instrument.*

Questionnaires were administered in English. The instrument included 3 open-ended questions, 31 multiple-choice questions, 42 visual analogue scale response questions and 29 'yes or no' type questions. When structured questionnaires are set, it is of importance to provide an opportunity for respondents to be able to record their views as accurately as possible, yet allow for quantitative analysis to be done. Use of single response (Yes/No) limits the degree of expression, but it is possible to gauge the responses more accurately using graded response scales. These include the point-scales and Visual Analogue Scale (VAS). VAS have been used in several studies and has been suggested to be superior to scales that measure graded responses (e.g. the 5-point and 7-point scales) in obtaining psychological response. VAS was favoured because of the ease of administration and the wide range of freedom on the scale that allows the respondent to record their view as a more accurate estimate, rather than choosing options given if it were for the other scales (Burns & Grove, 1999).

The Visual Analogue Scale (VAS) is a 100mm line representing a continuum of attitude ranging between the two opposing extremes of that point. Respondents had the opportunity to record their reactions to the statements put forward by drawing a mark on the scale to show where their views lie on the scale, which can then be measured using a millimetre scale to obtain the data for computer entry (Uys & Basson, 1996). *Directions on how to use the VAS have been incorporated in the cover page of the questionnaire.*

Questions focused on the positive and negative dimensions of attitudes regarding organ donation. Questionnaires from Cleveland & Johnson (1970), Claxton, (1975), Parisi & Katz, (1986), Coolican, (1987), Stoeckle, 1990) were reviewed and certain questions in the study are restructured around these works in order to optimise reliability and content validity. These questionnaires studied health care providers attitudes to cadaveric kidney transplantation; organ donor families perceptions of stressful experiences during the organ donation experience; physicians attitudes about caring for patients in persistent vegetative states; nurses knowledge, attitudes and beliefs regarding organ and tissue donation and transplantation; the perceptions and experiences of critical care nurses in caring for potential and actual organ donors; neonatal end-of-life decision making and physicians and a state wide survey of trauma surgeons and organ donation.

3.7. Pilot study.

A pilot study was conducted to refine the data collection and analysis techniques: Five medical doctors from the sample population who attend the July journal club doctors meeting were approached to complete the survey while waiting after work for the evening meeting to begin. When collecting the survey, their input in the form of short individual interviews was conducted. Information obtained included:

- How long the instrument took them to complete.
- If the instrument was user-friendly.
- If any of the questions were difficult to understand.
- If additional options needed to exist in answering certain questions.
- Any other input.

Following analysis of their surveys, the following was examined:

- If any questions were accidentally omitted or undetected.
- If questions appeared to have been interpreted correctly.

Following the pilot study, based on feedback and questionnaire analysis, certain changes were made to the original instrument, which primarily centred on correcting question numbering and ordering. Consensus was obtained as to the use of certain medical terminology in the questionnaire, which would optimise understanding and prevent misinterpretation.

Although the pilot study respondents verbalised that the questionnaire took them too long to complete (range 20– 60 minutes, average 30minutes), the respondents were unable to identify which, if any, questions to omit. The pilot study responses were not included in the final research due to the respondent's extraordinary involvement and specialisation with transplant patients and organ donors. In addition, the study population were not able to remain anonymous due to their relationship with the researcher and this was felt to potentially influence the results. Two pilot study respondents wished not to return the answered

questionnaires as they felt the information was of a personal nature, but provided a written report to the researcher on their feedback.

3.8. Method of Data Collection.

Data collection in the form of a 106-item questionnaire about organ donation and transplantation was performed during a two-month period during the spring of 2001. Permission was sought from the Medical superintendent of each hospital and department involved in the study to allow access to the medical doctors. The researcher visited each clinical and meeting area and the questionnaires are individually handed to the medical doctors on duty at that time, together with a covering letter. Additional questionnaires were left in each area for medical doctors on subsequent shifts to complete. A letter of explanation was attached to each questionnaire, assuring confidentiality. Consent was implied in the returning of the questionnaire. The documents were left with the doctors to allow sufficient time for completion. The completed questionnaire was placed into a sealed, unmarked envelope for collection later the same day by the researcher. The respondent had the opportunity to indicate on a separate form, the request for the skill answers or additional information on the topic, and the means in which the respondent would have liked the reply.

3.9. Variables.

In descriptive studies, no manipulation of variables is involved. Dependent and independent variables are not commonly used within this design since cause cannot usually be established beyond reasonable doubt. In the typical descriptive design utilised, the phenomenon is identified and variables are determined within the phenomenon, which are then described and interpreted (Burns & Grove, 1999).

Variables to be examined to determine role and relevance mostly appear in the demographic characteristics and consist of training and experiential exposure, place of birth, religious and cultural affiliations and current practise characteristics. Gender, age and population group are also requested but have been shown to have limited relevance in other studies. Additional variables such as the degree of exposure to the transplant process and having a friend in the transplant team or recipient base is likely to influence views, but is determined by the group's responses.

3.10. Validity & Reliability.

Validity determines the extent to which the instrument reflects the concept under study. Reliability is the extent to which that instrument consistently measures that study concept Burns & Grove, 1999). Reliability values on questionnaire items utilised to compile this questionnaire from other studies are considered to be acceptable, however, reliability in visual

analogue scale use, due to the erratic nature of the phenomena they measure, is unobtainable. Five additional transplant co-ordinators and transplant team members who assessed the research instrument for suitability of purpose and content confirmed validity.

3.11. Limitations.

- The sample utilised is not necessarily representative of the KwaZulu-Natal or South African medical doctor experience, therefore preventing the findings from being generalised out of the DMR setting.
- The use of a convenience and network sampling technique has been criticised for providing little opportunity for biases. This concern was avoided as best as possible by giving the questionnaire to the first individual or group of individuals presenting to the researcher on a random day of entry into the facilities, until the quota was reached. This sample had the benefits of being accessible, inexpensive and effective in obtaining information over a short time period. The large number of doctors sampled at each hospital also guarded against bias development, as this sample number exceeded the total number of doctors working in some hospitals. However, this remains a limitation of the study.

3.12. Data Capture / Analysis.

All questionnaires completed were read and the data captured and analysed on a computer database using SPSS® in order to calculate the percentage total of each answer option and potentially identify correlating variables. Two independent procurement specialists examined open-ended information evaluation questions and allocated a score for correct pointers mentioned by the respondent. This score was utilised as an independent variable.

3.13 Ethical considerations

Permission to carry out this research was obtained from the Research department of the Nelson R Mandela School of Medicine. In addition, the hospital superintendents and managers from all eight hospitals were approached for permission to participate in the study. The cover page explains the reason and nature of the study and mentions that the respondent may choose not to answer the questionnaire, should he or she so wish. In addition, it also mentions that individual answers would be kept confidential. In order to facilitate the latter, only the researcher had access to the completed questionnaires and destroyed them after use.

3.14 Summary

In this chapter, the researcher reported on the research design and methodology that was selected and utilized in formulating and conducting the study.

In chapter four, the results that were obtained from the analysis of the respondent's questionnaires will be systematically presented in the order an manner in which they were answered.

Chapter 4

*'No birth is an accident, No experience is without meaning,
And no life is without value.'*
- Gary Zukov -

CHAPTER 4.

RESULTS OF THE STUDY.

4.1. Introduction

Results by means of percentage distribution are displayed in the findings in order to indicate the frequencies of responses. Questions that are deemed have correct or incorrect answers are indicated by means of green (correct) or orange (incorrect) shading. Additional grey shading is attributed to scores of high frequency in order to indicate majority views or responses. The question and result may be correlated with the questionnaire presentation, which may be found in appendix B.

4.2. Goal of this chapter.

The purpose of this chapter is to present the results of the study in a clear and precise manner in order for realisations and conclusions to emerge. Subsequent studies would also be able to draw comparisons from the specific nature of the results presented.

4.3. Results.

Forty-three questionnaires ($N=43$) were returned from two hundred ($N=200$) personally delivered questionnaires circulated. The extension date was

further extended by six weeks to achieve this 22% response and return rate. Follow-up telephonic reminders and personal visits were made in 82% of questionnaires given. From observation, this additional time allocation did not appear to result in more 'text-book access' or increase the quality of answers provided. Further copies were provided to respondents in 18 cases, due to the originals being mislaid prior to completion. Eleven (N=11) respondents (5.5%) refused to answer the questions; four (N=4) due to time constraints, six (N=6) due to no knowledge of the topic and one (N=1) due to lack of remuneration from the study. Four (N=4) questionnaires (2%) were returned with ten or more uncompleted answers, but were included in the study as all had notes attached explaining that a knowledge deficit was the reason for non-completion.

4.3.1. Personal demographics.

Table 4.1.

- Country of upbringing (Question 1):

Country:	South Africa	Zambia	Pakistan	Ireland	Poland	Bangladesh
Respondents:	37	1	1	1	2	1

Colour Key:

Colour	Relevance:
23	Incorrect Answer
23	Correct Answer
23	Neutral or not commonly selected Answer
23	Most commonly selected answer
23	Commonly selected Answer

Table 4.2.

- Medical school attended for undergraduate studies (Question 2):

School:	University Natal Durban	University Cape Town	University Witwatersrand	University Stellenbosch	University Pretoria	MEDUNSA
Respondents:	14	7	7	2	2	1
School:	UNITRA	University Bangladesh	University Dublin	India Kastaburba -	Ireland	University Zambia
Respondents:	2	1	1	1	1	1
School:	OFS	University Poland				
Respondents:	1	2				

Table 4.3.

- Years practised as a medical doctor (Question 3):

Years:	0-4	5-9	10-14	15-19	20-24	25-29	>30
Respondents:	7	8	8	7	6	5	2

Table 4.4.

- Presence of postgraduate qualifications (Question 4):

Postgraduate qualifications:	Yes	No
Respondents:	32	11

Table 4.5.

- Medical school attended for postgraduate studies (Question 5):

School:	University Natal Durban	University Cape Town	WITS	Ireland	United Kingdom
Respondents:	27	3	1	1	1

Table 4.6.

- Field of current specialisation (Question 6):

Speciality:	Anaesthetics	Cardiology	Cardiothoracics	Critical care	Forensics
Respondents:	9	1	1	3	2
Speciality:	General practise	Nephrology	Neurology	Neurosurgery	Paediatrics
Respondents:	2	1	1	7	1
Speciality:	Surgery	Trauma	Medicine	Obstetrics & Gynaecology	
Respondents:	8	3	2	1	

Table 4.7.

- Classification of current practise (Question 7):

Practise:	Private only	Private with limited state	State only:	State with limited private
Respondents:	14	13	12	4

Table 4.8.

- Hospitals currently most frequented for medical practise (Question 8):

Hospital:	Addington	Edendale	Entabeni	King Edward	McCords
Respondents:	7	1	15	8	1
Hospital:	Usher Memorial	Prince Mshiyeni	St. Augustines	Umhlanga	Wentworth
Respondents:	1	1	24	1	8
Hospital:	Westville	Parklands	Mahatma Gandhi	Livingston	
Respondents:	3	1	1	1	

Table 4.9.

- Gender group classified as (Question 9):

Gender group:	Male	Female
Respondents:	32	11

Table 4.10.

- Age in years classified as (Question 10):

Age:	26-30	31-35	36-40	41-45	46-50	51-55
Respondents:	9	6	11	5	6	6

Table 4.11.

- Population group classified as (Question 11):

Population group:	Black	White	Indian	Coloured
Respondents:	3	19	19	2

Table 4.12.

- Faith or religion followed (Question 12):

Religion:	None	Islamic	Christian	Hindu
Respondents:	7	8	18	10

Table 4.13.

- Degree of personal religious importance (Question 13):

Religious importance	+1 to +3/4 (very important)	+3/4 to +1/2	+1/2 to + 1/4	+ 1/4 to 0 (Slightly important)	0 (neutral)
Respondents:	14	5	2	1	3
Religious importance	0 to -1/4 (Slightly unimportant)	-1/4 to -1/2	-1/2 to -3/4	-3/4 to -1 (No importance)	No answer
Respondents:	4		5	6	3

4.3.2. Personal views on organ donation.

Table 4.14.

- Classification of self as an organ donor (Question 14):

Classification:	Organ donor	Non Organ Donor:
Respondents:	24	19

Table 4.15.

- Organ donor card carrying status (Question 15):

Classification:	Card carrier:	Non Card carrier:
Respondents:	9	34

Table 4.16.

- Family discussion regarding organ donor wishes (Question 16):

Classification:	Family informed:	Family not informed:
Respondents:	16	27

Table 4.17.

- Acceptance of brain death diagnosis, if made on close relative (Q17):

Classification:	Would accept:	Would not accept:
Respondents:	41	2

Table 4.18.

- Preparedness to donate organs of brain dead close relative (Q18):

Classification:	Would donate:	Would not donate:
Respondents:	33	10

Table 4.19.

- Organs and tissues **most** inclined to donate (Q19):

Organ / tissue:	Heart	Lungs	Kidneys	Corneas	Skin	Bone	None
Respondents:	18	11	21	18	8	6	4

Table 4.20.

- Organs and tissues **least** inclined to donate (Q20):

Organ / tissue:	Heart	Lungs	Kidneys	Corneas	Skin	Bone	None
Respondents:	8	5	2	3	10	8	3

Table 4.21.

- Preparedness to personally receive organs of donor, should organ failure occur (Q21):

Classification:	Would receive:	Would not receive:
Respondents:	38	5

Table 4.22.

- Perception of the existence of community pressure on people to be organ donors (Q22):

Belief:	Do perceive pressure:	Do not perceive pressure:
Respondents:	7	36

4.3.3. Knowledge and skills on brain death and organ donation.

Table 4.23.

- Reception of any formal training on brain death and organ donation (Q23):

Classification:	Training received:	Training not received:
Respondents:	21	22

Table 4.24.

- Situation in which formal training was acquired (Q24):

Situation:	Medical School	CME Event	Congress
Respondents:	7	3	8
Situation:	In-service talk	Case review	Speciality meeting
Respondents:	10	4	11

Table 4.25.

- Standard of formal training received (Q25):

Information rated:	+1 to +3/4 (Excellent)	+3/4 to +1/2	+1/2 to + 1/4	+ 1/4 to 0 (Slightly good)	0 (neutral)
Respondents:	6	5	4	1	
Information rated:	0 to -1/4 (Slightly poor)	-1/4 to -1/2	-1/2 to -3/4	-3/4 to -1 (Poor)	No answer
Respondents:	1	1	6		

Table 4.26.

