

**FACTORS AFFECTING A DECISION  
ON CADAVERIC ORGAN DONATION  
IN BLACK AFRICAN FAMILIES**

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## ABSTRACT

Black Africans continue to be the group with low consent for cadaveric organ donation. However, the number of African Black patients with organ malfunctioning or failure continues to rise. Feelings associated with death and the novelty of the concept of organ donation to Blacks hinder the process of organ donation. Previous research indicate that although organ removal is not new in the Black African culture, its use for medical purposes is a recent development.

This study explores factors that have affected the decision of Black African families regarding cadaveric organ donation. It focuses on families which have been requested to donate by the Groote Schuur Hospital (GSH) transplant co-ordinators from 1994 to 1996. Further, it examines whether the attitudes held at the time of the request have changed. An understanding of the factors and recommendations are offered at the end.

Semi-structured interviews were conducted with ten Black African families from the greater Cape Town area at their homes. Their addresses were obtained from the records of the transplant co-ordinators at GSH. The data was analysed according to broad themes emerging from the interviews.

A number of different factors impacted on the decision regarding organ donation. These factors were discussed according to the following broad themes:

- relationship between death and organ donation;
- impact of language used during the request;
- time needed for consultation;
- gender considerations during consultations;
- death as transition to ancestry;
- juxtaposing Christianity and African belief systems;
- practical reasoning in organ donation;

- significance of the dying wish;
- paradox of organ donation by the refused;
- need for education;
- request context;
- relationship with dead loved one;
- impact of grief and loss;
- reimbursement; and
- racial considerations.

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**APPENDICES**

## **CHAPTER 1: INTRODUCTION AND LITERATURE REVIEW**

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### **INTRODUCTION**

Research in the field of organ donation and transplantation has consistently shown that there are more people in need of donor organs than there are people who actually donate organs. This is (or at least until recently has been) a world-wide phenomenon, with ongoing research informing attempts to bring about the little amelioration to the problem there is. Some countries have succeeded more than others in doing this. Despite this, the problem of low organ donation persists, and there seems to be issues that need further understanding to deal with this effectively.

The problem of low organ donorship exists across the world (Lowy & Martin, 1992), but past research has indicated that organ donorship is significantly lower in the Black population (Callender, 1987). The present study acknowledges the widespreadness of this problem, but focuses on low Black donorship as an area needing further understanding. With research having shifted from inquiring on the safety of organ transplant proceedings to actually endorsing it and trying to find ways to facilitate it (Craven & Rodin, 1992), people who have borne the minority status in countries like the United States have increasingly become included in the process. In the South African situation, despite the fact that Blacks assume numerical majority status, their participation in the field of organ donation specifically, has been likened to that of minority groups in other countries. Their knowledge about organ donation, cultural/religious complications of this issue, and communication between the health care professional and lay people have been found to impact on Blacks' preparedness to donate cadaveric organs (Pike, Kahn, & Jacobson, 1993). Findings in low organ donorship research mainly derive from retrospective record examination of the donors or potential donors, researching the attitudes on the concept of organ donation, and/or attempts at finding ways to deal with the problem of low organ donorship.

The aim of the present study falls in line with further attempts to understand low organ donorship, and possibly to inform ways as to how to deal with it. In particular, people who have already encountered requests to donate organs represent a population that has so far been scarcely researched. Therefore they bear the potential to increase understanding in this area. Renal

transplantation as the more advanced and more common sub-field in the broader field of organ donation and transplantation was used as the springboard to access information in this area.

## **RELEVANT BACKGROUND**

Over the past three decades, technical advances in surgery and intensive care have led to dramatic and increasingly successful attempts at organ transplant (Cohen, 1996). Specifically, kidney transplant has evolved from being an experimental procedure, which was considered for a few, highly selected individuals to its present status as a safe and effective treatment which is considered optimal for most patients with endstage renal disease (ESRD) (Levey & Kofke, 1986; Rodin & Abbey, 1992).

However, the process of organ donation has not grown proportionally with the advances in the process of actual organ transplantation. There has been a growing gap between the supply of organs and the need for these (Youngner, 1992). A brief review of previous research in this area will be carried out. Most researchers relate the problems regarding organ donation to specific countries. An attempt will be made in the present study to discuss the problem of low organ donation as it is highlighted, understood and dealt with in these different countries. Subsequent to that, research about the South African situation on organ donation, and specifically on Black organ donation, and how it relates to other countries, will be reviewed. The latter forms the point of departure for the current study.

### **The United States**

According to Hall, Callender, Yeager, Braber, Dunston and Pinn-Wiggins (1991), supplied statistics suggest that there are 20,882 patients on the waiting list for organ transplant of which three die daily because of the unavailability of organ donors. These authors add that fifty percent of patients in need of an organ transplant are Blacks, yet less than ten percent of organ donors are Blacks. Devney and Davidson (1991) specify that Black organ donors comprise only 8,8% of the general organ donor population.

Specifically on the kidney donation/transplantation subject, Davidson and Devney (1991) indicate that despite the fact that Blacks comprise only twelve percent of the US population, they seem to be disproportionately represented in the dialysis population. These authors proffer that thirty-four percent of the dialysis population is Black, and thirty percent of the national waiting list of kidney transplant are Black candidates. Taylor and Hart (1989) express the same sentiment in stating that ESRD was found to occur more in Blacks than in other racial groups, but in spite of this, the shortage of Black organ donors remained consistent in the US.

This seems to raise questions as to what leads to such a wide gap between the availability of organs and the number of patients in need of this service in the Black population. To add to this discordance Taylor and Hart (1989) state that the actual number of organs donated is no reflection that there is shortage of suitable cadaveric organ donors in the Black population. Further, Stuart, Veith and Cranford (1981) report that as long ago as 1968, Gallup polls indicated that 70% of the Americans were willing to donate their organs for transplant upon their deaths.

### **Puerto Rico**

Literature from this part of the world does not concentrate essentially on the incidence of Black refusal to donate organs, rather it addresses itself to the general Hispanic population of Puerto Rico. Similar concerns about organ donation as elsewhere in the world prevail. Dominiguez, Gonzalez, Otero, Torres and Santiago-Delpin (1991) state that due to the shortage of transplantable organs, it was hoped that in 1983 when the brain death law was introduced, legal concerns by institutions to facilitate organ donation would be dispelled, and the plight of low organ donation would be reduced. Studies following this indicated that this was not the case - organ donation had not improved.

These authors found that the attitude of Puerto Ricans was more positive when the question was on whether they would donate their own organs than it was when the request was of a relative's (cadaveric) organ. This shows a curious paradox on how these people view their own responsibility towards the deceased relative versus that of their own bodies. This paradox was partly what prompted the present study, which concentrates more on cadaveric organ donation than on living organ donation.

## **Singapore**

Due to the cosmopolitan nature of the Singapore population, different attitudes in relation to the concept of organ donation exist. Unlike the two countries that have been discussed before, Singapore is reported to have found a way to improve organ donation (Lim, Soh, Woo & Rauff, 1990, p. 2180). Their success is based on the consideration of three options in approaching the subject of organ donation, which are:

- i) Voluntary donation or the opt-in approach: Based on aided educational promotion of transplantation and donor cards;
- ii) Required request or legal compulsion of the health care community to request a cadaveric organ; and
- iii) Presumed consent or the opt-out approach: In this approach, unless the person has indicated otherwise, (s)he is presumed to have given consent.

Brink and Pike (1992) suggest that a shift towards the opt-out legislation brought about dramatic increases in the number of organs available for transplantation. They quote Singapore as one of the countries which profited from such a shift. To meet the needs of its citizens, the presumed consent option is coupled with the required consent one. This move was an attempt to accommodate Muslims, whose religion does not recognise brain death and has variable attitudes towards organ donation.

## **South Africa**

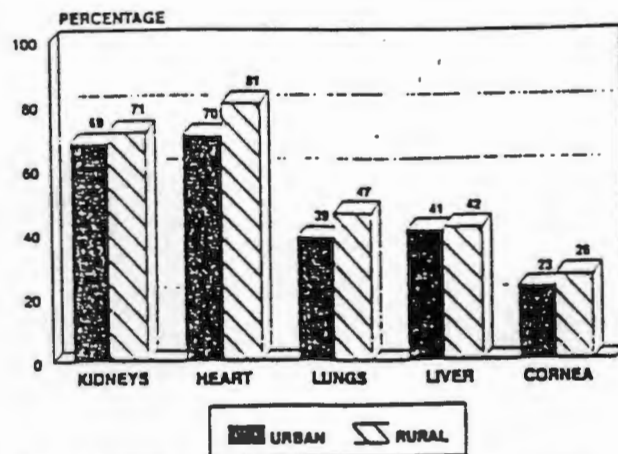
Parallels with the rest of the world where the opt-in procurement legislation is used, have been found in South Africa with regard to organ donation. Brink and Pike (1992) assert that the opt-out method is more suitable for societies with adequate information on organ donation, which South Africa is not as yet.

Most researchers in researching the South African population's attitude towards organ donation agree, in the same way as has been found in other countries (e.g. the USA), that the major part of the population harbours a positive attitude towards organ donation (Brink & Pike, 1992; Pike, Odell & Kahn, 1993). These authors as well as Cooper, de Villiers, Smith, Crombie, Boyd, Jacobson and Barnard (1982) attribute low organ donation to the reluctance of the health care professionals to refer potential organ donors for donation, while others attribute this to be due to the difference between the positive attitude and the actual act of donation.

Suggesting the need for further research in this area, researchers in the Garankuwa Hospital challenged Brink and Pike's (1992) optimism that there was a high number of Black people who are prepared to donate organs (Kobryn & Kowalczyk, 1993). They assert that the number of potential cadaveric donors has recently decreased in comparison to previous local data - with relatives of potential donors becoming increasingly reluctant to give consent to organ donation.

Brink and Pike (1992) also refer to the costliness of keeping a patient on prolonged dialysis as compared to actual renal transplant. They point out that addressing impediments in organ donation would increase the pool for available transplantable organs, which would in return reduce the need for patients to be on the costly prolonged dialysis.

Increased understanding on why Black relatives (used interchangeably with Blacks or African Black families) tend to refuse to give consent to donate will not only cut on costs, but could also contribute to increased graft survival as proffered by Modiba, Koto, Kowalczyk and Schoeman (1993). They concur with Hall et al. (1991) that the possibility of organ rejection is increased if the transplant is transracial. Pike, Kahn and Jacobson (1991) have found American findings by Callender (1987) to be generalizable to the South African situation. If this is true, then a similar problem should be expected to hold here too, where there are more Black patients than Black organ donors. The two diagrams below illustrate the relationship between attitude towards donation and the actual occurrence of donation.



Black South Africans — willingness to donate particular organs.

Figure 1: Willingness to donate particular organs (Pike et al., 1993, p.93)

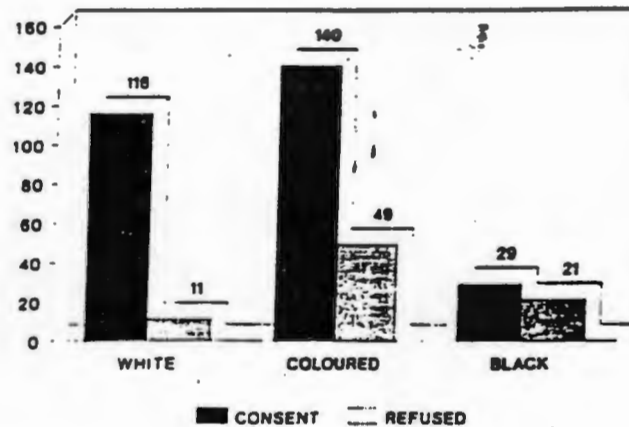


Figure 2: Occurrence of organ donation. (Pike et al., 1991, p.266)

In addition to the low numbers of Black people who are prepared to donate organs, Figure 2 also indicates that, only 29 requests were put to Black families as compared to the 115 and 140 requests made to Whites and Coloureds respectively. Amongst the reasons why some families are not approached for consent, Pike et al. (1991) cite prolonged hypertension, an underlying malignant disease, a history of diabetes, failure to meet criteria for brain death and HIV-I positivity. Specific reasons why only a few families were approached with the request have not been supplied.

It seems important that research should be pointed more towards examining the occurrence of refusal to donate from different angles, with the hope that some light may be shed on how to deal

with low Black organ donorship, and how to understand the dynamics at play in conceding and not conceding to donate a cadaveric organ.

### **Other countries**

In a study entitled "Brain death laws and patterns of consent to remove organs for transplantation from cadavers in the US and 28 other countries" Stuart, Veith & Cranford (1981) review possible modifications of attitudes, laws, and practices with regard to cadaver organs. Included in this study is South Africa, and countries such as Great Britain, Switzerland, Germany, France, Japan, India, Israel and others.

The results of this study concur with those of Brink and Pike (1992) in that they confirm improvement in the availability of transplantable cadaver organs in those countries which have utilised the opt-out method (or presumed consent) for organ donation. However, unlike Brink and Pike's (1992) findings that the presumed consent has solved the low organ donorship in Singapore, they are quick to point out that just the utilisation of the presumed consent option is not sufficient to ameliorate the problem of low organ donorship. Due to anticipated resistance, all of the English speaking countries included in this study (South Africa, Ireland, New Zealand, Australia, US, Canada, etc.) do not use the opt-out method.

