

The knowledge, attitudes and perceptions of organ procurement and donation
among medical doctors in critical care settings in academic hospitals in
Johannesburg, South Africa.

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A research report submitted to the Faculty of Health Sciences, University of the
Witwatersrand, in fulfilment for the degree of Master of Medicine.

Johannesburg, 2016

DECLARATION:

I, Cleo Solomon, hereby declare that the work presented is an authentic record of my own work. It is being submitted for the degree of Master of Medicine in the University of the Witwatersrand, Johannesburg. I have not submitted the work embodied in this report for the award of any other degree or diploma.

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ABSTRACT

Background: Statistics for the Johannesburg region demonstrate a low level of cadaveric organ donation within the public health care sector. The reasons for this are not clear. Information gathered in a previous study suggest that urban dwelling South Africans have a good attitude towards donation.

It was hypothesized that knowledge, attitudes and perceptions of organ donation within the medical community may be contributing to this, and thus may be identified as a potential target for future intervention in order to effect an increase in donation rates.

Methods: A self-administered questionnaire was completed by 105 of a total population of 190 doctors working in critical care, trauma, and accident and emergency departments in three academic hospitals in Johannesburg, South Africa. This cross sectional descriptive survey aimed to determine attitudes, knowledge and perceptions of doctors working in these settings towards organ donation and donor recruitment.

Results: 65/105 (61.9%) of respondents had a positive attitude towards donation. This was reflected in their own willingness to donate organs after brain death (95% CI: 51.9-71.2%). The majority (65.7%) were unaware of the presence of protocols for organ donor identification and referral. Only 46.7% of the respondents knew who to contact from an organ procurement organisation, once a donor is identified. Of the total respondents, 39% had ever managed a donor or contacted the transplant co-ordination team, and 39% knew the criteria for brain death. There was a significant association between a positive answer in the

questions relating to experience questions and actual knowledge of the criteria for brain death.

90/105 (85.7%) agreed that organ donation could assist the family of the donor with the grieving process. The presence of an organ procurement team was felt to be the best option for improving organ donation rates.

Conclusion: Doctors in critical care settings demonstrate similar levels of positive attitude towards donation as urban dwelling laypersons. Potential areas of intervention to improve donation rates include clearly defined protocols for donor identification and management, education regarding brain death criteria, and external support for family counselling.

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ABBREVIATIONS

A&E: Accident and Emergency

CMJAH: Charlotte Maxeke Johannesburg Academic Hospital

CHBAH: Chris Hani Baragwanath Academic

CKD: Chronic Kidney Disease

DGMC: Donald Gordon Medical Centre

ESRD: End stage renal disease

HJH: Helen Joseph Hospital

ICU: Intensive Care Unit

ODF: Organ Donor Foundation

RLKD: Related Living Kidney Donor

RRT: Renal replacement therapy

UCT: University of Cape Town

UK: United Kingdom of Great Britain and Northern Ireland

USA: United States of America

1. INTRODUCTION

Organ donation is the process of surgically removing organs from a deceased or living individual, and then transplanting the organ into the body of a recipient with end-stage organ failure. Organ transplantation is accepted worldwide as the management strategy of choice in chronic organ failure (1). For most patients with advanced organ failure, organ transplant is their only hope of survival.

1.1. **The global statistics: “The need is real”**

A global, consolidated database reflecting the number of individuals worldwide who are awaiting transplants is absent, and consequently an accurate estimation of this data cannot be obtained. The Global Observation on Donation and Transplantation (GODT) forms the only worldwide database for collection of statistics regarding donation and transplantation (2,3). The highest rates of deceased donation occur in the United States of America (USA) and Spain, conversely, the lowest rates are in Algeria, Mexico, Saudi Arabia, and South Africa. (Figure 1.1) (3).

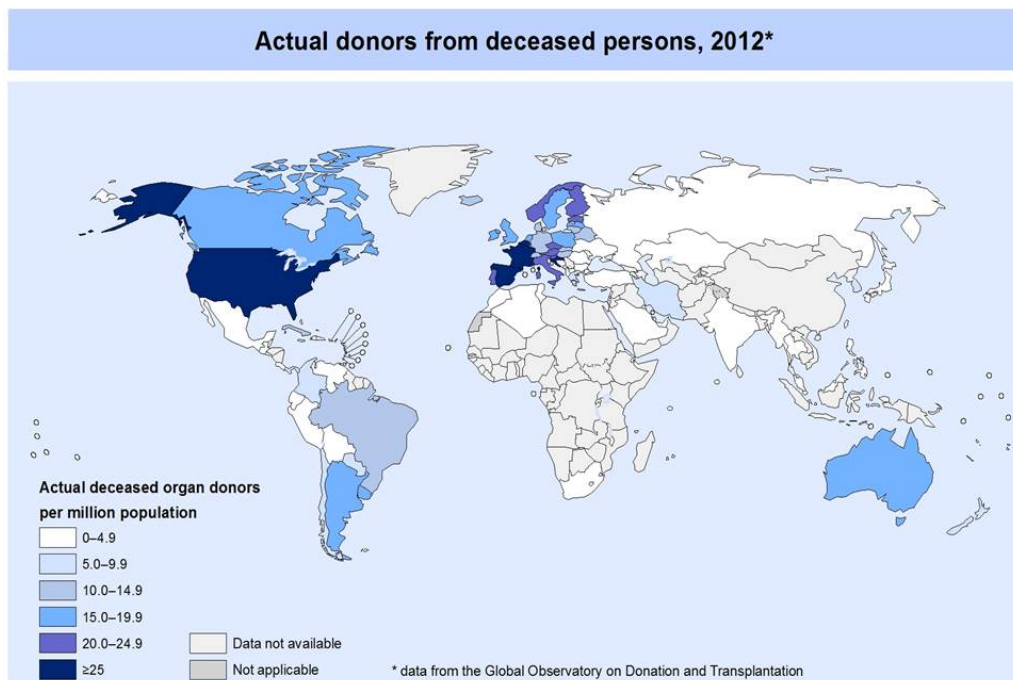


Figure 1.1: Worldwide rates of deceased organ donors (Global Observatory on Donation and Transplantation, in collaboration with the World Health Organization). Downloaded 01 December 2014. <http://issuu.com/o-n-t/docs/2012ad>

The USA holds the highest statistics with respect to rates of donation: 28 051 people received solid organ transplants and the absolute number of deceased donors was 22 187 in the year 2012(2). These statistics are a reflection of an effective and well-funded organ procurement programme, involving both education of the general public as well as auditing of medical institutions for the loss of potential donors.

1.2. Global statistics for renal replacement therapy

There is a lack of accurate international data on ESRD patients receiving therapy (including both dialysis and transplantation). The collection and analysis of this data is extremely intensive, both in time and resource requirements. Large time lapses between data collection and publication are the norm, thus information is usually outdated once it becomes available. At the end of 2005 a global estimate

representing 92% of the world's population showed that 1.9 million patients were receiving treatment of ESRD globally. Of these 1.455 million were on dialysis and 445 000 had a functional renal graft.

The trend worldwide has been that of an escalation in demand for RRT, with an average growth rate of 6-7% per annum (4). This increase is thought to be due to the epidemic of hypertension, diabetes mellitus, and an aging population as life expectancy increases(5). The recorded prevalence of RRT is lower in the developing world than in developed countries, possible reasons for this being inadequate capturing of data as well as poorer access to RRT in these financially constrained regions (6).