- Other sources of information acquired on brain death and organ donation (Q26):

Information source:	Other doctors	Nurses	Friends
Respondents:	20	7	1
Information source:	Transplant CoOrdinators	Journals	Posters & Pamphlets
Respondents:	14	24	9
Information source:	Hospital policy folders	Ward info. folders	Television
Respondents:	4	0	5
Information source:	Radio	Newspapers & magazines	The Internet
Respondents:	2	5	1

Table 4.27.

- Personal rating of knowledge and skills regarding brain death (Q27):

Information rated:	+1 to +3/4 (Excellent)	+3/4 to +1/2	+1/2 to + 1/4	+ 1/4 to 0 (Slightly good)	0 (neutral)
Respondents:	14	11	4	1	2
Information rated:	0 to -1/4 (Slightly poor)	-1/4 to -1/2	-1/2 to -3/4	-3/4 to -1 (Poor)	No answer
Respondents:	5	1	5	1	

Table 4.28.

- Personal rating of knowledge and skills regarding The Human Tissue Act (Q28):

Information rated:	+1 to +3/4 (Excellent)	+3/4 to +1/2	+1/2 to + 1/4	+ 1/4 to 0 (Slightly good)	0 (neutral)
Respondents:	5	2	5	1	
Information rated:	0 to -1/4 (Slightly poor)	-1/4 to -1/2	-1/2 to -3/4	-3/4 to -1 (Poor)	No answer
Respondents:	6	4	7	13	

Table 4.29.

- Personal rating of knowledge and skills regarding donor selection and criteria (Q29):

Information rated:	+1 to +3/4 (Excellent)	+3/4 to +1/2	+1/2 to + 1/4	+ 1/4 to 0 (Slightly good)	0 (neutral)
Respondents:	6	5	3	1	3
Information rated:	0 to -1/4 (Slightly poor)	-1/4 to -1/2	-1/2 to -3/4	-3/4 to -1 (Poor)	No answer
Respondents:	11	1	8	5	

Table 4.30.

- Possibility of certifying brain stem death while NOT on a ventilator (Q30):

Classification:	Possible	Not Possible
Respondents:	21	23

Table 4.31.

- Possibility of certifying brain stem death while having seizures (Q31):

Classification:	Possible	Not Possible
Respondents:	8	35

Table 4.32.

- Possibility of certifying brain stem death by cerebral angiography, if for any reason clinical testing cannot be performed (Q32):

Classification:	Possible	Not Possible
Respondents:	23	19

Table 4.33.

- Possibility of certifying brain stem death by use of an electroencephalogram in the ICU setting (Q33):

Classification:	Possible	Not Possible
Respondents:	17	26

Table 4.34.

- Possibility of a person dying from unnatural causes (eg: gunshot head from a hijacking) legally being permitted to be an organ donor (Question 34):

Classification:	Possible	Not Possible
Respondents:	27	15

Table 4.35.

- Possibility of a five year old patient being suitable as an organ donor (Q35):

Classification:	Possible	Not Possible
Respondents:	29	13

Table 4.36.

- Possibility of a patient with hyperthyroidism being suitable as an organ donor (Q36):

Classification:	Possible	Not Possible
Respondents:	23	19

Table 4.37.

- Possibility of donating corneas from someone who has had no pulse for 6 hours (Q37):

Classification:	Possible	Not Possible
Respondents:	33	10

Table 4.38.

- Possibility of donating kidneys from someone who has had no pulse for 6 hours (Q38):

Classification:	Possible	Not Possible
Respondents:	4	39

Table 4.38.

- Possibility of pathophysiological changes resulting from brain death causing organ damage (Q39):

Classification:	Possible	Not Possible
Respondents:	20	23

Table 4.39.

- Relevance of time period between brain stem death and organ recovery (Q40):

Classification:	Relevant	Not relevant
Respondents:	37	6

Table 4.40.

- Time on the death certificate when certification of brain stem death is completed at 08h00 and organ procurement is completed at 12h00 (Q41):

Classification:	08h00	12h00	Unknown
Respondents:	31	11	1

Table 4.41.

- Organs and tissues currently transplanted in KwaZulu-Natal (Q45):

Organ / Tissue:	kidney	heart	lungs	corneas
Respondents:	41	35	24	41
Organ / Tissue:	bone	Bone marrow	Heart valves	skin
Respondents:	19	18	19	15
Organ / Tissue:	intestine	liver	pancreas	Islet cells
Respondents:	11	7	1	0

Table 4.42.

- Hospitals currently transplanting solid organs in KwaZulu-Natal (Q46):

Hospital:	St. Augustines	Addington	Entabeni
Respondents:	37	22	25
Hospital:	King Edward	Wentworth	Not known
Respondents:	7	2	4
Hospital:	Westville	King George	
Respondents:	1	1	

Table 4.43.

- What the Human Tissue Act No 106 of 1994 specifies in relation to the personnel involved in diagnosing brain death (Q42):

Number:	Responses:
13	Two independent medical practitioners
13	Must not be a member of the transplant team
6	One must be qualified for more than five years
6	Do not know
4	Must take no further part in transplant process
4	Cannot be related to the patient
2	Cannot be conducted at the same time
2	Two senior practitioners
1	Minimum of two qualified medical personnel
1	One specialist and another doctor
1	Two neurologists or neurosurgeons
1	One Neurologist
1	Three doctors, not part of patient's treating team
1	One must be qualified longer than three years, the other longer than five years
1	Both need two years of post-graduate experience
1	Must be conducted two hours apart
1	Both must have more than four years of training medically
1	Must be conducted 6 hours apart
1	Both must have more than 5 years of medical training

Table 4.44.

- Prerequisites to be satisfied prior to one conducting the brain stem death tests (Q43):

Number:	Responses:
16	Normal body temperature
11	Knowledge of irreversible insult to brain
8	Do not know
7	Rule out causes of coma, eg: drugs or metabolic cause
6	No acid-base deficits or electrolyte abnormalities
6	Must not have drugs affecting CNS
5	Absence of any sedatives
5	Removal of neuromuscular blocking agents

4	Normal haemodynamics
4	Core temp >35 degrees Celcius
4	No hypoxia
3	No spontaneous respiration
3	No answer
3	Patient must not have received any muscle paralysing agents or sedatives for at least 24 hours
3	No drugs or paralysing agents
3	GCS 3/15
2	Corrected Hb, electrolytes & endocrine problems
2	Wait 24 hours after anaesthesia
2	Correct electrolytes and blood sugar
2	Blood pressure > 100
2	No anaesthesia
2	No intoxicants present, eg: drugs or alcohol
2	Seizures must be under control
1	No hypoglycaemia
1	Normal PCO ₂
1	Unresponsive
1	Remove confounding factors
1	GCS < 7/15
1	Fixed dilated pupils
1	Ear drum mechanism intact
1	Intact ear drums
1	ECG machine must be working
1	Normal thyroid tests
1	Core temp >36 degrees Celcius
1	Presence of ocular signs

Table 4.45.

- The clinical tests used to determine Brain Death (Q44):

Number:	Responses:
24	Pupillary reaction
23	Dolls eye movement
22	Caloric test
17	Gag reflex
14	Corneal reflex
13	Apnea test
8	No spontaneous respiration
8	Oculovestibular
7	Oculocephalic
5	GCS 3/15
3	Angio & EEG
3	Cough reflex
3	No idea
3	Loss of tendon reflexes
3	Tests of brain stem death
2	No pain response to cranial nerve testing
2	Cranial nerve reflexes absent
2	No spontaneous respiration despite normal CO ₂
2	No spontaneous respiration despite adequate CO ₂ stimulus in presence of good oxygenation
1	No respiratory effort despite PaCO ₂ >60mmHg
1	No motor, eye or verbal response

1	No motor or pain response to central pain stimulus, eg: sternal pressure
1	Cerebral angiogram
1	Hypercarbia above 50mmHg
1	Normothermia
1	No tachycardia in response to Atropine
1	Neurological examination
1	External pressure over facial area
1	Water in ears test
1	No spontaneous respiration after five minutes off ventilator with adequate hypoxia developing
1	No respiratory effort despite PaCO ₂ >40mmHg
1	No eyelash reflex
1	Conjunctival test
1	No spontaneous cardiac activity
1	No ECG trace
1	No recordable pulse or blood pressure
1	Absence of grimace
1	Spinal reflexes
1	Tracheal tug

4.3.4. Practise related issues on brain death and organ donation.

Table 4.46.

- Number of patients attended to in a year with a GCS <7/15 (Q47):

No. of patients:	none	< 10	10-20	>20
Respondents:	2	16	10	17

Table 4.47.

- Action taken after confirming brain death (Q48):

Respondents:	Action:
11	Continue active treatment, and contact the transplant co-ordinator
11	Contact the family to inform of brain death and contact the co-ordinator to request organ donation.
9	Personally discontinue treatment
7	Request termination of treatment from staff
6	Contact the family and offer all the options yourself, including organ donation
5	Continue active treatment, till patient arrests

Table 4.48.

- Personal efforts in contacting the Transplant co-ordinators (Q49):

Efforts:	Have contacted:	Have not contacted:
Respondents:	21	21

Table 4.49.

- Methods used in contacting the Transplant co-ordinators (Q51):

Respondents:	Methods:
13	Ask a sister for the number and get her to call them
8	Call medical emergencies (301 3737)and page them
7	Call hospital switch board and have them call the to phone you back
6	Look for a poster with the number in the duty room and call them personally.
5	Call a doctor colleague in the transplant team and inform him.
2	Any of the above
1	Other: Have their number in my cell phone

Table 4.50.

- Number of experiences with the Transplant team (Q51):

Experiences:	None	1-5	6-10	>10
Respondents:	16	11	4	11

Table 4.51.

- Quality of experiences with the Transplant team (Q52):

Information rated:	+1 to +3/4 (Very positive)	+3/4 to +1/2	+1/2 to + 1/4	+ 1/4 to 0 (Slightly positive)	0 (neutral)
Respondents:	14	6		5	2
Information rated:	0 to -1/4 (Slightly negative)	-1/4 to -1/2	-1/2 to -3/4	-3/4 to -1 (very negative)	No answer
Respondents:		1		1	14

Table 4.52.

- Greatest concerns when contacting the team or referring a patient:

Concerns:	Legal	Communication	Time	Ethical
Respondents:	7	9	9	8
Concerns:	Knowledge & skill	Confidentiality	Peer	Emotional
Respondents:	4	3	1	15

Table 4.53.

- Most positive aspect of involving the transplant co-ordinators in the treating team (Q54):

Respondents:	Aspects:
27	The comprehensive team approach
6	Decreased legal & emotional responsibility of physician
5	Other health care workers assisting with bereavement
1	Working with other disciplines

Table 4.54.

- Degree of support received with regards to referring a patient as a donor from medical colleagues (Q55):

Support rated:	+1 to +3/4 (Excellent)	+3/4 to +1/2	+1/2 to + 1/4	+ ¼ to 0 (Slightly good)	0 (neutral)
Respondents:	8	4	1	2	2
Support rated:	0 to -1/4 (Slightly poor)	-1/4 to -1/2	-1/2 to -3/4	-3/4 to -1 (Poor)	No answer
Respondents:	8	1		4	3

Table 4.55.

- Degree of support received with regards to referring a patient as a donor from hospital administrators (Q56):

Support rated:	+1 to +3/4 (Excellent)	+3/4 to +1/2	+1/2 to + 1/4	+ ¼ to 0 (Slightly good)	0 (neutral)
Respondents:	7	4	2	1	4
Support rated:	0 to -1/4 (Slightly poor)	-1/4 to -1/2	-1/2 to -3/4	-3/4 to -1 (Poor)	No answer
Respondents:	5		2	5	3

Table 4.56.

- Degree of support received with regards to referring a patient as a donor from nursing staff (Q57):

Support rated:	+1 to +3/4 (Excellent)	+3/4 to +1/2	+1/2 to + 1/4	+ ¼ to 0 (Slightly good)	0 (neutral)
Respondents:	8	7	2	2	2
Support rated:	0 to -1/4 (Slightly poor)	-1/4 to -1/2	-1/2 to -3/4	-3/4 to -1 (Poor)	No answer
Respondents:	4		3	2	3

Table 4.57.

- Patients least likely to be referred to the transplant co-ordinators following brain death certification (Q58):

Stereotype:	Child	Moslem female	African male
Respondents:	4	13	10
Stereotype:	Jewish leader	Japanese tourist	Colleagues father
Respondents:	2	5	0
Stereotype:	None – refer all	Other	Other
Respondents:	11	Jehova's Witness	Immediate family

Table 4.58.

- Reason identified for non-referral of above stereotypes (Q58):

Respondents:	Reasons:
5	Religion & superstition
3	Experience over the years as these groups do not consent
2	Cultural differences
1	Too small for donation
1	Emotional reasons
1	The question of ancestors
1	Language problems
1	Foreign legalities
1	Not open to organ donation
1	HIV Risk

Table 4.59.

- Involvement in caring for transplant recipients (Q59):

Involvement:	Involved	Not Involved
Respondents:	11	32

Table 4.60.

- Relationship with a friend or close colleague who is a transplant recipient (Q60):

Relation:	Have a relationship	Don't have a relationship
Respondents:	11	32

Table 4.61.

- Relationship with a friend or close colleague who belongs to the transplant team (Q61):

Relation:	Have a relationship	Don't have a relationship
Respondents:	22	21

Table 4.62.

- Possibility of referring more brain dead patients to the co-ordinators if personal knowledge on organ and tissue donation was upgraded (Q62):

Referrals:	Would increase referrals:	Would not affect referrals:
Respondents:	33	10

4.3.5. Attitudes and perceptions related to issues on brain death and organ donation.

Table 4.63.

- Medical & Clinical guidelines for deciding if a patient is brain dead are well established (Q63).

Opinion:	+1 to +3/4 (Strongly agree)	+3/4 to +1/2	+1/2 to + 1/4	+ 1/4 to 0 (Slightly agree)	0 (neutral)
Respondents:	28	6	1		3
Opinion:	0 to -1/4 (Slightly disagree)	-1/4 to -1/2	-1/2 to -3/4	-3/4 to -1 (Strongly disagree)	No answer
Respondents:	2	1	1	1	

Table 4.64.

- Transplantation is expensive, tertiary care medicine that is unacceptable in a developing country such as ours (Q64).