Legislative assistance seems to be one of the possible ways to overcome the obstacle towards finding a workable compromise between pure opt-in and pure opt-out approaches. Pertinent to the importance to legalise the presumed consent option is the need to reduce the incongruence between insistence on the right to life proclaimed by most countries, and the continued resistance to organ donation, an act which by definition is life-sustaining. Most of these countries have scrapped capital punishment in support of the right to life principle. It is in light of this that a brief review of the legal issues affecting the area of organ donation will be offered at the end of this review. Before that, different reasons that have been found to influence South Africans' decision to donate or not to donate will be cited.

## Reasons for refusal to donate

Reported findings on why people refuse to donate organs are variable. Hall et al. (1991, p. 2500) state that reasons for low organ donorship are similar in Black and White communities. However, they proceed to outline the most common reasons contributing to low Black organ donorship. These are:

- i) lack of transplant awareness
- ii) religious myths and misperceptions
- iii) a distrust of the medical community
- iv) a fear of premature declaration of death after signing an organ/tissue donor card
- v) a black donor preference for assurance of black receivership.

Most researchers in the field concur with Hall et al.'s (1991) findings except for the last one. From the literature reviewed, one other group raising same race preference by Black potential donors is Townsend, Rovelli and Schweizer (1990). This factor has been found by other researchers as a nonsignificant issue ( e.g. Pillay et al., 1990 & Pike et al., 1992). The latter researchers cite the difficulty in making decisions at a time of grief as well as the lack of knowledge of the donor's wishes about organ donation as an additional impediment to Blacks' giving consent to cadaveric organ donation.

Pike et al. (1993) identify the attitudes of the medical community as comprising the most important aspect of organ donation. Several other researchers (Taylor & Hart, 1989 & Pike et al. 1990) attribute part of the low organ donation problem to either reluctance by the medical professionals to refer suitable cadavers or poor communication between the medical professionals and the lay people. However, this is an area yet to be researched and specific details cannot be offered at this stage.

There is an apparent agreement regarding what is considered to be hampering improved numbers in organ donation generally and specifically with Black families. Despite such agreement, the problem persists, suggesting the need for more information. It is essential to build upon current knowledge about refusal and/or agreement to donate organs, and to further attempts at understanding and possibly dealing with the problem of low organ donation. The discussion on factors motivating people to donate organs ensues.

### **Factors facilitative of donation**

Low organ donorship is regarded as the single most challenging issue to the field of organ donation and transplant today. Research on why people engage in the altruistic deed of donating a cadaveric organ is not as prolific as research on why people refrain from doing this. However, there is a number of reasons which have been forwarded as accounting for the preparedness of people to donate organs.

Pike et al. (1991) proffer that some families derive some comfort from donating (a) cadaveric organ(s). They state that organ donation transforms the tragic situation of loss into something positive, from which the family can draw solace. This is in contrast to what is proffered by Pillay et al. (1990) that grief impacts negatively on people's abilities to make decisions. Deriving the stated solace seems a step beyond the initial stage during which one has to make a decision to donate. The former is a stage which most people do not get to due to grief.

Another factor suggested by Pike et al. (1991) is that by donating an organ of their loved one, families 'put off having to face the death (p. 267).' This is because families may donate a cadaveric organ to a living person in an attempt to (in some way) immortalise their loved one.

### **The question of (brain) death and organ donation**

It is important that this review allude to the question of brain death since it has been cited that if (or once) legalised it could bring about a reduction in the low organ donation problem (Dominguez et al., 1991).

In South Africa, the Human Tissue Act No 65 of 1983 provides for the donation and subsequent removal of human tissues for the purposes of therapy, research and the advancement of medicine inter alia. The question of brain death is not included in the Government Gazette, and according to Stuart et al. (1981) South Africa is one of those countries in which there is no specific law recognising brain death. Rather, it is accepted as a medical criterion on which basis death can be declared. A full review of aspects to consider when diagnosing brain death is beyond the scope of this study, and for a further consideration hereof, the reader is referred to Cooper et al.'s (1982) comprehensive study of "Medical, legal and administrative aspects of cadaveric organ donation in the RSA".

Suffice here to say that Cooper et al. (1982, p. 934) indicate that the rationale behind the diagnosis of brain death and its equation with death is based on the following two assumptions:

- i) no patient with certain well-defined clinical criteria survive, despite intensive therapy, and
- ii) these patients are shown to have widespread brain necrosis at autopsy.

Guidelines are offered to the examining medical practitioners, one of whom should have been registered with the SAMDC for a period not less than five years. The list used for this diagnosis is attached as appendix A.

The US counterpart of the SA Human Tissue Act incorporates the definition of death as per brain death in addition to other legal and medical criteria. Declaration of death as per brain death is defined as follows:

An individual who has sustained either 1) irreversible cessation of circulatory and respiratory functions, or 2) irreversible cessation of all function of the entire brain, including the brain stem, is dead. A determination of death must be made in accordance with accepted medical standards.

Although the literature reviewed applies mainly to the broader area of organ donation and transplant, kidney transplantation is the most common and widely researched area. It is also believed to bear the potential for improving understanding in the more general area of organ donation (Rodin & Abbey, 1992), hence the choice of the Renal Unit as the springboard for the

present study. Rodin and Abbey (1992) also posit that information in the field of kidney transplantation may guide the study of more recently available procedures. One may add that it may aid in understanding and dealing with problems associated with the broader field of organ donation.

This study investigates the continued problem of significantly low Black cadaveric organ donation in spite of vigorous research in this field. Attempts were made to explore some of the details raised repeatedly in the literature (e.g. Pike et al., 1992) without intention to generate generalizable data. According to reviewed literature, the approach used is different from other approaches that have been utilised to cover this area in the South African context . Previous studies emphasised exploring the numerical relationship between people's attitude and the subject of organ donation, as well as some demographic factors of the donor population (Pike, R. E., Kahn, D. & Jacobson, J. E., 1991; and Pike, R. E., Odell, J. A. & Kahn, D., 1993). Consequently, an exploratory, descriptive and essentially qualitative research approach is used to study the subject. The lack of adequate understanding is suggested by Pike et al. (1993) who recommend that 'more knowledge about the beliefs of the Black community with regard to specific organs and organ donation is required (p. 94).'

## CHAPTER 2: METHOD

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### Population

Due to the sensitive nature of the study, and its potential to impinge on the privacy of the information held by the hospital, the Research Ethics Committee of the Faculty of Medicine at the University of Cape Town was approached at the conception of this study, with a request to use the records kept by the transplant co-ordinators at Groote Schuur Hospital (GSH). A complete research proposal including a guarantee of confidentiality was sent to the committee for review, and the project obtained clearance.

The transplant co-ordinators' records classify people whose organs have been requested into three groups: White, Black and Mixed race (latter comprises Coloureds and Indians). The Black families who have been approached by the Groote Schuur Hospital (GSH) transplant co-ordinators with a request to donate cadaveric organs, with special focus on request for kidneys, served as the population of interest. According to the records, this is a relatively small number.

A decision was taken to limit the population to the period extending from 1994 to 1996. This was informed by an attempt to exclude those people who were approached for consent outside of the specified period of time. Some of the intended questions required specific information which due to time lapse could have been forgotten had this exclusionary measure not been used. Families most recently approached were also excluded in an attempt to avoid interfering with their mourning processes.

According to the records of the transplant co-ordinators at GSH a total number of 152 families were approached over this three year period. Out of these, 60 refused to donate and the rest consented. Thirty-two Black families have been approached with the request to donate a cadaveric organ during this specified period. Seventeen consented and fifteen refused. Put in a different way, Blacks constitute twenty-five percent of those who refused to donate and eleven percent of those who have agreed to donate.

## **The sample**

Because of the exploratory nature of this study, random sampling was deemed as unnecessary (Breakwell, 1995). Rather, quota sampling was used, which is referred to by Black and Champion (1976) as a sampling procedure in which the researcher obtains a desired number of participants by selecting those most accessible to him or her, and those that possess certain characteristics of interest to the researcher. In this case, an attempt was made to limit the sample to the Western Cape, and specifically to the greater Cape Town area. Families that were contacted came from Khayelitsha (4), Gugulethu (3), Langa (2), and Embekweni near Paarl (1).

Initially a sample of twenty families was selected from the records of the transplant coordinators. Eventually eleven family participants comprised the final sample because of the difficulty to locate some of the potential participants. One of the eleven was not prepared to go through with the interview, but she was prepared to discuss her feelings for her refusal to be interviewed and about organ donation. Another potential participant who had given consent for the removal of cadaveric organs simply refused to be interviewed because he felt the subject evoked an emotional pain he would much rather forget.

Essentially, five families who gave consent when approached to donate and five others who refused granted full interviews.

## **Data collection**

### ***The initial contact***

King (1994) suggest that the best recruitment strategy is for one to send a letter containing basic information about the study and what will be expected of the prospective participant as an initial contact. However, in this study, although such a letter was prepared, the experience of misunderstanding of the contents of the letter with the first few prospective participants suggested the need to combine this with a personal explanation of the contents of the letter, as well as the aims and objectives of the study. As a result, to avoid both the postal delays and the probability that prospective participants might not respond, for reasons other than outright

opposition to participating in the study, the researcher delivered letters personally, and helped the participants read the letters, answering questions where these were raised.

This followed after the researcher had sent a few letters to the prospective participants, and there had been a considerable delay in responding. The delay prompted the researcher to investigate. Arriving at the addresses recorded on the files, it was found that either the letters were not received, or someone vaguely remembered receiving such a letter, but did not know the addressee.

It was also necessary to deliver the letters personally because some of the addresses and the contact numbers recorded on the GSH files contained errors. As a result some of them were useful only to direct the researcher to someone who could serve as an informant regarding the whereabouts of the prospective participant family. It became obvious that personal tracing of the addresses and thereafter following the lead to the potential participant would be the most prudent way to proceed. This was laborious and time consuming, but it helped to speed up the process through eliminating as prospective participants those who were impossible to trace.

Contacting the participants via the telephone was also considered. However, similar problems as those encountered with the recorded addresses were experienced. Consequently this was discarded as a means for initial contact unless the initial visit to the participants' homes confirmed the number that was recorded or resulted in the attainment of a new, more reliable number.

Paying several visits to the homes of the participants nevertheless had its own positive aspects. Breakwell et al. (1995) suggest that taking time to meet prospective participants personally tends to promote rapport between the researcher and the prospective participants. King (1994) agrees with this view and indicates that the relationship that develops following the personal contact between the researcher and the participant should be viewed as part of the research and not a distraction from it. The initial contact allowed the participant an opportunity to see and talk to the researcher. On the whole, by the time the interviews were conducted, the participants were quite at ease with the researcher. It is hypothesised that

these circumstances contributed to the facilitation of more in-depth responses that participants offered. With those who refused, the advantage of personal contact as the initial means of contact was that it allowed the researcher an opportunity to at least ask a few questions regarding their refusal to be interviewed on this subject.

Personal contact with the researcher also could be seen as an additional means used to encourage prospective participants to participate, as one participant remarked:

*“I could sense that you are an honest, respecting person, so even though the family refuses to talk to you I am prepared to help you and to grant you the interview.”*

This participant came from a family that actually threatened to shoot the researcher. This happened after the researcher had gone to the family house repeatedly just to find the appropriate person to talk to and to set up the interview. The family perceived the researcher to be a police investigator singling the family out for some reason. Eventually when the interview was done, it was conducted with the assurance of the participant and the hope of the researcher that the participant’s brothers would not arrive and find the interview in progress.

### ***The instrument***

The data was collected qualitatively by means of a semistructured interview, in the language best understood by the interviewee (either Xhosa or English). The schedule used was developed through a review of questionnaires used in related studies and the literature in this area generally. Two interview schedules resulted from this exercise, one to accommodate those who gave permission and the other one for those who refused. Once the items were compiled they were grouped in terms of the topics they seemed to cover on the interview schedules. They were then translated into Xhosa by an experienced translator with the researcher fully participating in the process. Translating items from one language to another could impact on the validity of the results. To reduce the possibility of the negative impact on the results, the researcher personally conducted all the interviews. Knowledge of the original version of the item ensured that the participants responded to the intended item.

The interview was chosen as a means to collect data for a number of reasons. Quite importantly, education was not identified as one of the criteria for selecting participants. Therefore, it was anticipated that the sample would be variable on this criterion. Other means of data collection such as questionnaires would therefore prove to be impractical to use. Brenner, Brown and Canter (1985) and Newell (1993) cite the advantages of interviews as follows:

*i) They permit the collection of the most extensive data on each person interviewed.*

When the researcher started the interviews, he had no idea that there existed a link between the perception of crime and decision on organ donation. A questionnaire for example, would have missed the opportunity to find the details of the connection made by the participants.

*ii) They allow both parties to explore the central themes in the lifeworld of the interviewee.*

The concept of ancestors for instance is quite common in the lifeworld of Black Africans. However, the specific way in which it was understood and acted upon by the participants during the moment at which they had to respond to a request for a cadaveric organ was quite novel. The interview enabled the researcher to explore the manifestation of this concept as broadly as possible for each participant.

*iii) They are neither strictly structured nor entirely nondirective.*

Two of the participants indicated that they were not aware of the request having been made to them at the time of the death of their loved one. The semistructured interview allowed the researcher opportunity to glean some useful information from these people as well.