1.3. **South African renal replacement therapy statistics**

Determining the exact scale of the problem of CKD and ESRD in low to middle income countries, such as South Africa, has been fraught with difficulty. No unified registry recording ESRD and RRT exists for South Africa, or in Africa.

The public health care sector in South Africa provides dialysis to only a few patients who access tertiary level care, and who then meet selection criteria for RRT instituted by the South African department of health.

There is paucity of South African data regarding waiting times and mortality rate while awaiting transplantation. Data for the UK show a median waiting time of 1114 days in adults for a kidney transplant, and 145 days for liver transplantation (7). Data from the USA collected in 2005 showed a median waiting time of 1269, and 296 days for kidney and liver transplantation respectively(8). Both of these countries have superior rates of donation and thus it can be inferred that the

waiting times in South Africa may be considerably longer, or that the mortality rate while waiting may be higher.

According to the Organ Donation Foundation (ODF) of South Africa, 4300 individuals (both adults and children) are currently awaiting solid organ and corneal transplantation. The rates of organ donation, however, are declining at a rate of between 2% and 8.5% each year (9). The numbers of solid organ transplantations for South Africa are 376, 344, 337, 312 and 335 in the years 2009, 2010, 2011, 2012 and 2013 respectively.

In 2011, the rate of donation of solid organs reached its current nadir : 6.5 per million population (10). This prediction inferred from this trend is that the rate of transplantation could fall to below 1 per million population in the next few decades, thus widening the gap between “demand and supply” further.

The statistics of organ donation amongst patients specifically in the state sector are low. Over nine years (2009-2012) 257 donors were procured successfully within Gauteng province (Table 1.1), 47 of whom originated from public sector hospitals. Donors from Chris Hani Baragwanath Academic hospital made up 3.5% of the total number of donors over nine years (11). This indicates that the state sector is a potential target for enlarging the communal pool of organ donors. The reasons for the low rate of donation in South Africa are not clear.

1.4 The financial burdens associated with chronic organ failure.

1.4.1 Renal failure.

The financial demands of a patient receiving RRT are considerable, and are related to both costs of dialysis as well as the costs surrounding organ transplantation.

The average cost per session of haemodialysis in Africa was estimated at 100 US dollars in 2011 by Katz, T et al (6). In the United Kingdom and Northern Ireland (UK) the cost of maintaining one patient on RRT is estimated at £17,500 per annum for peritoneal dialysis and £35,000 per annum for haemodialysis. The cost for a kidney transplant is estimated at £17,000 with a subsequent cost of £5000 per annum for immunosuppressive therapy. This leads to a cost benefit of £25,800 in the second year post transplant and every subsequent year thereafter assuming that the cost of dialysis remains constant (12).

1.4.2 Liver failure

In the case of liver failure, the cost of care pre-transplant increases exponentially as the patient becomes progressively more ill. The Model for End-stage Liver Disease (MELD) score was originally designed to predict mortality after a transjugular intrahepatic portosystemic shunt (TIPS) procedure. This objective score was subsequently found to predict patients with end-stage liver failure and the complications thereof, and thus assists in determining the urgency for liver transplantation (13,14). Patients with higher MELD scores, therefore, have far higher costs incurred by the care they require to survive to transplantation. For patients with a MELD score of 35, monthly spending varied from \$19,548 to \$36,099 in the USA (15). There is a paucity of published data regarding the cost of this care as well as the wait-list mortality in South Africa.

The Donald Gordon Medical Centre (DGMC), in partnership with the University of the Witwatersrand in Johannesburg, is currently the only unit in South Africa with an active liver transplant programme in adults.

Year	Total number of donors in Gauteng province	Number of donors in CMJAH, CHBAH, HJH	CMJAH	CHBAH	HJH
2004	16	5	5	0	0
2005	24	5	5	0	0
2006	26	1	1	0	0
2007	32	3	2	1	0
2008	25	4	4	0	0
2009	30	6	4	1	1
2010	35	6	3	1	2
2011	34	7	5	2	0
2012	35	10	6	4	0
Total	257	47	35	9	3

Table 1.1: The absolute number of organ donors successfully referred within Gauteng Province, and from the three tertiary level hospitals in the Johannesburg region. (16)

1.5 Organ donor awareness

Community awareness and public education is important in any organ donation campaign. Until recently, however, it was not certain whether South Africans generally view donation in a positive light. A recent study examining the attitudes and perceptions of urban dwelling South Africans residing in the Gauteng and Western Cape regions have shown high rates of positive regard toward organ donation and a general willingness to donate (16). Data from the Western Cape points toward factors such as socio-economic status and race playing an important role in the provision of consent for deceased donation (17).

Before the problem can be explored further, it is necessary to give some background regarding the process of organ procurement and harvesting.

1.6 The process of organ donation

In Johannesburg, the DGMCC, which is affiliated to the University of the Witwatersrand co-ordinates the transplant process.

The organ procurement process starts with confirmation of brain death using the Harvard criteria (18). Initiation of the organ procurement process requires practitioners to have knowledge of the Harvard criteria for brain death. To avoid conflict of interests, personnel involved in the end of life care (declaration of death) cannot be involved in the transplantation of organs, nor in the care of the donor recipients.

Evaluation of the donor patient's medical well-being and specific evaluation of their organ function is performed. This assessment includes a number of blood and

radiological investigations. If these tests prove that the patient is a suitable candidate for organ donation, the family is counselled on the diagnosis and the prognosis of the patient, and are given the option to donate the organs of their relative. Once the family consents to donation, blood grouping and tissue typing is done. Recipients on the waiting list who are suitable matches are notified and they travel immediately to the hospital where the graft is to be transplanted. During all of the above steps resuscitation of the donor continues, and is crucial to ensure retrieval of viable organs.

Johannesburg has not yet initiated a donation after cardiac death (DCD) programme. This programme involves declaration of death using criteria indicating irreversible cessation of cardiopulmonary function, rather than criteria for brain death using neurologic criteria (19). In this practice the decision to donate has been made by the donor family in advance once there is certainty that death is inevitable. A surgical team remains scrubbed and on standby and immediately commence the harvesting surgery once a period of at least 2 minutes of spontaneous cardiopulmonary arrest has occurred(19). This technique is being actively used in the USA and Spain in order to improve donation rates.

1.7 Factors influencing organ procurement

The attitudes, knowledge and perceptions of doctors toward organ donation, as well as structural support and the existence of protocols for referral to organ procurement organisations, have been recognised as important in generating improved organ donation rates. The Spanish Transplant Management Programme has its focus on education of health professionals, training of “procurement co-ordinators”, and strict auditing of all deaths to detect potential donors who were

not identified and referred to the procurement team. This program is recognised as a successful intervention which resulted in a 100% increase in the rate of organ donation over 10 years, from 14 to 34 donors per million population (20).

The presence of referral triggers for identification of potential donors is also important. In many hospitals, the recognition of potential donors remains the responsibility of the individual department and doctors therein. When this method was used in the United States, large losses of potential donors were recorded (21). These findings have been confirmed further in the “Interim results of the United States’ national test of the rapid assessment of hospital procurement barriers in donation”(22). This investigation found that positive donation attitudes as well as knowledge were high, however the low use of a standardised referral criteria led to late or missed referrals (22).

