# Black critical care nurses' perceptions of organ donation and organ transplantation

by

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**SUPERVISOR: Dr ADH Botha**

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# DECLARATION

Student number: 21261394

I, Nancy Shubane, hereby declare that

**Black critical care nurses' perceptions of organ donation and organ transplantation**

is my original work, and that it has not been submitted before for any degree or examination at any other institution. All the sources that have been used or quoted have been acknowledged by means of complete references in the text and bibliography.

..... .....

**NANCY SHUBANE** **DATE**

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# ABSTRACT

## Title: Black critical care nurses' perceptions of organ donation and organ transplantation

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The aim of this study was to explore and describe black critical care nurses' perception of organ donation and organ transplantation. Qualitative methodology was used in this descriptive, explorative and contextual study.

The population was black critical care nurses working in Gauteng Province. Participants had to have exposure in their work to situations where organ harvesting or transplantation was done. Data gathering was done using in depth interviews.

The study resulted in six themes that emerged and these reflected positive as well as negative feelings. Participants agreed that there is a lack of information regarding organ donation and transplantation. Culture is also sometimes a barrier. The black community, both potential donors and professional nurses, need more information. The main recommendation of the study is that information be made available regarding organ donation and transplantation.

**Key terms:** Organ donation; organ transplantation; nurses' experiences.

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| | |
|---|---|
| AHRQ | Agency for health care research quality |
| CHCs | Community health centres |
| ICU | Intensive care unit |
| NGO | Non-governmental organisation |
| PHC | Primary health care |
| SADTR | South African Dialysis Transplantation Registry |
| SAMJ | South African Medical Journal |
| SANC | South African Nursing Council |
| TV | Television |
| UK | United Kingdom |
| US | United States |
| USA | United States of America |

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# CHAPTER 1

## Orientation to the study

### 1.1 INTRODUCTION

End stage organ failure gives rise to significant morbidity, which cannot even benefit from hospitalisation. The greatest gift a person can give to another is often considered to be an organ (Aston-Prior 2000:92). Organ donation and transplantation is seen as a gift of life because the objective of organ donation is to give the recipient a second chance in life.

The first successful renal transplant was performed in 1954 in Boston, in the United States of America (USA), using identical twins. Since then, more than one million patients have received cadaveric grafts and organs from living donors (Aston-Prior 2000:92). In organ donation and transplantation, an organ is taken from one person and transplanted into another person with end stage organ failure. The donor may be living, dying or dead. In South Africa, 232 renal transplantations were performed in 1992 and 2 453 patients were on dialysis, awaiting renal transplantation (South African Dialysis and Transplantation Registry 1992).

### 1.2 TRANSPLANTS IN A TRANSPLANT UNIT IN GAUTENG

In order to indicate the current situation to an extent in the transplant field in Gauteng Province, South Africa, the statistics for various transplants between 2004 and 2007 are reflected in tables 1.1 to 1.6. Data was used from one transplant unit in Gauteng (the name of this unit is withheld for confidentiality purposes). The researcher then did the calculations presented in the tables.

#### 1.2.1 Liver transplants

Since the introduction of clinical liver transplantation, the list of indications has rapidly expanded and the list of contraindications diminished. The diseases for which liver

transplants are most often indicated in adults include chronic active hepatitis, primary biliary disease, sclerosing cholangitis, autoimmune hepatitis, and alcoholic liver cirrhosis. Alcoholic liver cirrhosis, a subject of considerable controversy, is now recognised as an accepted indication for liver transplant if the patient has demonstrated the ability to abstain from alcohol and is clearly committed to continued abstinence (Hawker 2002:803).

In the case of a liver transplant, a part or the whole liver is always transplanted. The liver is always obtained from a cadaver donor because South African law does not allow a living donor to donate part of a liver to save end stage liver failure. In the United States, living donors are allowed to donate part of a liver to save a child from end stage liver failure.

**Table 1.1 Liver transplants in an organ transplant unit in Gauteng, 2004-2007**

| Biographical/ Physiological aspects | Children Age 0-13 | Adolescents Age 13-18 | Adults Over 18 years |
|---|---|---|---|
| **Gender** | | | |
| Male | 3 | 0 | 28 |
| Female | 6 | 1 | 22 |
| **Ethnic group** | | | |
| White | 3 | 0 | 40 |
| Black | 4 | 1 | 5 |
| Coloured | 1 | 0 | 1 |
| Asian | 1 | 0 | 4 |
| **Blood group** | | | |
| 0 | 3 | 0 | 23 |
| A | 5 | 1 | 21 |
| B | 0 | 0 | 1 |
| AB | 1 | 0 | 5 |
| **Total** | **9** | **1** | **50** |

**Total: 60**

### 1.2.2 Simultaneous kidney/pancreas transplant

For a simultaneous kidney/pancreas transplant, organs from a cadaver donor are always used (see table 1.2). These transplants are usually done on diabetic patients.

**Table 1.2 Simultaneous kidney/pancreas transplants in an organ transplant unit in Gauteng, 2004-2007**

| Biographical/ Physiological aspects | Children Age 0-13 | Adolescents Age 13-18 | Adults Over 18 years |
|---|---|---|---|
| **Gender** | | | |
| Male | 0 | 0 | 10 |
| Female | 0 | 0 | 12 |
| **Ethnic group** | | | |
| White | 0 | 0 | 20 |
| Black | 0 | 0 | 2 |
| Coloured | 0 | 0 | 0 |
| Asian | 0 | 0 | 0 |
| **Blood group** | | | |
| 0 | 0 | 0 | 13 |
| A | 0 | 0 | 6 |
| B | 0 | 0 | 3 |
| AB | 0 | 0 | 0 |
| **Total** | **0** | **0** | **22** |

**Total: 22**

### 1.2.3 Cadaver kidney transplant

Kidney transplants use kidneys mainly from cadavers but related transplants are also done (see 1.2.4). All kidneys suitable for transplantation are removed from suitable donors. Renal diseases responsible for renal failure treated by transplantation are chronic glomerulonephritis (50%); diabetic nephropathy (30%); chronic pyelonephritis (8%); malignant nephrosclerosis (6%); polycystic kidney disease (5%), and other renal diseases (6%).

**Table 1.3 Cadaver kidney transplants in an organ transplant unit in Gauteng, 2004-2007**

| Biographical/ Physiological aspects | Children Age 0-13 | Adolescents Age 13-18 | Adults Over 18 years |
|---|---|---|---|
| **Gender** | | | |
| Male | 2 | 0 | 24 |
| Female | 0 | 1 | 19 |
| **Ethnic group** | | | |
| White | 1 | 1 | 12 |
| Black | 0 | 0 | 20 |
| Coloured | 1 | 0 | 3 |
| Asian | 0 | 0 | 8 |
| **Blood group** | | | |
| 0 | 1 | 1 | 20 |
| A | 0 | 0 | 18 |
| B | 0 | 0 | 0 |
| AB | 1 | 0 | 5 |

| | | | |
|---|---|---|---|
| **Total** | **2** | **1** | **43** |

**Total: 43**

### 1.2.4 Related living kidney transplant

These transplants are mainly from living donors who are blood relatives of the recipients. The chances of rejection are much less compared to non-related living donors or cadaver donors. The donor could be a mother, father, sibling or even a cousin.

**Table 1.4 Related living kidney transplants in an organ transplant unit in Gauteng, 2004-2007**

| Biographical/ Physiological aspects | Children Age 0-13 | Adolescents Age 13-18 | Adults Over 18 years |
|---|---|---|---|
| **Gender** | | | |
| Male | 3 | 2 | 22 |
| Female | 0 | 2 | 8 |
| **Ethnic group** | | | |
| White | 3 | 2 | 14 |
| Black | 0 | 1 | 6 |
| Coloured | 0 | 1 | 3 |
| Asian | 0 | 0 | 7 |
| **Blood group** | | | |
| 0 | 1 | 2 | 11 |
| A | 1 | 1 | 11 |
| B | 1 | 1 | 8 |
| AB | 0 | 0 | 0 |
| **Total** | **3** | **4** | **30** |

**Total: 37**

### 1.2.5 Non-related living kidney transplant

Fewer non-related living kidney transplants are done than are required. The *Human Tissue Act* (Act 65 of 1983) (South Africa (Republic) 1983) stipulates the criteria for organ donation and transplantation to protect anyone taking advantage of the community due their ignorance or lack of knowledge. Selling of organs is standard practice in some countries abroad.

**Table 1.5 Non-related living kidney transplants in an organ transplant unit in Gauteng, 2004-2007**

| Biographical/ Physiological aspects | Children Age 0-13 | Adolescents Age 13-18 | Adults Over 18 years |
|---|---|---|---|
| **Gender** | | | |
| Male | 0 | 0 | 4 |
| Female | 0 | 0 | 1 |
| **Ethnic group** | | | |
| White | 0 | 0 | 2 |
| Black | 0 | 0 | 2 |
| Coloured | 0 | 0 | 0 |
| Asian | 0 | 0 | 1 |
| **Blood group** | | | |
| 0 | 0 | 0 | 3 |
| A | 0 | 0 | 0 |
| B | 0 | 0 | 2 |
| AB | 0 | 0 | 0 |
| **Total for age group** | **0** | **0** | **5** |

**Total 5**

### 1.2.6 Combined liver-kidney transplant and other transplants

Between 2004 and 2007 only one combined liver and kidney transplant was done. The two are rarely done together even though there is a high success rate. The unit where the data in the tables above was obtained does not accommodate heart and lung transplants. Heart, lung and combined heart-lung transplants are done at another unit in Gauteng to which the researcher did not have access. Data regarding heart-lung transplants are therefore not reflected above.

In the USA, Wittig (2001:203) pointed out the growing gap between the supply of available human organs and the critical number needed for transplants. In 2000, approximately 60 500 South Africans were waiting for organ transplantation.

## 1.3 BACKGROUND TO THE STUDY AND RESEARCH PROBLEM

Although information is readily available in most hospitals about organ donation, it does not appear to reach most people because there are still misconceptions and myths about organ donation and transplantation. According to Roark (1999:23), one of the myths is that people's organs might sometimes be removed before they are actually

dead, leaving them to wake up with an organ missing and this will minimise their chances of survival. Another myth is that life-sustaining treatment may be withheld in a hurry to retrieve organs.

In a study on South Africans' attitudes to organ donation, Pike, O'Dell and Kahn (1993:91) found that both educated and non-educated Whites and Blacks not involved in the health professions did not seem to understand much about and had many misconceptions about organ donation.

Regarding the need for increasing organ donation among African-Americans and Hispanic Americans, Roark (1999:26) found that cultural differences did not play a major role as the number of African-American respondents from rural and urban areas willing to donate their organs was comparable to the Hispanic American respondents. A minority objected to donating organs on behalf of relatives in cases of death and dying, saying that the individuals themselves should have made that decision before they died. It was not up to them to decide for these people. Others' fears were based on the myth that those individuals would not see their ancestors in heaven. Racial issues were also mentioned when they were specifically asked about donating an organ of one race to another. A minority said that it should not be from one race to another; it should be given to the same race to sustain that racial group.

In the USA, non-white people who need an organ wait about twice as long as Whites because of the difficulty of finding a donor. This contributes to organ donation among African-Americans being done less frequently than amongst the general population (Wittig 2001:203). McNatt (1992:34) maintains that Black patients have a significantly increased waiting time compared to White patients due to high levels of preformed human antibodies, many people having blood types 0 and B; second transplantation, and the rare human leucocyte antigen. According to Lynch (1990:21), due to a different genetic make-up, Blacks cannot receive a great percentage of organs donated by Whites.

Black critical care nurses' perceptions of organ donation and transplantation are important because:

- If it is found that African critical care nurses have a positive attitude towards organ donation, it should be reinforced to benefit patients.
- If the opposite is true, awareness programmes should be initiated.

The problem, however, is that it is not clear what Black South African critical care nurses' perceptions of organ donation and transplantation are.

## 1.4 OBJECTIVES

The objectives of the study are to

- determine what Black South African critical care nurses' perception of organ donation and transplantation
- explore and describe the perceptions of Black South African critical care nurses regarding organ donation and transplantation
- make recommendations in order to instil or strengthen positive attitudes in critical care nurses regarding organ donation and transplantation

## 1.5 RATIONALE FOR AND SIGNIFICANCE OF THE STUDY

Organ donation is a local as well as worldwide problem. The supply of organs fails to meet the demand. The waiting period is from weeks and months to years. Most patients are solely dependant on donors from cadavers, as organs such as hearts or livers are required.

According to McCurdie, Donald and Kahn (1992:43), 30% of cardiac patients who can benefit from donors at Groote Schuur Hospital die before a suitable donor can be found. Due to a shortage of organs, Belgian citizens were provided with the authority to register their decision to donate or oppose organ donation and given the opportunity to change their mind if they wanted to withdraw (Sells 1992:2401).

In the researcher's experience when a family is bereaved they are not properly prepared for donating an organ of their family member, especially when they are

informed about it for the first time. Roark (1999:23) found that some think that life-sustaining treatment will be discontinued or withheld in order to retrieve organs.

Critical care nurses, especially those working in trauma critical care units, are often involved in suggesting the referral of organs for donation and transplantation. It is therefore important to research the perception of African critical care nurses regarding organ donation and transplantation in order to determine whether there is sufficient awareness amongst these professionals on this special issue and if the perception is mainly a positive one.

## 1.6 RESEARCH DESIGN AND METHODOLOGY

An explorative descriptive and contextual study was done, using qualitative methodology. In qualitative studies, the reality is explored from an emic perspective, understanding life from the perspective of the participants in the setting under the study. Life is examined in an uncontrolled, naturalistic setting (Morse & Field 2002:18).

Qualitative research is sometimes referred to as soft science. It tends to emphasise the dynamic, holistic and individual aspects of the human experience and attempts to capture those aspects in their entirety, within the context of those who are experiencing them (Polit & Beck 2004:724).

## 1.7 DATA COLLECTION AND ANALYSIS

Data was collected by means of in-depth interviews, using a central question. Guba's (1989) model was used to ensure trustworthiness of the study (see chapter 2).

The data was analysed by doing content analysis. Content analysis is the process of organising and integrating qualitative data according to emerging themes and concepts (Polit & Beck 2004:714). In this case, the content was the transcribed interviews (see annexure 3). Content analysis allows the researcher to analyse large volumes of unstructured data. The data was then coded (see chapter 2).

## 1.8 DEFINITIONS OF TERMS

For the purposes of this study, the following terms are used as defined below.

- **Black South African critical care nurse**

A registered nurse is a person registered as a professional nurse according to the Nursing Act (Act 33 of 2005, as amended) (South Africa (Republic) 2005).

The term "Black South African critical care nurse" in this study refers to a Black South African professional nurse who is legally authorised to practice nursing through registration with the South African Nursing Council (SANC) and who is working in a critical care unit. The specific post registration qualification of "Intensive care" is not a prerequisite in this case. In the rest of the study, Black *African* professional nurse is used interchangeably with *South African*.

- **Critical care unit**

A critical care unit is a specially staffed and equipped hospital ward dedicated to the management of patients with life-threatening illnesses, injuries or complications (Oh 2002:3).

- **Perception**

*Collins English Dictionary* (1991:1156) defines perception as "the act or effect of perceiving; insight or intuition gained by perceiving; the ability or capacity to perceive; way of perceiving; awareness or consciousness; view", and perceive as "to become aware of (something) through the senses, esp. the sight; recognise or observe; to come to comprehend; grasp".

- **Donor**

A donor is "a person who makes a donation; any person who voluntarily gives blood, skin, etc., for use in the treatment of another person" (*Collins English Dictionary* 1991:464).

- **Transplant**

*Collins English Dictionary* (1991:1636) defines transplant as "to transfer (an organ or tissue) from one part of the body to another or from one person or animal to another during a grafting or transplant operation".

## 1.9 ETHICAL CONSIDERATIONS

The researcher adhered to the ethical principles required in health care research to protect participants from harm or risk (Holloway & Wheeler 1996:39). In this study, the researcher observed the following principles (see annexure 1):

### 1.9.1 Respect for persons

According to this principle, an individual is autonomous and has the right to self-determination and respect. This means that they have the right to decide whether or not to volunteer to participate in a study without any risk of penalty or judgmental treatment. They also have the right to withdraw from a study at any time, refuse to give information or to ask for clarification about the purpose of the study (Brink 1996:39). In this study, the participants were informed of the nature, purpose and aim of the study, the expected duration of the interview, and that participation was voluntary (see annexure I).