*iv) They provide flexibility to adapt to individual research situations*

In the present study, this advantage was manifested as stated in (iii) above. In addition in each household that the researcher visited, the character of the participants varied from just one individual acting as the participant, to a group of people all participating in giving responses. The interview allowed the researcher to be mindful of this in recording and analysing the responses.

v) *Any misunderstandings from either of the participants can be dealt with immediately such that the resultant data is unequivocally understood.*

With a particular case during the data gathering phase, the participant understood the contact to be a request itself. She felt if she agreed to be interviewed, she would be agreeing to donate an organ. This was brought about by her past experience with blood donation. She stated that she saw her blood being taken without her consent after she agreed to talk to the blood donation people. After the clarification of the purpose of the contact she was prepared to discuss her opinion on organ donation more openly.

vi) *They allow opportunity for expatiation.*

Since some of the issues raised in the interviews are already known in this field, the major contribution of this study was in terms of how people thought about them.

Breakwell et al. (1995) add that the interview method maximises chances of maintaining objectivity and achieving valid and reliable data. Newell (1993) supports this view in saying that the interview maintains the focus of the interaction between the interviewer and the interviewee without being overly directive. Consequently, the interviewee can determine the course of the interview without major concerns on the part of the interviewer that the data collected will be completely useless. All of these advantages of an interview are especially important considering that this was an exploratory study in which the researcher had to follow some of the information as it was raised. Lack of an opportunity to ask for clarity of what was brought up as well as the opportunity to hear this within its proper context would have rendered the responses discussed in the next session less valuable.

The interview guides (term used by Crabtree & Miller, 1992) and the letters that have been used during the initial contact period are attached to this document as appendices B and C.

## **CHAPTER 3: FINDINGS AND DISCUSSION**

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### **Introduction**

At the inception of this study, it was hypothesised that there would be significant differences between the group of people who have given permission for suitable cadaveric organs to be removed for transplantation and those who have refused to give such permission. The researcher was working on the supposition that there could be important lessons to be drawn from the consent group, which could inform attempts to convert more refusals into consents.

The information gathered in this study, revealed that the two groups were not that different in terms of their feelings about organ donation. The fact that some of these people have consented to cadaveric organ donation does not imply that they have fewer difficulties regarding the subject. They still have as much need for information about organ donation as those who have refused.

In addition, refusal to donate was not a result of lack of appreciation for the good brought about by organ donation. Most people do harbour a positive attitude towards organ donation (as the literature suggests), as long as they are not personally involved or on the donor end of the process.

The results reported below explore the complexities characterising the processes of request, donation (or lack thereof) and transplantation of cadaveric organs with Black families. Several broad themes guide the discussion of the factors raised, and implications for the future of organ donation conclude the discussion of these factors.

### **Death and criminality: relationship to cadaveric organ donation**

The most striking and unexpected theme which emerged from this research was how the subject of cadaveric organ donation is consistent with that of death and its accompanying experiences for the family. Some of the deaths implied in this study occurred through

violent, criminal means. The widespread dissatisfaction with the justice system to cope with the spiralling crime rate in South Africa became a factor that was raised over and over again, both directly and by implication during the interviews with the families.

Most of the deaths recorded by the transplant co-ordinators were not occasioned by natural phenomena. Specifically with regard to the population from which the present sample has been drawn, +/- 40% died of motor accidents or other traffic accident related causes, and +/- 45% died of assault or other violence related causes. The latter has some criminal implications, which were indicated as interfering with the process of cadaveric organ donation. One participant stated:

*"We are still troubled that no one has been arrested for this. If a White person is killed all police look for the killer, but if a poor, Black person is murdered, it's like only a bird has been killed. I wish they could look for those organs from the same rich people whose killers will be arrested. It feels like we are just seen as organ donors, and nothing else is given attention to. The killer of my brother lives in this community, but I have never seen him under arrest".*

There is an implication in this statement that the hospital staff and the justice and the security systems are connected, and the effects of failure of one are borne by other systems, and in this case, the health system. For this particular participant, the perceived failure of the justice and the security systems contributed to the decision not to donate a cadaveric organ. It was held back in retaliation for the perceived lack of effort from the police. The perceived connection between the justice, security and the health systems seems unfair and unfortunate for the health system. The occurrence of death through criminal means and the reported failure of the other two systems to deal with the situation are factors that the health or hospital system is not equipped to deal with.

In another case, a family member was responsible for accidentally killing the person whose organs the hospital requested. The effects of the circumstances under which the deceased died, raised complications for consent to donate his organs, since in the words of the participant:

*“... the community will say: They killed him, and now they are giving away his organs. They did not want him or care about him”.*

Organ donation in this family's case is portrayed as disposing of somebody's organs contemptuously. The life-giving, altruistic sense that is implied by the donation is overlooked, and there was a perception that donating the organs that were requested could come to intensify the guilt and the culpability that the family was experiencing already, for the part it played in the demise of the deceased.

### **The language used in the process of request**

The transplant co-ordinators at GSH are both non-Xhosa speaking. This suggests the existence of a potential for difficulties in understanding between the participants of this specific study and the co-ordinators. The co-ordinators appreciate this potential. They make the requests mainly in English, but due to the low education level of the participants a Xhosa speaking intermediary has been used. Even this was less than satisfactory since some of the participants still needed information to the extent that they resorted to general labourers at the hospital who seemed to be Xhosa-speaking, seeking more information or trying to confirm whether they have heard correctly. Such attempts have not always been fruitful as at other times they have served to alienate some people from or tarnish the process of organ donation. This is because these people are not particularly informed about or trained in the process of organ donation, and their responses would be devoid of the sensitivity a response from the transplant co-ordinator would bear.

In a specific case one participant asked about reimbursement after organ donation from one of the general labourers at GSH. He says the response he received from this general labourer was as follows:

*“ There is no reimbursement. All we are going to do is to mess with his body the whole night through”.*

Attempts to improve understanding between the two parties have been reported to fall short of the co-ordinators' intentions. One extreme case was presented in an interview with a family who up to the time of the interview, had a completely different grasp of what the co-ordinator was saying. According to the understanding of this family, no organs have ever been requested from them. They understood the request to be whether organs could be taken from some other child, and be given to their child in an attempt to help him (their child). This is what they consented to.

This family's response was recorded as a refusal. Therefore it is possible that a response recorded as a refusal has more than just one meaning. Examining this case, one can understand that the recorded refusal seems to indicate the inability to reach a desirable level of mutual understanding between the co-ordinator and the family. The family could not understand any English, and their grasp of Afrikaans, which they reported the person who was making the request had resorted to, was minimal. Although a Xhosa nurse was called eventually, the request had already been made and the nurse came just to report and to explain about the death. Overall, in this incident, there appears to have been a strong element of misunderstanding.

Language differences also seem to have an exclusionary effect on the Black families. In some cases, even when more than one member of the family participate in the decision on donation, some members can only speak Xhosa. The task of interpretation or translation is left to one or two members who transfer their understanding of what the co-ordinator is saying to the rest of the family. In the case mentioned above, both parents could not understand English, and the husband was the only one with a minimal understanding of Afrikaans. In some, there would be a relative who has been to school for longer than the others. Such a member would then be the one whom the transplant co-ordinators would speak to directly, sometimes despite the position of such a person in the family hierarchy. Unfortunately, often this person's position in the family hierarchy did not justify this, so that established decision-making power relations are interfered with.

This practice is thought to have an impact on the decision-making process in African families. Black African families have been found to have a tendency to take decisions as a collective

rather than one individual deciding unilaterally (Raum, 1972). With only one family member understanding the language of the co-ordinator, the ability of other participating family members would depend on what is understood by one member instead of everybody forming their own understanding and reaction.

### **Time needed for consultation**

This was cited as the subject needing the most urgent attention regarding the process of organ donation as it is today. The families who had consented and those who had refused to donate gave this reason as the most prominent source of dissatisfaction. Most Black Xhosa families in the Western Cape have important relatives in the rural Eastern Cape, and at times of death, very few decisions can be made without their participation. To support this, Read (1966) asserts that the death of a member of a family is a concern of a group of people and not one or two individuals. With all of the participants, the death report was immediately followed by a request for a family to donate an organ, depriving the family member(s) adequate opportunity to consult and to take a decision as part of a collective.

Moreover, concern about the brevity of the time between the death report and the request of a cadaveric organ raised feelings that the person who was requesting the organs lacked empathy for the misfortune that has befallen the families:

*“How could they ask me to donate the parts (organs) of my child when I was still in such pain, when I was still crying for him? How could they expect this?”*

*“... then it feels like the hospital staff is happy that someone has died from whom organs can then be requested.”*

Both these participants refused to donate. The statements point out that on the one hand, there are concerns on the part of the Black families that opportunity should be allowed for them to accept the death of their loved one. This ranges from an expectation of 24 hours to one week. On the other hand, there is appreciation that time is of essence, and considering the extent of care necessary to keep the organs viable (see Appendix A), it is necessary to act

quickly. In some of the cases it has been when there has been no compromise between the need to request urgently needed organs and the difficulty to come to terms with the death, that the outcome of a request to donate cadaveric organs was a refusal.

Due to its sensitive nature, a decision either to donate or not necessitates consultation between the family members. At times such consultation is not merely for the sake of reaching a decision, but it is necessary because of the scarcity of information on the subject of cadaveric organ donation with Black families. Therefore, it seems dealing with a difficult (or novel) situation as a collective is expected to grant the family a better chance to give an informed response.

### **Gender considerations during consultations**

In general, Black African families in South Africa are still strongly patriarchal. In situations like these, it has emerged in this sample that men in African families were accorded the right to intervene in the place of the rest of the family. Of the consenting families, only one has a woman as the sole signatory on releasing the organs for transplantation. Apparently she was the eldest child of the family. Although age accorded her a respectable and deciding role during the process of request, she still felt she had to consult with the men of her family before she could give consent. This was a specific case in which the man in the family, who normally would make the decision, was implicated in the demise of the deceased.

In all other cases of consent the main signatory, accorded the right to make such a decision for the family, was a man. If the man agreed, then the wife would also give consent, even though she might not be having a full understanding of the request process. One participant who gave consent together with her husband stated the following during the interview:

*“ ... I lost all understanding... My husband and the doctors were there, already telling me that if the machines were removed he would not live, and then they started telling me about donors and stuff. My understanding went completely blank, up to this day.”*

In one family the male representatives of the family were not readily available and male church elders who accompanied the family to the hospital assumed the patriarchal role for the family. Although they consulted with the deceased's mother and aunt before they turned down the request, they served as the intermediary between the transplant co-ordinators and the family. It can be deduced from this that men serve as the mouthpiece or the ultimate decision-makers during the process of organ request despite the need for consultation with other family members. This probably flows from the popular conception in traditional African countries (Godelier, 1982) that follows a patrilineal kinship system. This holds "that a child automatically belongs, at birth, to his father's lineage and clan (p.19)." In addition, once a woman gets married, she becomes ingested into the patriarchal system of her husband, and becomes subservient to it. To illustrate this, one participant said:

*"A married woman does not make decisions. The males in the paternal family would suspect that such woman has killed their child if she should be the one taking the decision to donate a cadaveric organ. The request should be directed to the males. Then they can consult you as the mother of the child. You cannot give consent over the family's child... one did not come with children to the marriage."*

The response to this particular request is recorded as having been turned down, despite the fact that this participant states that she is not aware of any request having been made. She felt that even if it had been made to her, she would not have donated on her own accord, as she believes that although the child was biologically hers, he belonged to the family of the husband and she had no right over the organs of their child.

### **Death as transition to ancestry**

As a group the participants believed in the existence of the ancestors, although the relationship between this belief and cadaveric organ donation varied. The concept of ancestors or *izinyanya* refers to a belief that after death one joins a spiritual world, that works in collaboration with and immediate subordination to God over human kind. The ancestors would then communicate personal messages or messages from God to living human beings through symbols like dreams (Ndlovu, 1997). For those who believed strongly in the fact that

the dead transit to being ancestral spirits, donating a cadaveric organ meant that the dead person would become a complaining ancestor:

*“ I was thinking that it does happen that a dead person should appear to us. What would we say if she appeared complaining about her organs which were donated? I felt this could happen, and I would end up worrying about this everytime I go visiting her grave, thinking that she was angry at me. It would be worse if it is an adult’s organs that have been donated”.*

This concept of a dead person being able to persecute those who are living through complaints is referred to as *uvukelo*.

The participants stated that the body had to be intact for the transition to ancestry. This diverges from Pike et al.’s (1993) position that there is no prescription that one needs all one’s organ to join one’s ancestors. It appeared essential for the participants to maintain good relations with the dead who it was felt could become persecutory if some of their organs could be donated. This idea resonates with Pillay et al.’s (1990) finding that one of the reasons that Black families refuse to donate organs is their religious beliefs. Apparently, greater emphasis is put on the subsequent relationship with the body or the prospective ancestor, than on the good that would result from this altruistic action. Usually, in this belief system, if an ancestor appears in displeasure, a ritual is performed which would appease him or her. An example is that of a dead person appearing in the dream of one of the family members, stating that he or she is cold. One participant indicated that the body or the bones would be exhumed, wrapped up in a blanket and reburied. Her family group believes that this activity would quieten him/her down. It follows then that one of the reasons why some of these families refused to donate was a feeling that should the dead person appear as an ancestral spirit, asking after his organs, it would be difficult to retrieve these as they would be functioning inside of a living being, over whom the family has no claim. As the subject of organ donation is something unusual in the Black African society, it is reasonable to infer that no ritual has been established yet, for appeasing an ancestor who is unhappy because his/her organs have been donated to somebody else after death. Avoidance to donate a cadaveric organ can therefore be equated

with an attempt to avoid an ongoing conflictual relationship with an ancestor, where there is no established way of dealing with this.