Several studies have been conducted investigating the attitudes of intensive care subspecialists toward organ donation in countries such as New Zealand, Australia, Spain and the UK (23–25). In one study, 58% of respondents stated that they would be amenable to donating their own organs, while 94% said they would agree to donation from a dependent. One third of the respondents from the same study felt that it was not their role to request organ donation. (24). Spanish professionals’ reasons for non-donation were the same as in the general public, with factors such as understanding the concept of brain death; an aversion to discussing the matter of donation and transplantation within the family; and fear of manipulation of the remains being sited (25). The reasoning among South African doctors who oppose organ transplant has not been investigated.

1.8 Knowledge, attitudes and perceptions of organ donation amongst South African doctors

South African studies describing the above mentioned attitudes among health care professionals are scarce. The only available evidence is from a study conducted in medical students suggests that most undergraduate medical students (26), and found that regardless of their attitudes towards donation, most were not registered as organ donors with Organ Donation Foundation. The individuals studied had very low rates of knowledge about solid organ transplantation, which may be a contributing factor to the low rates of registration. Medical students straddle the line between health professionals and laymen, and thus the results observed in this group cannot be readily extrapolated to qualified health professionals, who often have years of experience behind them.

There is currently no published literature describing the attitudes and level of knowledge regarding organ donation among South African doctors working in the settings of intensive care, emergency medicine and trauma. These particular disciplines are those from which most potential donors would be identified, as patients with brain injury or those on mechanical ventilation would typically be cared for within those areas. It is therefore of importance that doctors working in these units have insight into recognition of potential donors, counselling of families, notification of organ procurement organisations (25). A positive attitude towards organ donation play a role in successful family counseling and donor referral, although there is little data to support this in the literature.

1.9 Conclusion

The data outlined demonstrate the high demand for organ transplantation, both locally and internationally. Donation rates locally have, however, demonstrated a decline in recent years. Addressing this widening gap between demand and supply involves either primary prevention of organ failure, or methods to increase donation rates. These methods may include DCD, and an increase in donation rates with particular focus on the state sector. Both of these methods are dependent on a well-developed referral system managed and utilised by knowledgeable and motivated health care professionals.

2 METHODOLOGY

2.1 Study aim

The aim of the study is to determine the attitude, knowledge and perceptions, regarding organ donation and procurement, of doctors working in the critical care setting.

2.2 Methods

2.2.1 Research Design

This is a cross-sectional, descriptive study.

2.2.2 Location of study

The study was conducted at the three academic referral hospitals within the Johannesburg area: Helen Joseph Hospital (HJH), Chris Hani Baragwanath Academic Hospital (CHBAH), and Charlotte Maxeke Johannesburg Academic Hospital (CMJAH). Each hospital has its own Intensive Care Unit (ICU), which is staffed by specialist consultants in critical care; registrars training in various specialties including surgery, paediatrics, internal medicine and emergency medicine; and medical officers. Each hospital also has an accident and emergency area (or casualty) which receives undifferentiated patients who are triaged, resuscitated, stabilised and referred on to the appropriate department. These areas are staffed by interns, community service medical officers, medical officers, emergency medicine registrars, and specialist consultants in emergency medicine.

2.2.3 Study Participants

The study participants included qualified medical doctors managing critically ill patients in three state academic hospitals in Johannesburg, including interns, medical officers, registrars, fellows, and specialist consultants.

2.2.4 Data collection

2.2.4.1 The questionnaire

The method of data collection was an anonymous self-administered questionnaire (Appendix A), which was designed by the author, using questions asked in similar studies (Appendix B). This questionnaire was designed to assess the following with respect to organ donation and transplantation

- Demographics of the sample.
- Perceived knowledge.
- Actual knowledge.
- Prior experience with donors.
- Factors related to the hospital environment
- Perceptions of organ donation and its impact upon the surviving family
- Attitudes toward donation.
- Factors influencing negative attitudes.
- Willingness to donate one's own organs. This question was used as a surrogate marker of attitude toward donation, with a positive attitude being represented by the answer, "yes."
- Registration with the organ donor foundation.
- The reasons for a negative attitude towards organ donation.

- Whether or not the respondents feel that donation may help the donor family to grieve for their loved one, and why.
- The attitude of respondents towards living related organ donation, and donation of the organs of a dependent.

Each participant was provided with an information sheet detailing the study (Appendix C) and was provided with the opportunity to “opt-out” of the study. If a questionnaire was completed, consent was assumed.

Participants were sampled over a four month period between 01 September and 31 December 2014.

2.3 Pilot study

The questionnaire was piloted in June 2014. The questionnaire was distributed to five nephrology consultants and registrars working in the nephrology unit at CHBAH. These individuals were selected because their involvement with transplant recipients prohibits them from assisting in the identification and referral of potential organ donors. After piloting, the wording of the questionnaire as well as specific technical problems were dealt with and the main survey was then initiated after the revised questionnaire was approved by the ethics committee.

2.4 Questionnaire distribution and collection

The participants were given the questionnaires. A blank envelope was included with each form which was sealed after either completion of the form (or opting out of the study by not completing the questionnaire). The sealed envelopes were then placed into a box. Those who were not in attendance at the meeting, or who preferred to complete the survey in their own time, were given questionnaires

which were then collected at a later stage in the same manner. Those who returned blank questionnaires or who did not return the forms were labelled as “non-responders.”

Medical students, nursing staff and allied health professionals were excluded from the study. Any participants from the pilot study were excluded from the main study.

2.5 Ethics and permission

The research protocol for this study was unconditionally approved by the Human Research Ethics Committee for the University of the Witwatersrand (appendix D).

2.6 Data analysis

2.6.1 Sample size

At the time that the sampling was done, the total population size was 190. The key research question relates to the determination of proportions in the sample. Using a worst-case proportion of 50%, and 5% precision, and a population of 190, a sample size of 128 is required.

The achieved sample size of 105 is lower than target, which would result in a precision of 6.5% for the estimation of a 50% proportion, which is acceptable for a study of this nature.

Sample size for proportions was determined using the formula:

$$n = \frac{Z^2 P(1 - P)}{d^2}$$

where n = sample size, Z = Z-statistic for the chosen level of confidence, P = expected prevalence or proportion, d = precision (27)

2.7 Statistical analysis

Data analysis was carried out using SAS Software (version 9.3 for Windows.) The X^2 test was used to assess the relationships between categorical variables. Fisher's exact test was used for 2 x 2 tables or where the requirements for the X^2 test could not be met. The strength of the associations was measured by Cramer's V and the phi coefficient respectively. The following scale of interpretation was used:

0.50 and above	high/strong association
0.30 to 0.49	moderate association
0.10 to 0.29	weak association
below 0.10	little if any association

All statistical tests were two sided and $p < 0.05$ was considered statistically significant.

3 RESULTS

3.1 Response rate

The maximum sample size was 190 (the total number of doctors working in the hospital areas included in this study.) 143 (75.3%) received a questionnaire. 105 (73.4%) of questionnaires were returned (some partially completed.) The coverage of the total possible study population was 55.3%.

3.2 Descriptive analysis

3.2.1 Demographics

Demographic variables are represented below in tabular as well as graphical form.

3.2.1.1 Gender:

54.3% of the respondents were male. There was no missing data.

3.2.1.2 Age:

The median age of respondents was 32 years with a range = 24-61 years. The proportion of respondents aged 40 years or younger was 78.1%. Missing data was present in 4.8% of responses.