### 1.9.2 Informed consent

Participants must voluntarily agree to participate in a research study before they are involved in the study (Brink 1996:210). Participants must be legally and psychologically competent to give consent and must be aware that they are at liberty to withdraw at any time (De Vos 2002:65). The participants read the information in the letter of informed consent and gave verbal consent (see annexure 1).

### 1.9.3 Consent

The researcher obtained permission from the Research Ethics Committee of the University of Pretoria to conduct the study (see annexure 2).

## 1.10 SCOPE AND LIMITATIONS

This study wished to investigate Black African critical care nurses' perceptions of organ donation and transplantation, but was limited to the perceptions of nurses practising in critical care units in Gauteng Province. Consequently, the findings cannot be generalised to a larger population and were valid for this context only.

## 1.11 OUTLINE OF THE STUDY

Chapter 1 is an orientation to the study.

Chapter 2 describes the research design and methodology.

Chapter 3 discusses the results from the data analysis and interpretation.

Chapter 4 concludes the study, briefly discusses its limitations, and makes recommendations for practice and further research.

## 1.12 CONCLUSION

This chapter 1 discussed the rationale for and purpose and aim of the study. Knowledge and technical advancement in the field of transplantation has increased the demand for organ donation and transplantation. However, the supply of organs does not meet the demand due to the few sources of organs, technique of organ retrieval, and socio-cultural factors.

Chapter 2 discusses the research design and methodology.

# CHAPTER 2

# Research design and method

## 2.1 INTRODUCTION

Research is a major force in nursing and the knowledge generated from research changes practice, education and health policy (Burns & Grove 2003:IX). This chapter describes the research design and methodology of the study, as well as trustworthiness and ethical consideration.

## 2.2 RESEARCH PROBLEM

The research problem of this study was that it is not clear what Black critical care nurses' perceptions are of organ donation and transplantation. To examine the problem, the researcher undertook a qualitative study.

## 2.3 OBJECTIVES OF THE STUDY

The objectives of the study were to

- explore and describe Black critical care nurses' perceptions of organ donation and transplantation
- make recommendations to instil or strengthen positive attitudes in Black critical care nurses towards organ donation and transplantation

## 2.4 RESEARCH DESIGN

A research design is a framework that "serves as a bridge between the research question and the execution or implementation of the research" (Terre Blanche & Durrheim 1999:29). Denzin and Lincoln (2002:22) point out that it is the "scientifically designed and planned nature of observations that distinguishes research from other forms of observations. A research design describes a flexible set of methods for

collecting empirical material. It situates researchers in the empirical world and connects them to specific sites, persons or groups."

In this study, the researcher adopted a qualitative approach, using a descriptive, explorative and contextual design.

### 2.4.1 Descriptive

A descriptive study is designed to gain more information about characteristics within a particular field of study. Its purpose is to provide a picture of a situation as it naturally happens (Burns & Grove 2003:201). The aim is to obtain complete and accurate information about the phenomenon. Cormack (2000:213, 217) states that descriptive research is an appropriate design for areas of nursing where little theoretical or factual knowledge exists.

Descriptive research is usually non-experimental, presents a picture of the specific details of a situation, social setting or relationship and focuses on how and why questions. Furthermore, this approach endeavours to portray as accurate as possible accounts of characteristics of particular individuals, events or groups in real-life situations.

This study aimed to describe Black critical care nurses' perceptions of organ donation and transplantation. Data was collected by means of unstructured interviews. The study was concerned with description or classification rather than explanation (see annexure 3).

Except for Bhengu's (1995) study on organ donation and transplantation within the Zulu culture, the researcher found no research or literature available on Black South African critical care nurses' perceptions of organ donation and transplantation. Consequently, this study should provide a new perspective on the topic.

The rationale for adopting a qualitative approach was to study and describe current practice. This could form a basis for further research on the topic.

### 2.4.2 Explorative

The purpose of exploratory studies is to gain insight into a situation or phenomenon. According to De Vos (2002:139), explorative research is undertaken when

- a researcher is examining a new interest
- the subject is relatively new and unstudied
- a researcher seeks to test the feasibility of undertaking a more careful study
- a researcher wants to explore the methods to be used in a more extensive study

Exploratory studies are designed to increase knowledge and insight in a field of study that was not adequately explored previously (Burns & Grove 2003:374). As this was an area that had not been researched extensively, an explorative approach was used to gain more insight into the phenomenon of Black South African critical care nurses' perceptions of organ donation and transplantation. The questions asked in the interviews would yield descriptive data (see annexure 4).

Explorative analysis refers to "examining the data in a relatively unexplored field to become familiar with the nature of data" (Burns & Grove 2003:313).

### 2.4.3 Contextual

The context is "the circumstances in which a particular event occurs" (Munhall 2001:9). Contextual research is carried out in a specific environment and the results are relevant to the specific environment only (Burns & Grove 2003:38). This study wished to describe a specific group, namely Black critical care nurses', perceptions of a specific topic, in a specific geographical area, namely the Gauteng province of South Africa, which then was the setting.

Research results are used to give a better understanding of a specific phenomenon in a particular context (Burns & Grove 2003:313). This means that the results cannot be generalised to a larger population. The individual respondents in this study differed, which contributed to the uniqueness of the research context.

## 2.5 QUALITATIVE METHODOLOGY

Qualitative research refers to a method of inquiry that deals with issues of human complexity by exploring these issues directly. It usually focuses on the inherent complexity of humans, that is the ability of humans to shape and create their own experience and the idea that truth is a composite of realities (Polit & Beck 2004:724). Qualitative research tends to focus on dynamic, holistic and individual aspects of phenomena, and attempts to capture those aspects in their entirety, within the context of those who are experiencing them. As a form of inquiry, qualitative research can be used in any social science or healthcare discipline, and has frequently been used in nursing research (Holloway & Wheeler 1996:1).

The rationale for using this methodology was that the physical, socio-cultural and psychological environment influences behaviour. However, behaviour also goes beyond what is observed (Schmidt in Krefting 1991:21).

Qualitative studies usually aim for depth rather than quantity of understanding. They also attempt to understand the categories of information that emerge from the data (Terre Blanche & Durrheim 1994:42).

Qualitative studies are based on the following world-view (Burns & Grove 2003:357):

- There is no single reality.
- Reality is based on perceptions; it is different for each person and changes over time.
- What we know has meaning only within a given situation or context.

Qualitative research focuses on understanding the whole, within a holistic framework. It explores the depth, richness and complexity inherent in the phenomenon under study (Burns & Grove 2003:357). This approach was appropriate in this study because the researcher wanted to explore the perceptions, feelings and deeper understanding of Black critical care nurses regarding organ donation and transplantation. Black critical care nurses' perceptions of organ donation and transplantation cannot easily be determined by administering questionnaires with a limited number of questions about

specific aspects included in the questionnaire only, because perception is unique for each individual.

In order to discover the respondents' perceptions, then, the researcher studied them in their natural setting, talked to them in a familiar setting, and strove to study the phenomenon in its natural context (Polit & Beck 2004:246). This kind of research is important for healthcare professionals who focus on caring, communication and interaction (Holloway & Wheeler 1996:2).

The following characteristics of qualitative research were observed in this study (Holloway & Wheeler 1996:3-8):

- Qualitative research takes the emic perspective, that is, the insider's view. In this study, Black critical care nurses could be seen as insiders as their own perceptions were being studied.
- Researchers immerse and involve themselves in the setting of the group under study. In this study, the researcher was part of the Black critical care nurses under study and was also exposed to the same incidents as the respondents.
- The data has primacy; the theoretical framework is not predetermined by the data but is rather derived from it. Literature was studied extensively after the data collection.
- The research methodology aims to provide thick description of the data collection process. The researcher aims to do it in this chapter.
- Within the research context, a close relationship exists between the researcher and the respondents, and this relationship is based on a position of equality. The researcher herself did all the interviews. In the employment situation, her position was equal or comparable to those of the respondents.

### 2.5.1 Emic perspective

In this study, rather than imposing a framework of her own that might distort the participants' ideas, the researcher chose to examine the Black critical care nurses' perceptions of organ donation and transplantation. This study was based on the premise that individuals within the research context (the insiders or the Black critical

care nurses) were best placed to describe (in their own words) their own situations, feelings and perceptions relating to the topic (Burns & Grove 2003:367).

### 2.5.2 Immersion in the setting

Immersion in this study meant that the researcher formed part of the staff working in critical care units where organ donation and transplantation are practised. Through interaction, the researcher knew possible participants from whom perceptions of the field of study could be determined. The researcher was familiar with the experiences of Black critical care nurses (Holloway & Wheeler 1996:5). The researcher actively participated in the research process by involving herself, and gathering more information as she also worked in a transplant unit and had previously worked in a trauma unit where organ harvesting was done. Being an active participant is one of the main tools of qualitative research.

### 2.5.4 Primacy of data

Assumptions were not made, but a detailed account of reality was presented verbatim. The researcher ignored her preconceived ideas (bracketing). The intention was to get data about the Black critical care nurses' perceptions from the participants themselves. No restrictions were placed on the duration of the interviews, and participants were allowed to converse until they were satisfied that they had said what they wanted to. Ideas are generated from the data gathered and those ideas can help to improve or modify existing theories (Van Heerden 2005:44).

### 2.5.5 Research relationship

Being a healthcare professional and registered nurse working in a critical care unit with certain characteristics, helped the researcher establish a close research relationship with the participants (Holloway & Wheeler 1996:8). Such a relationship was important because it enabled the researcher to fully understand the occupational context and the participants' frame of reference and gain their trust. This equipped the researcher especially for using probing questions.

The following characteristics are important in order to be a good interviewer and to establish a close research relationship with the participants (Holloway &Wheeler 2000:8):

- Good listening skills
- Non-judgmental attitude
- Friendliness
- Openness and honesty
- Flexibility

The researcher attempted to adopt these characteristics during the data-collection process.

## 2.6 RESEARCH PROCEDURE

In order to conduct qualitative research, a certain research procedure or order of events had to be followed, including defining the population, selecting participants among the Black critical care nurses, and collecting data by interviewing the participants (see annexure 4).

### 2.6.1 Population and sampling

Population refers to “individuals in the universe who possess specific characteristics. It is a term that sets boundaries in the study” (De Vos 2002:198). The population in this study was all the Black critical care nurses working in critical care units in the Gauteng Province where either organ transplant patients were nursed or organ harvesting was done.

According to De Vos (2002:198), sampling means, “taking any portion of a population or a universe as representative of that population or universe”. Sampling involves “selecting a group of people or other elements with which to conduct research” (Burns & Grove 2003:233). Non-probability, purposive sampling was used which means the sample is composed of elements that contain most characteristics, representative or typical attributes of the population (De Vos 2002:207, 334). In non-probability sampling, also called judgmental sampling, researchers select participants based on personal

judgment about which ones will be most representative or informative (Polit & Beck 2004:729). Purposive sampling in this context is based on the fact that researchers use their knowledge about the population in order to handpick the cases to be included into the sample (Polit & Beck 2004:729).

In this study, it was not so much the sample size that was important, as the typical qualities or features of the sample group. The reliability of the results depended on these qualities or features which are listed below (selection criteria). The researcher purposively selected participants who were typical of the population under study.

To be selected to participate in this study, the participants had to

- be Black critical care nurses
- be working in private hospitals in the Gauteng Province
- have at least two years' working experience in critical care units with either organ donors or recipients forming part of the population of that unit
- be willing to speak English during interviews
- be registered nurses; a postgraduate qualification in critical care nursing was not mandatory

### 2.6.2 Pilot study

A pilot study is a small study conducted prior to a larger study to determine whether the methodology, procedure and analysis are adequate (De Vos 2002:210). The researcher conducted a pilot study, using one participant who met the inclusion criteria. The participant was targeted and interviewed, using the central question (see section 2.6.3), but not included in the main study. During this interview, the researcher realised that probing questions would be necessary. These were then formulated.

### 2.6.3 Data collection

According to Burns and Grove (2003:478), data collection is the identification of subjects and the precise, systematic gathering of information (data) relevant to the research purpose or the specific objectives, questions, or hypothesis of a study. In this

study, the researcher collected data in a place identified by the participants as convenient for the interview.

The researcher used an unstructured one-to-one interview in collecting data. Guiding or probing questions were also used. Interviewing was the suitable predominant mode of data or information collection as the researcher wanted to understand the participants' perceptions (De Vos 2002:292).

Interviewing involves verbal communication between the researcher and the participant during which information is provided to the researcher (Burns & Grove 2003:284). Interviews are a form of self-report; they allow collection of data from participants where the completion of questionnaires does not allow the participants to express themselves (Burns & Grove 2003:285). The integrity of the researcher, which includes attributes such as honesty, fairness, knowledge and experience, is essential to ensure the quality and ethical soundness of the research.

In this study, the researcher asked the participants the following central question:

**What is your perception of organ donation and transplantation?**

The interviews were tape-recorded, and data collection continued until data was saturated.

The interviews were then transcribed. The researcher read and reread the verbatim transcriptions, and identified categories and themes (see annexure 3).

The researcher used the following communication skills during interviewing:

- **Attentive listening**

This means listening actively and making use of all the senses. Paying attention to both verbal and non-verbal messages and not selecting or listening to what she wished to hear.

- **Paraphrasing**

This means listening to the participants' basic message and then repeating, or restating those thoughts or feelings in similar words. It may involve merely rephrasing an answer (Kvale 1996:135).

- **Clarifying**

This is a method of making the participants' message more understandable. If a participant's response is vague, unclear or confusing, the researcher needs to be able to ask for clarification. The interviewer brings unclear material into sharper focus (Brammer, Shostram & Abrego 1993:71).

- **Open-ended guiding questions or statements**

An open-ended question refers to a question in an interview or questionnaire that does not restrict participants' answers to pre-established alternatives (Polit & Beck 2004:726). It leads or invites participants to explore and elaborate on their thoughts or feelings. It also places responsibility on the participants to explore their experiences and feelings (see annexure 3).

- **Focusing**

Focusing refers to bringing a topic or question into focus in a loosely structured interview in order to guide the participant (Polit & Beck 2004:719). Focusing can be used if a participant's response is vague or unrelated. In that case, a researcher assists the participant to focus on the research topic.

- **Use of silence**

Natural pauses are used to give participants time to think about the question. This is important because they can then formulate what they really want to answer. Rather than making the interview a cross-examination situation by continually firing questions at the participant, the researcher can apply a therapist's technique of using silence to further the interview. By allowing pauses in the conversation, the participants have ample time

to associate and reflect, and then break the silence themselves with significant information (Kvale 1996:134).

➢ **Probing**

Probing is a technique that is used in order to obtain more useful or detailed information from a respondent in an interview. It refers to the interviewer's ability to help participants to identify and explore experiences, behaviours and feelings that will help them engage more constructively in any of the steps of communication (Polit & Beck 2004:728). Questions are asked to encourage participants to elaborate on the topic discussed. Follow-up questions that pursue the implications of answers to the central question are asked. This enables researchers to elicit more useful or detailed information from participants during interviews (Polit & Beck 2004:729).

As was stated previously, data collection continued until data was saturated. Saturation of data occurs when additional sampling provides no new information, only redundancy of previous collected data (Burns & Grove 2003:258).

Important factors in achieving saturation of data are (Polit & Beck 2004:57):

- Scope of the study: if it is broad, extensive data will be needed.
- Nature of the topic: if it is clear and easily discussed by the respondent, then fewer respondents are needed.
- The quality of the data obtained from respondents: it should be of nature that it could be effectively used for analysis.
- The design of the study: in some cases studies are designed in such a way that the number of interviews should be increased to achieve the objectives.

The researcher also made use of field notes and personal notes.

*Field notes* are a written account of the things that the researcher hears, sees, experiences and thinks in the course of collecting data or reflecting on data. They provide a system of remembering observations (Morse & Field 2002:91). The researcher kept a separate journal in order to record insights, reactions, questions and impressions about emerging patterns as well as ideas about correction to previous

knowledge and decisions about further steps to be taken. This was done after each interview to form a picture of each participant's experience of the interview and to add anything relevant that came out after the tape recorder was turned off.

*Personal notes* are the researcher's own reflection and experiences during the research (Wilson 1989:435). The researcher considered what insight she had of the experience of the respondents' perception of organ donation and transplantation.

## 2.7 DATA ANALYSIS

Data analysis involves breaking the data up into manageable themes, patterns, trends and relationships. The aim of analysis is to understand the various constitutive elements of one's data through an inspection of the relationships between concepts, constructs or variables (Mouton 2001:109).