Opinion:	+1 to +3/4 (Strongly agree)	+3/4 to +1/2	+1/2 to + 1/4	+ 1/4 to 0 (Slightly agree)	0 (neutral)
Respondents:	1	2	1		1
Opinion:	0 to -1/4 (Slightly disagree)	-1/4 to -1/2	-1/2 to -3/4	-3/4 to -1 (Strongly disagree)	No answer
Respondents:	9	1	3	23	1

Table 4.65.

- Chronic dialysis treatment is *more* cost-effective than Transplantation (Q65).

Opinion:	+1 to +3/4 (Strongly agree)	+3/4 to +1/2	+1/2 to + 1/4	+ 1/4 to 0 (Slightly agree)	0 (neutral)
Respondents:	1			1	5
Opinion:	0 to -1/4 (Slightly disagree)	-1/4 to -1/2	-1/2 to -3/4	-3/4 to -1 (Strongly disagree)	No answer
Respondents:	1		2	31	2

Table 4.66.

- Lung Transplantation is cost effective and has excellent results (Q66).

Opinion:	+1 to +3/4 (Strongly agree)	+3/4 to +1/2	+1/2 to + 1/4	+ 1/4 to 0 (Slightly agree)	0 (neutral)
Respondents:	1	5		7	5
Opinion:	0 to -1/4 (Slightly disagree)	-1/4 to -1/2	-1/2 to -3/4	-3/4 to -1 (Strongly disagree)	No answer
Respondents:	8	7	4	2	4

Table 4.67.

- The Transplant team is accessible to all hospitals in KZN who have potential donors (Q67).

Opinion:	+1 to +3/4 (Strongly agree)	+3/4 to +1/2	+1/2 to + 1/4	+ 1/4 to 0 (Slightly agree)	0 (neutral)
Respondents:	17	7	1	2	5
Opinion:	0 to -1/4 (Slightly disagree)	-1/4 to -1/2	-1/2 to -3/4	-3/4 to -1 (Strongly disagree)	No answer
Respondents:	4	2	1	2	2

Table 4.68.

- Organ donor referral, organ donation and procurement in KZN is a private hospital phenomenon (Q68).

Opinion:	+1 to +3/4 (Strongly agree)	+3/4 to +1/2	+1/2 to + 1/4	+ 1/4 to 0 (Slightly agree)	0 (neutral)
Respondents:	4	4	6	2	3
Opinion:	0 to -1/4 (Slightly disagree)	-1/4 to -1/2	-1/2 to -3/4	-3/4 to -1 (Strongly disagree)	No answer
Respondents:	3		8	10	3

Table 4.69.

- Access to organ transplants in KZN is afforded equally to private & provincial patients (Q69).

Opinion:	+1 to +3/4 (Strongly agree)	+3/4 to +1/2	+1/2 to + 1/4	+ 1/4 to 0 (Slightly agree)	0 (neutral)
Respondents:	9		1	3	3
Opinion:	0 to -1/4 (Slightly disagree)	-1/4 to -1/2	-1/2 to -3/4	-3/4 to -1 (Strongly disagree)	No answer
Respondents:	8		10	7	2

Table 4.70.

- Doctors don't like to become involved in making end of life decisions (Q70).

Opinion:	+1 to +3/4 (Strongly agree)	+3/4 to +1/2	+1/2 to + 1/4	+ 1/4 to 0 (Slightly agree)	0 (neutral)
Respondents:	20	6	2	3	1
Opinion:	0 to -1/4 (Slightly disagree)	-1/4 to -1/2	-1/2 to -3/4	-3/4 to -1 (Strongly disagree)	No answer
Respondents:	3	2	2	2	1

Table 4.71.

- Doctors experience a sense of personal failure when a patient under their care becomes brain dead (Q71).

Opinion:	+1 to +3/4 (Strongly agree)	+3/4 to +1/2	+1/2 to + 1/4	+ 1/4 to 0 (Slightly agree)	0 (neutral)
Respondents:	8	8	6	3	1
Opinion:	0 to -1/4 (Slightly disagree)	-1/4 to -1/2	-1/2 to -3/4	-3/4 to -1 (Strongly disagree)	No answer
Respondents:	5	2	3	5	1

Table 4.72.

- The doctors I work with think it is important to request organ & tissue donations from the families of potential donors (Q72).

Opinion:	+1 to +3/4 (Strongly agree)	+3/4 to +1/2	+1/2 to + 1/4	+ 1/4 to 0 (Slightly agree)	0 (neutral)
Respondents:	2	7	4		3
Opinion:	0 to -1/4 (Slightly disagree)	-1/4 to -1/2	-1/2 to -3/4	-3/4 to -1 (Strongly disagree)	No answer
Respondents:	14	2	6	3	2

Table 4.73.

- It has *failed* to be communicated that active assistance in organ procurement is a positive professional duty (Q73).

Opinion:	+1 to +3/4 (Strongly agree)	+3/4 to +1/2	+1/2 to + 1/4	+ 1/4 to 0 (Slightly agree)	0 (neutral)
Respondents:	12	9	6	2	2
Opinion:	0 to -1/4 (Slightly disagree)	-1/4 to -1/2	-1/2 to -3/4	-3/4 to -1 (Strongly disagree)	No answer
Respondents:	7	2		2	1

Table 4.74.

- Organ & tissue donation is a positive option for the family at the time of death of a loved one (Q74).

Opinion:	+1 to +3/4 (Strongly agree)	+3/4 to +1/2	+1/2 to + 1/4	+ 1/4 to 0 (Slightly agree)	0 (neutral)
Respondents:	10	12	5	1	5
Opinion:	0 to -1/4 (Slightly disagree)	-1/4 to -1/2	-1/2 to -3/4	-3/4 to -1 (Strongly disagree)	No answer
Respondents:	8				

Table 4.75.

- Organ donation helps families grieve and in the long-term can take the senselessness from a sudden tragedy (Q75).

Opinion:	+1 to +3/4 (Strongly agree)	+3/4 to +1/2	+1/2 to + 1/4	+ 1/4 to 0 (Slightly agree)	0 (neutral)
Respondents:	10	8	8	7	3
Opinion:	0 to -1/4 (Slightly disagree)	-1/4 to -1/2	-1/2 to -3/4	-3/4 to -1 (Strongly disagree)	No answer
Respondents:	4			1	1

Table 4.76.

- I don't personally feel at all comfortable requesting consent for organ or tissue donation from a grieving family (Q76).

Opinion:	+1 to +3/4 (Strongly agree)	+3/4 to +1/2	+1/2 to + 1/4	+ 1/4 to 0 (Slightly agree)	0 (neutral)
Respondents:	9	8	2		2
Opinion:	0 to -1/4 (Slightly disagree)	-1/4 to -1/2	-1/2 to -3/4	-3/4 to -1 (Strongly disagree)	No answer
Respondents:	1	3	6	10	2

Table 4.77.

- I feel it is more beneficial for the family and the health care team for the specially trained procurement co-ordinator to request consent for organ or tissue donation (Q77).

Opinion:	+1 to +3/4 (Strongly agree)	+3/4 to +1/2	+1/2 to + 1/4	+ 1/4 to 0 (Slightly agree)	0 (neutral)
Respondents:	22	10	5	1	1
Opinion:	0 to -1/4 (Slightly disagree)	-1/4 to -1/2	-1/2 to -3/4	-3/4 to -1 (Strongly disagree)	No answer
Respondents:	1	1			2

Table 4.78.

- Donor families would see somewhat of a conflict of interests for the primary doctor to approach them about organ donation (Q78).

Opinion:	+1 to +3/4 (Strongly agree)	+3/4 to +1/2	+1/2 to + 1/4	+ 1/4 to 0 (Slightly agree)	0 (neutral)
Respondents:	19	6	1	3	2
Opinion:	0 to -1/4 (Slightly disagree)	-1/4 to -1/2	-1/2 to -3/4	-3/4 to -1 (Strongly disagree)	No answer
Respondents:	5	2	2	1	2

Table 4.79.

- My medical colleagues are proficient at handling end of life decision making and breaking bad news to families (Q79).

Opinion:	+1 to +3/4 (Strongly agree)	+3/4 to +1/2	+1/2 to + 1/4	+ 1/4 to 0 (Slightly agree)	0 (neutral)
Respondents:	3	6	5	2	2
Opinion:	0 to -1/4 (Slightly disagree)	-1/4 to -1/2	-1/2 to -3/4	-3/4 to -1 (Strongly disagree)	No answer
Respondents:	3	1	5	12	4

Table 4.80.

- I find organ donor referral and management activities too time consuming (Q80).

Opinion:	+1 to +3/4 (Strongly agree)	+3/4 to +1/2	+1/2 to + 1/4	+ 1/4 to 0 (Slightly agree)	0 (neutral)
Respondents:	3	3	2	1	3
Opinion:	0 to -1/4 (Slightly disagree)	-1/4 to -1/2	-1/2 to -3/4	-3/4 to -1 (Strongly disagree)	No answer
Respondents:	8	4	7	9	3

Table 4.81.

- I have a concern as the primary doctor, regarding my legal liability in the organ donation and procurement process (Q81).

Opinion:	+1 to +3/4 (Strongly agree)	+3/4 to +1/2	+1/2 to + 1/4	+ 1/4 to 0 (Slightly agree)	0 (neutral)
Respondents:	5	7	1	2	2
Opinion:	0 to -1/4 (Slightly disagree)	-1/4 to -1/2	-1/2 to -3/4	-3/4 to -1 (Strongly disagree)	No answer
Respondents:	5		8	10	3

Table 4.82.

- I would rather withdraw from care in a GCS 3 patient, than continue care with the option of organ donation (Q82).

Opinion:	+1 to +3/4 (Strongly agree)	+3/4 to +1/2	+1/2 to + 1/4	+ 1/4 to 0 (Slightly agree)	0 (neutral)
Respondents:	2		2	1	4
Opinion:	0 to -1/4 (Slightly disagree)	-1/4 to -1/2	-1/2 to -3/4	-3/4 to -1 (Strongly disagree)	No answer
Respondents:	4		6	21	2

Table 4.83.

- Looking after an organ donor is part of my professional responsibility to the community, as other lives may be saved (Q83).

Opinion:	+1 to +3/4 (Strongly agree)	+3/4 to +1/2	+1/2 to + 1/4	+ 1/4 to 0 (Slightly agree)	0 (neutral)
Respondents:	19	5	3	2	2
Opinion:	0 to -1/4 (Slightly disagree)	-1/4 to -1/2	-1/2 to -3/4	-3/4 to -1 (Strongly disagree)	No answer
Respondents:	5			4	3

Table 4.84.

- Looking after an organ donor occupies an ICU bed and consumes resources, which could be used for the living (Q84).

Opinion:	+1 to +3/4 (Strongly agree)	+3/4 to +1/2	+1/2 to + 1/4	+ ¼ to 0 (Slightly agree)	0 (neutral)
Respondents:	2	3	1	1	2
Opinion:	0 to -1/4 (Slightly disagree)	-1/4 to -1/2	-1/2 to -3/4	-3/4 to -1 (Strongly disagree)	No answer
Respondents:	6	3	7	15	3

Table 4.85.

- I see organ donation as more of a sacrifice than a gift (Q85).

Opinion:	+1 to +3/4 (Strongly agree)	+3/4 to +1/2	+1/2 to + 1/4	+ ¼ to 0 (Slightly agree)	0 (neutral)
Respondents:		1		1	1
Opinion:	0 to -1/4 (Slightly disagree)	-1/4 to -1/2	-1/2 to -3/4	-3/4 to -1 (Strongly disagree)	No answer
Respondents:	6	2	9	20	3

Table 4.86.

- I believe that the donor should still receive an anaesthetic during procurement, even though he / she has no pain response or perception (Q86).

Opinion:	+1 to +3/4 (Strongly agree)	+3/4 to +1/2	+1/2 to + 1/4	+ ¼ to 0 (Slightly agree)	0 (neutral)
Respondents:	8	3	2		3
Opinion:	0 to -1/4 (Slightly disagree)	-1/4 to -1/2	-1/2 to -3/4	-3/4 to -1 (Strongly disagree)	No answer
Respondents:	6	1	5	11	4

Table 4.87.

- Brain stem death certification is absolute and has never yielded any "survivors" in international studies (Q87).

Opinion:	+1 to +3/4 (Strongly agree)	+3/4 to +1/2	+1/2 to +1/4	+ 1/4 to 0 (Slightly agree)	0 (neutral)
Respondents:	12	4	2	1	6
Opinion:	0 to -1/4 (Slightly disagree)	-1/4 to -1/2	-1/2 to -3/4	-3/4 to -1 (Strongly disagree)	Comments:
Respondents:	4		4	11	If performed correctly!

Table 4.88.

- The organs are recovered in a very professional, respectful manner.

Opinion:	+1 to +3/4 (Strongly agree)	+3/4 to +1/2	+1/2 to +1/4	+ 1/4 to 0 (Slightly agree)	0 (neutral)
Respondents:	21	9	3		2
Opinion:	0 to -1/4 (Slightly disagree)	-1/4 to -1/2	-1/2 to -3/4	-3/4 to -1 (Strongly disagree)	No answer:
Respondents:	4				4

Table 4.89.

- The organ procurement team behave ethically and responsibly (Q89).

Opinion:	+1 to +3/4 (Strongly agree)	+3/4 to +1/2	+1/2 to +1/4	+ 1/4 to 0 (Slightly agree)	0 (neutral)
Respondents:	17	11	1		2
Opinion:	0 to -1/4 (Slightly disagree)	-1/4 to -1/2	-1/2 to -3/4	-3/4 to -1 (Strongly disagree)	No answer
Respondents:	5	1	1		5

Table 4.90.

- The body is treated with dignity at all times (Q90).

Opinion:	+1 to +3/4 (Strongly agree)	+3/4 to +1/2	+1/2 to +1/4	+ 1/4 to 0 (Slightly agree)	0 (neutral)
Respondents:	22	9	1	1	3
Opinion:	0 to -1/4 (Slightly disagree)	-1/4 to -1/2	-1/2 to -3/4	-3/4 to -1 (Strongly disagree)	No answer
Respondents:	4				5

Table 4.91.

- The procurement operation is conducted by specialist surgeons under strictly sterile conditions (Q91).

Opinion:	+1 to +3/4 (Strongly agree)	+3/4 to +1/2	+1/2 to +1/4	+ 1/4 to 0 (Slightly agree)	0 (neutral)
Respondents:	26	5	1	2	2
Opinion:	0 to -1/4 (Slightly disagree)	-1/4 to -1/2	-1/2 to -3/4	-3/4 to -1 (Strongly disagree)	No answer
Respondents:	3				4

Table 4.92.