3.2.1.3 Highest qualification:

83 (79.1%) of the respondents had obtained only their MBBCh. Missing data was present in 2.6% of responses.

3.2.1.4 Religion:

The most prevalent religions were Christianity (52.4%), Islam (17.1%) and none / agnosticism / atheism (14.3%). The level of missing data was 6.7%.

3.2.2 Dependants

Sixty five (61.0%) of the respondents reported that they have dependants; of these, 44 (68.8%) reported that these dependants were under the age of 18. Thus, overall, 41.9% of the respondents had dependants under the age of 18. Missing data was present in 1% of responses.

Demographic	Category	Respondents Number	%
Gender	Male	57	54.3
	Female	48	45.7
Age	24-25y	7	6.7
	26-30y	32	30.5
	31-35y	25	23.8
	36-40y	18	17.1
	41y+	18	17.1
Highest qualification	MBBCh	83	79.0
	Specialist	8	7.6
	Subspecialist in critical care	5	4.8
	Subspecialist in discipline other than critical care	6	5.7
Religion	Christian	55	52.3
	Muslim	18	17.1
	none / agnostic / atheist	15	14.2
Dependents	No	40	38.1
	Yes	65	61.9

Table 3.1: Demographic variables in the study population.

3.2.2 Knowledge

This was divided into the following categories: Perceived knowledge and actual knowledge (appendix A).

3.2.2.1 Perceived knowledge

Of the respondents 56 (62.9%) were confident that they could certify brain death.

There was 1.0% missing data.

3.2.2.2 Actual knowledge

Of the respondents, 41 (39%) knew the criteria for brain death. Once a donor is identified, 49 (46.7%) of the respondents knew who to contact from an organ procurement organisation. A total of 38 (36%) respondents knew the maximum number of organs that can be harvested from a donor (Figure 3.1).

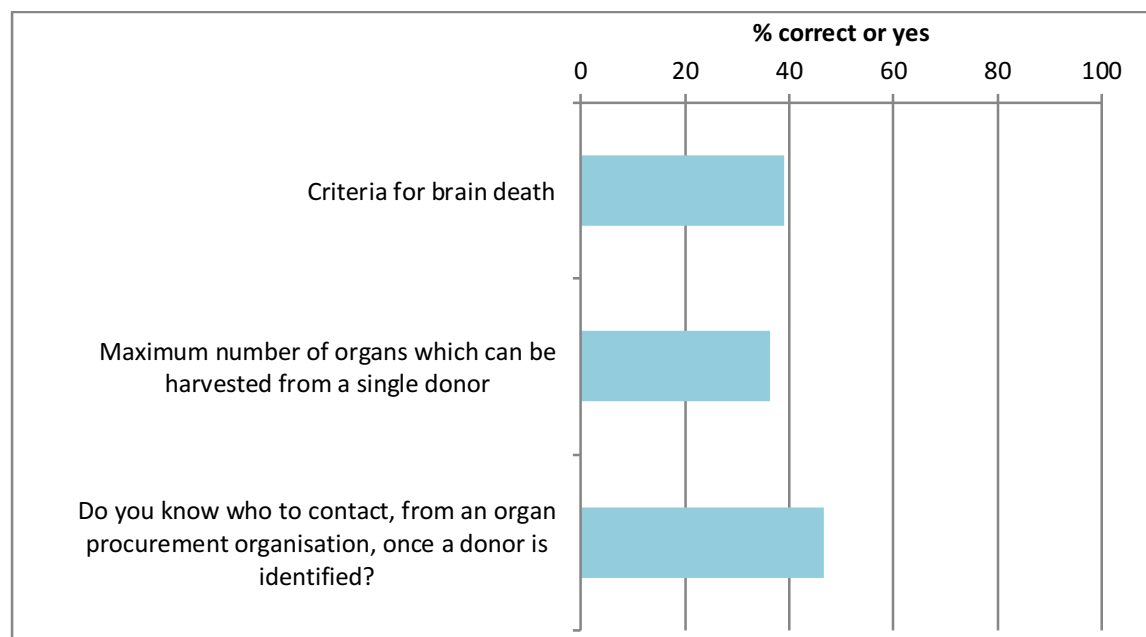


Figure 3.1: The percentage of the sample population who gave the correct answer to specific questions regarding organ donation, and who knew who to contact from the organ transplant co-ordination team once a potential donor is identified.

There was 7.6% and 6.7% missing data for questions 3a and 4. There was no missing data for question 7.

3.2.2.3 Prior Experience

Of the respondents, 64 (61.0%) had certified a patient as brain dead; 40 (38.1%) had managed a patient who became an organ donor; 40 (38.1%) had previously contacted the transplant co-ordination team; and 30 (28.6%) had ever counselled the family of a potential donor.

There was 1.0% missing data for each of questions 1 and 2. There was no missing data for questions 6 and 8.

3.2.3 Hospital environment

3.2.3.1 Protocols

Question 5 enquires about the presence or absence of specific protocols available for identification and referral of potential donors. Only 36 (34.3%) of the respondents reported that there were clear protocols for identification of a potential organ donor; 41 (39.1%) reported that there were no clear protocols, while 28(26.7%) did not answer the question or reported that they did not know.

3.2.3.2 Measures to improve donation rates

Question 11 asked the respondent to indicate specific measures that would assist the unit in increasing donation rates. Three options were given for this question as well as an opportunity to describe other suggestions. The three options were as follows:

- a. An organ procurement team that performs all the necessary measures, including counselling, contacting spiritual advisors, contacting appropriate professionals, etc.
- b. A nurse who is dedicated to counselling the family
- c. A team who provide educational talks and workshops on transplantation and organ donor procurement.

The respondent could select more than one option if they preferred.

Of the completed questionnaires collected, 1.9% of respondents did not answer this question. The percentage of respondents who selected the various options is shown below. Preference was shown for external measures, such as an organ procurement team (77.1%), rather than education within the unit (53.3%) or a dedicated nurse for counselling of families (29.5%).

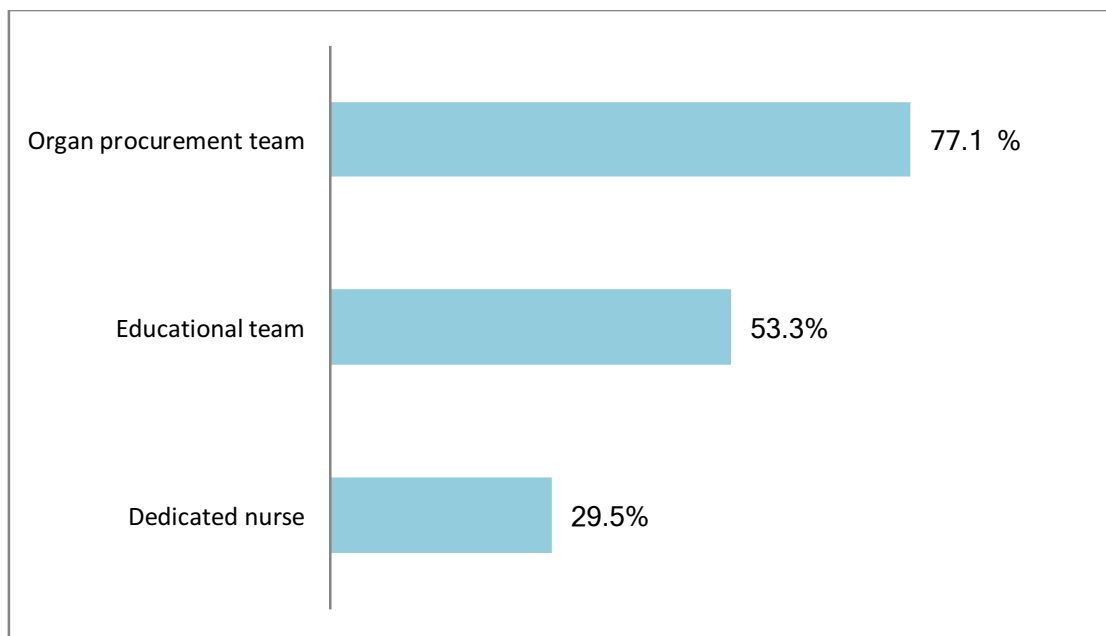


Figure 3.2: The percentage of respondents who preferred each of the options given for improvement of the rate of organ donor recruitment.