All the interviews were transcribed verbatim. The following six steps were used to analyse the data (Creswell 1998:200):

- Transcriptions were read through carefully and any ideas that came to mind were written down.
- One document was taken at a time, and careful analysis made to determine the underlying information
- A list was then made of topics that occurred. Similar topics were grouped together.
- The most descriptive wording for the topics grouped together was used as categories. Grouping related and inter-related topics together resulted in the total list of categories.
- A final decision on the naming for each category was made.
- An analysis was then performed again on the assembled data of all the transcriptions in each category to finalise themes and categories.

Finally, the categories were developed and the data organised according their properties. Categorised data was then discussed and literature control done.

## 2.8 LITERATURE CONTROL

After data analysis, the researcher undertook a literature control to compare information from the literature with the findings from the present study to determine similarities and differences. This is done to ensure that one does not merely duplicate other studies, and to discover what the most recent theories on the subject is (Mouton 2001:87). The literature review or control also provided the researcher with a background for the problem studied and was a strategy to ensure the trustworthiness of the data (Brink 1996:76).

## 2.9 TRUSTWORTHINESS

Trustworthiness, or in quantitative terminology validity and reliability, means that different language is needed to fit the qualitative view of research (Krefting 1991:215). The researcher ensured the trustworthiness of this study by using Guba's (1985) (Krefting 1991:215-222) four aspects of trustworthiness: credibility, transferability, dependability, and confirmability.

### 2.9.1 Credibility

Credibility is the alternative to internal validity, in which the goal is to demonstrate that the inquiry was conducted in such a manner as to ensure that the subject was accurately identified and described (De Vos 2002:351). Prolonged engagement is an aspect of credibility as it also implies prolonged interactions with the participants (Rossouw 2003:130). The researcher worked in the organ transplantation environment and with some of the participants in the specific study context and this made it possible for her to have time with and interact on a different level with them where their views on organ donation and organ transplantation were shared and, in doing so, enabled the researcher to reflect on this issue.

The credibility of the study was also enhanced by the fact that a literature review was conducted, and data validated by relevant literature. To further ensure credibility, bracketing was used in this study. According to Polit and Hungler (1997:215), bracketing refers to the process of identifying and holding in abeyance preconceived beliefs and opinions about the phenomenon by the researcher. The researcher did not

let her previous information influence this study and her preconceived ideas were put aside.

### 2.9.2 Transferability (also referred as applicability)

Transferability refers to the degree to which the findings can be applied to other settings or with other respondents if a degree of similarity exists (Mouton 2001:277). Each research situation is unique and cannot be generalised, but comparisons can be made. This researcher is of the opinion that some aspects relating to the respondents' perceptions of organ donation and transplantation in this study can be transferred to similar settings in South Africa. The researcher strove to achieve transferability by providing a dense description of the data and research context. Thick description is necessary to enable other researchers interested in making a transfer to reach a conclusion about whether transfer can be considered a possibility (Polit & Beck 2004:41).

### 2.9.3 Dependability (also referred as consistency)

In qualitative research, dependability is achieved by giving a complete description of the research methods and research context so that the opportunity of replicating the study can be created (Rossouw 2003:183). The key to this is to learn from the information rather than control it. The main instruments important for consistency in qualitative research are the researcher and the participants. In this study, the researcher alone collected all the data.

### 2.9.4 Confirmability (also referred as neutrality)

Confirmability refers to a freedom from bias in the whole research process. It is the degree to which the findings are the product of the inquiry and not of the researcher (Mouton 2001:278). Confirmability attempts to increase the worth of the findings by decreasing the distance between the researcher and the informants. This is usually achieved through prolonged contact with participants.

In this study, confirmability of data was achieved by conducting a literature control to evaluate the results of the data analysis. The findings were compared with relevant

literature to confirm or deny the results, thereby enhancing the trustworthiness of the study. Participants were also consulted to confirm findings or results.

Table 2.1 summarises the strategies employed to ensure trustworthiness in this study, including the specific criteria used.

**Table 2.1 Strategies to enhance trustworthiness of the study**

| Strategy | Criterion | Applicability |
|---|---|---|
| Credibility | Prolonged engagement | While working as a critical care nurse in the critical care setting, the researcher had contact with Black critical care nurses who had experienced caring for dying patients. Some of those patients were potential organ donors. The researcher also had experience in nursing patients' post-organ donation and transplant-tation.<br><br>The researcher invested sufficient time during data collection and gained an in-depth understanding of the group under study. |
| | Reflexivity | Throughout the research process, the researcher made use of field notes to describe and interpret the researcher's own conduct and experiences within the research context. The researcher used the field notes as an instrument to reflect on this study. |
| | Triangulation | Data from three sources, namely interviews, field notes, and literature, were compared.<br><br>The researcher collected and analysed data.<br><br>Information was also obtained by review to determine whether similar experiences had been documented. |
| | Member checking | Findings would be discussed with participants, if the researcher were unsure of the clarity of the data. |
| | Peer examination | The research process and findings were discussed with an academic suitably experienced in qualitative research methodology.<br><br>Consensus discussions took place between the researcher and this academic, who also acted as an independent coder.<br><br>If there are uncertainties participants in the study could be consulted to clarify data. |
| | Authority of the researcher | The researcher underwent training in research methodology. A study leader with experience in conducting qualitative research supervised the study. The researcher is knowledgeable about nursing practice involving organ donation and organ transplantation. |
| | Structural coherence | The focus was only on Black critical care nurses in Gauteng regarding their perceptions of organ donation and transplantation. Findings were relevant to the theme and context only and no attempt was made to generalise the findings. |
| | Referential adequacy | A sample copy of data collected is presented in the final document (see annexure 3). |

| Strategy | Criterion | Applicability |
|---|---|---|
| Transferability | Nominated sample<br>Dense description | Purposive sampling was used and substantiated.<br><br>A dense description of the research method and design was provided to enable comprehension of the research process. |
| Dependability | Description of research method | The same remark as in the previous section regarding dense description applied here. |
| | Code-recode procedure | Consensus discussions were held between the researcher and the co-coder (study leader). |
| Confirmability | Confirmability audit | Co-coder was involved in the data analysis and the coding process discussed. |
| | Reflexivity | Transcribed interviews were used in combination with the researcher's field notes for the data analysis. |

## 2.10 ETHICAL CONSIDERATIONS

To protect the rights of the participants, the Faculty of Health Sciences Ethics Committee at the University of Pretoria reviewed the research protocol. The researcher was given written approval to conduct the study.

The participants were informed of the nature, purpose and significance of the study, the aim of the interview, what the interview entailed, and the researcher's credentials. The researcher also assured the participants that only she would be aware of their identity. Moreover, participation was voluntary and they were free to withdraw from the study at any time should they so wish.

Researchers are ethically obliged to ensure that they are competent and adequately skilled to undertake the proposed study (De Vos 2002:32). The researcher had completed a module in methodology and was supervised by a lecturer who holds a doctorate degree.

## 2.11 CONCLUSION

This chapter discussed the research design and methodology, including data collection; data-collection instrument; data analysis; strategies to ensure trustworthiness, and ethical considerations

Chapter 3 discusses the findings and results of the study as well as the literature control.

# CHAPTER 3

# Results and literature control

## 3.1 INTRODUCTION

This chapter discusses the results of the data analysis and interpretation. The researcher conducted a literature review to support and indicate new findings in this study.

## 3.2 SAMPLE

Purposive sampling was used to select the respondents. Six registered nurses, able to communicate in English and working in specialised units, were willing to participate in the study. For the purpose of anonymity, the respondents did not have to indicate their exact number of years' experience or their age. Table 3.1 indicates the characteristics of the group.

**Table 3.1 Respondents' biographic details**

| Participant number | Gender | Relevant post-registration courses | Courses busy with | Home language | Type of unit where employed at the time of interview | Age group | Range of years of experience |
|---|---|---|---|---|---|---|---|
| 1 | Female | Diploma in critical care nursing. | Nil | Zulu | Critical care unit | 40-48 | 15-20 yrs |
| 2 | Female | Diploma in critical care nursing and B Cur I et A | M Cur in clinical ICU | English | Critical care unit | 25-30 | 5-8 yrs |
| 3 | Female | Diploma in trauma and emergency care | B Cur I et A | Zulu | Critical care unit | 35-40 | 10-15 yrs |
| 4 | Female | Diploma in critical care nursing. | Nil | Xhosa | Critical care unit Dealing with transplants | 45-50 | 15- 20 yrs |
| 5 | Female | Diploma in critical care nursing, | M Cur in clinical nursing | Xhosa | Critical care unit | 35-40 | 10-15 yrs |

| Participant number | Gender | Relevant post-registration courses | Courses busy with | Home language | Type of unit where employed at the time of interview | Age group | Range of years of experience |
|---|---|---|---|---|---|---|---|
| | | nursing administration and education. B Cur I et A | | | Dealing with transplants | | |
| 6 | Male | Diploma in general nursing and Diploma in trauma and emergency care | Nil | Tsonga | Trauma and emergency care unit | 25-30 | 5-10 yrs |

## 3.3 DATA COLLECTION

After informed consent was obtained from the respondents, arrangements were made to interview them. Unstructured interviews were conducted. The researcher asked the respondents the following central question:

**What is your perception of organ donation and transplantation?**

The researcher asked probing questions to gain more insight into issues raised. The interviews lasted about 45 minutes, and were tape-recorded and transcribed verbatim. Field notes were also taken during the interviews. Besides providing additional data, the notes also served as a guide and back up for the researcher when transcribing the data. Interviewing continued until data saturation had been reached.

## 3.4 DATA ANALYSIS

The data collected were carefully analysed and categorised into themes and categories, using content analysis. Content analysis is a qualitative analysis technique used to classify words in a text into themes and categories (Burns & Grove 2003:479). It is a systematic way of examining the content of messages or data. In this case, the content consisted of transcribed interviews.

## 3.5 RESULTS

Six themes with their categories were identified in this study (see table 3.2). The themes and categories are discussed in detail and linked to literature on similar or related issues. The themes provided a structure for detailing the various aspects of the study theme and highlighted most significant and problem areas. Table 3.2 lists the results (see section 3.6 for discussion).

**Table 3.2 Themes and categories in the respondents' perceptions of organ donation and transplantation**

| THEMES | | CATEGORIES | |
|---|---|---|---|
| 1 | Ethical and cultural issues | 1.1<br>1.2<br>1.3<br>1.4 | No respect for human feelings/dignity<br>Organ trafficking<br>Cultural shock<br>Beliefs and superstitions |
| 2 | Economic issues | 2.1<br>2.2 | Economic matters related to work<br>Cost effective |
| 3 | Information and education | 3.1<br>3.2 | Community awareness<br>Staff development |
| 4 | Experience of nurses | 4.1<br>4.2 | Positive feelings and experiences<br>Negative feelings and experiences |
| 5 | Perceptions of nurses of the experiences of patients and family members | 5.1<br>5.2 | Positive experiences<br>Negative experiences |
| 6 | Religious belief | 6.1 | Different views |

## 3.6 THEMES AND CATEGORIES

### 3.6.1 Ethical and cultural issues

*Ballière's Nurses' Dictionary* (1981:123) defines ethics as "a code of moral principles; the moral code governing a nurse's behaviour with her patients, their relatives and her colleagues".

Tjale and De Villiers (2004:217) point out "ethics is also related to and based on cultural principles. The question that should be asked is: right and good according to whom and in whose view?"

Regarding their experiences in organ donation and transplantation, the respondents referred to cultural and ethical issues. This indicated that for the respondents, cultural

and ethical issues were interwoven. The researcher therefore grouped the four related categories identified under the theme “cultural and ethical issues”.

Due to their cultural diversity and social background, most Blacks are not well informed about organ donation and transplantation. The respondents indicated that culture plays an important role in organ donation and transplantation. According to the respondents, some hear about organ donation when a family member is dying, and their hopes are raised that the patient will then be able to survive. They welcome this in a doubtful way, only to be told that the person they wish to see live can save someone else’s life. They have to let go in order to make another family happy, not theirs. According to one respondent:

> *Most of the Black community are culture orientated to such an extent that they believe if you are not related to that person, you are taking something that is not going to work because of the difference in cultural orientation. Maybe our ancestors will get angry or something terrible can happen because there are myths in our culture.*

In some cases, attitudes originate or are rooted in the culture. Pike et al (1993:93) found that public attitudes to organ donation were influenced by cultural beliefs as well as racial prejudices and superstitions in the South African context. Pike et al (1993:94) point out that although nothing prescribes that people need all their organs in order to join their ancestors, cultural beliefs are complex and cannot be overruled with scientific arguments.

#### *3.6.1.1 No respect for human feelings/dignity*

Regarding organ donation and transplantation, the respondents indicated that there was a lack of respect for human dignity in the procedure. They felt that it was not done in such a way that people still maintained their dignity. According to one respondent:

> *I was also involved in a situation where the patient had just died. And now there were all these sisters from the transplant unit, they were like falling all over the patient. For me, I felt it was inhuman. The person has to mourn for the lost child right now. Already we are coming up with a story that we need*

> *somebody to be opened up so that we can have the organs. Those are the situations that make me feel that I would rather let the patient die as he or she is.*

In a study on organ donation and transplantation within the Zulu culture, Bhengu (1995:67) found that the respondents stated that they must not be killed for their organs.

#### *3.6.1.2 Organ trafficking*

The respondents were of the opinion that organ donation could be a form of making money and not for therapeutic and other uses as stipulated in the Human Tissue Act, 65 of 1983, which governs the removal of tissue, blood or gametes from bodies of living persons. For example, in terms of the Act, tissue destined for transplantation may be removed only in a hospital or other authorised institution. According to a respondent:

> *We are being put in a situation where we have to be criminals, the people who are doing these operations and all that … Looking back there was some investigation being done where there was some organ trafficking going on. This was disclosed by the media to the public. That is when I felt rather let the patients have their own organs because what is happening is not honest. People are just making money out of the dead. I think it would be better if they leave the dead alone.*

An article published in the *Medical Chronicle* (Illegal kidney transplant: prominent surgeons and doctors 2005:1-2), supports these findings because in it, it is stated:

> *Prominent surgeons and doctors, including two professors, who participated in what the state says were illegal kidney transplant operations at Durban's St Augustine Hospital, have appeared in the Durban magistrate's court charged with fraud, assault and contravening the human tissue act.*
>
> *It is alleged that Brazilians were paid a few hundred dollars for their healthy kidneys, which were harvested at the Durban hospital and transplanted into Israeli patients who each paid the syndicate up to $120 000. In terms of the assault charges, it is alleged that the full implications were not properly explained to the donors and the operations were a serious assault on them.*

> *Contraventions of the Human Tissue Act relate to the alleged payments to the donors that took place here. Fraud charges relate to documentation, which misrepresented that the donors were relatives and that no money had exchanged hands.*

Amemiya, Suda, Khikawa and Fukuda (1992:2428) found that the majority of Hong Kong people had to go to Mainland China when organ donation and transplantation was needed. The donor sources were mainly from executed criminals. All recipients had to pay a substantial amount for a transplant, so these were basically for those who could afford it. The risk involved was not mentioned to any of the recipients. The first-year mortality was enormous; four times that of transplants done locally and there was a marked increase in morbidity related to chronic hepatitis, which was often acquired after the transplant. In Japan, the society for transplantation does not allow kidney transplants from non-related living donors, but transplantation of kidneys from spouses is sometimes allowed on condition that histo-compatibility and social problems are strictly considered (Amemiya et al 1992:2428).

#### *3.6.1.3 Cultural shock*

Culture is "the total of the inherited ideas, beliefs, values, and knowledge, which constitute the shared bases of social action; the total range of activities and ideas of a group of people with shared traditions, which are transmitted and reinforced by members of the group" (*Collins English Dictionary* 1991:387).

Bouwer, Dreyer, Herselman, Lock and Zeelie (1997:31) emphasise that culture is dynamic whatever way it is defined. It primarily provides guidelines for a way of life and is the result of the way that people have adapted to a particular environment.

In 1879, Tyler (cited in Andrews & Boyle 1995:10) wrote that culture is "the complex whole which includes knowledge, belief, art, morals, law, custom and any other capabilities acquired by man as a member of society. Culture represents a way of perceiving, behaving, and evaluating one's world." Cultural perceptions affect the way people are viewed and expected to act in various situations. A person's behaviour is determined by cultural influences as well as by personal characteristics (Andrews & Boyle 1995:9). Culture is learned not only through formal study but also through a

process of cultural osmosis in which the values, attitudes, roles and behaviours acceptable to and expected by the cultural group are absorbed.