### **Juxtaposing Christianity and African traditional beliefs**

Closely related to the subject of transition to ancestry is how the belief in ancestors is juxtaposed with the Christian faith. All of the families interviewed are Christians, with some practising and others not. In addition to this, they also believe in the existence of the ancestors. For most of them it was difficult to ascertain how they related the principles of Christianity to traditional beliefs in ancestors. On the one hand donating a cadaveric organ was seen as a sacrifice which is emulated following the Christian belief that God sent His only Son to earth to save the lives of sinners:

*“Why can we not learn from that and preserve the lives of others”.*

On the other hand, there were participants who due to their belief in the ancestors, held the body of a dead loved one as sacred, and that it should be buried with all its organs. They believed that their elders still believed in the existence of God, and that the ancestors were intermediaries between God and the living:

*“God will not personally appear to me. He will send my ancestor, a person I know to talk to me. I have never seen God, and therefore he will not personally appear to me”.*

This statement illustrates reverence for God. It can also be interpreted according to what Ndlovu (1997) reports in her work with transplant organ recipients, that ancestors have been humans and they can identify closely with the human condition. The implications of this is that although ancestors have transcended into the supernatural or spiritual world their human origin facilitates closeness with living human beings, reducing the implausibility of the supernatural concept.

The elevated status the dead are believed to transit to, result in a perception that organ donation subjects the body of the prospective ancestor to disrespectful treatment. These fly

directly in the face of Christianity, which holds that beyond death, one ceases to have any existence that would have a living-like impact on the living, arguably until the judgement day. According to the traditional beliefs, the task that Christianity holds is performed by Jesus Christ, that of interceding between man and God, is believed to be performed by the ancestors. No exploration of this paradox is provided. It would appear that these belief systems run parallel to each other, and though potentially irreconcilable and conflictual, continue to exist side by side nonetheless. At any given point in time, one could be held in dominance of the other.

### **Abstract beliefs and practical reasoning in organ donation**

It is not always the tension between traditional beliefs in ancestors and the Christian principles that impact on the decision to donate or not to donate an organ. Sometimes the influence comes from relating the appreciation of the importance of one's decision to the dialysis patient with the predominantly held beliefs. The following statement by one of the Christian participants who gave consent to donate clearly illustrated this point:

*"I felt that my faith did not allow me to donate an organ. It feels like if you donate one's organ, you also donate one's soul. But it would not help because there was nothing I could do with those organs".*

This argument by a Christian against organ donation is very similar to that held by those who believe in ancestors. However, due to what can be referred to as common sense or reasoning with himself the participant deviated from his religious belief, and gave consent for donation. Despite this, there are instances in which practical reasoning does not overcome the strength with which an individual holds on to the belief whose prescription is against organ donation:

*"We see the good of organ donation, but we also have our own beliefs. It cannot be helped because the latter exists strongly."*

This participant is a Christian, who in this particular instance held the traditional beliefs in dominance. Her appreciation of what organ donation meant still could not move her to accepting the request, since it would interfere with her belief system.

### ***Umyolelo: The dying wish***

The respect for the dead could potentially prove beneficial for the course of organ donation under certain circumstances. An exploration of how the families would react if the deceased had left a note or clear indication that s/he consented to his/her organs being transplanted to somebody else showed that this would be respected by the families.

In the Xhosa culture (as in other cultures), it is common to oblige the wishes of the dying person. In the specific cases related to this study, there was no expectation that the deceased would die at that particular time. These were sudden deaths which left no opportunity to leave a dying wish or *umyolelo*. As a result, the wishes of the deceased which were expressed earlier in his/her life would come to be respected in the same way as those of a person who has had time to prepare for his/her death, and therefore, to give a dying wish. Most of the families indicated that they would honour the deceased's wish to donate organs if this was expressed before death. The guilt that seems to characterise giving consent for the organs to be removed without a clear knowledge of the wishes of the deceased would be reduced.

When the participants were asked if they could consider signing a donor card (a photocopy attached as Appendix D), it became apparent that there would still be complications because they felt they would need to consult with their families, and a collective decision would prevail in spite of the wishes of the individual. Therefore, if the outcome of such a consultation yielded a negative outcome vis-à-vis organ donation, the wish of the individual could be overruled and it would as such not be accepted as his/her dying wish should accidental death occur. It is only those wishes which were not opposed by the family during the lifetime of the deceased that would be accepted as *umyolelo*.

### **The paradox of organ acceptance by the *refusers***

One of the factors introducing inconsistency to the idea that organ donation is not acceptable in the Black culture, is that most of the participants who believe that people should be buried with all their organs (since they are going to become ancestors), feel they would accept an organ if they needed one and someone was prepared to donate it. This they admitted to with reluctance, feeling that it would be “funny” because they have refused to help another. In most of the interviews, this question was asked right at the end. The participants seemed to assume a different perspective on this subject. Instead of being prospective organ donors, they became aware of the possibility that they could be on the other end of the process. In accepting this, they externalised their locus of control for they stated that if they are ill, then it is up to the doctor to decide on the best treatment. This seems like an attempt to escape from any personal responsibility over this subject.

Another indication of a wish to surrender the responsibility to be the one giving consent or refusing to was indicated by one participant who stated:

*“ I wish the doctors could just remove organs quietly, without placing a request, because we would then bury our loved ones believing that they are whole. Then no one would feel guilty of having donated an organ. It's whites who did that. They should just leave the face intact. If you give consent, the dead person will haunt you in your sleep.”*

Despite the apparent feeling that organ transplant would be accepted as the modus of treatment if the need arose, two people said they would not be prepared to accept donated organs for transplant. The first participant indicated that surgical intervention was still viewed with suspicion in the Black community, and therefore, because there would be no guarantee that he would survive the transplant, he would not accept a donated organ. The present study does not purport to assess the opinions of Blacks about surgical intervention, but it is possible that there could be more people who are not aware or not trusting of the technical advances in surgery and intensive care reported by Rodin and Abbey (1992). The statement by this participant suggests that in addition to the incongruence between the actual advances in transplant and the process of organ donation, there is a third factor: adequate information (or

lack thereof) about these advances. The lack of information factor is discussed below in the need for education section. It is likely that the lack of information could have a bearing both on the decision to donate and the decision to receive a cadaveric organ.

The second participant differed from the rest of her family in stating that if her organs should fail her, then it would be her time to die. Organ transplant would be unacceptable as an intervention which would prevent the course of her destiny.

### **Need for education**

Cadaveric organ donation and transplant has been declared one of the best ways in which to treat those with organ deficiencies, malfunctioning or failure (Levey & Kofke, 1986). Pike and Brink (1992) support this assertion in stating that one organ donor could bring about immense benefits to many patients. The number of Black patients is growing, and in some countries they represent the most rapidly growing number of transplant related patients (Taylor & Hart, 1989). These are the facts that Black participants in this study claimed to have little knowledge of. It is difficult to imagine that they had an adequate understanding of the subject given the brevity of time they had to make a decision. One participant raised a passionate need for such information when she said:

*"I was unable to ask questions because I did not know which questions to ask. I felt I was amongst all these learned people, so they would not lie to me. But I was still suspicious that if other parts were fine, why couldn't he be helped?"*

Most participants indicated that they were aware of the importance of organ donation. Nevertheless, they felt that such importance was not reflected in the attempts of the health system to give people information about organ donation. A comparison was drawn with blood donorship and AIDS education, the two subjects of which even children know something about. It is common practice to have private organisations distributing information about HIV/AIDS in work places and schools. The participants expressed a wish that such could happen around organ donation as well. This sample suggests that efforts should be increased to distribute information more widely.

In most cases families really confront the subject of organ donation for the first time when there has been death in the family, and usually, this is the most inopportune time to teach or learn about the subject.

### **Brain death, brain damage and oxygenation**

In addition to the expressed need for education around the subject of organ donation in general was the apparent need for education about specific routine operations characterising the process of cadaveric organ donation in particular. In most cases the transplant coordinators would give an explanation of brain death in the process of telling the family about the situation of their loved one. It was not clear if this had been done with all families in this sample, but it was found that none of the participants understood the concept of brain death, since this concept refers to a clinical diagnosis. A lay person might not have adequate medical sophistication to understand or appreciate it. To the participants, the brain dead loved one was equated with one who is brain damaged, whose existence or life beyond the hospital bed would be characterised by such functional deficiencies as would render him/her severely disabled. In discussing the concept of brain death, one of the participants was left with the impression that if her son lived, "he would be like a cabbage, and (she) would struggle with him." This can be interpreted as meaning that it was anticipated that the deceased would have depression-like vegetative symptoms with emphasis on incontinence. He would have to be fed, washed and require full-time supervision. Another participant stated that "it would have been better to have a mentally retarded XX (name of participant substituted) rather than to have a dead XX". Clearly, the medical staff have a different explanation for this concept. However, it is of concern that the participants who were in direct contact with the hospital staff are still carrying this understanding.

It would follow then that, some of the participants experience consent to organ donation as giving consent that further treatment should be stopped on their loved ones, and thereby could feel implicated in their demise.

The concept of oxygenation and the sight of one who is "connected to machines" was seen by some of the participants as indicative that their loved one was still alive. For one participant it

meant that the deceased was left with a few minutes before death. The idea that one who is oxygenated is still alive was further confirmed by a number of the participants who felt that giving consent for the organs to be removed would release their loved ones from suffering. Therefore it becomes apparent that organ donation is motivated by a variety of reasons, amongst which is the act of redemption for the one perceived to be in great pain, and for whom the disconnection of the oxygenating machines constitute the final loss of life, and therewith, the feeling of pain.

### **The physical context of the request**

Death in the African traditional context is a subject not easily talked about. This is partly because the body of a dead person is seen as being in transition to an elevated, supernatural existence, and therefore to be having an existence that the mortals should not have intimate exposure to. With few exceptions, participants reported being told about the demise of their loved ones while they were looking at the bodies. This could on the one hand be an attempt to deal with the potential disbelief that families may come to experience at hearing the death report. On the other hand, seen in the context of the belief that the deceased is in transition to another form of life, and the general denial reaction at first hearing about the demise of a loved one, such an approach was seen as inconsiderate, as one mother tearfully extorted:

*"... the request was made in the same room as the one (our son's) body was lying, in full view of the body."*

Looked in this way, such an approach may contribute to the reluctance of families to donate cadaveric organs.

In an attempt to treat the request sensitively the transplant co-ordinators usually try to find the person who has the legal power to give permission for the removal of organs (F. McCurdie, personal communication, January 30, 1998). Seeing that African Black families prefer to make decisions as a collective, when it is one's husband who has died, removing one from the rest of the family members who have accompanied her to the hospital to report the death and place the request, can be equated to forcing her out of her normal and cultural way of doing

things. Such a practice can expose the individual to increased emotional trauma as the buffer effect of the cultural norm is removed with her isolation from the rest of the family. This concern was raised by one of the participants who refused to donate because she felt the coordinators could have been more tactful, and reported the news to one of the family members who would know how to communicate this to her at a later stage.

### **The relationship with the dead loved one prior to the demise**

The relationship that existed between the deceased and the rest of the family prior to his/her death appeared to influence the decision to donate as well as feelings and reactions following the death report. Arndt and Gruber (1977) proffer that the age and the role significance of the dead person in the family influence the intensity of the feelings the family group experiences. The quality of relationships between this person and other family members is also of great importance in this regard. In the present study the deceased were mostly in their twenties or younger and they were males (84% of the total number, and 88% of the Black potential donors). In the African culture a son is expected to look after the name of the family. He is also seen as the potential provider of the family should anything happen to the father. This idea may have been affected by the high level of westernisation in the African population, but the sample used indicated that the feelings of loss following the death of a loved one were intensified by the thought that the family has lost one who was or could have become economically productive and helped the family.

In one family the deceased was nineteen years old, and was in standard nine (grade 11). His brother who paid for his education and was his guardian gave the following reaction to a request to donate:

*"He was the one we had pinned our hopes on. He was the highest educationally in the family, and judging from the way he was growing up, he could have been the one who would raise the standard of living in the family."*

One cannot claim that there is a positive relationship between the extent of pain caused by the demise of a loved one whose (anticipated) role in the family was significant, and the decision

not to donate a cadaveric organ. Still, experience with this sample has shown that part of the extent of the pain families experienced immediately after the death report correlated with the likelihood that the family would refuse to donate. It would follow then that the loss of a family member whose (anticipated) role was significant for the family signify a more than ordinary loss. This could in turn have a bearing on what the family decides on the organ donation subject.