- The family has a right to be given the option of organ donation, just as they have the right to choose cremation or burial of their loved one.

Opinion:	+1 to +3/4 (Strongly agree)	+3/4 to +1/2	+1/2 to +1/4	+ 1/4 to 0 (Slightly agree)	0 (neutral)
Respondents:	28		1	1	1
Opinion:	0 to -1/4 (Slightly disagree)	-1/4 to -1/2	-1/2 to -3/4	-3/4 to -1 (Strongly disagree)	No answer
Respondents:	3	1		1	7

Table 4.93.

- At the funeral, an open coffin is possible following organ and tissue donation (Q93).

Opinion:	+1 to +3/4 (Strongly agree)	+3/4 to +1/2	+1/2 to +1/4	+ 1/4 to 0 (Slightly agree)	0 (neutral)
Respondents:	26	3	1		4
Opinion:	0 to -1/4 (Slightly disagree)	-1/4 to -1/2	-1/2 to -3/4	-3/4 to -1 (Strongly disagree)	No answer
Respondents:	2			1	6

Table 4.94.

- Organ donation is costly for the donor family or donor medical aid, who cover the costs of the organ procurement (Q94).

Opinion:	+1 to +3/4 (Strongly agree)	+3/4 to +1/2	+1/2 to +1/4	+ 1/4 to 0 (Slightly agree)	0 (neutral)
Respondents:	2	2			1
Opinion:	0 to -1/4 (Slightly disagree)	-1/4 to -1/2	-1/2 to -3/4	-3/4 to -1 (Strongly disagree)	No answer
Respondents:	1	1	4	24	8

Table 4.95.

- It would be a good idea in South Africa, if heart beating or non-heart beating donor referrals were made mandatory by law, in order to increase the availability of organs (Q95).

Opinion:	+1 to +3/4 (Strongly agree)	+3/4 to +1/2	+1/2 to +1/4	+ 1/4 to 0 (Slightly agree)	0 (neutral)
Respondents:	12	4		4	2
Opinion:	0 to -1/4 (Slightly disagree)	-1/4 to -1/2	-1/2 to -3/4	-3/4 to -1 (Strongly disagree)	No answer
Respondents:	7		2	7	5

4.3.6. Recommendations related to issues on brain death and organ donation.

Table 4.96.

- Where should education regarding Organ Donation & Transplantation be introduced in the undergraduate Training programme? (Q97)

Year:	1st	2nd	3rd	4th	5th
Respondents:	1	1	1	9	31

Table 4.97.

- Under which discipline do you see this topic most belonging to? (Q98)

Discipline:	Bioethics	Neurosurgery	Neurology	Surgery
Respondents:	13	8	1	7
Discipline:	Forensics	Family medicine	Community	Psychiatry
Respondents:	7	9	1	
Discipline:	Anaesthetics	Critical care		
Respondents:	2	2		

Table 4.98.

- Would you like to see more in-service education / info on this topic?

Opinion:	Yes:	No:
Respondents:	38	5

Table 4.99.

- If you answered yes to the above question, where would you like to see this incorporated? (Q100)

Source:	Congresses	CME lectures	CME Prac skills	Seminars
Respondents:	7	20	7	7
Source:	Hospital Posters	Library displays	Hospital in-service	Journals
Respondents:	6	2	8	8

Table 4.100.

- In what format? (Q101)

Format:	PowerPoint lectures	Panel discussions	Group discussions	Slides
Respondents:	10	7	10	3
Format:	Overhead lectures	Congress debates	Case Presentations	Video
Respondents:	3	2	12	3
Format:	Multidisciplinary forum	email mailing updates	Additional library books & resources	Informal practical stations
Respondents:	13	1	2	6

Table 4.101.

- If there was a form at the ICU / Trauma facility in which you worked which outlined the prerequisites and each brain stem death test with its clinical details and incorporated an area for you to sign each test off as positive / negative, would you use the form? (Q102)

Opinion:	Yes:	No:
Respondents:	38	5

Table 4.102.

- If you answered 'yes' to question 102 above, which reason would most encourage you to use the Brain Stem Death Criteria form? (Q103)

Respondents:	Reasons:
23	All of the reasons mentioned.
7	To remind me of the tests, and serve as a systematic checklist.
7	To improve my medico legal cover by improving my documentation of the diagnosis.
1	To optimise my testing accuracy.
1	To make the diagnosis more official.

Table 4.103.

- If you answered “No” to the question above, which reason would most discourage you to use the Brain Stem Death Criteria form? (Q104)

Respondents:	Reasons:
3	I know the tests well enough not to need extra assistance.
2	Its up to the individual doctor as to how and with what tests Brain Death is determined.
	It makes the diagnosis too final and formal.
	Too much extra paperwork.
	All of the above.

Table 4.104.

- If there was a page attached to the form mentioned with simple diagrams to assist you to explaining the concept to relatives, would you find this useful? (Q105)

Opinion:	Yes:	No:
Respondents:	36	7

Table 4.105.

- If there was a page attached to the form mentioned in question 102 which consisted of a page for the family to take home, which explained brain stem death in easy to understand terminology, would you find this useful? (Q106)

Opinion:	Yes:	No:
Respondents:	40	3

Table 4.106.

- Would you like to know the outcomes of the study?

Opinion:	Yes:	No:
Respondents:	28	15

4.4 Summary.

In this chapter, the researcher reported on the research results. Responses from the questionnaires were presented in table format, according to the frequency and expression of respondent selection. Shading was used to highlight the most popular options chosen by the respondents as well as to indicate which answers were deemed correct, in certain questions. Data gathered and presented, will now be discussed and formulated in chapter five.

Chapter 5

*'All life has its seasons and cycles, and no one's personal
chaos can be permanent.*

*Winter, after all, gives way to spring and summer,
Though sometimes when branches stay dark and the earth
cracks with ice,
One thinks that spring and summer will never come... but
they always do.' - Truman Capote -*

CHAPTER 5.

ANALYSIS, CONCLUSIONS & RECOMMENDATIONS FROM THE RESULTS.

5.1. Introduction

In chapter four, the study results were presented after collecting the data from the research questionnaires. In this chapter, these results will be analysed and discussed, after which, conclusions and recommendations will be suggested.

5.2. Goal of the Chapter.

The discussion section of the research ties the research report together and gives the study meaning (Burns & Grove, 1999). Conclusions are said to be a synthesis of the findings, where the researcher is able to utilise logical reasoning and create a meaningful whole from information obtained through data analysis and previous research findings (Burns & Grove, 1999). In this chapter, the study results based on the evidence from the literature and questionnaire responses were translated and interpreted with the assistance of the framework in order to become findings. Thereafter, limitations, implications and future research recommendations were presented.

5.3. Analysis.

5.3.1. Personal Demographics.

Of the sample population, 86% (N=37) described their country of upbringing as South Africa. One respondent described being brought up in another African country, while five respondents cited overseas countries for being responsible for their upbringing. Interestingly, only 33% (N=14) of the sample attended the local University of Natal Durban for their undergraduate studies, while a further 47% (N=20) attended other South African universities. 16% (N=9) of the sample attended undergraduate medical training programmes outside of South Africa. This information is important, since the study is therefore representative of local, national and international training and educational input, and does not focus on any one particular responsible medical school facility

A wide range of responses occurred from medical doctors with regards to years practised in the profession with responses received from those with limited to those with extensive experience (see pg 34). 74% (N=32) of respondents had postgraduate qualifications, 63% (N=27) having been received from the University of Natal Durban. It appears from this sample that medical doctors tend to settle and work in the region in which they acquired their postgraduate training. Most of this training was reported to be in the fields of anaesthetics, surgery and neurosurgery. Similar numbers of

respondents worked in the categories of private practise only, private with limited state practise and state practise only. The category of state with limited private appeared to contribute the least responses. Hospitals most frequented for medical practise included St. Augustines, Entabeni, King Edward VIII, Wentworth and Addington hospitals, in descending order. This information was interesting to the researcher, since organ donation activities take place more commonly in the private sector. Therefore, 63% (N=27) of respondents had most probably had some degree of exposure or opportunity of interacting with the transplant team at some stage.

74% (N=32) of the respondents were male and 26% (N=11) female, all falling in fairly equal and widely dispersed age categories between the years of 26 and 55. The majority of the sample was classified in terms of population group as white or Indian, with only 7% (N=3) and 5% (N=2) from the Black and Coloured populations respectively. Again, this information was acquired in order to ensure that the study population was representative in terms of age, race, experience, speciality and religion, in order to optimise the validity of the results.

The majority of respondents followed the Christian religion (42%) while 24% (N=10) described their faith as Hindu and 19% (N=8) as Islamic. Interestingly, 16% (N=7) of the sample population did not report following any faith or religion. In describing the degree of personal religious importance, 44% (N=19) suggest high levels of importance with 26% (N=11) citing low

levels of importance. Interestingly, most individuals citing high levels of religious importance responded from the Islamic and Hindu faith.

5.4. Discussion framework.

As discussed in Chapter 2.3, Fazio's attitude to behaviour process model will be used to present the findings of the study. By utilising this approach, aspects of the model can be utilised not only for the purpose of providing a logical structure, but also to establish the interrelationship between the components as well as discovering the importance and contribution of each subcomponent to achieving the whole.

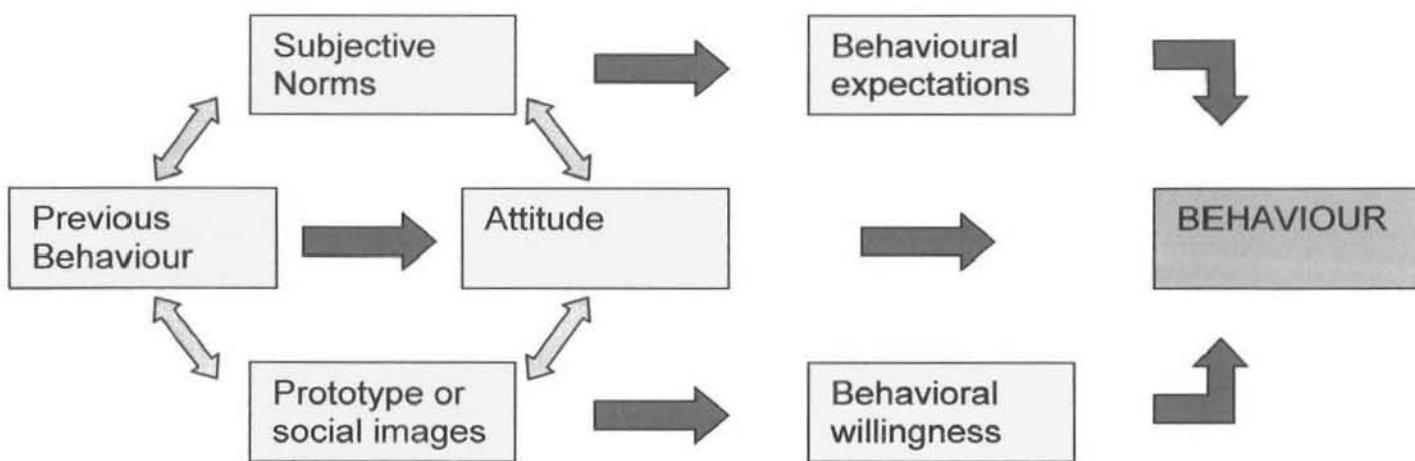


Figure 2: Fazio's attitude to behaviour process model, otherwise captioned the "Willingness model" (Fazio, 1989, Fazio & Roskos-Eewoldson, 1994)

According to the theory proposed by the researchers, the *Willingness model* explains that behaviour is often influenced by several factors, including:

5.4.1. Previous behaviour.

5.4.1.a Knowledge and Skills with regards to previous behaviour.

Contributions from highly respected lecturers and early teaching experiences often leave lasting and profound impressions on learners, which later go on to shape and influence their future practise (Baron & Byrne 2000). Very disturbingly, 51% (N=22) of the sample reported never having received any formal training on brain death or organ donation. This finding was also discovered in two American studies, where only 26% of medical school programmes offered any training on coping with death and dying or dealing with end of life issues (McPhee, 2000; vonGunten, Ferris & Emanuel, 2000). Of the local doctors who had received training, only 16% (N=7) cited medical school as the source, while the majority of information was cited to be provided at speciality meetings, in-service lectures or congresses. Interestingly, the standard of training received was most commonly described as being either very good, or very poor.

This finding alone could contribute to negatively shape the medical doctors views on brain death and organ donation in that by failing to incorporate and provide a holistic basic contribution to the learner's knowledge base, this alone is sending a message that the subject may not be considered important or relevant to current medical practise. In addition, it fails to offer professional sanction and communicate acceptance and inclusion into

medical diagnosis and end of life options. In failing to teach under and post graduate students the skills required for brain stem death testing and organ donation referral procedure, it also places the medical doctor in a position of being uncertain and unsafe in conducting such practises. If he or she feels that the practise is unadvocated, unsupported, untaught and unimportant, then the behaviour he or she will follow, based on what she has been exposed to in the classroom will also be vague and undirected. Unfortunately, generations of such students graduating to the work place will reinforce this ambivalence for the younger doctors and will also fail to provide the necessary guidance and advice for subsequent referral or procurement activity.

Other sources of information depended upon for information include mainly journals, other doctors and transplant co-ordinators. Interestingly, it appears that doctors are turning to journals due to a scarcity of information elsewhere as they cite forums, discussions and case presentations as recommendations for further training on the subject. It is also a concern that other doctors are being consulted for further information, as only 12% (N=5) of respondents had a reasonable overall knowledge on the topic. This finding supports an American public attitudes survey where it was found that the community did not view physicians as an important source of information on organ donation (AMA, 2001). Unfortunately, it was not ascertained whether these doctors who were consulted commonly by respondents were peers or whether they were perhaps neurosurgeons or transplant specialists in their fields.

With regards to awareness, 66% (N=34) of respondents knew which organs and tissues were currently being transplanted in the KZN facilities and which facilities these were. Interestingly, 25% (N=11) mentioned the current news headlines and possibility of including the small intestine as the next organ transplanted in KZN.

70% (N=30) of respondents view their knowledge and skills regarding brain death as good, 59% (N=25) as very good. However, 70% (N=30) of respondents rate their knowledge and skills on the human tissue act on the poor scale and 59% (N=25) of respondents also rate their knowledge and skills on donor selection criteria on the poor scale.