The respondents affirmed the role of culture in people's perceptions of organ donation and transplantation. For example:

> *I believe culture plays a major role. Like in my culture, for instance, everybody would like to bury their relatives whole. They think if they take some organs then it means that the person is not whole. They always want to bury the person with everything, all the organs intact. With that kind of culture it is difficult to allow your family to donate an organ or to be an organ donor yourself. You believe that you have to go back to your maker whole like as you came to earth with all your organs intact. So I do think that culture plays a very important role.*

> *We always believe from the Xhosa background that what I have is mine and I cannot take somebody else's organ because we come from a different cultural background; for example, when a child is born, the family has to do some rituals.*

Some people think health problems are related to culture. Each culture ascribes a cause to a pathological condition and prescribes ways of diagnosing, preventing and treating mental and physical disorders. What is regarded as pathological in one society may be regarded as normal in another (Bouwer et al 1997:32).

South Africa has a pluralistic society with people of different cultures and diverse and conflicting values, beliefs and practices (Bhengu 1995: 16). These diversities are also reflected in people's attitudes towards organ donation and other health issues.

In a study among Afro-Americans and Hispanic Americans, Roark (1999:26) found that cultural differences did not play a major role when it came to organ donation. Most of the Afro-American and White respondents from rural and urban areas were willing to donate their organs. A minority of the respondents objected to donating relatives' organs when they were at the point of death or had passed away. According to these respondents, the decision to donate organs should have been made by the relatives when they were healthy. They stated that it was not up to them to decide for the dying relative. Others had a fear of donating eyes, saying that they would not be able to see

their ancestors in heaven. Furthermore, Roark asked the respondents specifically about the transplantation of an organ from another racial group. A minority stated that inter-racial donations should not be made because donations should be made to sustain a racial group (Roark 1999:26).

#### *3.5.1.4 Beliefs and superstitions*

The respondents perceived beliefs and superstitions as a contributing factor and the researcher identified it as a theme. *Collins English Dictionary* (1991:142) defines belief as "a principle, proposition, idea, etc, accepted as true; opinion, conviction; religious faith; trust or confidence, as in a person or a person's abilities, probity, etc." A superstition is an "irrational belief usually founded on ignorance or fear and characterised by obsessive reverence for omens, charms, etc.; a notion, act or ritual that derives from such belief; any irrational belief, esp. with regard to the unknown" (*Collins English Dictionary* 1991:1548). According to Bairds, Corkie and Grant (1991:3), superstitions are "non-evidenced information carried from generation to generation. A belief is a conviction of truth about the world and the life within it e.g. a person 's experience of sickness is strongly influenced by the belief held about that health problem, for instance, a health practitioner sees it as a biological phenomenon yet some patients experience sickness as a crisis of faith or a consequence of failed relationships including ancestral relationships." In indigenous health systems, "illness is more frequently believed to be caused intentionally and ascribed to supernatural (mystical) causes" (De Villiers in Bouwer et al 1997:34). According to the respondents:

> *If a person has received an organ they will think that the person is not living his/her life. He or she is living the life a person who has donated the organ. It is like they will be judging the recipient's movements; they will think that the donor is living his/her life in the recipient's body.*

> *I was involved in a situation where the patient had received an organ. He was a young man. Unfortunately, it was very traumatic because he was 30 years old and without children. He was very concerned that he is now going to live with somebody else's organ, he wanted clarification or to be counselled. Nurses did not see his concern; they felt that he did not appreciate it. I felt that we forget that people are individuals and they are unique, and that it was his right to raise it.*

The indigenous health belief systems in Southern Africa advance three main types of supernatural causes (Bouwer et al 1997:34):

- The activities of the ancestor spirits and associated supernatural beings, such as God and the river people among the Xhosa, and the *Molapo* spirits among the Pedi.
- The malevolent infliction of harm by a person perpetrating acts or witchcraft or sorcery known as *boloi* among the Sotho and *vhuloi* among the Vendas.
- The idea that illness may automatically follow an action such as the breach of a taboo.

According to Krige (1988:284), the traditional Zulus believe that man consists of:

- The body (*Umzimba*).
- The spirit or soul (*Indlozi* or *Ithongo*).
- The shadow or personality, which is hazily defined and is connected to the ancestral spirit in the Zulu mind. The shadow is that which ultimately becomes the ancestral spirit (*ithongo* or *indlozi*) when the body dies. *Amathongo* (ancestral spirits) live underground and occupy positions as they did while alive.

Although the ancestors are believed to be concerned about the interest and well-being of their descendants, if angered they may cause misfortune, of which illness is one form. Illness may also result when the duties owing to the ancestors, particularly at crucial times during the individual's life cycle, have been neglected. Some people feel the lifespan is predetermined by God therefore if the time for life to end has come, let it be rather than have an organ transplantation (Bhengu 1995:76).

Cadaver organ donation is less common among Afro-Americans for various reasons, including a lack of awareness about organ donation; mistrust of the medical community, and religious reasons. Anecdotal reports suggest that Afro-Americans do not donate organs because of cultural and religious barriers. Failure to adequately educate the Afro-American community about organ donation and a lack of sensitivity to racial issues

are among the main factors associated with poor participation in organ donation (Roark 1999:22).

From the above description it appears as if above cultural belief could play an important role. It seems as if donating an organ from the body may not threaten ancestral protection.

The availability of organs for transplantation is influenced by the attitudes of both the public at large and the medical community. Pike et al (1993:94) maintain that a shortage of organs shows a lack of knowledge and misconceptions. For example, in South Africa, some people argue that they can't donate their organs like corneas, as they need to see their ancestors in heaven when they die (Pike et al 1993:94).

In Japan, the most serious obstacle to transplantation is the lack of organ donation. The first heart transplant was performed in 1968 and a complaint of murder was lodged against the transplant surgeon who performed it, for the removal of the heart. This led to heart, lung, and liver transplantation being discontinued (Amemiya et al 1992:2427). A group of medical doctors also lodged a complaint of murder against the transplant surgeons who performed a combined pancreas-kidney transplantation using organs procured from a brain dead donor (Amemiya et al 1992:2428).

### 3.6.2 Economic issues

Economic matters involve money and are of concern to the patient awaiting organ transplantation of any kind. In this study, the respondents referred to money-related issues, and the economic advantages and benefits.

Medical consultation entails expense and poverty is one of the main problems for many Black South Africans. Although they may be treated as state patients at hospital and clinics, and therefore pay minimum fees or nothing at all, many are still faced with the high cost of transport. If they do not have money, they do not consult a practitioner or keep follow up consultations (Bouwer et al 1997:39). Proximity is important in consultation. Western medical facilities and practitioners are often removed from patients because of unequal distribution in South Africa. People in urban areas have an

advantage over rural people as regards the range of availability of facilities and access to them (Bouwer et al 1997:39).

Some of the respondents were very positive about the effect of organ transplantation, seeing it as something that saved money.

#### *3.6.2.1 Economic work advantage*

Some of the respondents maintained that patients receiving organs would benefit economically related to work or quality of life. As one respondent put it:

> *To me, organ donation is a very good thing. It is good for the recipient, to give him or her second chance in life. For those with kidney failure, haemodialysis is too expensive. When a person has received a kidney, it is going to be easy to manage his life and time. Less money will be spent on treatment. It will not be like going for dialysis three times a week. Even your life changes, you can do your own things at your own time, and are able to do a full day's job.*

Cerilli (1988:487) emphasises that the quality of life for successful transplant patients surpasses that of patients undergoing alternative therapies. Transplant patients are more likely to be working full time or still at school than are patients on alternative therapeutic regimens (Cerilli 1988:487).

A kidney transplant is considered the treatment of choice for the majority of patients suffering from end stage renal failure. The only viable treatment alternative is dialysis. However, from the patient's perspective, dialysis is time-consuming and severely affects quality of life and the way they look (Cerilli 1988:487).

#### *3.6.2.2 Cost effectiveness*

Some of the respondents had experience working in an environment where patients received dialysis. They emphasised the cost effectiveness of transplantation compared to dialysis treatment:

> *Organ transplantation is cost effective considering the fact that travelling to the hospital every alternate day is no longer necessary. This saves a lot of money and time. Time is money. Having time on your hands, you can do a lot of things, concentrate on your job or do some other business. You are able to make long-term plans about job-related issues.*

In 1988 funding for transplantation recipients who required immunosuppressive therapy after transplantation was initiated in the USA (Martinelli 1993:236). According to O'Dell, Brink, Robson and Kahn (1992:394), funding in South Africa for transplantation is not satisfactory, and the impression is that organ transplantation is an expensive procedure that can only benefit the rich and not the have-nots. The fact of the matter is that the results are comparable if not better than other forms of treatment. The surgical and intensive care costs of heart transplantation are no more expensive than those of other major cardiac procedures.

The annual cost of dialysis per patient in the UK is around three times higher than the annual cost for maintenance of a patient after kidney transplantation. Indeed since the procedure is now considered routine, the cost of the operation itself is low. Thus in economic terms, transplantation is the preferred option (Martinelli 1993:236).

### 3.6.3 Information and education

Health promotion information is distributed mostly through patient education. This also helps in community development and organisation, health advocacy and legislation. This increases the options available to people in making informed choices conducive to health. Furthermore, enhancing life skills facilitates the opportunities for people to exercise more control over their own health and their environment.

Community awareness and staff development were grouped under this theme.

### *3.6.3.1 Community awareness*

The mass media, especially newspapers, radio and television, are powerful means to raise community awareness. However, media exposure does not occur equally across all social groups. People with higher formal education pay more attention to printed media, especially magazines, the news and information programmes on TV compared to people with lower educational levels (Koelen & Van Dan Ban 2005:115). According to the respondents:

> *I think education, lots of education. I said before that we can do this education in the media posters on the wall, newspaper, television, you can educate people. Have organ donation week.*

> *I believe the church leaders reach more people than the media can do, especially in rural areas. Almost everybody belongs to the some kind of church or religion. So all religious leaders can also be educated about organ donation and transplantation and they can take these messages to their followers that can also be an important place to start from.*

> *Children at an early age kind of pick up information easily, especially when they are in school and you teach them such things. It is very important because their beliefs are being formed at that young age. If they believe from that age that organ donation and transplantation is a good thing and will help the community, they will grow up believing it.*

According to Mailula (2005:3), a study funded by the US Agency for Healthcare Research and Quality (AHRQ) found that African communities need good information about the donation process. Africans often do not have all the information they need to make decisions about organ donation process.

The South African Organ Donor Foundation, a non-profit, non-government organisation (NGO) was established in 1988. Medic Alert and the Lions Club of South Africa initially started the foundation, and the objectives of the foundation are to:

- Address the critical shortage of donors in South Africa so that the number of organ transplantations can increase.

- Create awareness of organ donation to adults and children.
- Educate the public about the importance of organ donation and create an informed society who understands the issues surrounding the subject of organ donation (Organ Donor Foundation of Southern Africa 1992:1):

Intensive care nurses, operating room nurses and emergency room nurses often approach families of potential donors, namely brain dead patients. Due to lack of knowledge and experience, potential donors are not adequately referred to transplant experts, because nurses lose objectivity and become emotionally involved with them and the bereaved family, and therefore become reluctant to raise the issue of organ donation (Maher & Strong 1989:357).

Cadaver organ donation is less common in African-Americans for several reasons, including a lack of awareness about organ donation; mistrust of the medical community; religious reasons, as well as cultural and religious barriers. Failure to adequately educate the African-American community about organ donation and a lack of sensitivity to racial issues are the primary factors associated with poor participation in organ donation (Roark 1999:22).

#### *3.6.3.2 Staff development*

Some ignorance still exists among the nursing staff. When faced with a difficult situation and not equipped with knowledge, it becomes a problem because critical care nurses do not always know what to expect in their working environment. Some of the respondents pointed out:

> *I do not think nurses have enough information. Some of the ones I spoke to said they are not interested; others said in our culture we do not do this.*

> *I think, even myself, if I have the necessary information about organ donation and transplantation I can tell the community or educate them.*

> *We need information because, even myself, when I grew up, I grew up knowing that when you die you must go to heaven being complete. If you go to heaven*

*with one eye, you will have many questions to answer to God as to where the other eye is.*

Professional nurses face increasing demands. Thorough training has always been necessary in order to provide basic services. Health is part of a multisectoral approach to developing and meeting the basic needs of all people. Nurses are expected to act as leaders in the process of change and to coordinate multidimensional teamwork. Training is therefore necessary. Nurses will continue to play a key role in the health of the community (Bouwer et al 1997:12).

### 3.6.4 The respondents' experience

In the course of working with post-transplant patients, the respondents realised that patients were benefiting from this programme. They felt that it was beneficial to the patients, especially having seen the patients before and after transplantation (see annexure 3).

Accordingly, the theme of positive feelings and experiences emerged.

#### *3.6.4.1 Positive feelings and experiences*

Most recipients express their gratitude after organ transplantation and feel that they have been given a second chance in life. They see this as a gift of life. Organ transplantation changes their life for better. According to the respondents:

*I spoke to one of the liver recipients. He told me that before they did the transplant on him, when the children asked him to go out he could not, because he was always tired. He said now he is eager to go out and do all the things that he was not able to do.*

*The staff where I work were very excited. It was our first transplant since the nuns opened the hospital more than 50 years ago. The nurses were happy and excited with the success. We felt confident that we had managed to make a change. This will benefit the patient more. And we were also happy that we could make a difference.*

Changes are always not as fast as expected or informed. According to Dutton (1987:648-649), “What has been the impact on my life? Everyone said I would be back to normal in three months, but this did not happen, though I was eating normally (legally). Following this, life improved considerably, with the most significant benefit being the freedom conferred: freedom to visit friends, an awareness that there were no longer rigid time constraints to be imposed. As the fatigue diminished, the patterns of rest and activity associated with normal, everyday living could be resumed and there was a sense of being back in control of the new, independent life. However, I had been on haemodialysis for so long, that I had forgotten what the patterns of rest and activity associated with normal, everyday living were.”

### 3.6.5 Respondents’ perceptions of the experiences of patients and family members

The respondents described their perceptions of organ donation and transplantation. Positive as well as negative experiences were identified.

#### *3.6.5.1 Positive experiences*

According to most of the respondents:

> *It was a good move for the patient to accept that kidney because she was on the waiting list for so long that she was being dialysed maybe three times a week and came from a rural area.*

> *To me, organ donation, I think, is a very good thing. It is good for the recipient to be given a second chance in life, especially those who have kidney failure. Haemodialysis is very expensive. If you have a transplant, less money is needed for the management of the transplanted organ.*

> *The first one I observed was a family. The donor was the wife and the husband was a recipient. The husband was very excited. The wife was overweight by then, but she was so eager to donate for her husband that she managed to lose weight in no time, so that she was able to donate for her husband.*

When a patient is called in for a transplant, it is a worrying and an exciting time for both the recipient and the family. The wait could be anything from a few weeks to several years and it is probably the time when many patients have the most doubts.

#### *3.6.5.2 Negative experiences*

The respondents revealed different perceptions of the patients and their family. Some felt that patients' psychological, social and emotional needs should be addressed. The social and psychological impact varied. According to the respondents:

> *I think transplantation is very difficult and emotionally frustrating for the patient and the family. The patient thinks that now he or she is using somebody else' s organ, moreover that person died so that others could have those organs.*

> *My first experience regarding organ transplantation was scary because I was a student then. I did not expect that a recipient who had received an organ could reject it, and the recipient could be sick, compromising his or her health.*

Transplant patients need to be well informed regarding their condition to understand why most of the things regarding their condition were necessary, especially management of diet, medication, and so on.

Dutton (1987:644) emphasises that the psychological adjustment that takes place following transplantation should not be underestimated. Fears about rejection, side effects of the drugs, other complications and having to find employment are just some of the aspects with which the patient will need help. Occasionally, some patients remain in the sick role, putting extra stress on their family (Dutton 1987:644).