The open ended section of this question received a variety of answers. Suggestions were made as follows:

- Community based educational activities in order to alter the cultural stigma surrounding organ transplantation.
- The introduction of an “opt-out” clause, such as that used in the United Kingdom.
- Extended counselling services for families including psychologists and social workers.

3.2.4 Perception of the cultural and psychological impact of donation.

3.2.4.1 Counselling

Of the total respondents, 51 (48.6%) felt comfortable counselling the family of a potential organ donor from a different religious / cultural background to their own (no missing data).

3.2.4.2 Grieving process

From the respondents, 90 (85.7%) agreed that organ donation could assist the family of the donor with the grieving process (3.8% missing data).

3.3 Attitudes

3.3.1 Willingness to donate.

Of the 105 respondents, 65 (61.9%) indicated that they were willing to donate their own organs in the event of brain death ($p=0.044$).

3.3.1.1 Registration as organ donor

Of the 61.9% (n=65) respondents who were willing to donate their organs in the event of brain death, only 21.5% were registered as organ donors, while the rest were not (no missing data). Thus, overall, 13.3% (14/105) of the respondents were registered as organ donors.

3.3.1.2 Reasons for not donating own organs

For the 38.1% (n=40) respondents NOT willing to donate their own organs, the reasons are shown below. More than one reason could be given per responder (Figure 3.3). The most popular reason was religious / cultural beliefs (67.5%).

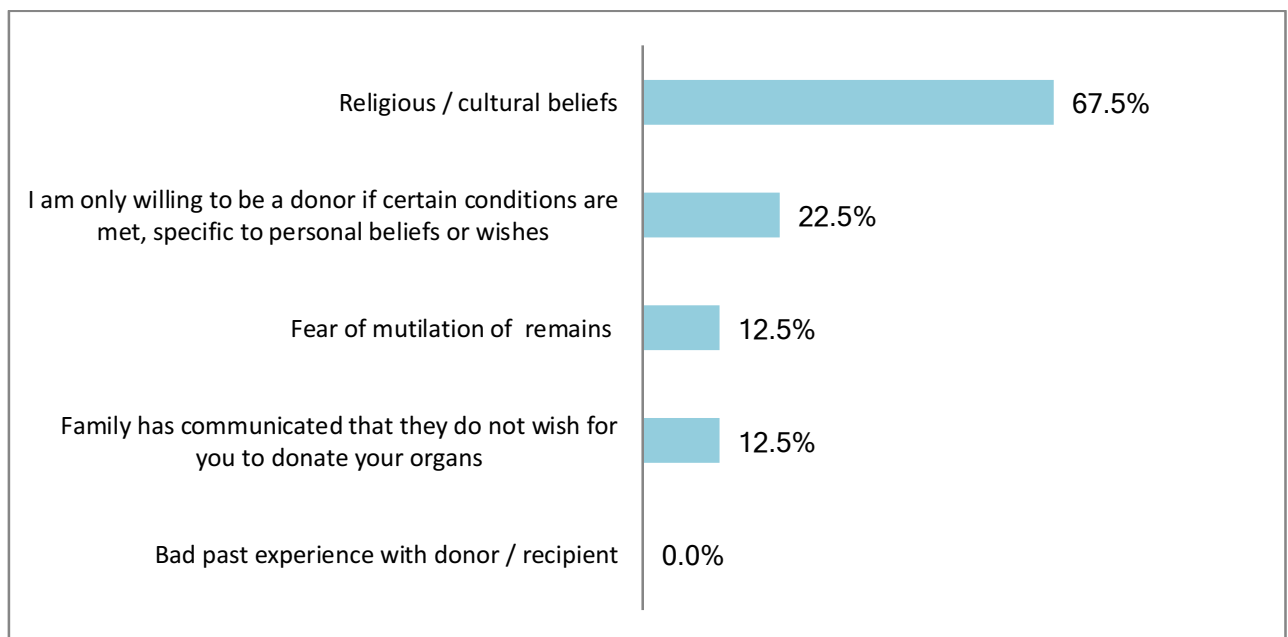


Figure 3.3: A chart illustrating the main reasons given for not wishing to donate one's own organs after brain death.

Respondents were also given the opportunity to describe their reasons for not wanting to donate their own organs. The only response to this which differed from the questions above was that donation had never been considered before and time

was needed to think this possibility over. Some preferred to donate only under specific conditions which were given as follows:

- Donation must be followed by monetary compensation of the donor's family.
- The recipient of the organs must be known and approved by the donor's family
- Assurance of a proper and culturally appropriate burial after donation.
- Donation must follow an appropriate amount of time in which the family can grieve and consider their options.

3.3.2 Donation of a dependant's organs in the event of brain death

59.1% (n=62) indicated that they would consent to donating a dependent's organs in the event of brain death. 3.8% (n=4) of respondents did not answer this question.

3.3.3 Willingness to donate

81.0% (n=85) of the respondents indicated that they would consent to being a related living kidney donor, should a relative require organ transplantation. 2.9% (n=3) of data was missing due to non-response.

3.4 Relationship between attitude and willingness to be a living related kidney donor.

73.0% of the respondents who were not willing to donate their own organs were prepared to be related living donors. Of the respondents who were willing to donate their own organs after death, 89.2% were also willing to be living related donors. The effect size was small (phi coefficient=0.21).

3.5 Relationship between attitude and demographics

3.5.1 The willingness to donate one's own organs after brain death.

3.5.1.1 Gender

Females were more willing to donate their own organs after brain death. This association was statistically significant ($p = 0.044$) but weak (phi coefficient 0.02).

3.5.1.2 Age, religion and highest level of qualification:

No significant association was noted with any of these variables.

3.5.1.3 The presence of dependents

The presence of dependents was found to be significant in one's willingness to donate one's own organs ($p = 0.041$). The association was weak (phi coefficient 0.21).

3.5.2 Donation of a dependant's organs in the event of brain death

There was no significant association between the age of the dependants (within those respondents who had dependants) and consent to donation of a dependant's organs in the event of brain death.

3.6 Relationship between experience and actual knowledge

3.6.1 Knowledge of criteria for brain death

There was a significant association between the questions related to experience and knowledge of the criteria for brain death. The results are illustrated in figure 3.4.