When viewing the scoring on the knowledge and skill questions, an overall success score of the sample population was 34%. This finding was similarly reported by an Ohio 1994 study as well as a Portuguese 1994 study and a Massachusetts 1998 study where doctors in both general and critical care environments had an unexpectedly low knowledge of donor selection, legal specifications and brain death (Coelho & Fontan, 1994; Youngner & Landevelt, 1989).

Interestingly, the questions relating to issues surrounding brain stem death testing were the *least* successfully answered. The lowest scores were achieved in the area of prerequisites to be satisfied prior to brain stem death testing and Human Tissue Act (No. 106 of 1984) specifications in relation to the personnel involved in brain stem death testing. Only 30% (N=26) of

respondents knew that personnel involved in brain stem death testing have to be two independent medical doctors who are not members of the transplant team. Only 14% (N=6) knew that one of these doctors had to be qualified for longer than five years. Most incorrect answers cited the personnel involved as requiring more advanced training and experience than the law requires. 14% (N=6) of respondents did not know what the Act stated at all.

With regards to the prerequisites to be satisfied before commencing testing, this question elicited the most *unspecific* and *unclear* of all the open-ended questions. Many respondents had some information on the subject, but were unable to provide the specific values and time periods required. 26% (N=8) of respondents said that they did not know any of the prerequisites to be followed. This is unfortunate, since brain stem death testing should not be performed until the prerequisites have first been met. The most commonly acknowledged prerequisite was that there had to be evidence of a major and irreversible brain insult.

The clinical tests to confirm brain death question received the most correct answers. However, 7% (N=3) of the sample group expressed that they had no knowledge on how to perform these tests at all. The tests most commonly mentioned included the Pupillary reaction, Dolls Eye / Oculocephalic test and Cold Caloric / Oculovestibular test. The test most unclearly defined with the most varying responses was the Apnea test. A minority of respondents also incorrectly cited an absence of blood pressure, ECG trace or cardiac activity as being symptomatic of brain stem death (see table).

5.4.1.b. Practise related issues with regards to previous behaviour.

The DMR sample appears to be exposed to a large number of patients per year who present with a Glasgow Coma Score of less than 7/15. 40% (N=17) of the sample expresses attending to more than twenty such patients per year. Only 6% (N=2) of the sample were not commonly exposed to such patients in their practise. This is important, since regular exposure to managing the severely comatose patient should predictably result in increased knowledge and proficiency at performing brain death criteria, which is not found in the study.

This is an area for concern as it may provide an area for medico-legal incidents to occur with patients being incorrectly certified by inappropriate personnel who are unfamiliar with the criteria, after failing to follow the specified prerequisites for testing. It may also create the perception that brain death testing is not a rigorous, safe, conclusive and reliable exercise. This perception obviously will have negative connotations when considering organ donation as an option for the brain dead patient.

In terms of action taken after confirming brain death, 67% (N=37) of doctors usually delegate the responsibility of discontinuing treatment or contacting the co-ordinators to other members of the health care team. 53% (N=21) of responses do not consider or accommodate organ donation as an option. Interestingly, the 14% (N=6) of doctors who offer the option of organ donation

to the family themselves have never worked with the transplant team. This could possibly be due to the lack of training that the doctor has received in this area, the uncertainty of specific information that is communicated to the family, or possibly due to the nature of the uncoupled request, which has been shown to adversely affect consent rates.

With regards to contacting the transplant team, 50% (N=21) of doctors report having done so at some stage. Most doctors request the nursing sister to contact the team on his or her behalf. The majority of the sample (37%) reported never having an experience with the team in the past, while 25% (N=11) reported more than ten experiences. A further 38% (N=15) reported between one and ten experiences. The majority of responses to evaluating the doctors perception of quality of his or her interaction with the team were either very positive or yielded no answer, due to never being in contact with the team. Interestingly, an overwhelming 80% (N=33) of respondents stated that if their knowledge on organ and tissue donation were upgraded, they would increase their referrals to the transplant team.

The greatest concerns reported when contacting the team or referring a patient were those of emotion, communication and time, while the most positive aspect of involving the team was that of the comprehensive team approach which was formed. These findings were concurrent with the McPhee (2000) study on close of life concerns. Doctors perceived the majority of their support with regards to referring a patient primarily from the nursing staff, but also to a lesser extent from their medical; colleagues and

hospital administrators, in descending order. Nursing staff were found in Kubler-Ross (1997) studies to be more willing to learn and amend their attitudes than the doctors. The state and private sample categories differed here in that doctors working predominantly in the state environment stated that they received slightly poor support from medical and nursing colleagues, with state hospital administrators perceived to be the most negative to their referrals to the transplant team. Many responses from the provincial sector however, were based on expectation, rather than actual experience, since only 2% (N=1) of state doctors reported actual experience of referring a potential donor within a provincial hospital. As many as half of all respondents reported having a relationship with a friend or close colleague in the transplant team. Only 25% (N=11) of doctors either cared for or knew a transplant recipient.

Patients which doctors reported to be least inclined to refer would be a Moslem female and an African male. Reasons cited were those of religion, cultural differences and the doctor's own experiences with these groups not consenting over the years. A Canadian study by Moore (2000), reinforced that no religion is absolutely opposed to organ donation and that medical and nursing staff should not exclude approaching certain families that have been stereotyped as generally nonparticipative in the donor process. Interestingly, 26% (N=11) of the local sample stated, often with exclamation marks, that they would refer all patients. This may be due to the policies that the private hospitals have which makes referral of all potential organ donors mandatory.

5.4.2. Social images of what people or places who engage or are associated in engaging in certain forms of behaviour (e.g. Prototypes).

The social image of organ donation as a whole and of organ donors themselves was projected in a very positive light by the respondents. Over 60% (N=28) of medical doctors saw organ donation as a positive option for a grieving family and were aware of the beneficial effects which organ donation can have on bereavement and grief resolution. Over 65% (N=30) saw organ donation as part of a gift process to which every family has a right to access after the loss of a loved one, in which financial costs did not adversely affect the donor family or medical scheme of the donor. Over 65% (N=32-39) of respondents also felt that the body was treated with dignity and that the organs were recovered with respect under sterile conditions by a procurement team which behaved ethically and responsibly. Interestingly, the majority of respondents who responded to the above-mentioned series in the negative or neutral context, answered negatively to the control question as to whether the operation was conducted by specialist surgeons under sterile conditions. It would appear that those doctors who have not witnessed organ procurement or participated actively in organ donation envisage a more negative scenario than their more experienced counterparts. Fear of the unknown appears to be a reality for at least 9% (N=4) of respondents.

The sample was divided in deciding whether organ donor referral, organ procurement and donation was a private hospital phenomenon. They were also fairly undecided as a group as to whether transplants were equally accessible to private and provincial patients, although many reported strong concerns that provincial patients may indeed have less access. In cross-referencing the question regarding transplantation facilities, private hospital facilities were mentioned more often, with more accuracy than their provincial counterparts. They did, however generally believe that the transplant team was accessible to all hospitals in KZN and that it should rather be up to the transplant co-ordinator to request consent from families, instead of the primary doctor.

5.4.3. Attitude.

5.4.3.1. Personal views on organ donation

Only 56% (N=24) of respondents classified themselves as organ donors. Only 37% (N=16) have discussed their wish with their family, while only 31% (N=9) of the sample carries donor cards. Interestingly, 95% (N=41) would accept a diagnosis of brain death if made on one of their close relatives and 77% (N=33) would be prepared to donate their relative's organs. Of the tissues they would be most likely to donate, the kidneys, corneas and heart were most commonly selected. Of the tissues they would be least likely to

donate, the skin, bone and heart were most commonly selected. The emotive nature of the heart is an interesting finding.

In a sample where just over half of the individuals would describe themselves as organ donors, a remarkable 88% (N=38) would be personally prepared to receive a donated organ, should they go into organ failure. This translates to 42% (N=18) of the population who are not willing to give, but are keen to receive organs. 84% (N=36) of the sample do not perceive the existence of community pressure on people to be organ donors. Interestingly, many of the individuals who do *not* classify themselves as organ donors, do perceive the existence of such pressure.

5.4.3.2. Personal views on brain stem death.

This attitude category generates reason for concern, as there appears to be general uncertainty and insecurity surrounding the implications and interpretation of a brain dead diagnosis. This finding was not reported in a German 1997 study where doctors were found to accept brain death criteria (Schweidtmann & Muthny, 1997). Only 65% (N=35) of the local sample believes that medical and clinical guidelines for deciding if a patient is brain dead are well established, while 12 % (N=5) disagree with the statement altogether. An alarming 44% (N=19) believe that brain death certification is not absolute and that survivors have been reported in international studies. This insecurity may reflect the perception that the tests are perhaps being incorrectly conducted, which following the findings from this study, cannot be

ruled out. In addition, 30% (N=13) feel that the donor should receive an anaesthetic during organ procurement, even though there is no pain perception or response. With regards to time issued on the death certificate, 30% (N=13) incorrectly stated that the person is only dead following organ procurement, instead of at the time of brain stem death certification.

This brings forward a concern that is probably linked to the respondent's knowledge deficit and uncertainty as discovered in the 'previous experience' component discussed in the framework. If more than a third of doctors, most of whom have post-graduate training are in doubt as to whether the donor is really dead at the time of brain stem death, then there is little wonder why many of them do not wish to be organ donors. In addition, the anxiety this must invoke in definitively referring a patient for organ donation when there is some doubt as to whether he or she may survive may prevent the doctor from contacting the referral team. Paradoxically, however, 95% (N=41) of doctors said that they would accept the diagnosis of brain death on a relative with 77% (N=33) prepared to donate relatives' organs. However, local experience in KZN has suggested that doctors struggle to accept this diagnosis on a relative and seldom progress to donate a loved ones organs following brain death certification. As is stated by Kubler-Ross (1997), that with regards to attitudes and practises on death and dying are concerned, "where the obstacle and fear is great, so the need is as great". From what has been determined, the need is probably translated to be knowledge, team affirmation, religious approval and general hospital staff support.

A number of footnotes were included by the respondents in the questionnaire, pointing out that the brain death tests are only as certain as the tester, and that the certainty depends on the tests being conducted correctly. This appears to be an area of concern in the doctor sample. Local experience would substantiate this concern, as many staff can cite examples where active treatment has been discontinued in cases where brain death tests have been done incorrectly by poorly experienced personnel, and the patient has continued to survive till discharge, despite the active withdrawal of life support. These anecdotal reports and hospital fables are often retold and converted to suit the purpose of the story-teller, often with unfortunate implications after conclusions are incorrectly drawn.

5.4.4. Whether others engage in this behaviour (Subjective norms).

This issue can be viewed from two different perspectives, firstly from a personal angle as in personally being an organ donor in a community where this is seen as beneficial to society. The second is from a professional angle where organ donor referrals and procurement activity is seen as normal medical behaviour and occurs within your sphere of work on a regular basis.

Firstly, personal organ donor status is not usually open to general public knowledge, but it is seen as a fairly normal and public-spirited choice in society. However, certain religions although not opposed to organ donation, have followers who are not aware of the exact standing of the faith or may

even use the presumed stance of the faith as an excuse for preventing him or her from making an educated decision. Persons describing themselves as non-organ donors frequently report the perception of community pressure on them to be donors, indicating that they have a conscience on not being a donor. This is probably exacerbated by the fact that the non-donors would agree to receive. Generally speaking, the doctor's personal choice on organ donation does not appear to affect his patient referral policy.

From a professional perspective, there is a 73% (N=31) general consensus that medical doctors don't like to become involved in making end of life decisions and an overwhelming 63% (N=25) of respondents report experiencing feelings of personal failure at this stage. (The latter finding was also reported in vonGunten's 2000 American end of life care study). Once brain death occurs, 16% (N=7) feel that looking after an organ donor is not part of their professional responsibility in order to save the lives of other community members and 16% (N=7) feel that the donor would be occupying an ICU bed which could be used for the living. Interestingly, doctors involved with predominantly state work, are more strongly assertive about resource and responsibility issues and appear to see organ donor activities in a negative light due to their existing workload, time constraints and facility stressors. Doctors involved in private work did not report time or ICU bed issues to be problematic and were more positive in terms of their professional affiliation to supporting the organ donor network. Private sector staff were also conscious of their colleague's involvement and perceived a higher degree of support from the medical, nursing and administrative sectors. In

this component, it may appear that these issues may explain the scarcity of provincial referrals and the relative absence of procurement activity that has been occurring within this sector.

63% (N=28) of respondents feel that the physicians that they work with think it is *not* important to request organ and tissue donations from the families of potential donors and 67% (N=29) agree that it has failed to be communicated that active assistance in organ procurement is a positive professional duty.

The subjective norm appears to have an important role to play in influencing doctor's behaviour in the organ donor process.

5.4.5. The extent to which a person is willing to perform these actions under a variety of circumstances (Behavioural willingness)

Behavioural willingness follows on and interacts with the component of subjective norms. If your colleagues are all conducting organ donor activities around you, this will provide an easy circumstance in which to function. Similarly, if accessing and retaining an ICU bed for your brain dead patient has never been an issue in your department, then this too will provide a stress free circumstance in which to function. Making a stand and introducing a new concept or challenging an old dogma will usually adversely affect behavioural willingness in an individual, since most people will seek to avoid

conflict situations, even if it entails compromising on individual ideals or creativity.

Medical staff in general report that they are not proficient at handling end of life decision making and breaking bad news to families. If an individual perceives himself or herself to be inferior or substandard in performing a task, they will probably seek to avoid or spend as little time as possible on the issue. As a result, in dealing with grieving families, medical staff report delegating these activities to other members of the team or else fail to deal with them holistically with a supportive knowledge and experience base. Behavioural willingness to spend more time on the topic may not be conducive to making an informed decision regarding organ donation, but may encourage the doctor to involve the co-ordinators in the treating team, in order to assist with bereavement and the explanation and end-of-life option process.

Many respondents believe it would be easier to make referrals if it were made mandatory by law. Perhaps this would remove the decision from the doctor as well as even for the family, as occurs with the mandatory post mortem requirements specified for unnatural deaths. Perhaps this would remove some of the emotion and uneasiness from the request and reduce the variables for the treating team and the family. Support, again, may be influential in this aspect as negative input from any source at this stage may arrest organ donor referral or procurement efforts.