### **Grief and loss as factors in organ donation**

The feelings experienced at receiving the death report could have an impact on the decision-making process of the family about organ donation. Hellman (1994) differentiates between two types of death namely biological and social deaths. The former refers to the end of the human organism, and the latter assumes the continuation of life-like impact beyond the pronouncement of death. Social death, which would be the final death in this sense, occurs after months following the biological death. In the period between the two types of death the soul of the deceased is assumed to be in some state of limbo and partly still a member of society. The most significant fact that is raised is that such a soul is potentially dangerous. It can only be kept appeased through the observation of certain rituals like wearing black and refraining from entertainment-related activities at the home of the deceased.

Potentially, organ donation and the implied permission to “violate” the body of the one who is still in the process of dying (social death) would constitute a procedure for which the non-western societies have not prepared for. Pike et al. (1993) state that Blacks do not have traditional views on organ donation since its medical use is a recent concept. All participants expressed a sincere request for more information. There were feelings that the publicity of this subject does not reflect the extend of the need.

More factors have been cited in explaining the vicissitudes of how people react to the experience of loss. Bowlby (cited in Klein, 1994, p.108) posits that :

*"...during the early phases of grieving a bereaved person usually does not believe that the loss can really be permanent; he therefore continues as though it were still possible not only to recover the lost person, but to reproach him for his actions."*

A statement by one of the participants at the bedside of the deceased illustrates Bowlby's position:

*"I prayed to God that he should live so I could tell him that one should listen when told: no, you see what these things could lead to?"*

Underlying both these processes is the fact that immediately after death, there are too many processes that the family goes through. Consequently a request for a cadaveric organ might not receive the attention it could at a different point in time. There are incidents cited in the literature about the process of grieving which indicate it to be a difficult time to make such important decisions as donating a cadaveric organ. An example is cited from Ramphele (1995, p.49) on how she experienced her mother during the period between her father's death and his funeral:

*"The sight of my grieving mother ... as she sat near my father's coffin was a confirmation of the reality of the loss and the finality of death. My father was unreachable, he lay motionless in the coffin. My mother was also unreachable as a nurturing figure to share my grief - she was nursing her own wounds and could not comfort even her own children."*

This quotation clearly depicts the kind of impact loss due to death could have on people. It clarifies that immediately after the death report, reaching out to the next person and committing an altruistic deed could be difficult. The impact could be too strong, leading to one using one's energy just for personal survival. In the case quoted above, the relevant person to speak to would have been Ramphele's mother, but it is hypothesised that the impact the loss had on her would have rendered it difficult if not impossible to make a decision based on the need to extend a helping hand to another during a painful moment. This resonates with Pillay et al.'s (1990) finding that grief interferes with the ability to make decisions on cadaveric organ donation.

## **Reimbursement and other financial considerations**

This did not come up as a strong issue during the interviews. Those who raised it felt it would only be fair that some tangible symbol of gratitude be received from the hospital, which did not necessarily have to be in monetary terms. They stated that it was a basic African practice, that if one has given one needs to receive a sign of appreciation.

The kind of appreciation that people require seems to relate to the nature of their need at any given point in time. The participants explained that it was going to be difficult burying their loved ones because they did not have the financial means to do so. Therefore, their enquiry about the possibility of reimbursement can be understood as the beginning of the more general process to get financial help for the funeral costs, and not as an expression of entitlement.

Other financial issues raised related to the travelling costs to and from the hospital. Some of the participants explained the inconvenience suffered through having to wait for the request process, sometimes until means to get back home were unavailable. They felt the hospital should give assistance since they saw travelling to the hospital as part of allowing the hospital staff to perform their duty. This was particularly significant for those who felt that the request should be made after some time the death report had been communicated. This concern seem to be related to the socio-economic conditions of these families, for whom the loss of transport money means a significant financial loss.

Concerns about some form of reimbursement might not have a direct bearing on the decision whether to donate or not. However, they seem important to reduce perceived inconsideration regarding the process and to render the request donor-friendly.

## **About the race of the recipient**

Until fairly recently, the South African population has been divided and defined according to racial categories. Considering research that has been done in other countries, where race was not an issue in deciding whether to donate or not, it was interesting to find that this was not a significant issue on its own with this sample as well. Notably, participants preferred to donate

a cadaveric organ of a loved one to one of the family members who needed it. Asked specifically if they would object to donating a cadaveric organ purely on the basis of the racial group to which the prospective recipient belonged, all the participants identified this as a non-issue.

This finding concurs with the general perception held in this field, in contrast to the findings cited by Townsend et al. (1990) and Hall et al. (1991) which hold that Blacks have a preference for a black recipient. It is possible that by implication, a Black potential recipient who is a relative to the potential donor would be racially the same as the potential donor. As a result the same preference could be found to apply in this case as well. Nonetheless, despite this apparent racial similarity, preference seems to be more along the line of relation than race. Participants who were opposed to organ donation indicated that they would still be reluctant to donate even if the prospective recipient was Black, as long as they were not part of the relational system.

#### **Attitude about donation: Changed or unchanged?**

Asked if they would be prepared to donate in future, the participants gave various responses. Some indicated that they would not donate, while others said their decision would depend on a variety of reasons some of which have been discussed.

Some participants stated that they would be happy to donate. They did not raise any pre-conditions for their positive inclination towards organ donation. These were amongst those who had given consent to organ donation before. Other participants said they would agree to donate if organs would be used to help a family member or a close friend. Alternatively, one participant raised a preference that she would be more likely to donate a cadaveric organ if it would be used to help someone who had a purpose in life, such as a young father or mother who is a bread winner in his/her family.

The majority of the participants stated that they would need to consult with their families. This did not change regardless of whether the request was of their own organs or of a family member's. Another unexpected finding was that previous consent did not necessarily mean

that the family would donate again in future. Further, some of the participants who had refused to donate in the past stated they could consider donating in future. They said this depended on their perception of the approach by the hospital staff. Some of the factors they felt needed strong attention are giving the death report tactfully and allowing time to process and accept death. One appreciates the difficulties this would raise in terms of time and money needed to keep the organs viable.

### **Summary**

The aim of this study was to explore the different factors affecting a decision on donating a cadaveric organ in Black families. The content of themes raised before were explored further and some new themes emerged. Factors and themes raised had the following impact on the participants:

Some of the deaths were a result of crime. Some participants felt that the justice and the security systems were not serious enough in addressing the criminal actions resulting the death of their loved ones. Therefore, they refused to donate in retaliation. In other instances, family members were implicated in the demise. So consent was withheld to avoid a negative perception of the family by the larger community.

Some participants did not understand the language used during the process of request. Attempts by transplant co-ordinators failed to result into a satisfactory level of mutual understanding. Language differences have led to a misunderstanding of what was communicated. Other attempts to improve mutual understanding affected the structure of the families through changing the normal positions people assume for the duration of the request process.

The families indicated that they needed time to deal with the death report before they could be approached with a request for organ donation. They experienced the brevity of time between the two as inconsiderate and tactless.

Despite the need for time to consult, a decision taken by the male members of the family attracted more respect than the women's. The traditional concept that the child belongs to the paternal family and not to his mother is still observed. Therefore the decision taken by the man/men in the family prevailed regardless of how the woman/women feel about organ donation.

Ancestors are highly respected in the African belief system, and death is seen as a process of transition to ancestry. The participants compared giving consent for organ donation to allowing the hospital staff to treat the prospective ancestor with disrespect. Apparently, the families felt that giving permission this way would result in guilt feelings and persecution by the ancestor. Due to its recency, there are no established African rituals to deal with an ancestor who is complaining about organ donation. Some expected that they would not experience the guilt and persecution if the organs were taken without their knowledge.

The sample consisted of Christians who also believed in the existence of ancestors. For some, Christianity encouraged organ donation while others stated that organ donation was against their African traditional beliefs. However, at other times the appreciation of organ donation as a life-restoring process prevailed over the religious beliefs.

These participants stated that they would respect their loved ones' dying wish even if it was against their belief system. This feeling would relate positively to attempts to get people to sign donor cards. The consents on the donor cards could be respected as the dying wishes of the deceased.

Except for two, the participants said they would accept organ transplant as a means of treatment should they suffer organ malfunction or failure. This is paradoxical seeing that some felt organ donation was unacceptable in the African Black culture. Two participants would not accept organ transplantation because they felt it interfered with one's destiny or surgical procedures were not safe, respectively.

The process of organ donation has specific concepts which are incomprehensible to the lay person. Participants expressed a strong need for education about organ donation.

The physical context during the request should be attended to by the hospital staff making the request. Making the request in the same room as where the dead body is lying and removing the potential signatory from the rest of the family contributed to the reluctance to donate.

Feelings characterising the grief process interfered with decision-making regarding organ request. The families indicated that dealing with death acceptance was too painful a time to consider cadaveric organ donation. This period was particularly difficult if there existed a significant positive emotional investment in the deceased.

The sample saw financial returns following consent to donate as an expression of gratitude. Some participants stated they struggled to meet the financial costs of the funeral. They felt they would have appreciated some assistance in this regard when and if they donated. However, this was not considered a deciding factor on whether to donate or not. The participants felt the race of the potential recipient was not essential in their decision.

Overall, the participants who knew they had donated in the past said they would consider donating again. Of those who had refused, some said they would not consider donating, and others said they would if certain concerns raised above were attended to.

## CHAPTER 4: CONCLUSION AND RECOMMENDATIONS FOR THE FUTURE

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Although the researcher set out to use a bigger sample, only 10 families were interviewed in the end. They were interviewed at their own homes. This meant that more family members were available for the interview, adding to the comprehensiveness of the interviews. Further, the smaller sample, and the fact that the interviews were conducted in the participants' own language, facilitated a deeper and broader exploration of themes.

A larger sample could have improved the applicability of the results to a broader portion of the population. However, given the difficulty one encountered in locating participants, the considerable time and cost involved, the findings of this study offer important implications essential for consideration in the future.

This study has revealed that a request for a cadaveric organ implies that death has occurred (at times due to assault or other crime related means). One can use the just world hypothesis, in which people believe that the world is just and benevolent until some violation of this belief has occurred (Basoglu, 1993). Such a violation has an extremely destabilising effect on an individual. In this case the murder of a loved one seems to represent this violation. It seems possible that as a result, the altruistic nature of people, which would otherwise manifest under non-violated just world circumstances is affected negatively. People experience difficulties with organ donation because one of the very important beliefs they have had, viz. the preservation of human life, has been violated through the killing (or death) of their loved one.

Moreover, there seems to be a relationship between the spiralling crime rate in South Africa and the difficulty some people have in giving permission for the removal of cadaveric organs for transplantation. These people expressed feelings of despondency regarding the ability of the security and the justice systems to protect and maintain their lives. To use the ideas proffered by the social exchange theorists (Argyle, 1991), people are more likely to engage in those activities which they anticipate will bring about valued personal outcomes. Life preservation seems to be the outcome of interest in this case, and because of the perceived

failure by society to preserve the lives of their loved ones, people's ability to give to society becomes negatively impacted upon.

Related to the experiences of these participants following the occurrence of death, is the need to appreciate the debilitating effects of grief for most people. The findings imply that the process of decision making on cadaveric organ donation becomes extremely difficult immediately after receiving the death report. Apparently, more time is needed to deal with the news. Otherwise it seems essential to investigate the family structure (through some brief interview) to inform the tact with which the request should be made. This could ensure that the pain caused by death on the family would not be exacerbated by the request for a cadaveric organ.

A structural assessment of the family would also ensure that suitable organs are not lost for reasons such as the consultation of the wrong person in the family hierarchy. Consulting the right person in the family would necessitate a provision of conditions that would allow optimal mutual understanding between the co-ordinators and the family concerned. The findings of the present study and previous research (e.g. Pike et al., 1993) suggest that one of the ways to ensure that these conditions prevail is the availability of a trained, experienced translator or a professional who would be able to speak the language familiar to the black families. It is believed that this would ensure that Black families refuse or give permission to what they have understood fully.

The traditional African belief system bears a strong influence on organ donation. One of the ways to deal with people's conceptions of how cadaveric organ donation relates to their beliefs is giving them adequate information before the occurrence of death and the moment of request. The impact of the death report and the novelty of the request placed to the family at the time of death seem to interact, reducing chances of family consent. As suggested by the participants in the present study, lessons should be taken from how the HIV/AIDS information has been distributed. The parallel between these two subjects is also made pertinent by the fact that lack of transplantable organs leads to death occurrence which is as frequent as three deaths per day in the United States (Hall et al., 1991). This renders poor organ donation as one of the most serious life threats.

Further implications relate to lack of some basic knowledge regarding the different procedures characterising the process of organ donation and transplant. Once again, lessons could be derived from the vigour with which the HIV/AIDS epidemic has been attended to by health professionals. The participants expressed a strong need for education. Such concepts as brain death, brain damage, oxygenation and the advances in surgical intervention need to be explained. The fact that they are not well understood seems to contribute to the difficulty characterising the decision-making process regarding cadaveric organ donation.

Providing education on organ donation is essential to expel myths held about this process. Some participants expressed their concerns about the abuse of Blacks by the organ transplant practice in the past. The truth about this could not be ascertained, as well as the extent to which it influences the decision on whether to donate or not. However, it is possible that such concerns could be dealt with by giving people adequate information about the uses of organ donation.

Time needed between the death report and the request for a cadaveric organ was raised amongst the most important factors needing serious attention. On the one hand, allowing more time for the family to accept the death report would mean spending huge amounts of money on keeping the cadaveric organs viable. Given its present financial status and the expense of other legitimate needs, the health department can hardly afford this. On the other hand Blacks need the time to consult with important others in their family. Taking the decision as individuals has serious implications regarding the person's relationship with other members of the family after the decision has been made. This seems like a predicament which future research should help explore.