### 3.6.8 Religious belief

Religious views on organ donation differ. According to the respondents,

> *Yes, I strongly believe that religion plays an important role in organ donation and transplantation because some religions believe that you know what you came to earth with and it is what **you must** go to God with. As you are, so you*

*cannot receive anything from anyone else. With Jehovah's Witnesses, you cannot even receive blood transfusion. So I believe that religion plays a part. Traditional believers also do not want to donate any part of their body because they want to go to their Maker as they came to earth, so I think religion does play a part in organ donation and transplantation. As a medical person, I think that if you die there is no use for your body. Your soul is the only thing that matters, not your body. If you donate your body or organs to another person to have life or to a medical school so that they can study more on how to improve medical care, I think it is a good thing.*

*First of all, I believe in the fact that people are meant to go the way they came. For me, I would rather let people make their own decisions without feeling intimidated or guilty. If a person is dying, let the person go with all the organs that they came with. I think that is how it should be religiously.*

Among African-American women residing in a small Southern community, Wittig (2001:206) found that they "strongly believe that God would take care of them, regardless of their decisions relating to organ donation. They believe that God cures illnesses among the righteous and that organ donation is unnecessary for those who live right. The women who did not wish to be organ donors, all expressed this belief. Those who indicated that they would be donors expressed a similar belief that God would care for them until it was time 'to go home'."

Furthermore, regardless of their decision to donate or not to donate organs, they all made reference to God. According to Wittig (2001:206), they related health outcomes to "His Grace" and future health was frequently viewed as the result of possible divine intervention; "of course God takes care of me and he would if I needed a kidney or whatever"; "well, good people don't drink so as to need a liver"; "the Lord helps them that help themselves", and finally that "God intends for the wicked to suffer because he God says you reap what you sow".

## 3.7 CONCLUSION

This chapter discussed the results of the data analysis and interpretation, with reference to the literature review.

Chapter 4 concludes the study and makes recommendations for practice and further research.

# CHAPTER 4

# Conclusion and recommendations

## 4.1 INTRODUCTION

This chapter discusses the outcomes of the study and its limitations, and makes recommendations for practice and further research. Through the data analysis the researcher identified themes and categories related to the respondents' perceptions of organ donation and transplantation. The recommendations are based on the findings.

## 4.2 OUTCOMES OF THE STUDY

The objectives of the study were met as follows:

- The first objective was to determine Black critical care nurses' perceptions of organ donation and transplantation. This objective was met by collecting and analysing data, and formulating themes and categories (see chapters 2 and 3).
- The second objective was to explore and describe Black critical care nurses' perceptions of organ donation and transplantation. The results and the literature review achieved this objective.
- The last objective was to make recommendations in order to instil or strengthen positive attitudes in critical care nurses towards organ donation and transplantation. The recommendations are made in this chapter.

## 4.3 LIMITATIONS OF THE STUDY

The researcher identified the following limitations:

This study was limited to the perceptions of a sample of Black nurses practising in critical care units in Gauteng Province. Consequently, the findings cannot be

generalised to a larger population and were valid for this context only. Generalising findings from a purposive sample to the broader population can be very risky in most instances (Polit & Hungler 1997:230).

Most of the respondents felt that they did not know enough about organ donation and transplantation even though they had heard about it.

Most of the respondents were women. It was not possible to find a reasonable number of male nurses to participate in the study. Therefore it was not possible to determine whether male Black critical care nurses' perceptions would have differed.

## 4.4 RECOMMENDATIONS

Based on the results of the study, the researcher makes the following recommendations for practice and further research. The themes and categories provided a framework for structuring the recommendations.

### 4.4.1 Recommendations for practice

#### *4.4.1.1 Ethical and cultural issues*

The following recommendations are relevant to ethical and cultural issues.

- ***Respect for human feelings/dignity***

➢ It is recommended that nurses in the organ donation and transplantation field be made aware of how to show respect for people's feelings. Human dignity and how it could be held in high regard throughout harvesting as well as the transplantation process should be emphasised.

The donor, although brain dead, should not be handled just as a dead body but with respect/kindness. At the same time, the next of kin's feelings should be respected. They should be given a chance to say farewell, show sadness and not be forced into signing consent for donating organs of the deceased.

In the traditional African culture, there is a strong bond and interdependence between the living and the dead (ancestors) and it is important that this bond is respected. If this bond is not kept, the ancestors would show disapproval by visiting to their offspring in the form of ill health, misfortune, disease, and even death. This also applies to cultural aspects.

It is notoriously well known that in African communities, body parts and organs are used as *muti* (medicine) for witchcraft. Therefore this has a negative connotation and may affect people's attitudes towards organ donation and transplantation adversely. People might be hesitant to give away parts of the body and bury an incomplete person for fear of losing ancestral protection (Henning cited in Bhengu 1995:34). Shangase, Randeree and Schleubusch (1993:7) suggest sympathetic appreciation of cultural relativity as a prerequisite for success in work outside one's own community (see also recommendations on culture). Bhengu (1995:81) states that due to ancestor worship, it is normal in the Zulu culture to offer sacrifices to their ancestors and the respondents deemed it fit to include organ donation and transplantation among these rituals, like reporting organ donation and transplantation or to appease ancestors if it was done without the ancestors knowing. They would, for instance, slaughter a goat or burn incense. Bhengu (1995:91) points out that special attention should be paid to the traditional healers who reflect most misconceptions, yet are the most trusted members of the Zulu community and can, in turn, be utilised for educational campaigns on the topic.

➢ It is recommended that the principles of self-determination or autonomy be respected during organ donation.

The patient receiving an organ has the right to be informed of the following:

- The proposed treatment
- Risks attached
- What to expect in respect to pain, recovery, disfigurement and cost
- Other satisfactory options and success rates

➢ It is recommended that fairness in allocating organs should be observed at all times.

Harries and De Lone (1992:47) and McNatt (1992:343) identify the following inequities in the allocation of organs:

- More men than women receive organs for transplantation.
- More White than Black people receive organs for transplantation.
- More rich than poor people especially in "rewarded gifting" situations receive kidneys.
- More young than old people receive transplants.
- Black patients have a significantly longer waiting period compared to White patients.

McNatt (1992:343) maintains that minority groups must be made to feel that their group has equal access to transplantation thus excluding obstacles like age, money, celebrity, race, physical handicap, or geography in the allocation of organs.

➢ It is recommended that people be made aware of the criteria followed when selecting recipients and donors. Shade (cited in Wittig 2001:203) indicates that Non-Whites wait about twice as long as Whites because of the difficulty in finding a suitable donor.

The following criteria apply in one of KwaZulu-Natal's hospitals for selection for the transplantation programme:

- Psychosocial stability with an adequate support system
- Good communication with health care centre
- Safe water supply

The criterion of a safe water supply means that some patients living in rural areas or informal settlements would not have an equal opportunity for selection (Bhengu 1995:37).

- ***Organ trafficking and legal aspects***

➢ It is recommended that nurses be made aware of all the regulations on organ donation and transplantation as contained in the *Human Tissue Act* (Act 65 of 1983).

Regarding the removal of tissue, blood or gametes from bodies of living persons for therapeutic and other uses, the following aspects must be adhered to:

- Tissue destined for transplantation may be removed only in a hospital or other authorised institution.
- The Medical Superintendent of the hospital or institution must provide written authorisation and may not carry out the transplantation himself.
- Removal of tissue may only be effected with the consent of the donor; in the case of a minor, the consent of the parents or guardian should be given in writing.
- In the case of donors of 14 years or older, who are mentally competent, no parental consent (or guardian) is required before removal of replaceable tissue like bone.
- The donor must have met the criteria for brainstem dead certification before being declared brain dead in case of a cadaver donor.
- Two doctors, one of whom must have been practising for at least 5 years, must establish death. The two doctors may not be members of the transplantation team.
- Tissue removed in order to save a person's life (as the organ was threatening the person's life or the organ was detached from the body and cannot be saved, e.g. bone from an amputated leg after an accident) may be used for any of the above-mentioned purposes.

According to the *Human Tissue Act* (Act 65 of 1983), consent is a prerequisite, except for medico-legal autopsy and can be given under the following circumstances:

- By a deceased person **prior** to his death in a will or any document attested by two competent witnesses.
- The person giving consent must be 14 years and older.

- Consent can also be a verbal statement in the presence of at least two witnesses. The prospective donor may wear an identity tag. The consent may be revoked by the donor prior to his death but not by a relative.
- A spouse, any major child, any parent, guardian, any major brother or sister of the deceased can give consent after death only if the deceased has not forbidden it.

If none of the above can be traced and provided the deceased had not given contrary instructions prior to death, the Director General: National Health and Population Development or someone authorised by him can give consent. The purpose must be to save someone's life and the official concerned must be convinced that all reasonable steps have been taken to trace the relatives if the deceased is unidentified.

Some countries, especially members of the World Health Organization, prohibit the sale of organs by law and no form of incentive other than altruism and volunteerism is allowed for organ donation (Bhengu 1995:40).

Strong and Strong (1985:239) maintain that shortage of organs has forced some countries to allow the sale of organs, e.g. some developing countries like Long Island. In some countries children are sold and sacrificed for their organs (Pike 1992:14). In the Philippines, the family of a brain dead person is promised payment of hospital bills and funeral costs in return for organs (Pike 1992:14).

Martinelli (1993:245) found that rewarded gifting is practised in India, where the recipient

- pays the cost of donor selection
- pays for immediate follow-up
- lifelong health insurance for the donor

In South Africa, hospital fees are waived from the time of brain stem death certification. However, McNatt (1992:341-343) proposes some financial incentives to balance organ transplantation and organ donor supply, such as

- providing funeral expenses
- reducing estate taxes for families of cadaver donors
- government regulated incentives, e.g. medical care to be free
- brokered donation

In the USA, Harries and De Lone (1992:49) emphasise that the privileged have an advantage of multiple listing, by booking an organ in more than one state to shorten their waiting period. Harries and De Lone (1992:49) strongly criticise the commercialisation of human organs on the basis that it puts those who have the means at an advantage and may lead to financial exploitation of the vulnerable, like the poor, especially in the context of gross economic hardship.

Martinelli (1993:241) refers to the 1983 Gallup Society survey finding that married Blacks with higher incomes were more willing to consider organ donation than single Blacks with lower incomes.

South Africa practises the required consent or opt in approach in which consent is either requested from the next of kin or indicated by the donor before death in the form of Medic Alert discs, donor cards or bracelets (McNatt 1992:341; Pike et al 1993:261).

According to Matthewman (1993:45), the advantage of required consent is volunteerism and donor autonomy. In addition, education about newer laws and not the law itself was responsible for the increase in the number of organ donors.

The disadvantage is that this approach does not normally lead to an increase in donation of organs unless the community concerned is well informed and altruistic to give informed consent, and the health care personnel are well motivated to approach families (McNatt 1992:341; Pike et al 1993:264).
Belgium, Austria and other European countries practise the presumed consent or opt out approach, which gives the physician the legal right to remove organs from brain dead individuals without the consent of the patient or family unless the patient or the family have indicated objection to organ donation previously (Pike et al 1993:264). Presumed consent has dramatically increased the availability of organs for transplantation in countries where it is implemented. Ward (1993:44) maintains that

presumed consent removes the burden of having to make an important decision at the traumatic time of bereavement. Moreover, it relieves the hospital staff of the unenviable task of approaching the relatives for permission to remove organs. However, McNatt (1992:342) maintains that the presumed consent approach violates the principle of autonomy and volunteerism on the part of the donor. This approach may change attitudes towards the deceased; for example, regarding them as "spare parts" rather than deceased persons.

Matthewman (1993:45) claims that the presumed consent approach can alienate people and cause them to lose trust in health professions, making it even more difficult to discuss organ donation. Presumed consent is not yet lawful in South Africa therefore it is good to be knowledgeable about it but also to know that it is not done this way in South Africa.

- ***Cultural shock***

➢ It is recommended that it be recognised that organ donation can lead to cultural shock. Therefore, the importance of cultural sensitivity and recognising different cultures in this nursing context is important (also see beliefs and superstitions below).

Cultural sensitivity programmes should be made available for professionals working in the field of organ donation and transplantation.

- ***Beliefs and superstitions***

➢ It is recommended that the beliefs and superstitions of nurses working with organ donation and transplantation patients be addressed. In addition, that it be recognised that patients come from different backgrounds with certain beliefs and superstitions, and this should be taken into consideration and handled sensitively.

Professionals working in this field should read up on the beliefs and superstitions of other cultures.

#### *4.4.1.2 Economic factors*

The following recommendations are relevant to economic factors.

- ***Saving money***

➢ It is recommended that potential donors as well as recipients of organs be made aware of the money that can be saved after organ transplantation. For example, the financial strain of haemodialysis could motivate potential donors to donate organs.

Bhengu (1995:76) found that in one case the members of a congregation were motivated to donate organs because of the experience of a person in financial difficulty from haemodialysis and the church members' efforts to collect funds.

- ***Cost effectiveness***

➢ It is recommended that the cost effectiveness of organ donation be emphasised to donors as well as recipients.

After organ transplantation, the recipient saves money on the trip to renal dialysis three times per week and that time could be allocated for something else. The recipient can do a full day's work after a successful transplant therefore he or she will be an economically active member of society.

#### *4.4.1.3 Information and education*

The following recommendations are relevant to providing information to the community and educating professionals.

- ***Community awareness***

➢ It is recommended that serious efforts be made to eliminate the following obstacles to knowledge about organ donation and transplantation:

- Language differences preventing communication between families and health care workers.
- Public mistrust of health care personnel, which is not necessarily confined to Blacks (Yang, Abrams, Smolinski & Nathan 1993:2487).
- Misconceptions about brain stem death criteria; for example, premature declaration of death for the purpose of organ retrieval.
- Inappropriate timing of the request for organs, such as during the traumatic time of bereavement when the family is not in a position to grasp the concept.

➢ It is recommended that **public awareness campaigns** be launched to motivate individuals to donate organs and to accept the idea of transplantation. People themselves would give consent voluntarily while still alive (Bhengu 1995:92).

➢ It is recommended that the **content of educational campaigns** be attended to as follows:

- The content of education to be given should be designed to meet the needs of the particular community.
- Basic anatomy and physiology principles should be explained to avoid confusion about organs and their functions. Bhengu (1995:72) refers to the confusion of not being able to differentiate between reproductive organs and renal function; the fear of reproducing a different offspring, change of gender, or getting sexually transmitted infections.

- The organs that can be donated need to be specified when explaining the concepts in anatomy and physiology.
- How individuals should indicate that they want to donate their organs should be explained. Bhengu (1995:89) and Simmons (1995:316) emphasise direct contact during discussion of organ donation and transplantation rather than the use of remote mass media programmes.
- Legal aspects of communicating the wish to donate organs should be explained. If the deceased expressed a wish to donate organs, the family or next of kin's decision will be taken as final. If they decide that they do not want the organs to be donated, their decision cannot be overruled.

➢ Regarding the **implementation of educational campaigns**, it is recommended that the following be considered:

- The campaigns must be run throughout the year while the communities are being familiarised with the idea of organ donation and transplantation.
- It would be of benefit to the community if organ donation campaigns can be run throughout the year rather than during the organ donor month only (Simmons 1995:315; Coupe 1990:35).
- Direct contact is preferred. Therefore community health nurses should be asked to include organ donation and transplantation in their existing health education programmes in community health centres (CHCs) and primary health care (PHC) services. Due to the need of information and demand for organs, there is a great need for awareness.
- Health workers of the same culture should be used where possible, because they understand their clients' worldview (e.g., ancestor worship). The language barrier is also an obstacle as 99.9% of transplant coordinators are English-speaking South Africans and not conversant with African languages or African communities' background. Thus it is difficult for them to make them understand or to understand their cultural background and make it easier for them to understand. Bundezi (1992) (cited in Bhengu 1995:89) emphasises that the translator should be conversant not just with the language but also with the patient's culture. Shangase et al (1993:7) point out that the Zulu language has no

terminology to explain concepts like loss of renal function and electrolyte imbalance. This stresses the need that language that is more or next to the people concerned should be used to create a better understanding and to be able to clarify the subjects being explained.

- With regard to the use of the media, the most widely used media and the highest listener or viewing times when families are together should be assessed to trigger discussions.
- People who know the subject and have experience in the field should conduct discussions in the media. They should also be able to answer people's questions appropriately and anticipate people's concerns about organ donation and transplantation.
- Open days should be organised and individuals from the community invited to see the purpose of haemodialysis and transplantation units. This would allow them to compare the expenses involved with these procedures.
- The Organ Donor Foundation of Southern Africa is involved in educational campaigns (e.g., talks in churches, service organisations, women's groups, armed forces and schools). These talks are given by transplant co-coordinators and transplant recipients and the foundation's campaign should be promoted.
- The appointment of Black transplant coordinators may help improve communication (Pike et al 1993:267).