5.4.6. What individuals plan to do in the future (Behavioural intentions)

Most responses in this regard are cited as fairly positive, in that 95% (N=41) would accept a diagnosis of brain death on a relative and 77% (N=33) would be prepared to donate a loved ones organs. 63% (N=31) of doctors would like to continue care in a GCS 3 patient, with the option of organ donation and between 84% (N=36) and 93% (N=40) would like to use the proposed specially designed forms to compliment their diagnosis, explanation and reinforcement of brain death for patients and families in the future. 88% (N=33) would like additional information on the subject and 65% (N=28) are interested on the results of he study, with 77% (N=32) stating that if they had extra knowledge on the topic, they would like to refer more patients.

5.5. Conclusions.

- Personal demographics, religion, etc is a poor indicator or predictor of behaviour on issues surrounding brain death and organ donation.
- A strong knowledge and skills deficit exists with regards to conducting brain death criteria, identifying potential donors and practising in accordance to the regulations laid down by the Human Tissue Act.
- Great uncertainty surrounds the issues of brain death, which can mostly be attributed to a lack of knowledge or insight to the phenomena.

- Medical doctors are functioning as 'Gate Keepers' to the organ donor process in numerous ways, often with the perception that they are functioning relatively well, but with evidence that proves this not to be the case. This study echoes the findings of international studies cited in the literature study which found that medical doctors knowledge of brain stem death and donor referral criteria in the majority of cases fail to support organ donor identification, referral and procurement efforts (Bidigare & Oreman, 1991; Griffin, 1992; Sophie, 1983; Younger & Landeveld, 1989).

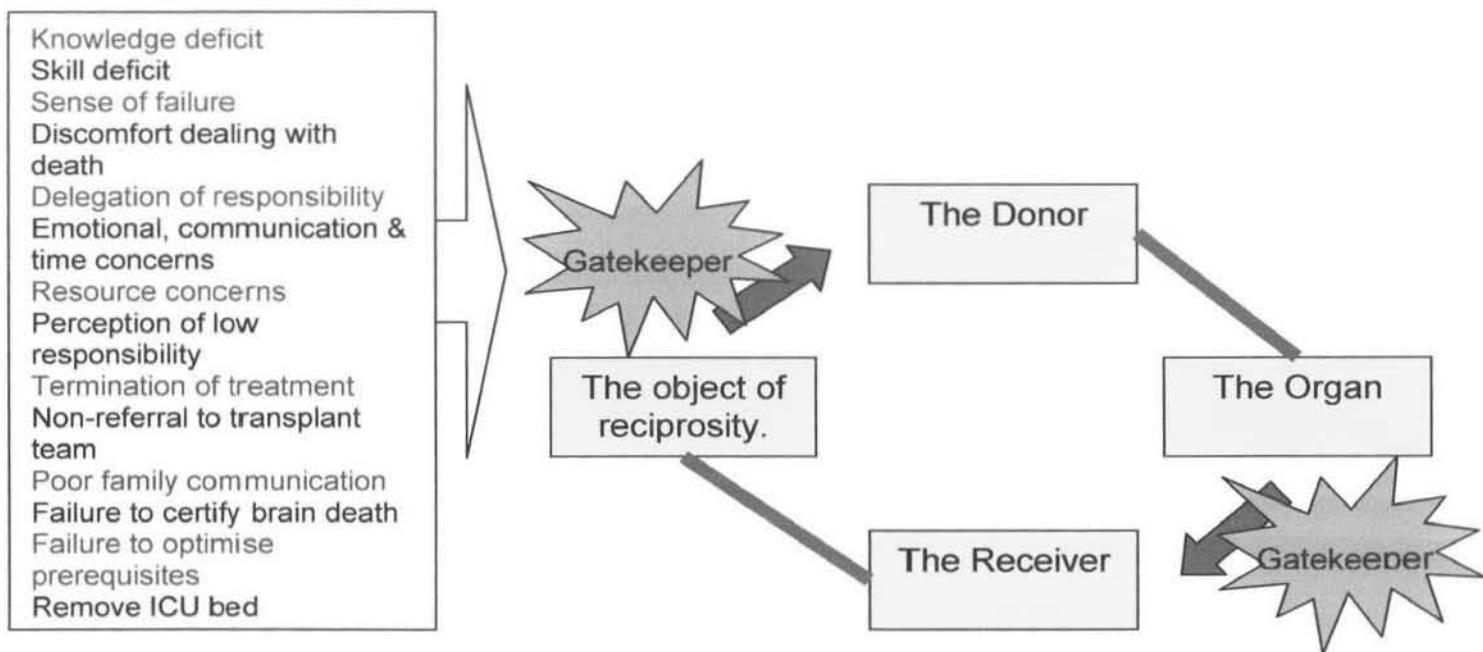


Figure 3. The Gift Exchange Theory, as applied to the process of cadaveric organ transplantation with the roles of gatekeeper from the referral facility clarified. (As adapted from Sque and Payne ,1994).

- Medical School under and postgraduate programmes need to urgently incorporate programmes into the syllabus which will effectively and

holistically deal with end of life issues, coping with death and dying, communicating bad news to families and diagnosing brain death.

- Continuing Medical Education programmes need to urgently incorporate sessions, which will effectively and holistically deal with end of life issues, coping with death and dying and diagnosing brain death.
- Due to the high proportion of religious variability and degree of importance described, this aspect needs to be included and incorporated into medical and community teachings if holistic health care and religious tolerance is to be cultivated and encouraged. Religious advisors also need to provide more clarity and practical guidance on medical issues such as organ donation and brain death acceptance, in order to provide more guidance for the community. Failure to do so could introduce religion as a gatekeeper in the donor process and contribute to weakening the essential bonds of kinship, which are strengthened by gift giving (Verndale and Packard, 1990).
- Journals need to embrace the role they are currently playing in educating the medical profession on issues surrounding brain death and organ donation.
- Support from medical, nursing, legal and administrative staff is vital for the existence and growth of a referral, procurement and transplant structure, since environment has proven to be a potent factor in shaping behaviour, especially in the provincial setting.
- Supportive and complimentary documentation outlining the personnel regulations, prerequisites and brain stem death testing as well as

diagrams and simple text for family explanation and clarification needs to be introduced and made available to provincial and private high care units.

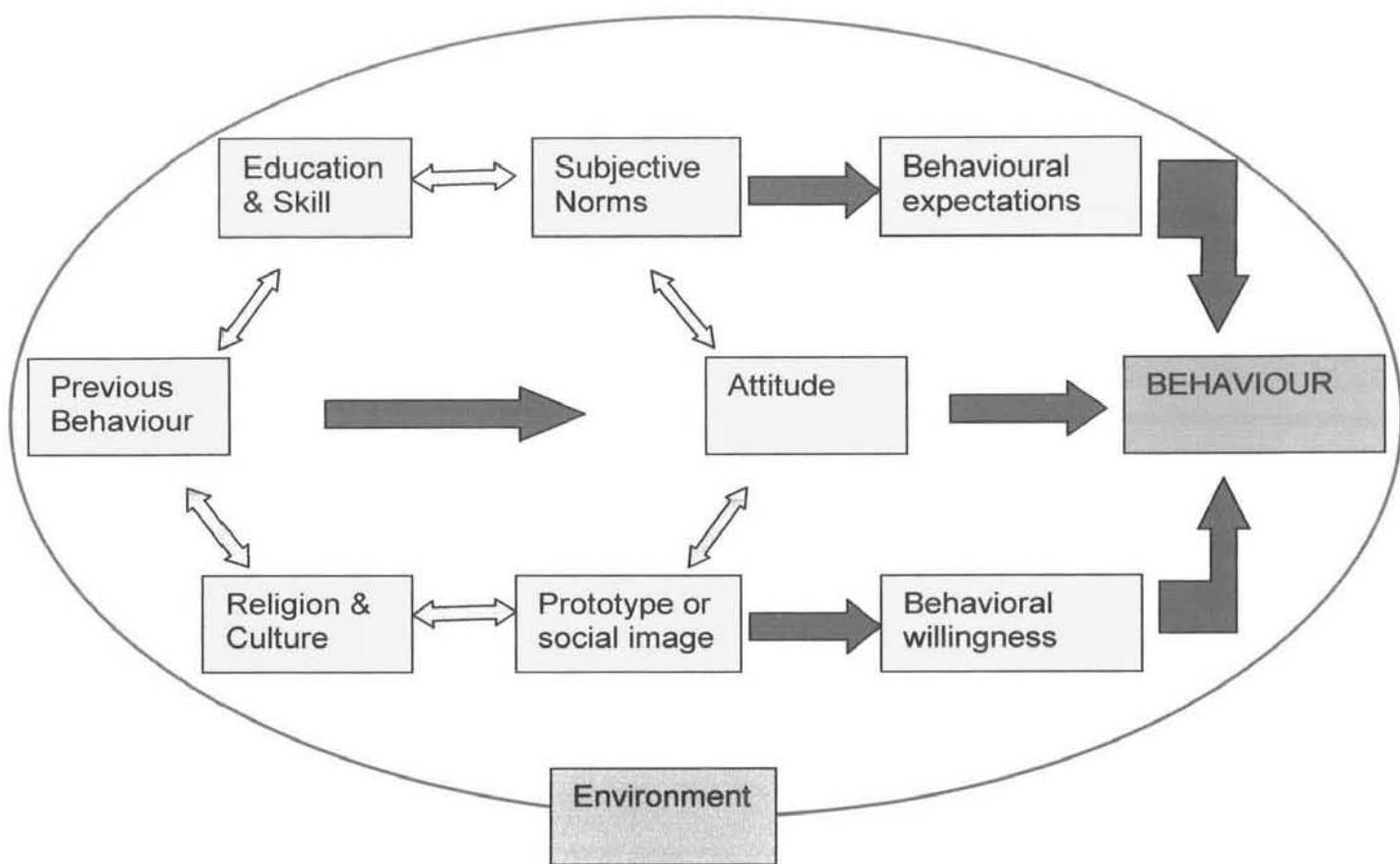


Figure 4. The adapted Fazio's attitude to behaviour process model for Organ Donation behaviour by medical doctors, otherwise captioned the “Physician Organ Donation Willingness model” (Fazio, 1989, Fazio & Roskos-Eewoldson, 1994, Dickson 2001.)

- A new framework, as outlined above, needs to be considered for understanding the behavioural motivations and influences of this category of people for this particular topic. The introduction of 'education and skill' as well as 'religion and culture' and 'environment'

components may assist in providing a more holistic framework, based on the study findings. These recommendations have also been cited in European neonatal end of life studies as well as English nursing organ donation support studies as being important contributors for attitude development and shaping (Kent & Owens, 1995; Rabagliato, Cuttini, et.al, 2000; Watkinson, 1995).

5.6. Limitations.

- Unfortunately, the sample size of the study jeopardises the validity of the results and prevents any degree of generalisability from resulting.
- The nature of the sample population being very busy medical doctors with more pressing priorities, issues and workloads that are all more important than completing an external individuals additional paperwork makes for very difficult work on the part of the researcher. Increasing the time period available for return failed to be constructive, as questionnaires left at a venue for periods of longer than a week were often mislaid and doctors were predictably not in the same venue or department for any length of time.
- Although the information obtained was received from a variable population in terms of age, gender, experience, place of study and work, speciality choice and religion, had the sample numbers in the study been greater, it may have been easier to more confidently define trends in the responses given.

- Due to the limited exposure of state doctors to the topic in question, certain responses were omitted in completing the questionnaire, which prevented their views from being ascertained.
- The researcher was a transplant co-ordinator. This may have coloured responses from the respondents.

5.7. Recommendations.

- Since 52% (N=20) of respondents suggested incorporating organ donation and transplantation into the Bioethics and Forensic course during the fifth year, this should be recommended to the local university for consideration, in light of the current findings.
- Since 88% (N=38) of respondents would like to see more information on this topic, CME providers, hospitals and Journals need to be made aware of the input.
- If the topic is considered for in-service, seminar, speciality meeting or congress purpose, it should be presented in the format of multidisciplinary forum, case presentation, group discussion and powerpoint lecture, in decreasing level of recommendation.
- The government should consider implementing a carefully worded support document that advocates giving the option of organ donation to each and every potential family.
- Each hospital group or facility, as well as the department of health should issue a support document where organ referral, donor

management and procurement efforts are sanctioned and recommended. A summary of this document should be displayed in high care areas such as casualty, CAT scan and Intensive Care.

- The development of a program and teaching module which would deal with the issues of death and dying within the multidisciplinary team should be arranged and implemented. Such a team should include focus on sudden traumatic death as well as the chronic dying process. Due to the frequency which these situations are encountered in the medical profession, such a program should be given value and incorporate practical as well as ethical and personal issues.

5.8. Implications of the findings.

- It appears that the findings have serious implications for medical practise as well as for organ and tissue donation in that there is a severe knowledge and skills deficit that has been discovered by the study.
- Due to the major shortfall discovered, there needs to be urgent remedial action in terms of continuing medical education (CME) efforts as well as more progressive developmental efforts to prevent future under and postgraduate students from being disadvantaged in this manner.
- Supportive documentation should be compiled to protect the medical doctor and the patient from being incorrectly certified as brain dead and to encourage doctors to certify patients safely, according to the

criteria displayed. By providing a family handout, this may assist the doctor who is finding the family interaction difficult, to communicate the explanation with more guidance and reinforcement.

- Organ procurement, forensic and transplantation teams must exercise the utmost caution in ensuring that brain dead patients referred to the co-ordinating team have been certified according to the correct criteria before organ donation is considered.
- Doctors should be more actively involved in CME's on organ donor referral and management, since many report being supportive and express interest in becoming more involved if they had more information and insight into the process.
- The issues surrounding death and dying as a whole need more attention and focus at under and post graduate education levels.

5.9. Recommendations for further research.

- The present study could be extended to incorporate responses from other areas in KwaZulu-Natal, which would provide a larger sample and obtain a perspective from rural and outlying regions.
- Should future research be carried out with this sample group, it would be recommended that telephonic questionnaires be conducted between the hours of 17h00 and 18h30. Doctors appear more open to telephonic verbal information sharing than completing additional paperwork in the form of questionnaires.

- It would be interesting to compare these findings with future studies in other provinces and compile a national findings document.
- Following the introduction of formal and informal teaching programmes on brain death, organ donation and transplantation, it would be interesting to reissue the questionnaires in three to five years time and evaluate any changes that occurred.
- Nursing, hospital administration and paramedical views on organ donation and transplantation in the DMR would be interesting to compare to the medical doctor findings.