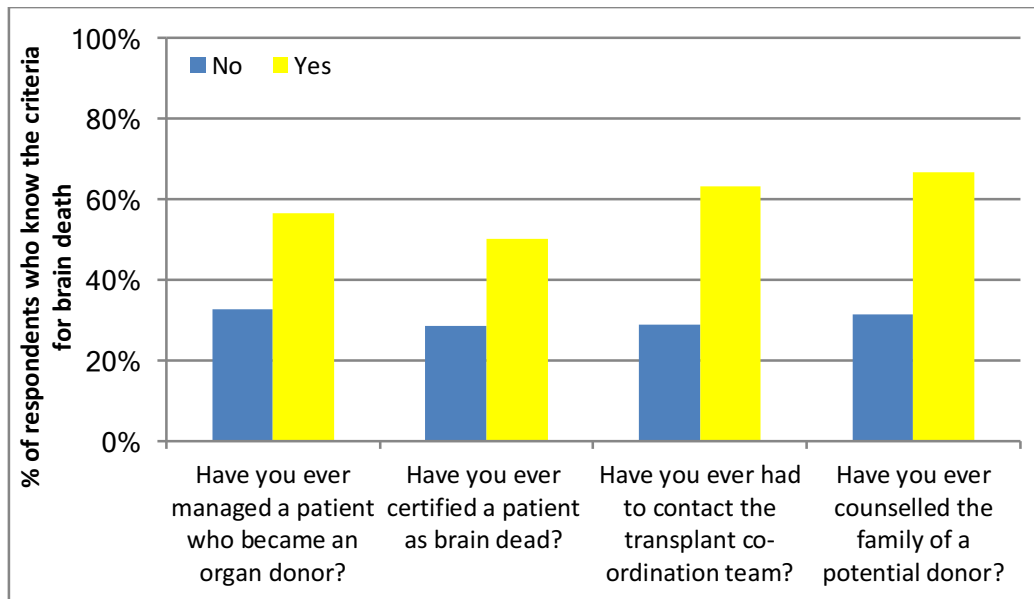


Figure 3.4: The relationship between knowledge of criteria for brain death, and four measures of experience.

3.6.2 Knowledge of maximum number of organs which can be harvested from a potential donor

There was no significant association between questions related to experience and knowledge of the maximum number of organs which can be harvested.

3.6.3 Knowledge of who to contact once a potential donor was identified

There was a significant association between the questions related to experience and knowledge of who to contact once a potential donor has been identified (figure 3.5).

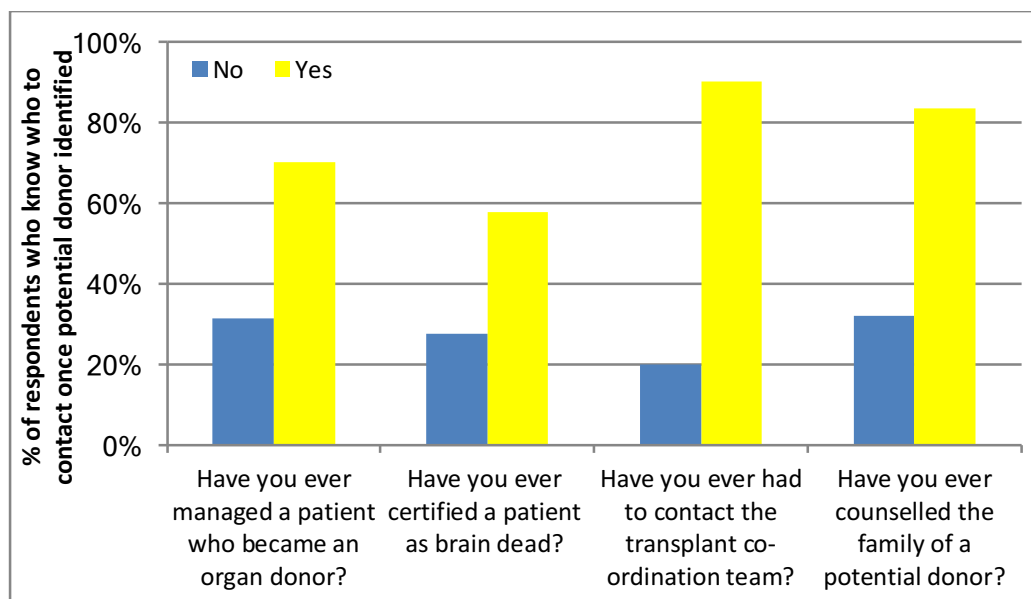


Figure 3.5: A graph illustrating the association between knowledge of who to contact once a potential donor is identified and four measures of prior experience.

3.7 Relationship between perceived knowledge and actual knowledge

Confidence in the ability to certify brain death was significantly associated with knowledge of the criteria for brain death ($p < 0.0001$; phi coefficient=0.45).

Amongst those who were confident in their ability to certify brain death, 50.0% knew the criteria for brain death, compared to only 9.7% among those who were not confident in their ability to certify brain death.

Confidence in the ability to certify brain death was significantly associated with knowledge of who to contact once a potential donor had been identified ($p < 0.0001$; phi coefficient=0.34). Amongst those who were confident in their ability to certify brain death, 59.1% knew who to contact, compared to only 23.7% among those who were not confident in their ability to certify brain death.

4. DISCUSSION

4.1 Study population and demographics

This sample was made up of young doctors, the majority of whom were 40 years or younger. Most held a Bachelor of Medicine and Bachelor of Surgery (MBBCh) as their highest qualifications. Whilst a large proportion of respondents reported experience with certification of brain death, relatively few had experience with management of a confirmed organ donor and referral to an organ transplant co-ordination team.

4.2 Attitude to donation

Attitudes towards donation in this sample reflected those observed in a similar study amongst urban dwelling laypersons residing in a similar area to the sample population (16). The majority of respondents had a positive attitude towards donation reflected in their own willingness to donate organs after brain death. Despite this positive attitude, the minority (21.5%) were registered with the ODF. This is similar to the findings from a study using medical students (28). The reasons for low registration levels are not clear, however possible reasons are as follows:

- Lack of knowledge of how to register.
- Poor information on where to register.
- Lack of awareness of how organ donation changes and saves lives.
- Absence of a living will or advance directive in young, otherwise well individuals.

Significance was observed between willingness to donate one's organs after death; and both willingness to be a living related kidney donor or willingness to donate the organs of a deceased dependent.

The majority of doctors, who were unwilling to be organ donors cited cultural and religious factors as reasons for a negative response. Another common concern was the proper burial of remains. These responses are similar to those provided by urban-dwelling South African laypersons (18). It is of interest that 5 doctors (4.7%) felt monetary compensation would be necessary for them to donate, and that 3 (2.9%) were only willing to donate to a known and approved of recipient. No doctors from this study reported an adverse opinion toward organ donation because of a bad prior experience with a donor or recipient.

4.3 Demographic variables affecting attitude to donation

Demographic variables which showed an association with positive regard towards donation were female gender, and the absence of dependents. These associations were weak however, thus this finding should be interpreted with reserve. There was no association found between highest level of education, religion or age of the respondent and their attitude towards organ donation. This is in contradiction to the findings from a larger study among laypersons, which showed an association between Islamic beliefs and a negative attitude towards donation (18). However, in our study, there was a high percentage of missing data with respect to religion. Only 18 (17.1%) of participants listed Islam as their religion, making analysis difficult.