➢ It is recommended that **target populations** be identified for educational campaigns, including the following:

- Nurses working in non-transplant intensive care units, operating rooms, casualty and surgical units (Bhengu 1996:43).
- Law enforcement officers as well as members of the local fire department and other individuals who may be instrumental in organ procurement (Coupe 1990:34).
- Community health nurses for their close contact with the community and because often they are of the same culture as the community.

- Religious leaders to clear their religious aspects and provide Scriptural verses relevant to extension of life on organ donation and transplantation.
- Clergy and ministers could indicate that medical and advanced technological resources used to provide organ transplants and sustain life are acceptable practices in the Church. The introjections of ideas such as the notion that God gave us the abilities to perform these procedures could be beneficial (Wittig 2001:209).
- Staff of the same culture in the transplant unit should use their terminology and phraseology to clarify and explain concepts to patients and their relatives.
- Transplanted and live donors should discuss the effect of transplantation and organ donation, respectively.
- Community organisations, such as burial clubs, as they are already engaged in activities of preparing for death.

- ***Staff development***

➢ It is recommended that the entire health team be equipped with information on organ donation and transplantation to enable and facilitate knowledge transfer in the workplace, when the need arises, as well as to provide good care, when necessary.

There is a need for staff development programmes to be implemented to maintain the standard. Theory and skills taught in the classroom should be followed through into the workplace and established in actual practice. Theory and practica must be integrated so that people realise that it is not just theory that does not exist in the real world.

Orientation programmes on organ donation and transplantation are essential. Urden, Stacy and Lough (2006:6) state that sufficient inquisitive practitioners who strive for best practices in order to provide optimal care need to be employed to care for the rapidly growing population of critically ill patients (potential donors should be identified, referred properly and proper nursing care be continued).

Lack of knowledge makes people less confident and unable to render total quality nursing care. Coupe (1990:28) maintains that nurses do not refer potential donors adequately due to lack of knowledge and experience of organ donation and transplantation. Monett (1992:34) claims that nurses become emotionally involved with the patient and the bereaved family, thus become reluctant to raise the question of organ donation, feeling that "the family has had enough". Coupe (1990:36) contends that health care personnel have both knowledge and interpersonal problems regarding the following aspects of organ donation and transplantation and staff development could focus on these aspects:

- Legal and medical aspects of organ donation and transplantation, like criteria for transplants and legislation such as the *Human Tissue Act* (Act 65 of 1983) (South Africa (Republic) 1983).
- Relationship of brain stem death and organ donation.
- Interpersonal and communication skills to approach a grieving family and a family of a different language.
- Hospital policies regarding procurement and allocation of organs.
- Assertiveness, to act as the patient's advocate.
- Knowledge of referral units or hospitals and procedures for referral.
- Donor maintenance.

Some of the respondents stated that they needed to be educated, as the last time they had heard about organ donation and transplantation was during their training and most of the information did not make sense to them as they thought it was something very rare. In-service training would help keep them well informed and up to date.

Awareness and development programmes to enhance organ donation and transplantation should be implemented and promoted, in a way that would create a mind shift in the nursing profession.

➢ It is recommended that the following methods be used to promote awareness of organ donation and transplantation:

- Seminars
- Panel discussions
- Conferences

The study concluded that most of the respondents did not have enough information on organ donation and transplantation, therefore, it is recommended that the above be used to equip them with the required information. Wittig (2001:203) maintains that although some explanation for low organ donation rates has been addressed, there is still much that is not understood.

#### *4.4.1.4 Recommendations for nurses' experiences*

The following recommendations are relevant for nurses' experiences.

- ***Positive feelings and experiences***

➢ It is recommended that if nurses feel good about the results achieved (successful organ transplantation), the results should be spread to the community so that they can see the benefit of it.

Word of mouth is a powerful method of spreading a message, as first-hand information is the best because is not altered. The results of organ donation and transplantation are seldom made known.

- ***Negative feelings***

➢ It is recommended that nurses with negative feelings about organ donation and transplantation be counselled, educated and supported in the process of nursing donors or recipients of organs. Programmes that will help them to understand the need of saving a life through organ donation and transplantation should be free. Strategies like values clarification could be used.

#### *4.4.1.5 Nurses' perceptions of the experiences of patients and family members*

The following recommendations are made for nurses' perceptions of the experiences of the patients and family members.

- ***Positive experiences***

➢ It is recommended that positive experiences of organ donation and transplantation be shared. Facilitate and encourage the spread of positive information. Good working relationships between the coordinators and the nurses looking after the recipient and the donors should be spoken about.

- ***Negative experiences***

➢ It is recommended that family and patients be educated about organ donation and transplantation, including the side effects of medication and the complications. They should be aware that sometimes healing could take months. The chances of rejection should also be explained as this devastates them most.

#### *4.4.1.6 Religious and philosophical factors*

➢ It is recommended that different religious and life-view backgrounds be respected. This also plays an important role, as we live in an open society where human rights are respected.

Organ donation is seen as a good deed in religious terms. To the researcher coercion seems to be a problem among husbands who coerce their wives into donating organs to them such as kidneys. This problem may be related to the traditionally imposed social standing of women as subordinate to men and men as providers of social position and the good things in life.

➢ It is recommended that information on different religions related to religious practices be made available, such as the following:

- *Christianity*

  Organ donation and transplantation is a modern concept. The Bible does not directly address this question, but the researcher, as a Christian, is of the opinion that a decision of this nature can only be made between a person, their family, and God. A guideline could be that a person should prayerfully consider what God would want them to do in regard to donating their organs upon death because in James 1:5 the message is "if anyone of you lacks wisdom let him ask God who gives to everyone without reserve and without reproach" (The Holy Bible 1983:900), which is considered the light of life for guidance. "If you feel led to donate organs, then there is no reason you should not. If you do not feel led to do so, you should not feel guilty about it and you should not allow yourself to be coerced by someone" (Mailula 2005).

  Donation and transplantation are strongly encouraged by Seventh Day Adventists who are also a sub-group within the Christian faith. They have many transplant hospitals, including Loma Linda in California. Loma Linda specialises in paediatric heart transplantation (Mailula 2005).

- *Buddhism*

  Buddhists believe that organ donation is a matter of individual conscience and place a high value on acts of compassion. Mailula (2005) stated that Gyomay Masao, president and founder of the Buddhist Temple of Chicago indicated that they honor those who donate their bodies and organs to the advancement of medical science and to saving lives. The importance of letting loved ones' know your wishes is stressed.

- *Hinduism*

  Mailula (2005) also indicated that the Hinduism Temple Society of North America does not prohibit Hindus from donating their organs. This act is an individual decision. Trivedi (cited in Mailula 2005) in this *Transplantation Proceedings* article states that "Hindu mythology has stories in which parts

of the human body are used for the benefit of other humans and society. There is nothing in the Hindu religion indicating that parts of humans, dead or alive, cannot be used to alleviate the suffering of other humans."

- *Islam*

  The religion of Islam believes in the principle of saving human lives. According to Sachedina (1990) (cited in Mailula 2005) in his Transplantation Proceedings' article, *Views on Organ Transplantation*, "the majority of Muslim scholars belonging to various schools of Islamic law have invoked the principle of the priority of saving human life and have permitted organ transplant as a necessity to procure that noble end" (Mailula 2005).

- *Jehovah's Witness*

  Mailula (2005) indicated that according to the Watch Tower Society, Jehovah's Witnesses believe organ donation is a matter of individual decision. Jehovah's Witnesses are often assumed to be opposed to donation because of their belief against blood transfusion. However, this merely means that blood must be removed from the organs and tissue before being transplanted. This would make transplantation impossible.

- *Judaism*

  According to Mailula (2005), all branches of Judaism (Orthodox, Conservative Reform and Reconstructionist) support and encourage organ donation. In 1999, the Rabbinical Court of America (Orthodox) approved organ donation as permissible, and even required from brain-dead patients.

### 4.4.2 Recommendations for further research

There is a need for research in the critical care environment in order to foster high-level patient care, especially in the field of organ donation and transplantation. There is a great need for organs. Every year, thousands of people die while waiting for organ

transplantation. The researcher therefore makes the following recommendations for further research:

- A quantitative study of critical care nurses' perceptions of organ donation and transplantation over a wider area could be done.
- A qualitative study of community perceptions of organ donation and transplantation in rural and urban areas should be done.
- The general public's perceptions and understanding of organ donation and transplantation should be investigated.
- A comparative study should be done of critical care nurses' perceptions of organ donation and transplantation in South Africa and those of other countries.

## 4.5 REFLECTION OF THIS STUDY

The study emanated from the researcher's own experience working in a level 1 trauma unit and trauma ICU prior to working in a general ICU where patients were admitted post-operatively following organ transplantation.

The researcher realised that there was a lot of uncertainty and no system or programme in place to help nurses to deal with the family of the potential donor when coordinators introduced the subject of organ donation and transplantation.

The researcher found prevailing specific problems related to critical care nurses' perceptions of organ donation and transplantation in the nursing clinical environment. The study was undertaken to understand their perceptions of organ donation and transplantation. Among the nurses, some were totally comfortable with organ donation and transplantation while others were completely against it.

## 4.6 CONCLUSION

The researcher ventured on a journey into Black critical care nurses' perceptions of organ donation transplantation. The entry point was from a position of realising a lack of information and misunderstanding among the nursing staff on organ donation and transplantation. The study indicated that there is a need for education on the subject.

The consequent recommendations for nursing education, cultural and ethical issues, kinship and social factors, and implementation of educational programmes should benefit transplant units and the community at large.

# CHAPTER 1

## Orientation to the study

### 1.1 INTRODUCTION

End stage organ failure gives rise to significant morbidity, which cannot even benefit from hospitalisation. The greatest gift a person can give to another is often considered to be an organ (Aston-Prior 2000:92). Organ donation and transplantation is seen as a gift of life because the objective of organ donation is to give the recipient a second chance in life.

The first successful renal transplant was performed in 1954 in Boston, in the United States of America (USA), using identical twins. Since then, more than one million patients have received cadaveric grafts and organs from living donors (Aston-Prior 2000:92). In organ donation and transplantation, an organ is taken from one person and transplanted into another person with end stage organ failure. The donor may be living, dying or dead. In South Africa, 232 renal transplantations were performed in 1992 and 2 453 patients were on dialysis, awaiting renal transplantation (South African Dialysis and Transplantation Registry 1992).

### 1.2 TRANSPLANTS IN A TRANSPLANT UNIT IN GAUTENG

In order to indicate the current situation to an extent in the transplant field in Gauteng Province, South Africa, the statistics for various transplants between 2004 and 2007 are reflected in tables 1.1 to 1.6. Data was used from one transplant unit in Gauteng (the name of this unit is withheld for confidentiality purposes). The researcher then did the calculations presented in the tables.

#### 1.2.1 Liver transplants

Since the introduction of clinical liver transplantation, the list of indications has rapidly expanded and the list of contraindications diminished. The diseases for which liver

transplants are most often indicated in adults include chronic active hepatitis, primary biliary disease, sclerosing cholangitis, autoimmune hepatitis, and alcoholic liver cirrhosis. Alcoholic liver cirrhosis, a subject of considerable controversy, is now recognised as an accepted indication for liver transplant if the patient has demonstrated the ability to abstain from alcohol and is clearly committed to continued abstinence (Hawker 2002:803).

In the case of a liver transplant, a part or the whole liver is always transplanted. The liver is always obtained from a cadaver donor because South African law does not allow a living donor to donate part of a liver to save end stage liver failure. In the United States, living donors are allowed to donate part of a liver to save a child from end stage liver failure.

**Table 1.1 Liver transplants in an organ transplant unit in Gauteng, 2004-2007**

| Biographical/ Physiological aspects | Children Age 0-13 | Adolescents Age 13-18 | Adults Over 18 years |
|---|---|---|---|
| **Gender** | | | |
| Male | 3 | 0 | 28 |
| Female | 6 | 1 | 22 |
| **Ethnic group** | | | |
| White | 3 | 0 | 40 |
| Black | 4 | 1 | 5 |
| Coloured | 1 | 0 | 1 |
| Asian | 1 | 0 | 4 |
| **Blood group** | | | |
| 0 | 3 | 0 | 23 |
| A | 5 | 1 | 21 |
| B | 0 | 0 | 1 |
| AB | 1 | 0 | 5 |
| **Total** | **9** | **1** | **50** |

**Total: 60**

### 1.2.2 Simultaneous kidney/pancreas transplant

For a simultaneous kidney/pancreas transplant, organs from a cadaver donor are always used (see table 1.2). These transplants are usually done on diabetic patients.

**Table 1.2 Simultaneous kidney/pancreas transplants in an organ transplant unit in Gauteng, 2004-2007**

| Biographical/ Physiological aspects | Children Age 0-13 | Adolescents Age 13-18 | Adults Over 18 years |
|---|---|---|---|
| **Gender** | | | |
| Male | 0 | 0 | 10 |
| Female | 0 | 0 | 12 |
| **Ethnic group** | | | |
| White | 0 | 0 | 20 |
| Black | 0 | 0 | 2 |
| Coloured | 0 | 0 | 0 |
| Asian | 0 | 0 | 0 |
| **Blood group** | | | |
| 0 | 0 | 0 | 13 |
| A | 0 | 0 | 6 |
| B | 0 | 0 | 3 |
| AB | 0 | 0 | 0 |
| **Total** | **0** | **0** | **22** |

**Total: 22**

### 1.2.3 Cadaver kidney transplant

Kidney transplants use kidneys mainly from cadavers but related transplants are also done (see 1.2.4). All kidneys suitable for transplantation are removed from suitable donors. Renal diseases responsible for renal failure treated by transplantation are chronic glomerulonephritis (50%); diabetic nephropathy (30%); chronic pyelonephritis (8%); malignant nephrosclerosis (6%); polycystic kidney disease (5%), and other renal diseases (6%).

**Table 1.3 Cadaver kidney transplants in an organ transplant unit in Gauteng, 2004-2007**

| Biographical/ Physiological aspects | Children Age 0-13 | Adolescents Age 13-18 | Adults Over 18 years |
|---|---|---|---|
| **Gender** | | | |
| Male | 2 | 0 | 24 |
| Female | 0 | 1 | 19 |
| **Ethnic group** | | | |
| White | 1 | 1 | 12 |
| Black | 0 | 0 | 20 |
| Coloured | 1 | 0 | 3 |
| Asian | 0 | 0 | 8 |
| **Blood group** | | | |
| 0 | 1 | 1 | 20 |
| A | 0 | 0 | 18 |
| B | 0 | 0 | 0 |
| AB | 1 | 0 | 5 |

| | | | |
|---|---|---|---|
| **Total** | **2** | **1** | **43** |

**Total: 43**

### 1.2.4 Related living kidney transplant

These transplants are mainly from living donors who are blood relatives of the recipients. The chances of rejection are much less compared to non-related living donors or cadaver donors. The donor could be a mother, father, sibling or even a cousin.

**Table 1.4 Related living kidney transplants in an organ transplant unit in Gauteng, 2004-2007**

| Biographical/ Physiological aspects | Children Age 0-13 | Adolescents Age 13-18 | Adults Over 18 years |
|---|---|---|---|
| **Gender** | | | |
| Male | 3 | 2 | 22 |
| Female | 0 | 2 | 8 |
| **Ethnic group** | | | |
| White | 3 | 2 | 14 |
| Black | 0 | 1 | 6 |
| Coloured | 0 | 1 | 3 |
| Asian | 0 | 0 | 7 |
| **Blood group** | | | |
| 0 | 1 | 2 | 11 |
| A | 1 | 1 | 11 |
| B | 1 | 1 | 8 |
| AB | 0 | 0 | 0 |
| **Total** | **3** | **4** | **30** |

**Total: 37**

### 1.2.5 Non-related living kidney transplant

Fewer non-related living kidney transplants are done than are required. The *Human Tissue Act* (Act 65 of 1983) (South Africa (Republic) 1983) stipulates the criteria for organ donation and transplantation to protect anyone taking advantage of the community due their ignorance or lack of knowledge. Selling of organs is standard practice in some countries abroad.