5.10. Final Summary.

The views of medical doctors regarding organ donation and transplantation in the Durban Functional Region were examined in an exploratory and explanatory study, which included a descriptive, convenience sampled study of 43 graduate and postgraduate professionals, practicing in the private and provincial sectors. Characteristics were obtained from a 106-item questionnaire that were later divided into component contributions according to Fazio's attitude to behavior process model (Fazio, 1989; Fazio & Roskos-Eewoldson, 1994). Variables which were analysed include personal demographics, personal views, knowledge and skills, practice-related issues, attitudes and perceptions as well as future recommendations.

Analysis of the information revealed that most medical doctors approved of organ donation practices and viewed transplantation as a significant role-

player in both the community and medical sectors. However, a knowledge and skills deficit combined with religious presumptions and general uncertainty regarding issues surrounding the practical, legal and emotional concepts of brain death may be responsible for the relatively low personal dedication and practice participation rate among the sample. Medical doctors from the provincial sector appeared to have considerable concerns which included: time constraints; a perceived lack of support from colleagues, nurses and hospital administrators; a lack of medico-legal awareness relating to organ donation and brain death and a scarcity of experience and insight into the transplant process. In order to address the paucity of awareness pertaining to brain death and organ donation activities, the findings indicate that formal and interactive education programs are required in which issues surrounding death and dying can be explored by a multidisciplinary team. It appears that this team must comprise doctors, lawyers, religious leaders, psychologists, administrators, nurses, donor families and transplant co-ordinators. This development may serve to emphasize the professional importance of holistic bereavement counselling, improve doctor and patient satisfaction, increase organ donation referrals and transplantation rates as well as diminish medico-legal concerns.

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'There are years that ask questions and years that answer.'
- Zora Neale Hurston -

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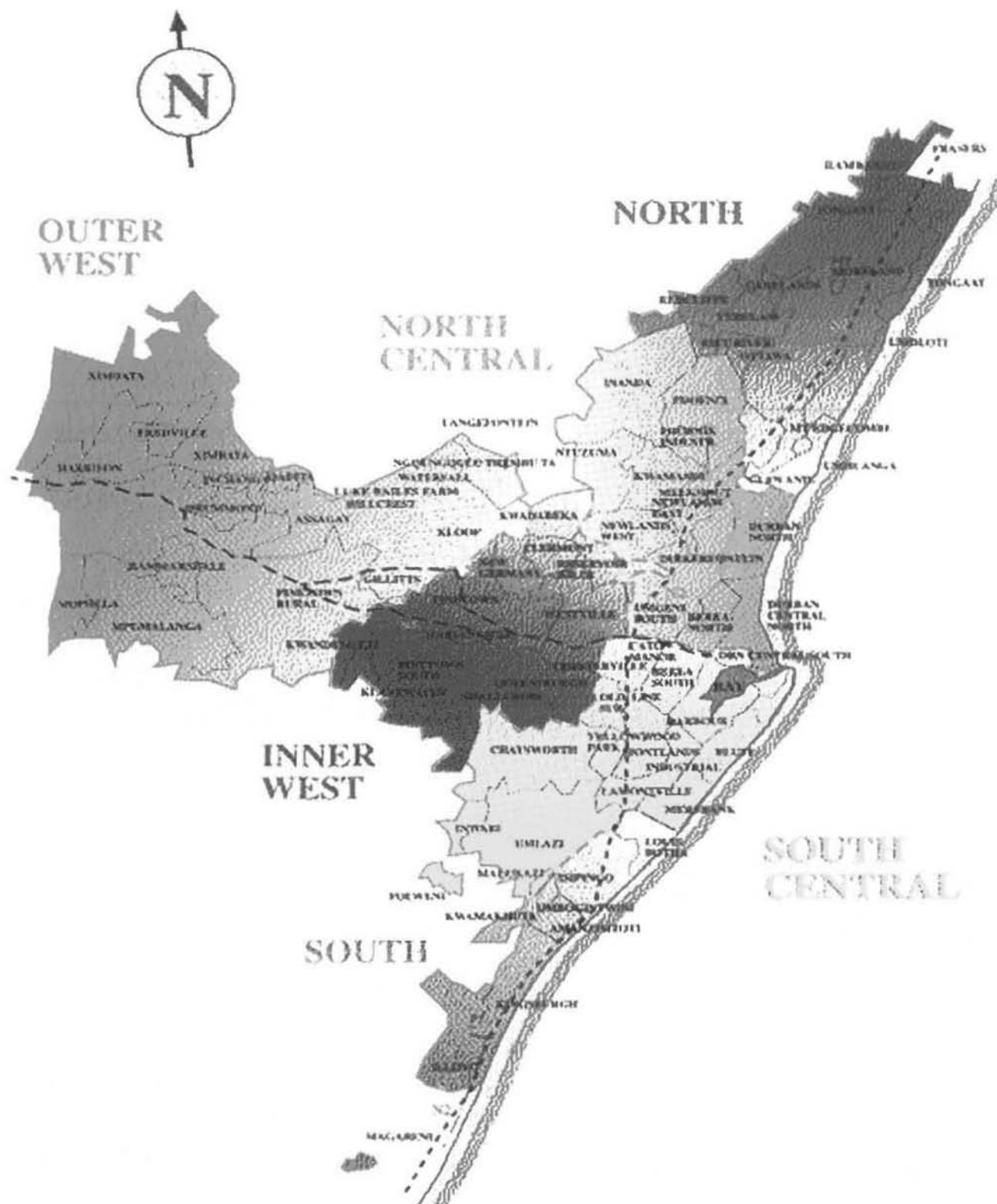
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Appendices

*'There is no medicine like hope, no incentive so great
And no tonic so powerful
as expectation of something tomorrow.'* - O.S. Marsden -

Appendix A

(1997 Road Traffic Accident Statistics)



Appendix B

QUESTIONNAIRE

focusing on:

A Survey of Medical Doctor's views on Cadaveric Organ Donation and Transplantation.

This questionnaire forms part of a survey being carried out by the University of Natal faculties of Community & Development and Health Sciences. It has been found in the United States that all other health care professionals take their cues regarding organ procurement from doctors within their area of practise (Prottas & Batten, 1998). The aim of this survey is to collect local South African information regarding the skills, attitudes and perceptions of physicians in The Durban Metropolitan Region, relating to Organ Donation & Transplantation In order to obtain this information; the researchers have sent a copy of this questionnaire to a wide sample of doctors from 8 different hospitals within the DMR. Permission to carry out this survey has been granted by the Research Ethical Committee of the Nelson R Mandela School of Medicine – University of Natal, and the Medical Superintendent of your facility. Your participation would be very much appreciated, however, you may choose not to complete this form, should you so wish. Please read carefully through this cover page before responding to the questionnaire.

This questionnaire contains various questions/statements, which you are kindly asked to fill in your response and return to the Head of Department / Transplant Division before 31st of October 2001.

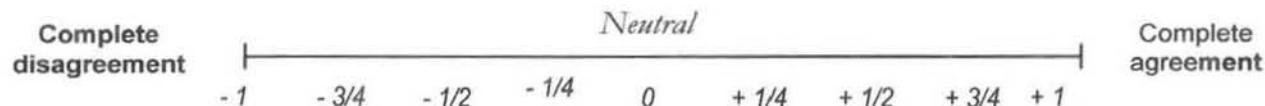
To complete the questionnaire, please note the following:

Kindly respond in the format as appropriately instructed

Where the statement or question requires a graded response, a **Visual Analogue Scale** is provided for you to place your response. *Below is a sample Visual Analogue Scale*



NOTE: The Visual Analogue Scale allows you to **place your own view as an estimate in the scale given by putting a cross on the respective point along the line.** The scale ranges from one extreme e.g. *strongly disagree* to the opposite extreme e.g. *strongly agree*. The fractionated marks shown below illustrate the different points of calibration on the visual scale.



PLACE A MARK ANYWHERE ALONG THE SCALE LINE TO RECORD YOUR VIEW. VIEWS CAN VARY FROM COMPLETE DISAGREEMENT TO COMPLETE AGREEMENT.

For the Yes/No or choice response, please circle the appropriate option e.g. Yes  No

NOTE: Completion of this questionnaire should take you approximately 20 minutes.
Kindly Provide frank and honest answers to these opinion-related questions.

Remember, although there are some right and wrong answers; we are interested in your input and opinion.

Responses made in this study are anonymous and will be kept individually confidential.

For feedback or additional information on this subject or on the questionnaire, please hand in the separate form as enclosed on the back page.

A: PERSONAL DEMOGRAPHICS & CHARACTERISTICS:

1. Which country were you brought up in?

South Africa / Zimbabwe / Botswana / Namibia / Kenya / Cuba / USA / UK / Australia / New Zealand / Pakistan / USSR / India / Other _____

2. At which Medical School did you complete your undergraduate training?

UND / Wits / Stellenbosch / UCT / UNITRA / Pretoria / MEDUNSA / OFS / Other _____

3. How many years have you been practising as a Medical Doctor?

0-4 5-9 10-14 15-19 20-24 25-29 >30

4. Do you have any postgraduate qualifications? Yes / No

5. At which Medical School did you complete your postgraduate training?

UND / Wits / Stellenbosch / UCT / UNITRA / Pretoria / MEDUNSA / OFS / Other _____

6. What is your field of current specialisation?

7. What kind of practise do you classify yourself as being a part of?

Private only	Private with limited state	State only
State with limited private	Equal state & private	Other _____

8. List the 2 main hospitals where you spend the most time practising medicine?

9. What gender group do you classify yourself as part of?

Male Female

10. What age group in years do you classify yourself as part of?

20-25	26-30	31-35	36-40	41-45	46-50	51-55
56-60	61-65	> 66				

11. What population group do you classify yourself as part of?

Black White Indian Coloured Other: _____

12. Which faith or religion do you follow?

None	Islamic	Christian	Jehovah Witness	Hindu
Jewish	African (<i>please state</i>) _____	Other (<i>please state</i>) _____		

13. How important would you say your religion is to you?

Very Important | No importance

B: PERSONAL VIEWS ON ORGAN DONATION:

14. Would you classify yourself as an organ donor ? Yes / No

15. If so, do you carry an organ donor card? Yes / No

16. Have you informed your family of your wishes regarding your decision? Yes / No

17. Would you accept a diagnosis of Brain Death if it was made on one of your close relatives?

Yes / No

18. Would you then be prepared to donate the organs of that close relative? Yes / No

19. What organs or tissues would you be MOST inclined to donate?

Heart Lungs Kidneys Corneas Skin Bone

20. What organs or tissues would you be LEAST inclined to donate?

Heart Lungs Kidneys Corneas Skin Bone

21. If you were to go into organ failure, would YOU RECIEVE a donated organ from a cadaver donor?

Yes / No

22. Do you believe that there is community pressure on people to be organ donors? Yes / No

C: KNOWLEDGE & SKILLS:

23. Did you ever receive any formal training on Brain Death & Organ Donation? Yes / No

24. If you answered "yes" to the above question, where was this information provided?

At a medical school lecture At a CME event At a congress

At an in-service talk At a case review At a speciality meeting

25. How would you rate the information which you received from the above mentioned training?

Excellent | Poor

26. Where have you received other information on Brain Death & Organ Donation from?

Other Doctors	Nurses	Friends	Transplant Coordinators
Journals	Posters & pamphlets	Hospital Policy Folders	Ward Information folders.
Television	Radio	Newspapers & Magazines	The Internet.

27. How would you personally rate your knowledge and skills regarding Brain Death?

Excellent | _____ | Poor

28. How would you personally rate your knowledge and skills regarding The Human Tissue Act?

Excellent | _____ | Poor

29. How would you personally rate your knowledge and skills regarding donor selection & criteria?

Excellent | _____ | Poor

30. Is it possible to certify a patient Brain Dead who is not on a ventilator? Yes / No

31. Can a patient having seizure activity be certified brain dead? Yes / No

32. Can cerebral angiography's be used to determine brain death if , for any reason, all the clinical tests cannot be performed? Yes / No

33. Is an electroencephalogram (EEG) conducted in the ICU setting a reliable test for Brain Death?

Yes / No

34. Is a patient who dies from an Unnatural cause (eg: gunshot head wound from a hijacking) legally permitted to be an organ donor? Yes / No

35. Is a 5 year old patient suitable as an organ donor? Yes / No

36. Is a patient with hyperthyroidism suitable as an organ donor? Yes / No

37. Can corneas be donated from someone who has had no pulse for 6 hours? Yes / No

38. Can kidneys be donated from someone who has had no pulse for 6 hours? Yes / No

39. Do the pathophysiological changes resulting from brain death cause organ damage? Yes / No

40. Does it matter how long after brain death the organs are recovered? Yes / No

41. A patient is certified brain dead at 08h00 and following family consent is taken for heart and kidney procurement which was completed at 12h00. The time of death on the death certificate is:

08h00 / 12h00 / Other (please state) _____

42. What does the South African Human Tissue Act specify in relation to the personnel involved in diagnosing brain death?

43. What prerequisites must be satisfied prior to one conducting the brain stem death tests?

44. What are the clinical tests used to determine brain death?

45. What organs or tissues are currently transplanted in KwaZulu-Natal?

Liver	Kidney	Heart	Lungs	Pancreas	Islet Cell
Corneas	Bone	Bone marrow	Heart valve	Skin	Intestine

46. Which hospitals are transplanting *solid organs* in KwaZulu-Natal?

D: PRACTISE RELATED ISSUES:

47. How many patients do you attend to in a year with a GCS < 7 / 15?

0 1 2 3 4 5 6 7 8 9 10 >10 >20

48. What do you as a physician usually do after confirming brain stem death?

- a.)Request termination of care from staff.
- b.)Personally discontinue care eg: turn off ventilator and / or ionotropic support.
- c.)Continue active care, until patient arrests.
- d.)Continue active care & contact the Transplant Co-ordinator.
- e.)Contact the family and offer them all the options yourself, including organ donation.
- f.)Contact the family to inform of Brain death and contact the Co-ordinator to request organ donation.