4.4 Knowledge and experience

4.4.1 Prior experience

Hands-on experience with identified and confirmed organ donors was low, with less than 40% of respondents having ever managed a donor or contacted the transplant co-ordination team. Those who are experienced must play an important role in transmission of information to the inexperienced, and thereby improve overall donor identification and referral rates.

4.4 Actual Knowledge

Whilst 62.9% of respondents felt confident that they could certify brain death, only 50% of them actually knew the criteria for doing so. Only 41 (39%) of respondents knew the correct answer for the maximum number of organs that can be harvested from a single donor.

Unsurprisingly, there was a statistically significant and strong association between confidence in knowledge of the criteria for brain death, and actual knowledge of this. However, only 50% of those who were confident that they could perform this task actually had the necessary knowledge to do so. This implies that there are many individuals working in critical care settings who are not aware of a deficiency in their knowledge, and thus may not be motivated to seek out this information themselves. Thus, they would need external input in order to further their knowledge basis and increase awareness surrounding brain death and potential donor identification.

4.5 Perceived Knowledge

There was also a moderate but statistically significant association noted between perceived knowledge of the criteria for brain death, and the knowledge of whom to contact once a donor is identified. Confirmation of the knowledge of the respondent regarding contact information was not elicited, and thus there may be a similar discrepancy to this actual versus perceived knowledge as that observed with respect to the criteria for certification of brain death.

4.6 Protocols

Only 34.3% of the respondents reported that there were clear protocols for identification of a potential organ donor; 39.1% reported that there were no clear protocols, while the remainder (26.7%) did not answer the question or reported that they did not know. Protocol availability is certainly an essential component of any organ transplant and procurement drive, and is extremely cost effective and easy to implement. Whilst the organ transplant co-ordination team in Johannesburg has made efforts to ensure their information is available for after hours support, this service can only have meaningful benefit if the seniors in the home unit participate in dissemination of this information to less experienced staff, whom are invariably present after hours when such potential donors first present.

4.7 Counselling

Slightly less than half (48.6%) of the respondents felt comfortable counselling the family of a potential organ donor from a different religious or cultural background to their own. Most doctors (85.7%) agreed that organ donation could assist the family of the donor with the grieving process. This information could also be used

to guide practitioners towards recognition of the necessity for counselling and offering families the option to donate their loved one's organs, which may in fact benefit the bereaved. This also offers doctors who may be faced with a sense of helplessness and futility in the face of such tragedy, to obtain a sense of empowerment, because of the ability to benefit the family and other patients despite a poor outcome to the primary patient. The therapeutic benefits of this would be an interesting area for future study.

Respondents demonstrated a preference for external measures, such as an organ procurement team (77.1%), rather than education within the unit (53.3%) or a dedicated nurse for counselling of families (29.5%), when given potential options for improving donation rates. This may reflect the fact doctors feel they need further support to improve donor identification and referral.

4.8 Limitations

The population sampled was made of mainly of young doctors, whose highest degree was an Bachelor of Medicine and Bachelor of Surgery. More experienced, and more knowledgeable, individuals made up the minority, and may have been under-represented.

Doctors working in the trauma unit at CMJAH could not be sampled. This resulted in under representation of this group, who form a crucial part of the donor referral process. The number of doctors in this unit fluctuates, however it has on average 15-20 staff at any one time, making up approximately 7-10% of the total population.

The small sample size resulted in precision (6.5%) which was lower than the ideal (5%). Datasets were also incomplete due to missing data from the respondents.

The sample was also biased in that only academic hospitals were selected for study; the private sector was excluded; and the majority of the sample were composed of junior doctors. The majority of the sample population were Christian (52.4%), with very small numbers of participants representing the other major religions. Islam was represented by 18 individuals, 17.1% of the sample, which made interpretations of findings within this group difficult.

In terms of study design, the questionnaire used was designed using questions presented to participants in previous similar studies. The questionnaire itself was not validated. The wording used in the questionnaire, albeit carefully designed, may well have created ambiguity or may have introduced bias. An example of this is evident in the unexpected absence of association between experience, and knowledge of the number of organs that can be harvested from a single donor. This indicates that this particular question (or its answer) may have been ambiguous, or that the participants may have had correct answers not accounted for in the model responses.

Response bias in the questions related to perceived knowledge is an important consideration, as the responses (although anonymous) may have reflected that response that the participant deemed socially or professionally desirable, rather than their true level of confidence.

5 CONCLUSIONS

The population sampled was made of mainly of young doctors, whose highest degree was an MBBCh. More experienced and thus more knowledgeable individuals made up the minority. The attitude of doctors was generally positive, and appears to reflect the attitudes observed in laypersons residing in the same area (18). Willingness to donate one's own organs was associated with female gender; the absence of dependents; willingness to donate the organs of a dependent; as well as willingness to be a living related donor. However, the association between willingness to donate and demographic variables was weak and only marginally significant. Those who had negative attitudes towards donation gave cultural or religious reasons for their opinions, which is also similar to the reasons for the same attitude amongst laypersons (18).

The level of experience with potential or identified donors was generally low, which may serve to explain the low level of knowledge with respect to donation protocols and the certification of brain death. Most doctors sampled did not know who to contact once a donor is identified, and many were also not aware of clear protocols in their institution regarding donor referral.

Cultural dissimilarities between patients and doctors was not reported to influence willingness to counsel families of potential donors, and many doctors felt that grieving is assisted and positively influenced by organ donation. Many also indicated that donation provides those bereaved with a sense of comfort in the knowledge that their loved one was able to give the gift of life after their death.

The results of this study may help to guide future interventions in the form of educational programmes, and expansion of existing support structures such as in

unit consultant level input with respect to education. The impact of external means to improve transplantation can only become effective if the primary provider recognises the potential for donation and the need for such support. Future study opportunity lies in the exploration of this hypothesis by determining if donation rates are altered in response to educational interventions.

6 APPENDICES

6.1 Appendix A: Questionnaire

This questionnaire should take roughly 5 minutes to complete.

Your participation is valuable and your opinions are extremely important.

Please feel free to answer these questions honestly without fear of submitting the “wrong” answer.

Please answer ALL questions (20 in total).

Indicate your response by placing a cross (X) in the relevant block or writing your answer in the space provided.

1. Most doctors have never encountered or managed an organ donor. Have you ever managed a patient who became an organ donor? (In other words, the patient was declared brain dead, and his or her organs were then donated for transplantation.)

Yes	No
-----	----

The criteria for brain death are used to determine if true brain death has occurred and thus if a patient is an appropriate candidate for organ donation. Many doctors are not sure about these criteria and need to look them up or get senior assistance in order to certify brain death.

2. Have you ever certified a patient as brain dead?

Yes	No
-----	----

Once brain death is certified an organ transplantation co-ordination team is contacted and the patient's family is counselled regarding the poor prognosis of the patient and the option of donating their loved one's organs.

3. Are you confident that you are able to certify brain death?

Yes	No
-----	----

3a. If you answered "yes" to question three (3), please identify which **one** of the following options is **not** a criterion for brain death: please mark the **incorrect** option clearly with a tick or cross in the right hand column

Absent corneal reflexes	
Absent cough with tracheal suctioning	
Apnoea as demonstrated by apnoea test	
Decerebrate or decorticate posturing.	
Coma	

4. What is the maximum number of organs which can be harvested from a single donor (excluding any ophthalmic tissue)?

Answer: _____

—

5. Are there clear protocols in your hospital for identification of a potential organ donor?

Yes	No	Don't know
-----	----	------------

Often, doctors don't know who they should call once they have identified a potential donor.