Future research should also explore what compromises could be made between the practical concerns the medical staff have regarding organ donation and transplant, and the different characteristics of the black culture, and in this case, the Xhosa culture. More information is still necessary to explain the concept of burying one without some of one's organs, and its relationship to the transition to ancestry. The paradox in this case seems to be that it is still acceptable burying one without some of one's organs as long as the decision was taken by someone other than the living family members. It seems possible that part of the problem lies

with the feelings of the person who has made the decision more than with the prospective ancestor. It is hypothesised that the discussion and the untangling hereof would be informative not only for the field of organ donation, but for the growing Black generation as well. Information would be produced which would add to knowledge regarding the relationship between the living and the ancestors.

The fact that soon South Africa will be following the likes of the United States and Netherlands with regard to the type of driving licences used is of great significance for the field of organ donation. It is encouraging that at least the driving population will not be confronted with the decision on organ donation for the first time when death has occurred. The new driver's licence will have a section where one should indicate whether one would like to donate or not. The biggest challenge would be to ensure that people receive adequate information to make informed decisions.

## REFERENCES

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Argyle, M. (1991). Co-operation. London: Routledge

Arndt, H. C. M. & Gruber, M. (1977). Helping families cope with acute grief and anticipatory grief. In E. R. Prichard, J. Collard, B. A. Orcutt, A. H. Kutschner, Seeland, I. & N. Lefkowitz (Eds.), Social work with the dying patient and the family (38 - 48). New York: University Press.

Basoglu, M. (1993). Behavioural and cognitive approach in the treatment of torture-related psychological problems. In M. Basoglu (Ed.), Torture and its treatment - Current treatment approaches (pp 402 - 429). London: Cambridge University Press.

Black, J. A. & Champion, D. J. (1976). Methods and issues in social research. New York: John Wiley & Sons.

Breakwell, G.M., (1995). Interviewing. In G.M. Breakwell, S. Hammond, & C. Fife-Schaw (Eds.), Research methods in psychology (pp. 230 - 242). London: Sage Publications

Brenner, M., Brown, J. & Canter, D. (1985). The research interview - uses and approaches. London: Academic Press.

Brink, J. & Pike, R. (1992). Transplantation in developing countries. South African Medical Journal, 82, 149 - 150

Callender, C.O. (1987). Organ donation in the Black population: Where do we go from here. Transplantation, 19, pp 36 - 40.

- Cohen, A. R. (1996). Surgical disorders of the fourth ventricle. Cambridge: Blackwell Science.
- Cooper, D. K. C., De Villiers, J. C., Smith, L. S., Crombie, Y., Boyd, S. T., Jacobson, J. E. & Barnard, C. N. (1982). South African Medical Journal, 62, pp 933 - 938
- Crabtree, B. F. & Miller, W. L. (1992). Doing qualitative research. London: Sage Publications
- Devney, P. & Davidson, M. N. (1991). Attitudinal Barriers to Organ Donation Among Black Americans. Transplantation Proceedings, 23, No. 5, 2531 - 2532.
- Dominiguez, J. M., Gonzalez, Z. A., Otero, L. A., Torres, A. & Santiago-Delpin, E. A. (1991). Knowledge and attitude about organ donation in a Hispanic population. Transplantation Proceedings, 23, No. 2, 1804 - 1806.
- Fernandez, M., Zayas, E., Gonzalez, Z. A., Otero, L. A. & Santiago-Delpin, E. A. (1991). Factors in meager organ donation pattern of Hispanic Population. Transplantation Proceedings, 23, No. 2, 1799 - 1801.
- Godelier, M. (1982). The making of great men: Male dominance and power among the New Guinea Baruya. New York: Cambridge University Press
- Hall, L. E., Callender, C.O., Yeager, C. L., Barber, J. B., Dunston, G. M. & Pinn-Wiggins, V. W. (1991). Transplantation Proceedings, 23, No. 5, 2500 - 2504.
- Hellman, C. G. (1994). Culture, health and illness (3<sup>rd</sup> ed.). Oxford: Butterworth - Heinemann
- Klein, J. (1994). Our need for others and its roots in infancy. New York: Routledge.

King, N. (1994). The qualitative research interview. In C. Cassell & G. Symon (Eds.), Qualitative methods in organizational research (p. 14 - 36). London: Sage Publications.

Kobryn, A. & Kowalczyk, J. (1993). Attitudes to organ donation. South African Medical Journal, 83, 148.

Levey, W.A. & Kofke, H.J. (1986). Postoperative critical care procedures of the Massachusetts General Hospital. Boston: Little Brown.

Lim, S. M. L., Soh, P., Woo, K. T. & Rauff, A. (1990). Organ donation in Singapore. Transplant Proceedings, 22, No. 5, 2179 - 2180.

Lowy, F. & Martin, D. (1992). Ethical considerations in transplantation. In J. Craven & M. G. Rodin (Eds.), Aspects of organ transplantation. (p. 109 - 120). London: Oxford Medical Publications.

Modiba, M. C. M., Koto, Z., Kowalczyk, J., Kobryn, A. & Schoeman, H. S. (1993). Effect of donor race on graft survival in Black South African recipients of cadaveric renal allografts. Transplant Proceedings, 25, No. 4, 2454 - 2455.

Ndlovu, P. P. (1997). Subjective frameworks of meaning of kidney transplantation among African recipients. Unpublished master's thesis, University of Cape Town, Cape Town.

Newell, R. (1993). Questionnaires. In N. Gilbert (Ed.), Researching social life (94 - 114). London: Sage Publications.

Pike, R. E., Odell, J. A. & Kahn, D. (1993). Public attitudes to organ donation in South Africa. South African Medical Journal, 83, 91 - 94.

Pike, R. E., Kahn, D. & Jacobson, J. E. (1991). Demographic factors influencing consent for cadaver organ donation. South African Medical Journal, 79, 264 - 267.

Pillay, P., Van Thiel, D. H., Gavaler, J. S., & Starzl, T. E. (1990). Effect of race on organ donation and recipient survival in liver transplantation. Digestive Diseases and Sciences, 35, No. 11, 1391 - 1396.

Ramphela, M. (1995). Mamphela Ramphela: A life. Cape Town: David Phillips.

Raum, O. F. (1972). Transition and change in rural community. East London: Fort Hare University Press.

Read, M. (1966). Culture, health, and disease - social and cultural influences on health programmes in developing countries. London: Tavistock Publications.

Rodin, G. & Abbey, S. (1992). Kidney transplantation. In J. Craven & M. G. Rodin (Eds.), Psychiatric aspects of organ transplantation (145 - 163). London: Oxford Medical Publications.

Stuart, F. P., Veith, F. J. & Cranford, R. E. (1981). Brain death laws and patterns of consent to remove organs for transplantation from cadavers in the United States and 28 other countries. Transplantation, 31, 4, 238 - 244.

Taylor, S. & Hart, C. (1989). Organ donation in Blacks and minorities in Houston: Strategies for educating potential donor families. Transplantation Proceedings, 21, No. 6, 3973 - 3974.

Townsend, M. E., Rovelli, M. A. & Schweizer, R. T. (1990). Transplantation Proceedings, 22, No. 2, 324 - 325.

Youngner, S. J. (1992). In J. Craven & M. G. Rodin (Eds.), Psychiatric aspects of organ transplantation (121 - 130). London: Oxford Medical Publications.

# CLINICAL APPROACH TO CADAVER ORGAN DONORS

## CERTIFICATION OF BRAIN DEATH

The diagnosis of brain death is a clinical diagnosis (an EEG is not required). Certification is done by 2 registered doctors who are independent of the transplant team; one of whom must have been registered for  $\geq 5$  years.

1. The cause of death must be specifiable and irreversible
2. The effects of CNS depressing drugs and muscle relaxants must be excluded
3. The rectal temperature must be  $>35^{\circ}\text{C}$
4. All the brain stem reflexes must be absent
  - Pupils fixed and usually dilated
  - Absent corneal reflex
  - No gag reflex or response to tracheal suctioning
  - Absent vestibulo-ocular reflex (cold caloric test)
 

Check that tympanic membranes are intact  
Inject 30ml ice cold water into each ear  
There should be no eye movement of any kind
  - Absent oculo-cephalic reflex (doll's eye movement)
  - No motor response within the cranial nerve distribution to stimulation of any somatic area eg grimacing
  - **NB** Spinal and tendon reflexes may be present
5. There must be no spontaneous respiration
  - Preoxygenate with 100%  $\text{O}_2$  for 10 minutes
  - Ensure that the  $\text{pCO}_2$  is more than 5.3kPa (40mmHg)
  - Disconnect ventilator
  - Administer  $\text{O}_2$  at 6l/min via ET Tube
  - Observe for any spontaneous respiration for 10 minutes
  - **NB** If bradycardia or arrhythmias occur reconnect ventilator and use other means to determine brain death

## MANAGEMENT OF THE DONOR

1. Maintain adequate ventilation
2. Maintain systolic blood pressure over 100mmHg
  - Good IV line (preferably central line)
  - May need large volumes of fluid (usually crystalloid)
  - Inotrope if adequately hydrated
3. Maintain urinary output over 100ml/hr
  - Urinary catheter
  - Fluids
  - Low dose dopamine if necessary ( $<5\mu\text{g}/\text{kg}/\text{min}$ )
  - Vasopressin if necessary for severe diabetes insipidus (20iu vasopressin/200ml saline and titrate to output)
4. Maintain electrolyte balance
5. Maintain body temperature over  $35^{\circ}\text{C}$
6. Contact next of kin who will be required by the transplant team for consent
7. CONTACT YOUR NEAREST TRANSPLANT CENTRE

## NATIONAL CONTACT NUMBERS FOR DONOR REFERRAL

### BLOEMFONTEIN

Universitas Hospital - Renal Unit (051) 405-3911 ext 3510

### CAPE TOWN

Groote Schuur Hospital - Transplant Co-ordinator (24hrs)

**Bleep:** (021) 404-3333 code 1684  
(021) 404-3316

Tygerberg Hospital - Transplant Co-ordinator (24hrs)

**Bleep:** (021) 938-4911 code 573  
(021) 938-6035

City Park Hospital - Transplant Co-ordinator (24hrs)

**Bleep:** (021) 480-6111 code 1251  
**Cell ph:** 0824558024

### DURBAN

Addington Hospital - Transplant Co-ordinator (24hrs)

**Bleep:** (031) 207-2000 code A424/A425  
(031) 32111 ext 395/380/425  
(031) 32-5757

St Augustine's Hospital - Transplant Co-ordinator (24hrs)

**Bleep:** (031) 301-3737 code 441  
(031) 21-1221 ext 2133

### JOHANNESBURG

Johannesburg Hospital - Transplant Co-ordinator (24hrs)

**Bleep:** (011) 488-4911/ LR1415/LR1316  
(011) 488-3562/488-3573

Clinic Holdings Johannesburg - Transplant Co-ordinator (24hrs)

**Bleep:** (011) 650-5050 code 33931/48441  
(011) 489-1272

Baragwanath Hospital - Renal Unit (011) 933-1100

### PRETORIA

HF Verwoerd - Renal Unit

(012) 354-1000

Clinic Holdings Pretoria - Transplant Co-ordinator (24hrs)

**Bleep:** (012) 333-6000 code 6260  
(012) 343-2360

### EYE BANK FOUNDATION OF SOUTH AFRICA

**Office hours:** (021) 47-5151

**After hours:** (021) 23-3333 code 477

### WHOLE BODY DONATION

UCT Medical School - Anatomy Dept - (021) 406-6911

Tygerberg Hospital - Medical School - (021) 938-9311/9397

Wits Medical School - Anatomy Dept - (011) 647-2309/2209

University of Pretoria - Tissue Bank - (012) 354-1000 ext 6297

## SELECTED REFERENCES

1. Cooper DKC, de Villiers JC, Smith LS et al. Medical, legal and administrative aspects of cadaveric organ donation in the RSA. *S Afr Med J* Vol 62 p 934-938, 11 Dec 1982
2. Pallis C. Diagnosis of brain stem death. *Br Med J* Vol 285 p1641-1644, 4 December 1982
3. Black PM. Brain Death. *New Eng Journ Med* Vol 299, No 7 p338-334, 17 Aug 1978



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**Appendix B**  
**Interview guides**

**BIOGRAPHICAL DETAILS**

Number of respondent:.....(e.g. 1A or 1B)

Initials of responded: .....

Initials of deceased:.....

Gender of responded: .....

Age of deceased: .....

Date of interview: .....

Place of interview: 1 at home 2 at the institution 3 elsewhere,  
(namely) .....

**BIOGRAPHICAL DETAILS**

Number of respondent:.....(e.g. 1A or 1B)

Initials of responded: .....

Initials of deceased:.....

Gender of responded: .....

Age of deceased: .....

Date of interview: .....

Place of interview: 1 at home 2 at the institution 3 elsewhere,  
(namely) .....