**Table 1.5 Non-related living kidney transplants in an organ transplant unit in Gauteng, 2004-2007**

| Biographical/ Physiological aspects | Children Age 0-13 | Adolescents Age 13-18 | Adults Over 18 years |
|---|---|---|---|
| **Gender** | | | |
| Male | 0 | 0 | 4 |
| Female | 0 | 0 | 1 |
| **Ethnic group** | | | |
| White | 0 | 0 | 2 |
| Black | 0 | 0 | 2 |
| Coloured | 0 | 0 | 0 |
| Asian | 0 | 0 | 1 |
| **Blood group** | | | |
| 0 | 0 | 0 | 3 |
| A | 0 | 0 | 0 |
| B | 0 | 0 | 2 |
| AB | 0 | 0 | 0 |
| **Total for age group** | **0** | **0** | **5** |

**Total 5**

### 1.2.6 Combined liver-kidney transplant and other transplants

Between 2004 and 2007 only one combined liver and kidney transplant was done. The two are rarely done together even though there is a high success rate. The unit where the data in the tables above was obtained does not accommodate heart and lung transplants. Heart, lung and combined heart-lung transplants are done at another unit in Gauteng to which the researcher did not have access. Data regarding heart-lung transplants are therefore not reflected above.

In the USA, Wittig (2001:203) pointed out the growing gap between the supply of available human organs and the critical number needed for transplants. In 2000, approximately 60 500 South Africans were waiting for organ transplantation.

## 1.3 BACKGROUND TO THE STUDY AND RESEARCH PROBLEM

Although information is readily available in most hospitals about organ donation, it does not appear to reach most people because there are still misconceptions and myths about organ donation and transplantation. According to Roark (1999:23), one of the myths is that people's organs might sometimes be removed before they are actually

dead, leaving them to wake up with an organ missing and this will minimise their chances of survival. Another myth is that life-sustaining treatment may be withheld in a hurry to retrieve organs.

In a study on South Africans' attitudes to organ donation, Pike, O'Dell and Kahn (1993:91) found that both educated and non-educated Whites and Blacks not involved in the health professions did not seem to understand much about and had many misconceptions about organ donation.

Regarding the need for increasing organ donation among African-Americans and Hispanic Americans, Roark (1999:26) found that cultural differences did not play a major role as the number of African-American respondents from rural and urban areas willing to donate their organs was comparable to the Hispanic American respondents. A minority objected to donating organs on behalf of relatives in cases of death and dying, saying that the individuals themselves should have made that decision before they died. It was not up to them to decide for these people. Others' fears were based on the myth that those individuals would not see their ancestors in heaven. Racial issues were also mentioned when they were specifically asked about donating an organ of one race to another. A minority said that it should not be from one race to another; it should be given to the same race to sustain that racial group.

In the USA, non-white people who need an organ wait about twice as long as Whites because of the difficulty of finding a donor. This contributes to organ donation among African-Americans being done less frequently than amongst the general population (Wittig 2001:203). McNatt (1992:34) maintains that Black patients have a significantly increased waiting time compared to White patients due to high levels of preformed human antibodies, many people having blood types 0 and B; second transplantation, and the rare human leucocyte antigen. According to Lynch (1990:21), due to a different genetic make-up, Blacks cannot receive a great percentage of organs donated by Whites.

Black critical care nurses' perceptions of organ donation and transplantation are important because:

- If it is found that African critical care nurses have a positive attitude towards organ donation, it should be reinforced to benefit patients.
- If the opposite is true, awareness programmes should be initiated.

The problem, however, is that it is not clear what Black South African critical care nurses' perceptions of organ donation and transplantation are.

## 1.4 OBJECTIVES

The objectives of the study are to

- determine what Black South African critical care nurses' perception of organ donation and transplantation
- explore and describe the perceptions of Black South African critical care nurses regarding organ donation and transplantation
- make recommendations in order to instil or strengthen positive attitudes in critical care nurses regarding organ donation and transplantation

## 1.5 RATIONALE FOR AND SIGNIFICANCE OF THE STUDY

Organ donation is a local as well as worldwide problem. The supply of organs fails to meet the demand. The waiting period is from weeks and months to years. Most patients are solely dependant on donors from cadavers, as organs such as hearts or livers are required.

According to McCurdie, Donald and Kahn (1992:43), 30% of cardiac patients who can benefit from donors at Groote Schuur Hospital die before a suitable donor can be found. Due to a shortage of organs, Belgian citizens were provided with the authority to register their decision to donate or oppose organ donation and given the opportunity to change their mind if they wanted to withdraw (Sells 1992:2401).

In the researcher's experience when a family is bereaved they are not properly prepared for donating an organ of their family member, especially when they are

informed about it for the first time. Roark (1999:23) found that some think that life-sustaining treatment will be discontinued or withheld in order to retrieve organs.

Critical care nurses, especially those working in trauma critical care units, are often involved in suggesting the referral of organs for donation and transplantation. It is therefore important to research the perception of African critical care nurses regarding organ donation and transplantation in order to determine whether there is sufficient awareness amongst these professionals on this special issue and if the perception is mainly a positive one.

## 1.6 RESEARCH DESIGN AND METHODOLOGY

An explorative descriptive and contextual study was done, using qualitative methodology. In qualitative studies, the reality is explored from an emic perspective, understanding life from the perspective of the participants in the setting under the study. Life is examined in an uncontrolled, naturalistic setting (Morse & Field 2002:18).

Qualitative research is sometimes referred to as soft science. It tends to emphasise the dynamic, holistic and individual aspects of the human experience and attempts to capture those aspects in their entirety, within the context of those who are experiencing them (Polit & Beck 2004:724).

## 1.7 DATA COLLECTION AND ANALYSIS

Data was collected by means of in-depth interviews, using a central question. Guba's (1989) model was used to ensure trustworthiness of the study (see chapter 2).

The data was analysed by doing content analysis. Content analysis is the process of organising and integrating qualitative data according to emerging themes and concepts (Polit & Beck 2004:714). In this case, the content was the transcribed interviews (see annexure 3). Content analysis allows the researcher to analyse large volumes of unstructured data. The data was then coded (see chapter 2).

## 1.8 DEFINITIONS OF TERMS

For the purposes of this study, the following terms are used as defined below.

- **Black South African critical care nurse**

A registered nurse is a person registered as a professional nurse according to the Nursing Act (Act 33 of 2005, as amended) (South Africa (Republic) 2005).

The term "Black South African critical care nurse" in this study refers to a Black South African professional nurse who is legally authorised to practice nursing through registration with the South African Nursing Council (SANC) and who is working in a critical care unit. The specific post registration qualification of "Intensive care" is not a prerequisite in this case. In the rest of the study, Black *African* professional nurse is used interchangeably with *South African*.

- **Critical care unit**

A critical care unit is a specially staffed and equipped hospital ward dedicated to the management of patients with life-threatening illnesses, injuries or complications (Oh 2002:3).

- **Perception**

*Collins English Dictionary* (1991:1156) defines perception as "the act or effect of perceiving; insight or intuition gained by perceiving; the ability or capacity to perceive; way of perceiving; awareness or consciousness; view", and perceive as "to become aware of (something) through the senses, esp. the sight; recognise or observe; to come to comprehend; grasp".

- **Donor**

A donor is "a person who makes a donation; any person who voluntarily gives blood, skin, etc., for use in the treatment of another person" (*Collins English Dictionary* 1991:464).

- **Transplant**

*Collins English Dictionary* (1991:1636) defines transplant as "to transfer (an organ or tissue) from one part of the body to another or from one person or animal to another during a grafting or transplant operation".

## 1.9 ETHICAL CONSIDERATIONS

The researcher adhered to the ethical principles required in health care research to protect participants from harm or risk (Holloway & Wheeler 1996:39). In this study, the researcher observed the following principles (see annexure 1):

### 1.9.1 Respect for persons

According to this principle, an individual is autonomous and has the right to self-determination and respect. This means that they have the right to decide whether or not to volunteer to participate in a study without any risk of penalty or judgmental treatment. They also have the right to withdraw from a study at any time, refuse to give information or to ask for clarification about the purpose of the study (Brink 1996:39). In this study, the participants were informed of the nature, purpose and aim of the study, the expected duration of the interview, and that participation was voluntary (see annexure I).

### 1.9.2 Informed consent

Participants must voluntarily agree to participate in a research study before they are involved in the study (Brink 1996:210). Participants must be legally and psychologically competent to give consent and must be aware that they are at liberty to withdraw at any time (De Vos 2002:65). The participants read the information in the letter of informed consent and gave verbal consent (see annexure 1).

### 1.9.3 Consent

The researcher obtained permission from the Research Ethics Committee of the University of Pretoria to conduct the study (see annexure 2).

## 1.10 SCOPE AND LIMITATIONS

This study wished to investigate Black African critical care nurses' perceptions of organ donation and transplantation, but was limited to the perceptions of nurses practising in critical care units in Gauteng Province. Consequently, the findings cannot be generalised to a larger population and were valid for this context only.

## 1.11 OUTLINE OF THE STUDY

Chapter 1 is an orientation to the study.

Chapter 2 describes the research design and methodology.

Chapter 3 discusses the results from the data analysis and interpretation.

Chapter 4 concludes the study, briefly discusses its limitations, and makes recommendations for practice and further research.

## 1.12 CONCLUSION

This chapter 1 discussed the rationale for and purpose and aim of the study. Knowledge and technical advancement in the field of transplantation has increased the demand for organ donation and transplantation. However, the supply of organs does not meet the demand due to the few sources of organs, technique of organ retrieval, and socio-cultural factors.

Chapter 2 discusses the research design and methodology.

# CHAPTER 2

# Research design and method

## 2.1 INTRODUCTION

Research is a major force in nursing and the knowledge generated from research changes practice, education and health policy (Burns & Grove 2003:IX). This chapter describes the research design and methodology of the study, as well as trustworthiness and ethical consideration.

## 2.2 RESEARCH PROBLEM

The research problem of this study was that it is not clear what Black critical care nurses' perceptions are of organ donation and transplantation. To examine the problem, the researcher undertook a qualitative study.

## 2.3 OBJECTIVES OF THE STUDY

The objectives of the study were to

- explore and describe Black critical care nurses' perceptions of organ donation and transplantation
- make recommendations to instil or strengthen positive attitudes in Black critical care nurses towards organ donation and transplantation

## 2.4 RESEARCH DESIGN

A research design is a framework that "serves as a bridge between the research question and the execution or implementation of the research" (Terre Blanche & Durrheim 1999:29). Denzin and Lincoln (2002:22) point out that it is the "scientifically designed and planned nature of observations that distinguishes research from other forms of observations. A research design describes a flexible set of methods for

collecting empirical material. It situates researchers in the empirical world and connects them to specific sites, persons or groups."

In this study, the researcher adopted a qualitative approach, using a descriptive, explorative and contextual design.

### 2.4.1 Descriptive

A descriptive study is designed to gain more information about characteristics within a particular field of study. Its purpose is to provide a picture of a situation as it naturally happens (Burns & Grove 2003:201). The aim is to obtain complete and accurate information about the phenomenon. Cormack (2000:213, 217) states that descriptive research is an appropriate design for areas of nursing where little theoretical or factual knowledge exists.

Descriptive research is usually non-experimental, presents a picture of the specific details of a situation, social setting or relationship and focuses on how and why questions. Furthermore, this approach endeavours to portray as accurate as possible accounts of characteristics of particular individuals, events or groups in real-life situations.

This study aimed to describe Black critical care nurses' perceptions of organ donation and transplantation. Data was collected by means of unstructured interviews. The study was concerned with description or classification rather than explanation (see annexure 3).

Except for Bhengu's (1995) study on organ donation and transplantation within the Zulu culture, the researcher found no research or literature available on Black South African critical care nurses' perceptions of organ donation and transplantation. Consequently, this study should provide a new perspective on the topic.

The rationale for adopting a qualitative approach was to study and describe current practice. This could form a basis for further research on the topic.

### 2.4.2 Explorative

The purpose of exploratory studies is to gain insight into a situation or phenomenon. According to De Vos (2002:139), explorative research is undertaken when

- a researcher is examining a new interest
- the subject is relatively new and unstudied
- a researcher seeks to test the feasibility of undertaking a more careful study
- a researcher wants to explore the methods to be used in a more extensive study

Exploratory studies are designed to increase knowledge and insight in a field of study that was not adequately explored previously (Burns & Grove 2003:374). As this was an area that had not been researched extensively, an explorative approach was used to gain more insight into the phenomenon of Black South African critical care nurses' perceptions of organ donation and transplantation. The questions asked in the interviews would yield descriptive data (see annexure 4).

Explorative analysis refers to "examining the data in a relatively unexplored field to become familiar with the nature of data" (Burns & Grove 2003:313).

### 2.4.3 Contextual

The context is "the circumstances in which a particular event occurs" (Munhall 2001:9). Contextual research is carried out in a specific environment and the results are relevant to the specific environment only (Burns & Grove 2003:38). This study wished to describe a specific group, namely Black critical care nurses', perceptions of a specific topic, in a specific geographical area, namely the Gauteng province of South Africa, which then was the setting.

Research results are used to give a better understanding of a specific phenomenon in a particular context (Burns & Grove 2003:313). This means that the results cannot be generalised to a larger population. The individual respondents in this study differed, which contributed to the uniqueness of the research context.

## 2.5 QUALITATIVE METHODOLOGY

Qualitative research refers to a method of inquiry that deals with issues of human complexity by exploring these issues directly. It usually focuses on the inherent complexity of humans, that is the ability of humans to shape and create their own experience and the idea that truth is a composite of realities (Polit & Beck 2004:724). Qualitative research tends to focus on dynamic, holistic and individual aspects of phenomena, and attempts to capture those aspects in their entirety, within the context of those who are experiencing them. As a form of inquiry, qualitative research can be used in any social science or healthcare discipline, and has frequently been used in nursing research (Holloway & Wheeler 1996:1).

The rationale for using this methodology was that the physical, socio-cultural and psychological environment influences behaviour. However, behaviour also goes beyond what is observed (Schmidt in Krefting 1991:21).

Qualitative studies usually aim for depth rather than quantity of understanding. They also attempt to understand the categories of information that emerge from the data (Terre Blanche & Durrheim 1994:42).

Qualitative studies are based on the following world-view (Burns & Grove 2003:357):

- There is no single reality.
- Reality is based on perceptions; it is different for each person and changes over time.
- What we know has meaning only within a given situation or context.

Qualitative research focuses on understanding the whole, within a holistic framework. It explores the depth, richness and complexity inherent in the phenomenon under study (Burns & Grove 2003:357). This approach was appropriate in this study because the researcher wanted to explore the perceptions, feelings and deeper understanding of Black critical care nurses regarding organ donation and transplantation. Black critical care nurses' perceptions of organ donation and transplantation cannot easily be determined by administering questionnaires with a limited number of questions about

specific aspects included in the questionnaire only, because perception is unique for each individual.

In order to discover the respondents' perceptions, then, the researcher studied them in their natural setting, talked to them in a familiar setting, and strove to study the phenomenon in its natural context (Polit & Beck 2004:246). This kind of research is important for healthcare professionals who focus on caring, communication and interaction (Holloway & Wheeler 1996:2).

The following characteristics of qualitative research were observed in this study (Holloway & Wheeler 1996:3-8):

- Qualitative research takes the emic perspective, that is, the insider's view. In this study, Black critical care nurses could be seen as insiders as their own perceptions were being studied.
- Researchers immerse and involve themselves in the setting of the group under study. In this study, the researcher was part of the Black critical care nurses under study and was also exposed to the same incidents as the respondents.
- The data has primacy; the theoretical framework is not predetermined by the data but is rather derived from it. Literature was studied extensively after the data collection.
- The research methodology aims to provide thick description of the data collection process. The researcher aims to do it in this chapter.
- Within the research context, a close relationship exists between the researcher and the respondents, and this relationship is based on a position of equality. The researcher herself did all the interviews. In the employment situation, her position was equal or comparable to those of the respondents.

### 2.5.1 Emic perspective

In this study, rather than imposing a framework of her own that might distort the participants' ideas, the researcher chose to examine the Black critical care nurses' perceptions of organ donation and transplantation. This study was based on the premise that individuals within the research context (the insiders or the Black critical

care nurses) were best placed to describe (in their own words) their own situations, feelings and perceptions relating to the topic (Burns & Grove 2003:367).

### 2.5.2 Immersion in the setting

Immersion in this study meant that the researcher formed part of the staff working in critical care units where organ donation and transplantation are practised. Through interaction, the researcher knew possible participants from whom perceptions of the field of study could be determined. The researcher was familiar with the experiences of Black critical care nurses (Holloway & Wheeler 1996:5). The researcher actively participated in the research process by involving herself, and gathering more information as she also worked in a transplant unit and had previously worked in a trauma unit where organ harvesting was done. Being an active participant is one of the main tools of qualitative research.