49. Have you ever contacted the Transplant Co-ordinators before? Yes / No

50. If you had to contact a Transplant Co-ordinator, how would you go about doing it?

- a.) Ask the sister for the number and get her to call them.
 - b.) Look for a poster with the number in the duty room and call them personally.
 - c.) Call Medical Emergencies (301 3737) and page them.
 - d.) Call hospital Switch Board and have them call them to phone you back
 - e.) Contact a doctor colleague in the Transplant Team and tell him / her.
 - f.) Other

51. How many experiences with the Transplant Team have you had?

0 1 2 3 4 5 6 7 8 9 10 ≥ 10

52. How would you describe the experiences?



53. What are your greatest concerns when contacting the team or referring a patient?

Legal issues communication issues time issues ethical issues
Knowledge & skill issues confidentiality issues peer issues emotional issues

54. What is the most positive aspect of involving the transplant Coordinators in the treating team?

- a.) Comprehensive team approach
 - b.) Other Health Care Workers assisting with bereavement
 - c.) Working with other disciplines
 - d.) Decreased legal & emotional responsibility of physician

55. How would you rate the support given to you with regards to referring a patient as a donor from your *medical* colleagues?

Excellent  Poor

56. How would you rate the support given to you with regards to referring a patient as a donor from your hospital administrators?

Excellent _____ Poor

57. How would you rate the support given to you with regards to referring a patient as a donor from your *nursing* staff?

Excellent Poor

58. Which one of the following patients would you currently be *LEAST* likely to refer to the procurement coordinator team following Brain stem death certification?

Give a reason for your answer just cited in question 58:

59. Are you professionally involved in caring for transplant recipients? Yes / No

60. Do you have a friend or close colleague who is a transplant recipient? Yes / No

61. Do you have a friend or close colleague within the transplant team? Yes / No

62. If you had more knowledge about organ & tissue donation, would you routinely refer patients who were dead or brain stem dead to the co-ordinators? Yes / No

E: ATTITUDES & PERCEPTIONS:

63. Medical & Clinical guidelines for deciding if a patient is brain dead are well established.



64. Transplantation is expensive, tertiary care medicine which is unacceptable in a developing country such as ours.



65. Chronic dialysis treatment is *more* cost-effective than Transplantation.



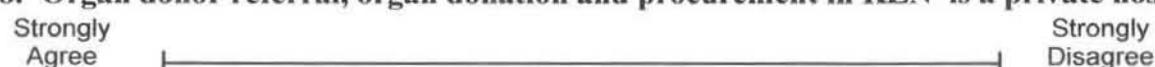
66. Lung Transplantation is cost effective and has excellent results.



67. The Transplant team is accessible to all hospitals in KZN who have potential donors.



68. Organ donor referral, organ donation and procurement in KZN is a private hospital phenomenon.



69. Access to organ transplants in KZN is afforded equally to private & provincial patients.



70. Physicians *don't* like to become involved in making end of life decisions.



71. Physicians experience a sense of personal failure when a patient under their care becomes brain dead.
- Strongly Agree | _____ | Strongly Disagree
72. The physicians I work with think it is important to request organ & tissue donations from the families of potential donors.
- Strongly Agree | _____ | Strongly Disagree
73. It has failed to be communicated that active assistance in organ procurement is a positive professional duty.
- Strongly Agree | _____ | Strongly Disagree
74. Organ & tissue donation is a positive option for the family at the time of death of a loved one.
- Strongly Agree | _____ | Strongly Disagree
75. Organ donation helps families grieve and in the long-term can take the senselessness from a sudden tragedy.
- Strongly Agree | _____ | Strongly Disagree
76. I don't personally feel at all comfortable requesting consent for organ or tissue donation from a grieving family.
- Strongly Agree | _____ | Strongly Disagree
77. I feel it is more beneficial for the family and the health care team for the specially trained procurement co-ordinator to request consent for organ or tissue donation.
- Strongly Agree | _____ | Strongly Disagree
78. Donor families would see somewhat of a conflict of interests for the primary doctor to approach them about organ donation.
- Strongly Agree | _____ | Strongly Disagree
79. My medical colleagues are proficient at handling end of life decision making and breaking bad news to families.
- Strongly Agree | _____ | Strongly Disagree
80. I find organ donor referral and management activities too time consuming.
- Strongly Agree | _____ | Strongly Disagree

81. I have a concern as the primary doctor, regarding my legal liability in the organ donation and procurement process.



82. I would rather withdraw from care in a GCS 3 patient, than continue care with the option of organ donation.



83. Looking after an organ donor is part of my professional responsibility to the community, as other lives may be saved.



84. Looking after an organ donor occupies an ICU bed and consumes resources, which could be used for the living.



85. I see organ donation as more of a sacrifice than a gift.



86. I believe that the donor should still receive an anaesthetic during procurement, even though he / she has no pain response or perception.



87. Brain stem death certification is absolute and has never yielded any "survivors" in international studies.



88. The organs are recovered in a very professional, respectful manner.



89. The organ procurement team behave ethically and responsibly.



90. The body is treated with dignity at all times.



91. The procurement operation is conducted by specialist surgeons under strictly sterile conditions.



92. The family has a right to be given the option of organ donation, just as they have the right to choose cremation or burial of their loved one.



93. At the funeral, an open coffin is possible following organ and tissue donation.



94. Organ donation is costly for the donor family or donor medical aid, who cover the costs of the organ procurement.



95. It would be a good idea in South Africa, if heart beating or non heart beating donor referrals were made mandatory by law, in order to increase the availability of organs.



F: RECOMMENDATIONS:

97. Where should education regarding Organ Donation & Transplantation be introduced in the undergraduate Training programme?

1st Year 2nd Year 3rd Year 4th Year 5th Year

98. Under which discipline do you see this topic most belonging to?

Bioethics	Neurosurgery	Neurology	Surgery
Forensics	Family Medicine	Community Health	Psychiatry

99. Would you like to see more in-service education / info on this topic? Yes / No

100. If you answered yes to the above question, where would you like to see this incorporated?

Congresses	CME Lectures	CME Practical Skills	Seminars
Hospital Posters	Library Displays	Hospital In-services	Journals

101. In what format?

PowerPoint lectures	Panel discussions	Group discussions	Slides
Overhead lectures	Informal practical stations	Case Presentations	Video
Multidisciplinary forum	email mailing updates	Additional library books & resources	
Congress papers	Other _____		

102. If there was a form at the ICU / Trauma facility in which you worked which outlined the prerequisites and each brain stem death test with its clinical details and incorporated an area for you to sign each test off as positive / negative, would you use the form? Yes / No

103. If you answered ‘yes’ to question 102 above, which reason would most *encourage* you to use the Brain Stem Death Criteria form?

- a.) To improve my medico legal cover by improving my documentation of the diagnosis.
- b.) To optimise my testing accuracy.
- c.) To remind me of the tests, and serve as a systematic checklist.
- d.) To make the diagnosis more official.
- e.) All of the above.

104. If you answered “No” to question 102 above, which reason would most *discourage* you to use the Brain Stem Death Criteria form?

- a.) Too much extra paperwork.
- b.) I know the tests well enough not to need extra assistance.
- c.) Its up to the individual doctor as to how and with what tests Brain Death is determined.
- d.) It makes the diagnosis too final and formal.
- e.) All of the above.

105. If there was a page attached to the form mentioned in question 102 with simple diagrams to assist you to explaining the concept to relatives, would you find this useful? Yes / No.

106. If there was a page attached to the form mentioned in question 102 which consisted of a page for the family to take home, which explained brain stem death in easy to understand terminology, would you find this useful? Yes / No.

XX

THANK YOU FOR COMPLETING THE QUESTIONNAIRE!

XX

Please Turn Over

Appendix C.

Please answer one final question:

Would you like to know the outcomes of the study?	Yes / No
--	-----------------

If you answered "yes" to the above, please complete the following:

Organ Donation & Transplantation feedback request slip:

Name: _____

Department: _____

Hospital: _____

Preferred means of contact: Email

Department Notice Board

Email address: _____

If none of the above are available to you, please supply the following:

Postal address: _____

The Diagnosis of Brain Death : The Clinical Examination.

Dr. S. T. Boyd
Sr. L. Dickson
Ms. V. C. Wentink
Prof. M. A. Dada
Dr. S. Nadví



The widespread use of Mechanical Ventilators that prevent respiratory arrest has transformed the course of terminal neurologic disorders.



Basic concepts:

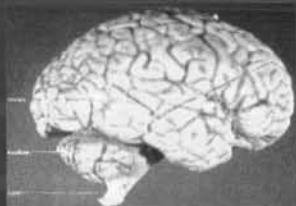
- The Brain Stem is the center of brain function: Without it, no life exists.

(Conference of Medical Royal Colleges & their faculties in the UK, 1976)

- Physicians, HCW's, members of the clergy and lay people throughout the world have accepted fully that a person is dead when his / her brain is dead.

(Wijdicks, 2001)

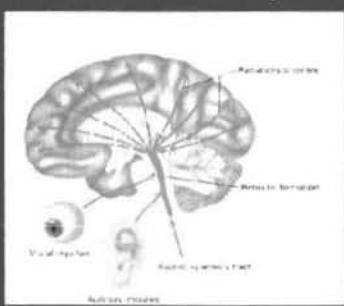
Anatomical Concepts:



- The Brain Stem consists of the mid brain, pons & medulla oblongata.

The Brain Stem:

Connector, regulator, controller, initiator, conveyor



The clinical neurological examination remains the standard for the determination of Brain Death, and has been adapted by most countries, including South Africa.





The Clinical Examination of patients who are presumed to be Brain Dead must be performed *with precision.*



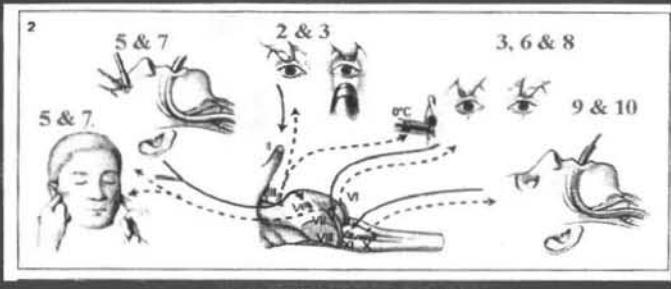
A complete clinical Neurological Exam includes:

- Documentation of Coma.
- Absence of Brain stem reflexes.
- Apnoea.



Brain Stem Reflexes:

- Solid Arrows = Afferent limbs
- Broken Arrows= Efferent limbs



The Declaration of Brain Death requires not only a series of careful neurological tests, but also the establishment of:

- Cause
- Irreversibility
- Recognition & Tx of misleading / co-founding factors.
- Interpretation of neuroimaging
- Understanding lab. test implications



Tests Include:

- Absence of motor responses.
- Absence of pupillary response to light.
- Absence of corneal reflexes.
- Absence of gag reflexes.
- Absence of coughing to carina stimulation.
- Absence of oculocephalic response
- Absence of oculovestibular response.
- Absence of sucking & rooting reflex.
- Absence of respiratory drive.

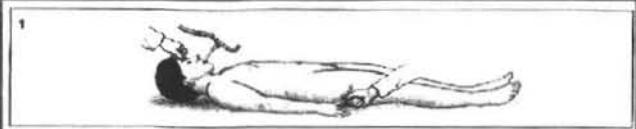
TEST NO. 1 :

An absence of motor response to a standardised painful stimulus, such as pressing hard on the supraorbital nerve.





TEST NO. 1 :
No motor / eye response to centrally applied pain stimulus:



Adapted from
Wijdicks, 2001



TEST NO. 3 :

An absence of corneal reflex by blinking or moving the eyelid to touching the edge of the cornea with a swab to produce an adequate stimulus.



TEST NO. 5 :

An absence of cough response to tracheal and bronchial suctioning.



TEST NO. 2 :
An absence of pupillary response to bright light. Pupils can be round or oval shaped in the mid or fully dilated position.



TEST NO. 4 :

An absence of gag response to deep suctioning down the back of both sides of the throat.



TEST NO. 6 :

Oculocephalic / 'Doll's Eye' Test.

- Exclude cervical spine injury beforehand.





No oculocephalic eye movements should be elicited by rapid turning of the head.



“Dolls Eye” Test:



Adapted from
Wijdicks,
2001



TEST NO. 7:

Oculovestibular / ‘Cold Caloric’ Test.

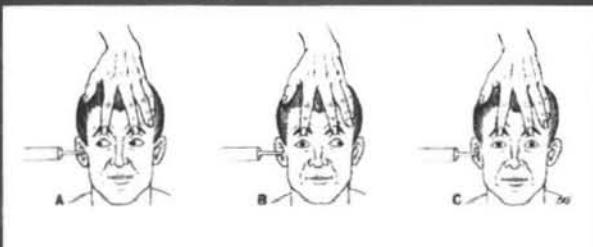
- Exclude clotted blood in the ear canal or a ruptured tympanum beforehand.



No tonic deviation eye movements towards the side of the stimulus should be elicited during 1 minute with slow irrigation of 50ml iced water into the ear.



“Cold Caloric” Test:

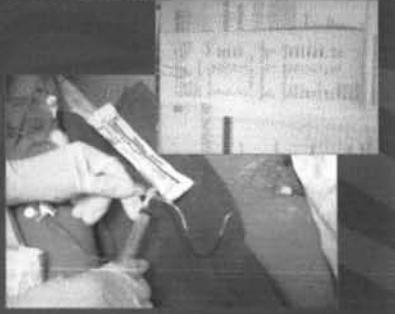


Adapted from Wijdicks, 2001



TEST NO. 8 :
Apnoea Test.

- Prior to performing Apnoea Testing, the PCO₂ should be around 37mmHg and the patient should be well preoxygenated.





- The Ventilator is disconnected from the patient and a supply of 6l/min of humidified O₂ is administered passively down the tracheal tube.



- The doctor & one other HCW perform the test, one will monitor time & respiratory effort, the other will monitor vital signs.



TIME
↓
RESPIRATORY
EFFORT ↑

- The patient is assessed for 10 minutes off the ventilator and the PCO₂ is reexamined. It should exceed 55mmHg. If breathing or instability occur, the patient is reconnected.



Donor Support : Thermoregulation

- "Space Blankets" help to maintain temperature, but active warming requires "Bear Hugger" type assistance.



Donor Support : Oxygenation & Acid-Base Balance.

- Monitor blood gases & treat results if necessary.



Recording & Reporting:

- Documentation
- Data entry
- Report generation

Donor Support: Ventilation:

- Mechanical ventilation
- Respiratory support
- Oxygen delivery

Donor Support: CVP monitoring:

- CVP IV
- Line for monitoring
- Monitoring & hemodynamic support

Donor Support: IV Fluid & Infotropes....

- Balancing Act
- Fluid management
- Infotropes

Donor Support: Urine Output & composition:

- Urine collection
- Composition analysis
- Output measurement

Sustaining Homeostasis & Care:

- Intensive care
- Monitoring
- Support