## GENERAL QUESTIONS

1. How are you related to .....
2. What is your civil (marital) status?
3. What education did you have?
4. Do you have a job?
5. Approximately what is your monthly income?
6. Are you a member of a religious group? If yes, which one?
7. How much does religiosity mean in your life?
8. For how long was ..... ill before (s)he died?
9. Was his/her death expected?
10. How did you experience ..... 's death?
11. Have you ever discussed organ donation with the deceased before? (Check if the deceased was donor card carrier).
12. A: Did you see ..... 's body before the removal operation?
13. Did you see ..... 's body before burial after the removal operation?
14. B: Will you explain what you experienced at each of these moments?  
Moment A:  
Moment B:

It is also not uncommon to say some last thing to the deceased after death, or would like to say something or to do something or would like to e.g. take final note of the deceased.

15. At that moment did you say/do /think something, and if so, what? Explore the response.

In 19\_\_ your \_\_\_\_\_ died and you were asked by the hospital staff to donate \_\_\_\_\_.  
I would like to ask you a few questions about that if you do not mind.

### **DONATION WAS REQUESTED AND CONSENT WAS REFUSED**

#### **THE PERIOD AFTER DEATH**

1. Before this death, did you ever consider organ donation before the question was put to you?

If yes, explain.

#### **THE WAY IN WHICH THE REQUEST WAS MADE TO YOU**

2. Who first approached you with the request to donate an organ?

3. Was the person male or female?

4. Before the request did you have any contact with the person who made the request?

5. What language were you addressed in?

6. Would you have preferred a different language?

7. Can you remember what was said to you? Please say what you can remember.

8. Please indicate how you experienced the manner of the person who came to you with the request.

9. What was your first reaction to the request?

10. Who was with you at the time? Did you talk about it? With whom?

11. Did you have enough privacy to consult and to think about the donation at your leisure?

12. To which extent did you feel pressurized by the request?

13. How clear was it to you that the doctor had no more lifesaving help to offer your family member?

14. How many of those present were involved in the decision of whether to donate or not?

15. How long did it take you to reach a decision?

16. How much time would you have liked in which to make the decision? ... Hours/ Minutes

17. (If you did not make the decision on your own) Was there a difference of opinion amongst those involved in the decision of whether to donate or not?

18. (If not covered prior to this) Did the religious beliefs play part in the making of the decision?
19. During the whole procedure, did you have the need for an intermediary between you and the medical staff (e.g. someone helping you to decide according to what you personally believed in and not according to what you thought the doctors wanted).
20. Was there someone like that available
21. Were you encouraged to ask questions?
22. How satisfied were you with the clarity of the information given?
23. Do you have any suggestions as to how to improve the posing of the request?
24. Do you have more suggestions on how to improve the guidance of the next of kin by the hospital?

#### DELIBERATIONS ON WHETHER TO ALLOW OR NOT TO ALLOW DONATION OF ORGANS

25. What were the reasons for refusal? (shortly note the arguments: keywords)
26. What did the doctors or nurses do when you refused?
27. Would you have changed your mind if the burial costs were paid?
28. Would you have changed your mind if, by donating you stood a better chance of receiving an organ yourself, if you could ever need one?
29. Would you have decided differently if a clear wish was left by the deceased?
30. Would you have decided differently if you knew who the recipient was going to be?

#### AFTER DEATH AND THE EVENTUAL DONOR PROCEDURE

31. In the period after death was there consistently a person to whom you could take questions about donation?
32. Afterwards, was there any disagreement amongst the next of kin about the decision that was made?
33. Would you consider donating a relative's cadaveric organ in future?
34. Would you consider donating your own tissues or organs after your death?

## DONATION WAS CONSENTED TO

In 199\_ your \_\_\_\_\_ died, and you were asked by the hospital staff to donate \_\_\_\_\_ . I would like to ask you some questions about that if you do not mind.

1. Before this death, did you ever consider organ donation?

### THE WAY IN WHICH THE REQUEST WAS MADE TO YOU

1. Who first approached you with the request to donate an organ?

2. Was the person male or female?

3. Before the request did you have any contact with the person who made the request?

4. What language were you addressed in?

5. Would you have preferred a different language?

6. Can you remember what was said to you? Please say what you can remember.

7. Please indicate how you experienced the manner of the person who came to you with the request.

8. What was your first reaction to the request?

9. Who was with you at the time? Did you talk about it? With whom?

10. Did you have enough privacy to consult and to think about the donation at your leisure?

11. To which extent did you feel pressurized by the request?

12. How clear was it to you that the doctor had no more lifesaving help to offer your family member?

13. Was the request for donation asked during the same conversation as the information of the death?

14. If in two conversations, how much time expired between the two conversations?

15. How much time would you have liked between these two conversations?

16. How many family members/friends, etc. were present at the time of request?

17. How many of those present were involved in the decision of whether to donate or not?

18. How long did it take you to make the decision?

19. How much time would you have liked in which to make the decision? ... Hours/ Minutes

20. (If you did not make the decision on your own) Was there a difference of opinion amongst those involved in the decision on whether to donate or not?

21. (If not covered prior to this) Did the religious beliefs play part in the making of the decision?

22. During the whole procedure, did you have the need for an intermediary between you and the medical staff (e.g. someone to help you decide according to what you personally believe in, and not according to what you thought the doctors wanted).

23. Was there someone like that available?

24. Were you encouraged to ask questions?

25. How satisfied were you with the clarity of the information given?

26. Do you have any suggestions as to how to improve the posing of the request?

27. Do you have more suggestions on how to improve the guidance of the next of kin by the hospital?

28. For which organs was permission requested for?

29. Were there organs that you categorically and specifically did not want donated?

30. Were more organs taken out than permission was granted?

31. How satisfied or dissatisfied were you about your reception at the hospital?

32. Do you have any more suggestions on how to improve the reception?

#### EXPERIENCE AFTER PERMISSION WAS GRANTED FOR TRANSPLANTATION

33. How satisfied or dissatisfied are you with the relationship with the transplant coordinator?

34. During the operation did you leave the hospital or did you wait there?

35. If you waited, to which extent did you feel that you were in the way or unnecessarily present during the operation?

36. Did you see the deceased after death and before the removal of the organs?

37. (Whether or not the deceased was seen after death and before the removal of the organ(s))  
What meaning do you attach to this?

38. Was there opportunity to visit the deceased at the hospital after the organ-removal operation?

39. How important was this to you?

40. After the removal operation were there moments during which you wanted to see .....for which there was no opportunity? If affirmative, ask the responded to elaborate.

41. Did the appearance of the deceased change after the removal operation? Were you told it would happen? How did you react?

42. Were there ever moments when you thought that the amount of care was less for the deceased because (s)he was a prospective donor?

#### AFTER THE DEATH AND THE EVENTUAL DONOR PROCEDURE

43. To which extent did you feel the need for contact with the hospital?

#### SUGGESTIONS AS TO HOW THE NEXT OF KIN SHOULD BE TREATED DURING THE PERIOD AROUND THE ORGAN REQUEST AND DONATION

44. In the period after the death, was there consistently a person whom you could take your questions about donation to, and who assisted you during the donor procedure?

45. If not, how would you have experienced it, had there been a person to whom you could always take your questions about donation, and who assisted you during the donor procedure?

46. Would you like to donate your tissues or organs for transplantation after your death?

#### THE PERIOD AFTER DEATH AND EVENTUAL CONTACT WITH THE COORDINATOR

46. Afterwards, was there any disagreement amongst the next of kin about the decision that was made?

47. What further contact did you have with the transplant coordinator?

48. How satisfied or dissatisfied are you with the contact or lack of it with the transplant coordinator?

49. Have you received any information from the hospital staff concerning the recipients of the organ?

50. Would you like to know who the recipients are?

51. Would you like some contact with the recipients?

52. Do you feel that in a certain way the deceased lives forth through the donated organs?/What personal meaning does the donation have for you?

53. Would you donate organs again if you ever faced the choice?

54. Do you believe that you are entitled to partial compensation for the costs of the burial?

55. Would you have accepted a financial compensation for the donation?

### General details

1. Uzalana njani no.....?
2. Ingaba utshatile na?
3. Ufunde kangakanani?
4. Unawo umsebenzi?
5. Urhola malini ngenyanga?
6. Ingaba ulilungu lenkonzo? Ukuba ewe, yeyiphi?
7. Kuthetha ntoni ukukholwa ebomini bakho?
8. Ugule kangakanani u.....phambi kokuba asweleke?
9. Ukufa kwakhe kwakulindelekile?
10. Ukusweleka kuka.....ukuve njani?
11. Wawukhe wathetha ngokunikezela ngelungu lomzimba nomfi ngaphambili?  
(Khangela ukuba umfi wayengenalo ikhadi lokunikezela ngelungu lomzimba)
12. A: Wawusibonile isidumbu sika.....phambi kokuba asuswe ilungu?
13. Wawusibonile isidumbu sika.....phambi kokuba singcwatywe emva kokususwa ilungu?
14. B: Ungakuchaza owawukuvile kula maxesha?

Ixesha A:

Ixesha B:

Kuqhelekile ukutsho into yokugqibela kumfi emva kokufa, okanye kukho nto ongathanda ukuyitsho, okanye wenze into, okanye ungathanda uku umz. uthathe inowuti yokugqibela yomfi.

15. Ngelo xesha wathetha/ wenza/ wacinga into, ukuba kunjalo, yintoni?

## CONSENT WAS REFUSED

Ngo 199\_ i.....yakho yasweleka, yaye wacelwa ngamalungu esibhedlele ukuba unikezela.....Ndiza kuthanda ukubuza imibuzo ngoko ukuba awukhathazeki.

1. Phambi koku kufa , wakhe wacinga ngokunikezela ngelungu?

## INDLELA ISICELO ESENGIWA NGAYO KUWE

2. Ngubani owokuqala ukuza kuwe ezekucela unikezele ngelungu?

3. Ingaba wayeyindoda okanye umfazi?

4. Phambi kwesicelo ubunalo unxibelelwano nalo mntu weza kucela?

5. Loluphi ulwimi owacelwa ngalo?

6. Wawunokukhetha olunye ulwimi olwahlukileyo?

7. Ungakukhumbula okwathethwa kuwe? Nceda utsho oko usakukhumbulayo?

8. Nceda ubonise ukuba wayiva njani indlela lo mntu weza kucela ngayo?

9. Yaba yintoni intshukumo yakho yokuqala kwisicelo eso?

10. Wawunabani ngelo xesha? Wathetha ngayo? Nabani?

11. Ingaba unalo ngokwaneleyo ithuba lokuba wedwa ucinge ngokunikezela ilungu?

12. Isicelo sasinoxinzelelo olungakanani?

13. Yayicace kangakanani into yokuba ugqirha wayengenancedo ewaye nokulinika ilungu lefemeli yakho?

14. Kwabo babekho bangaphi abathatha isigqibo sokuba unikezele ngelungu?

15. Ikuthathe ixesha elingakanani ufikelela esigqibeni?

16. Ubunokuthanda ixesha elingakanani ukwenza isigqibo (Iyure /imizuzu)

17. (Uba akuthathanga isigqibo uwedwa) Kwakukho ukungaboni ngasonye kwabo babechaphazeleka ekuthatheni isigqibo?

18. (Uba ayikachazwa phambi koku) Ingaba inkolo inendima eyidlalileyo ekwenzeni isigqibo?

19. Ngexesha lalonkqubo, kwakukhona imfuneko yomnye umntu wesithathu phakathi kwakho nogqirha? (umz. umntu onokunceda ekwenzeni isigqibo kwinto okholelwa kuyo).

20. Ukhona umntu onjalo owayekho?

21. Waukhuthazwa ukuba ubuze imibuzo?

22. Wawoneliseke kangakanani kukucaca kwenkcazelo owayinikwayo?

23. Unayo ingcebiso malunga nokuphuculwa indlela isicelo esenziwa ngayo?

24. Unayo ingcebiso malunga nokuphuculwa ukuphathwa kwezizalwana sisibhedlele?

### INGXOXO MALUNGA NOKUVUMA OKANYE UKUNGAVUMI UKUNIKELA NGELUNGU

25. Yayizeziphi izizathu ezakubangela ukuba wale?  
(Shortly note the arguments: keywords)

26. Oogqira okanye abongikazi benza ntoni wawala?

27. Ubunokutshintsha ingqondo ukuba ngaba iindleko zomngcwabo zazizakubhatalwa?

28. Ubunokutshintsha ingqondo ukuba ngaba ngokunikela ubuzibeka ethubeni elihle lokufumana ilungu wena ngokunokwakho, uba belikhona ubunokulifuna?

29. Ubunokwenza isigqibo esahlukileyo ukuba u..... wayeshiye umnqweno ocacileyo ololohlobo?

30. Ubunokwenza isigqibo esahlukileyo ukuba ubumazi umntu ozakulifumana ilungu wawuzakunikela ngalo?

### EMVA KOKUSWELEKA KUDE KUBESEKUPHELENI KWENKQUBO YONIKEZELO

31. Ngexesha emva kokusweleka kwakukho umntu wawunokubuzwa kuye imibuzo malunga nonikezelo?

32. Emveni koko, kwabakho ungavumelani phakathi kwezizalwane ngesigqibo esenziwayo?

33. Ubunokucinga ngokunikezela ngelungu lesizalwane esiswelekileyo ngexesha elizayo?

34. Ubunokucinga ngokunikezela ngelungu lakho emveni kokusweleka kwakho?

## **DONATION WAS CONSENTED TO**

Ngo 199- u.....wakho wasweleka, yaye wacelwa ngamalungu esibhedlele ukuba unikezele nge..... Ndizakuthanda ukubuza imibuzo ngoko ukuba awukhathazeki.