6. Have you ever had to contact the transplant co-ordination team?

Yes	No
-----	----

7. Do you know who to contact, from an organ procurement organisation, once a donor is identified?

Yes	No
-----	----

8. Have you ever counselled the family of a potential donor?

Yes	No
-----	----

9. Do you feel comfortable counselling a family (of a potential donor) from a different religious or cultural background to your own?

Yes	No
-----	----

10. Many people are uncertain about how the family of an organ donor feel after the procedure is completed. In your opinion, is it possible for organ donation to assist the family of the donor with the grieving process?

Yes	No
-----	----

Please explain your answer:

11. If your unit was audited, and you were asked to improve the rate of donations, what measures would you find helpful in optimising donation rates? Please select the appropriate option/s, or describe your suggestion. Please indicate your answer/s with a cross (X) in the right hand column)

a.	An organ procurement team that performs all the necessary measures, including counselling, contacting spiritual advisors, contacting appropriate involved professionals, etc.	
b.	A nurse who is dedicated to counselling the family.	
c.	A team who provide educational talks and workshops on transplantation and organ donor procurement.	

d. Other: Please describe your thoughts and suggestions

12. Would you be willing to donate your organs, should you suffer brain death?

Please note that brain death implies an irreversible state of complete neurological death, which is always followed by somatic death within a variable time period. This is not the same as a vegetative state where neurological responses may still be observed, and from which the sufferer may recover.

Yes	No
-----	----

Yes: Go to question 13.

No: Go to question 14.

13. Are you registered as an organ donor?

Yes	No
-----	----

Continue with Question 15.

14. Why do you prefer not to donate your organs? (Mark all reasons which apply.)

Please indicate your answer/s with a cross (X) in the right hand column)

a.	Religious or cultural beliefs.	
b.	Fear of mutilation of the remains.	

c.	Bad past experience with a donor or recipient.	
d.	Your family has communicated that they do not wish for you to donate your organs.	
e.	I am only willing to be a donor if certain conditions are met, which are specific to my personal beliefs or wishes	

Other reasons not mentioned above: please describe.

If you marked option “e” with a cross, please indicate your specific conditions and your reasoning behind them. Your response is completely anonymous.

15. Would you consent to donating a dependent's organs, should they suffer brain death?

Yes	No
-----	----

16. Would you be willing to be a living related kidney donor, if a relative required organ transplantation?

Yes	No
-----	----

17. What is your gender?

Male	
Female	

18. Please state your age.

	years
--	-------

19. What is your highest qualification? (Please place a X next to the relevant option)

MBBCh (Bachelor of Medicine and Bachelor of Surgery)	
Specialist (eg: FCS, FCP, FCOG, etc)	
Specialist with certificate in critical care	
Specialist with certificate in sub-specialty other than critical care	

20. What is your religion? Please indicate “atheist” or “agnostic” or “none” if you do not ascribe to any religion.

—

21. Do you have dependents?

Yes	No
-----	----

22. If the answer to the previous question is yes, are they under the age of 18?

Yes	No
-----	----

Thank you for your participation

6.2 Appendix B: References and motivation for questionnaire

design.

Question	Reason for asking this question	Reference this question is taken from
1, 2	Prior experience will impact on the responses to the questions which are asked hereafter.	
3,4	These questions will be used as a rough indication of level of knowledge regarding organ donation.	
5	The lack of clear protocols for identification of a potential organ donor has been identified as an impediment to prompt recognition and referral of organ donors and their families to the relevant organ procurement teams.	Ehrle R. Timely referral of potential organ donors. Prog Transplant. 2008 March;18(1):17-21
6, 8	Prior experience will impact on the responses to the questions which are asked hereafter.	
7	This indicates knowledge of existing support structures.	
10	Please see the body of the research proposal.	Marck CH, Weiland TJ, et al. Personal attitudes and beliefs regarding organ and tissue donation: a cross-sectional survey of Australian emergency department clinicians. Prog Transplant. 2012 Sep;22(3):317-22.
9, 12, 13, 14, 15, 16		Pearson IY, Zurynski Y. A survey of personal and professional attitudes of intensivists to organ donation and transplantation. Anaesth Intensive Care. 1995 Feb;23(1):68-74.

		Sobnach S, Borkum M, Hoffman R, et al. Medical students' knowledge about organ transplantation: A South African Perspective. Transplant Proceedings. 2010 Nov;42(9):3368-71. doi: 10.1016/j.transproceed.2010.08.036.
11		Ríos A, Ramírez P, Martínez L, et al. Are personnel in transplant hospitals in favor of cadaveric organ donation? Multivariate attitudinal study in a hospital with a solid organ transplant program. Clin Transplant. 2006 Nov-Dec;20(6):743-54.
17-21	Determination of demographic factors which may impact on the response to the previous questions.	

6.3 Appendix C: Participant information and consent form

Dear colleague,

I would like to invite you to participate in my study.

I am a registrar in internal medicine conducting my Masters in medicine research. The rates of organ donation in South Africa are very low and are on a decline, whilst the number of patients with organ failure awaiting transplant continues to increase steadily. The reasons for these low rates of donation, particularly in the public sector, are not clear. A large study on the knowledge, attitudes and perceptions of urban dwelling South Africans toward organ donation has recently been conducted. However, similar data representing the attitudes, knowledge and perceptions of critical care doctors, who play a vital role in identifying and referring potential organ donors to transplant co-ordination teams, is scarce. This leads me to my topic:

“Organ donation in the public sector: A study of the knowledge, attitudes and perceptions regarding organ procurement and donation among medical doctors in emergency and intensive care settings in three academic hospitals in Johannesburg, South Africa”

I am investigating this topic by means of a survey, involving the completion of the attached questionnaire. This will include questions about your personal views on organ donation as well as some specific questions relating to organ donor identification and recruitment, as well as the process of donation itself.

This survey is strictly anonymous, and participation is optional. If you do not wish to participate then please leave your form blank. If you complete a form, your consent will be assumed.

For any questions or feedback regarding the questionnaire or the study, please do not hesitate to contact me.

Cleo Solomon

0825757440

cleo.solomon24@gmail.com

7 Appendix D: Ethics clearance certificate



R14/49 Dr Cleo Solomon

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M140117

NAME: Dr Cleo Solomon

(Principal Investigator)

DEPARTMENT: Dept of Internal Medicine
CH Baragwanath Academic Hospital

PROJECT TITLE: The Knowledge, Attitudes and Perceptions of Organ
Procurement and Donation Among Medical Doctors
in Critical Care Settings in Academic Hospitals in
Johannesburg, South Africa (Title Changed 05 May 2015)

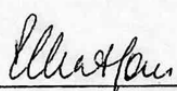
DATE CONSIDERED: 31/01/2014

DECISION: Approved unconditionally

CONDITIONS:

SUPERVISOR: Dr Graham Paget

APPROVED BY:


Professor P Cleaton-Jones, Chairperson, HREC (Medical)

DATE OF APPROVAL: 11/05/2015

This clearance certificate is valid for 5 years from date of approval. Extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Secretary in Room 10004, 10th floor, Senate House, University.

I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated, from the research protocol as approved, I/we undertake to resubmit the application to the Committee. **I agree to submit a yearly progress report.**

Principal Investigator Signature _____

Date _____

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

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