1. Phambi kokufa, wawukhe wacinga ngokuphisa ngelungu phambi kokuba ubuzwe oko?

## **INDLELA ISICELO ESENGIWA NGAYO.**

2. Ngubani owokuqala ukuza kucela ukuba uphise ngelungu?

3. Lo mntu wayeyindoda okanye umfazi?

4. Phambi kwesicelo ubunalo unxibelelwano nalo mntu weza kucela?

5. Loluphi ulwimi owacelwa ngalo?

6. Wawunokukhetha olunye ulwimi olwahlukileyo?

7. Ungakukhumbula okwathethwa kuwe? Nceda utsho oko usakukhumbulayo.

8. Nceda ubonise ukuba wayiva njani indlela lo mntu weza kucela ngayo.

9. Yaba yintoni intsukumo yakho yokuqala kwesi sicelo?

10. Wawunabani ngelo xesha? Nathetha ngayo? Nabani?

11. Ingaba unalo ngokwaneleyo ithuba lokuba wedwa ucinge ngokunikezela ngelungu?

12. Isicelo sasinoxinzelelo olungakanani?

13. Yayicace kangakanani kuwe into yokuba ugqirha wayengenancedo e waye nokunika ilungu lefemeli yakho?

14. Ingaba isicelo sonikezelo sabuzwa ngexesha lencazelo ngokufa?

15. Ukuba kukwezoncoko (conversations) zombini, kwaphela ixesha elingakanani phakathi kwazo?

16. Lixesha elingakanani ubunokulithanda phakathi kwezi ncoko zimbini?

17. Bangaphi abahlobo / izizalwana ezazikho ngexesha lesicelo?

18. Bangaphi ababekhona abachaphazeleka esigqibeni sokuba unikezele okanye hayi?

19. Kukuthathe ixesha elingakanani ukufikelela esigqibeni?

20. Leliphi ixesha ubunokulithanda ekwenzeni izigqibo?.....Iiyure / Imizuzu?
21. (Ukuba akuthathanga isigqibo uwedwa) Ingaba kwakukho umahluko ngezimvo kwabo babechaphazeleka kwisigqibo sokuba unikezele ngelungu okanye hayi?
22. Ingaba inkolo inendima eyayidlalayo ekwenzeni izigqibo?
23. Ngexesha lale nkqubo, kwakukhona imfuneko yomnye umntu wesithathu phakathi kwakho nogqirha(umz. umntu onokunceda ekwenzeni isigqibo kwinto okholelwa kuyo).
24. Ukhona umntu onjalo owaye ekho?
25. Wawukhuthazwa ukuba ubuze imibuzo?
26. Wawoneliseke kangakanani kukucaca kwenkcazelo eyaye inikezelwe?
27. Ingaba unangcebiso yokuphucula indlela isicelo esabekwa ngayo?
28. Zikhona ezinye iingcebiso onazo ngokuphucula inkokhelo/ukuphathwa kwezizalwana esibhedlele?
29. Ngawaphi amalungu ekwavunyelwana kuwo?
30. Kwakukho amalungu owawungafuni ukunikezela ngawo?
31. Akhona amanye amalungu athathwayo ngaphandle kwemvume yakho?
32. Wawoneliseke kangakanani yindlela owamkelwa ngayo esibhedlele?
33. Unangcebiso unayo ngokuphucula indlela ekwamkelwa ngayo (reception) esibhedlele?
34. Wawoneliseke kangakanani lunxibelelwano (relationship) lwakho nomntu ophethe lo mcimbi wokunikezela ngelungu?
35. Ngexesha loqhaqho, wasishiya esibhedlele okanye walinda khona apho?
36. Ukuba walinda, uziva kangakanani ukuba ubukho bakho ngexesha loqhaqho lwalungabalulekanga?
37. Umfi wambona emva kokufa naphambi kokususwa kwelungu?
38. (Nokuba zange abonwe umfi emva kokufa naphambi kokususwa kwelungu) Ungathini ngoku (What meaning can you make out of this)?
39. Lalikhona ithuba lokutyelela umfi esibhedlele emva kokususwa kwelungu?
40. Kwakubaluleke kangakanani kuwe oko?

41. Emveni koqhaqho akhona amathuba apho wawufuna ukubona..... yaye kungekho thuba? *Ukuba kunjalo cela umphenduli acacise.*
42. Ubume (*appearance*) bomfi batshintsha kwimo yabo emva koqhaqho? Wawuxelelwe ukuba oko kuzakwenzeka? Yaba yintoni intshukumo yakho?
43. Akhona amathuba apho wawucinga ukuba inkathalo ewaye eyifumana umfi yayincinci kuba wayeza kuba ngumnikezeli?
44. Uziva kuyimfuneko kangakanani ukunxibelelana nesibhedlele?
45. Ngexesha emva kokufa, ukhona umntu owaye unokumbuza ngonikezelo, nowakuncedayo ngexesha lonikezelo?
46. Ukuba hayi, nge waziva njani ukuba ebekhona, ukhona umntu owaye unokumbuza ngonikezelo, nowakuncedayo ngexesha lonikezelo?
47. Emva koko, kukhona ukungavumelani nezizalwane malunga nesigqibo esenziwayo?
48. Loluphi olunye unxibelelwano onalo nomenzi tyando/umphathi womcimbi wonikelo?
49. Waneliseke kangakanani lunxulumano okanye ukungabikho kwalo nomenzi tyando/..?
50. Ukhe wafumana inkcazelo esibhedlele malunga nomntu owafumana ilungu elo?
51. Ungathanda ukumazi?
52. Ungathanda ukunxibelelana naye?
53. Ucinga ukuba ngenye indlela umfi uhleli ubomi (lives forth) nelungu elinikezelweyo?/ Luthetha ntoni unikezelo kuwe?
54. Ubunokunikezela ngelungu kwakhona ?
55. Ucinga ukuba kufuneka kubekho imbuyekezo malunga neendleko zomngwabo?

## Appendix C

13 October 1997

Dear

**Re: Research on Black family cadaveric organ donation**

I am Kgamadi Kometsi, an assistant lecturer and an intern clinical psychologist at the University of Cape Town, Department of Psychology.

I am conducting a research on what has facilitated consent or refusal on Black families to donate the organs of their loved ones who have passed away in the last three years. It is for this reason that I am requesting that you be part of this project (i.e. part of the sample that is going to be interviewed).

All information shared and discussed in the interview will be treated with absolute confidentiality. The researcher will be the only one having access to the interview tapes and transcripts. At no point in time will the identity of those who have agreed to be part of the study be disclosed.

However, should you not wish to be part of the research, you reserve the right to decline to participate. This will in no way jeopardise your relationship with Groote Schuur Hospital generally, or the Renal Unit specifically.

Should you agree to participate in the research, a time and place agreeable to you and the researcher will be set for the interview. Times and dates will be adjusted to your convenience within the confines of the time available for the study.

Date:

Time:

Place:

Please respond to the above by writing back to me at the address stated below or phone at the numbers appearing below:

Address: D303 Forest Hill  
Main Road  
7700 Mowbray

Tel: (021) 650 3907/ 650 3437 (w)  
685 4768 (h)

Thanking you in advance  
Kgamadi Kometsi



## Child Guidance Clinic

University of Cape Town · Chapel Road  
Rosebank 7700, Cape, South Africa  
Telephone: (021) 650-3901  
Fax: (021) 689-1006  
E-mail: [cgcd@protem.uct.ac.za](mailto:cgcd@protem.uct.ac.za)

13 Eyedwarha 1997

Obekekileyo

### Uphando kwifemeli eNtsundu ngonikezelo ngelungu lomntu oswelekileyo

NdinguKgamadi Kometsi, umhlohli nesazi ngengqondo esisaqeqeshwayo kwiDyunivesithi yaseKapa, kwiSebe lweziFundo ngeNgqondo.

Ndenza uphando ngokukhokhelele ekuvumeni okanye ekungavumeni kwiifemeli eziNtsundu ekunikezeleni ngamalungu wabo babathandayo abasweleka kule minyaka mithathu igqithileyo. Kungesi sizathu ndicela ukuba ube lilungu loluphando (oko kukuthi ube yinxalenye yabo bazakudliwa iindlebe).

Yonke inkcazelo ekuxoxwe ngayo kudliwano-ndlebe iyakugcinwa iyimfihlelo enkulu. Abaphandi ngabo kuphela abanelungela lokufikelela kwiteyiphu nakumaxwebhu odliwano-ndlebe.

Kodwa ukuba unqwenela ukungathabathi nxaxheba kulodliwano ndlebe, unalo ilungelo lokwala ukuthabatha inxaxheba. Lo nto ayingekhe naphantsi kweziphii iimeko ibeke unxibelelwano lwakho nesibhedlele iGrootte Schuur okanye iRenal Unit.

Ukuba uyavuma ukuthabatha inxaxheba, ixesha nendawo enigqibe ngazo nomphandi ziya kulungiselelwa udliwano-ndlebe. Ixesha nomhla liya kwenziwa ukuba lilungelelane neemfuno zakho.

Umhla:

Ixesha:

Indawo:

Nceda phendula koku kungasentla ngokubhalela mna kule dilesi ingezantsi okanye utsalele umnxeba kwezinombolo zingezantsi:

**Idilesi: D303 Forest Hills**

**Main Road**

**7700 Mowbray**

**Ifoni: (021) 650 3907 / 650 3437 (emsebenzini)**

**685 4768 (ekhaya)**

**Enkosi**

**Kgamadi Kometsi**

Donor cards

ORGAN DONOR

Call Toll-Free 0800 22 66 11

ORGAN DONOR FOUNDATION

P.O. Box 551 - 9000 - Toronto, Ontario M8Z 1G6

Side 1

LEGAL DOCUMENT

Carry this card with you at all times

I, \_\_\_\_\_ Full name in block capitals  
 donate my kidneys/heart/liver/pancreas/corneas/skin/bones  
 to any authorized medical institution to be used for  
 transplantation after my death.

Signatures of next of kin/family members:

Name: \_\_\_\_\_ Name: \_\_\_\_\_  
 Relation: \_\_\_\_\_ Relation: \_\_\_\_\_  
 Tel: \_\_\_\_\_ Tel: \_\_\_\_\_

In the event of my death please contact one of the above persons

Signature of donor: \_\_\_\_\_ Date: \_\_\_\_\_

Side 2

The South African donor card

Donor  
Codicil

Side 1

Persoonlike besonderhede

Naam \_\_\_\_\_  
 Geboortedatum 18-05-61  
 Adres Koningstraat 38  
 Postcode + Woonplaats  
 6511 LB Nymegen  
 In geval van nood aanschryven:

Naam \_\_\_\_\_  
 Relatie zus  
 Adres v. Spet en huizestr 15  
 Postcode + Woonplaats  
 Boxmeer  
 Telefoon  
 04855 72348  
 Huisarts \_\_\_\_\_ Tel. \_\_\_\_\_

Side 2

The Netherlands donor card

ALABAMA DRIVER LICENSE

Alabama the Beautiful

EXPIRATION DATE 10-02-2000

LONDON R. HAGAN DIRECTOR OF PUBLIC SAFETY

266 SOUTH GAY STREET APT 12  
 AUBURN AL 36830

NUMBER 6206786 SEX M DATE OF BIRTH 11-01-1965

CLASS D ENORSE 09-30-1996 S.S. NUMBER 421-39-6215

HGT 5'11 WHT 160 EYES BRO HAIR BLK B-CARD RESTRICTIONS A

SIGNATURE \_\_\_\_\_ 41A 96274124

Side 1

CLASSES / TYPES

1 OPERATOR VEHICLE WITH SEATBELT  
 2 OPERATOR VEHICLE WITH SEATBELT AND AIR BAGS  
 3 OPERATOR VEHICLE WITH SEATBELT AND AIR BAGS AND  
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ENDORSEMENTS

H HAZARD  
 M MARIJUANA  
 P PASSENGER  
 T TRIPLE / DOUBLE  
 X HAZARDOUS / DANGEROUS

RESTRICTIONS

1 LEFT FOOT ACCELERATOR  
 2 MECHANICAL SIGNALS  
 3 SCHOOL BUS OR CLASS D  
 4 VESSEL DAYLIGHT ONLY  
 5 WITHIN STATE COMMENCE ONLY  
 6 LEARNER'S LICENSE  
 7 IDENTIFICATION CARD ONLY

I HEREBY MAKE AN ANATOMICAL LEFT UNDER-PLACEMENT OF THE CODE OF ALABAMA 22-10-01 TO BE EFFECTIVE UPON MY DEATH. PLEASE CHECK AND SIGN

EVERYTHING  KIDNEYS  LIVER  EYES  HEAR  LUNGS

DATE \_\_\_\_\_ DONOR \_\_\_\_\_

WITNESS \_\_\_\_\_ WITNESS \_\_\_\_\_

GIVE NOTICE OF CHANGE OF ADDRESS WITH FULL NAME AND DRIVER LICENSE NUMBER WITHIN 30 DAYS TO DRIVER LICENSE DIVISION, PO BOX 1471 MONTGOMERY AL 36102-1471

UNDER 21 AT ISSUANCE

Side 2

The American driver licence