### 2.5.4 Primacy of data

Assumptions were not made, but a detailed account of reality was presented verbatim. The researcher ignored her preconceived ideas (bracketing). The intention was to get data about the Black critical care nurses' perceptions from the participants themselves. No restrictions were placed on the duration of the interviews, and participants were allowed to converse until they were satisfied that they had said what they wanted to. Ideas are generated from the data gathered and those ideas can help to improve or modify existing theories (Van Heerden 2005:44).

### 2.5.5 Research relationship

Being a healthcare professional and registered nurse working in a critical care unit with certain characteristics, helped the researcher establish a close research relationship with the participants (Holloway & Wheeler 1996:8). Such a relationship was important because it enabled the researcher to fully understand the occupational context and the participants' frame of reference and gain their trust. This equipped the researcher especially for using probing questions.

The following characteristics are important in order to be a good interviewer and to establish a close research relationship with the participants (Holloway &Wheeler 2000:8):

- Good listening skills
- Non-judgmental attitude
- Friendliness
- Openness and honesty
- Flexibility

The researcher attempted to adopt these characteristics during the data-collection process.

## 2.6 RESEARCH PROCEDURE

In order to conduct qualitative research, a certain research procedure or order of events had to be followed, including defining the population, selecting participants among the Black critical care nurses, and collecting data by interviewing the participants (see annexure 4).

### 2.6.1 Population and sampling

Population refers to “individuals in the universe who possess specific characteristics. It is a term that sets boundaries in the study” (De Vos 2002:198). The population in this study was all the Black critical care nurses working in critical care units in the Gauteng Province where either organ transplant patients were nursed or organ harvesting was done.

According to De Vos (2002:198), sampling means, “taking any portion of a population or a universe as representative of that population or universe”. Sampling involves “selecting a group of people or other elements with which to conduct research” (Burns & Grove 2003:233). Non-probability, purposive sampling was used which means the sample is composed of elements that contain most characteristics, representative or typical attributes of the population (De Vos 2002:207, 334). In non-probability sampling, also called judgmental sampling, researchers select participants based on personal

judgment about which ones will be most representative or informative (Polit & Beck 2004:729). Purposive sampling in this context is based on the fact that researchers use their knowledge about the population in order to handpick the cases to be included into the sample (Polit & Beck 2004:729).

In this study, it was not so much the sample size that was important, as the typical qualities or features of the sample group. The reliability of the results depended on these qualities or features which are listed below (selection criteria). The researcher purposively selected participants who were typical of the population under study.

To be selected to participate in this study, the participants had to

- be Black critical care nurses
- be working in private hospitals in the Gauteng Province
- have at least two years' working experience in critical care units with either organ donors or recipients forming part of the population of that unit
- be willing to speak English during interviews
- be registered nurses; a postgraduate qualification in critical care nursing was not mandatory

### 2.6.2 Pilot study

A pilot study is a small study conducted prior to a larger study to determine whether the methodology, procedure and analysis are adequate (De Vos 2002:210). The researcher conducted a pilot study, using one participant who met the inclusion criteria. The participant was targeted and interviewed, using the central question (see section 2.6.3), but not included in the main study. During this interview, the researcher realised that probing questions would be necessary. These were then formulated.

### 2.6.3 Data collection

According to Burns and Grove (2003:478), data collection is the identification of subjects and the precise, systematic gathering of information (data) relevant to the research purpose or the specific objectives, questions, or hypothesis of a study. In this

study, the researcher collected data in a place identified by the participants as convenient for the interview.

The researcher used an unstructured one-to-one interview in collecting data. Guiding or probing questions were also used. Interviewing was the suitable predominant mode of data or information collection as the researcher wanted to understand the participants' perceptions (De Vos 2002:292).

Interviewing involves verbal communication between the researcher and the participant during which information is provided to the researcher (Burns & Grove 2003:284). Interviews are a form of self-report; they allow collection of data from participants where the completion of questionnaires does not allow the participants to express themselves (Burns & Grove 2003:285). The integrity of the researcher, which includes attributes such as honesty, fairness, knowledge and experience, is essential to ensure the quality and ethical soundness of the research.

In this study, the researcher asked the participants the following central question:

**What is your perception of organ donation and transplantation?**

The interviews were tape-recorded, and data collection continued until data was saturated.

The interviews were then transcribed. The researcher read and reread the verbatim transcriptions, and identified categories and themes (see annexure 3).

The researcher used the following communication skills during interviewing:

- **Attentive listening**

This means listening actively and making use of all the senses. Paying attention to both verbal and non-verbal messages and not selecting or listening to what she wished to hear.

- **Paraphrasing**

This means listening to the participants' basic message and then repeating, or restating those thoughts or feelings in similar words. It may involve merely rephrasing an answer (Kvale 1996:135).

- **Clarifying**

This is a method of making the participants' message more understandable. If a participant's response is vague, unclear or confusing, the researcher needs to be able to ask for clarification. The interviewer brings unclear material into sharper focus (Brammer, Shostram & Abrego 1993:71).

- **Open-ended guiding questions or statements**

An open-ended question refers to a question in an interview or questionnaire that does not restrict participants' answers to pre-established alternatives (Polit & Beck 2004:726). It leads or invites participants to explore and elaborate on their thoughts or feelings. It also places responsibility on the participants to explore their experiences and feelings (see annexure 3).

- **Focusing**

Focusing refers to bringing a topic or question into focus in a loosely structured interview in order to guide the participant (Polit & Beck 2004:719). Focusing can be used if a participant's response is vague or unrelated. In that case, a researcher assists the participant to focus on the research topic.

- **Use of silence**

Natural pauses are used to give participants time to think about the question. This is important because they can then formulate what they really want to answer. Rather than making the interview a cross-examination situation by continually firing questions at the participant, the researcher can apply a therapist's technique of using silence to further the interview. By allowing pauses in the conversation, the participants have ample time

to associate and reflect, and then break the silence themselves with significant information (Kvale 1996:134).

➢ **Probing**

Probing is a technique that is used in order to obtain more useful or detailed information from a respondent in an interview. It refers to the interviewer's ability to help participants to identify and explore experiences, behaviours and feelings that will help them engage more constructively in any of the steps of communication (Polit & Beck 2004:728). Questions are asked to encourage participants to elaborate on the topic discussed. Follow-up questions that pursue the implications of answers to the central question are asked. This enables researchers to elicit more useful or detailed information from participants during interviews (Polit & Beck 2004:729).

As was stated previously, data collection continued until data was saturated. Saturation of data occurs when additional sampling provides no new information, only redundancy of previous collected data (Burns & Grove 2003:258).

Important factors in achieving saturation of data are (Polit & Beck 2004:57):

- Scope of the study: if it is broad, extensive data will be needed.
- Nature of the topic: if it is clear and easily discussed by the respondent, then fewer respondents are needed.
- The quality of the data obtained from respondents: it should be of nature that it could be effectively used for analysis.
- The design of the study: in some cases studies are designed in such a way that the number of interviews should be increased to achieve the objectives.

The researcher also made use of field notes and personal notes.

*Field notes* are a written account of the things that the researcher hears, sees, experiences and thinks in the course of collecting data or reflecting on data. They provide a system of remembering observations (Morse & Field 2002:91). The researcher kept a separate journal in order to record insights, reactions, questions and impressions about emerging patterns as well as ideas about correction to previous

knowledge and decisions about further steps to be taken. This was done after each interview to form a picture of each participant's experience of the interview and to add anything relevant that came out after the tape recorder was turned off.

*Personal notes* are the researcher's own reflection and experiences during the research (Wilson 1989:435). The researcher considered what insight she had of the experience of the respondents' perception of organ donation and transplantation.

## 2.7 DATA ANALYSIS

Data analysis involves breaking the data up into manageable themes, patterns, trends and relationships. The aim of analysis is to understand the various constitutive elements of one's data through an inspection of the relationships between concepts, constructs or variables (Mouton 2001:109).

All the interviews were transcribed verbatim. The following six steps were used to analyse the data (Creswell 1998:200):

- Transcriptions were read through carefully and any ideas that came to mind were written down.
- One document was taken at a time, and careful analysis made to determine the underlying information
- A list was then made of topics that occurred. Similar topics were grouped together.
- The most descriptive wording for the topics grouped together was used as categories. Grouping related and inter-related topics together resulted in the total list of categories.
- A final decision on the naming for each category was made.
- An analysis was then performed again on the assembled data of all the transcriptions in each category to finalise themes and categories.

Finally, the categories were developed and the data organised according their properties. Categorised data was then discussed and literature control done.

## 2.8 LITERATURE CONTROL

After data analysis, the researcher undertook a literature control to compare information from the literature with the findings from the present study to determine similarities and differences. This is done to ensure that one does not merely duplicate other studies, and to discover what the most recent theories on the subject is (Mouton 2001:87). The literature review or control also provided the researcher with a background for the problem studied and was a strategy to ensure the trustworthiness of the data (Brink 1996:76).

## 2.9 TRUSTWORTHINESS

Trustworthiness, or in quantitative terminology validity and reliability, means that different language is needed to fit the qualitative view of research (Krefting 1991:215). The researcher ensured the trustworthiness of this study by using Guba's (1985) (Krefting 1991:215-222) four aspects of trustworthiness: credibility, transferability, dependability, and confirmability.

### 2.9.1 Credibility

Credibility is the alternative to internal validity, in which the goal is to demonstrate that the inquiry was conducted in such a manner as to ensure that the subject was accurately identified and described (De Vos 2002:351). Prolonged engagement is an aspect of credibility as it also implies prolonged interactions with the participants (Rossouw 2003:130). The researcher worked in the organ transplantation environment and with some of the participants in the specific study context and this made it possible for her to have time with and interact on a different level with them where their views on organ donation and organ transplantation were shared and, in doing so, enabled the researcher to reflect on this issue.

The credibility of the study was also enhanced by the fact that a literature review was conducted, and data validated by relevant literature. To further ensure credibility, bracketing was used in this study. According to Polit and Hungler (1997:215), bracketing refers to the process of identifying and holding in abeyance preconceived beliefs and opinions about the phenomenon by the researcher. The researcher did not

let her previous information influence this study and her preconceived ideas were put aside.

### 2.9.2 Transferability (also referred as applicability)

Transferability refers to the degree to which the findings can be applied to other settings or with other respondents if a degree of similarity exists (Mouton 2001:277). Each research situation is unique and cannot be generalised, but comparisons can be made. This researcher is of the opinion that some aspects relating to the respondents' perceptions of organ donation and transplantation in this study can be transferred to similar settings in South Africa. The researcher strove to achieve transferability by providing a dense description of the data and research context. Thick description is necessary to enable other researchers interested in making a transfer to reach a conclusion about whether transfer can be considered a possibility (Polit & Beck 2004:41).

### 2.9.3 Dependability (also referred as consistency)

In qualitative research, dependability is achieved by giving a complete description of the research methods and research context so that the opportunity of replicating the study can be created (Rossouw 2003:183). The key to this is to learn from the information rather than control it. The main instruments important for consistency in qualitative research are the researcher and the participants. In this study, the researcher alone collected all the data.

### 2.9.4 Confirmability (also referred as neutrality)

Confirmability refers to a freedom from bias in the whole research process. It is the degree to which the findings are the product of the inquiry and not of the researcher (Mouton 2001:278). Confirmability attempts to increase the worth of the findings by decreasing the distance between the researcher and the informants. This is usually achieved through prolonged contact with participants.

In this study, confirmability of data was achieved by conducting a literature control to evaluate the results of the data analysis. The findings were compared with relevant

literature to confirm or deny the results, thereby enhancing the trustworthiness of the study. Participants were also consulted to confirm findings or results.

Table 2.1 summarises the strategies employed to ensure trustworthiness in this study, including the specific criteria used.

**Table 2.1 Strategies to enhance trustworthiness of the study**

| Strategy | Criterion | Applicability |
|---|---|---|
| Credibility | Prolonged engagement | While working as a critical care nurse in the critical care setting, the researcher had contact with Black critical care nurses who had experienced caring for dying patients. Some of those patients were potential organ donors. The researcher also had experience in nursing patients' post-organ donation and transplant-tation.<br><br>The researcher invested sufficient time during data collection and gained an in-depth understanding of the group under study. |
| | Reflexivity | Throughout the research process, the researcher made use of field notes to describe and interpret the researcher's own conduct and experiences within the research context. The researcher used the field notes as an instrument to reflect on this study. |
| | Triangulation | Data from three sources, namely interviews, field notes, and literature, were compared.<br><br>The researcher collected and analysed data.<br><br>Information was also obtained by review to determine whether similar experiences had been documented. |
| | Member checking | Findings would be discussed with participants, if the researcher were unsure of the clarity of the data. |
| | Peer examination | The research process and findings were discussed with an academic suitably experienced in qualitative research methodology.<br><br>Consensus discussions took place between the researcher and this academic, who also acted as an independent coder.<br><br>If there are uncertainties participants in the study could be consulted to clarify data. |
| | Authority of the researcher | The researcher underwent training in research methodology. A study leader with experience in conducting qualitative research supervised the study. The researcher is knowledgeable about nursing practice involving organ donation and organ transplantation. |
| | Structural coherence | The focus was only on Black critical care nurses in Gauteng regarding their perceptions of organ donation and transplantation. Findings were relevant to the theme and context only and no attempt was made to generalise the findings. |
| | Referential adequacy | A sample copy of data collected is presented in the final document (see annexure 3). |

| Strategy | Criterion | Applicability |
|---|---|---|
| Transferability | Nominated sample<br>Dense description | Purposive sampling was used and substantiated.<br><br>A dense description of the research method and design was provided to enable comprehension of the research process. |
| Dependability | Description of research method | The same remark as in the previous section regarding dense description applied here. |
| | Code-recode procedure | Consensus discussions were held between the researcher and the co-coder (study leader). |
| Confirmability | Confirmability audit | Co-coder was involved in the data analysis and the coding process discussed. |
| | Reflexivity | Transcribed interviews were used in combination with the researcher's field notes for the data analysis. |

## 2.10 ETHICAL CONSIDERATIONS

To protect the rights of the participants, the Faculty of Health Sciences Ethics Committee at the University of Pretoria reviewed the research protocol. The researcher was given written approval to conduct the study.

The participants were informed of the nature, purpose and significance of the study, the aim of the interview, what the interview entailed, and the researcher's credentials. The researcher also assured the participants that only she would be aware of their identity. Moreover, participation was voluntary and they were free to withdraw from the study at any time should they so wish.

Researchers are ethically obliged to ensure that they are competent and adequately skilled to undertake the proposed study (De Vos 2002:32). The researcher had completed a module in methodology and was supervised by a lecturer who holds a doctorate degree.

## 2.11 CONCLUSION

This chapter discussed the research design and methodology, including data collection; data-collection instrument; data analysis; strategies to ensure trustworthiness, and ethical considerations

Chapter 3 discusses the findings and results of the study as well as the literature control.

# CHAPTER 3

# Results and literature control

## 3.1 INTRODUCTION

This chapter discusses the results of the data analysis and interpretation. The researcher conducted a literature review to support and indicate new findings in this study.

## 3.2 SAMPLE

Purposive sampling was used to select the respondents. Six registered nurses, able to communicate in English and working in specialised units, were willing to participate in the study. For the purpose of anonymity, the respondents did not have to indicate their exact number of years' experience or their age. Table 3.1 indicates the characteristics of the group.

**Table 3.1 Respondents' biographic details**

| Participant number | Gender | Relevant post-registration courses | Courses busy with | Home language | Type of unit where employed at the time of interview | Age group | Range of years of experience |
|---|---|---|---|---|---|---|---|
| 1 | Female | Diploma in critical care nursing. | Nil | Zulu | Critical care unit | 40-48 | 15-20 yrs |
| 2 | Female | Diploma in critical care nursing and B Cur I et A | M Cur in clinical ICU | English | Critical care unit | 25-30 | 5-8 yrs |
| 3 | Female | Diploma in trauma and emergency care | B Cur I et A | Zulu | Critical care unit | 35-40 | 10-15 yrs |
| 4 | Female | Diploma in critical care nursing. | Nil | Xhosa | Critical care unit Dealing with transplants | 45-50 | 15- 20 yrs |
| 5 | Female | Diploma in critical care nursing, | M Cur in clinical nursing | Xhosa | Critical care unit | 35-40 | 10-15 yrs |

| Participant number | Gender | Relevant post-registration courses | Courses busy with | Home language | Type of unit where employed at the time of interview | Age group | Range of years of experience |
|---|---|---|---|---|---|---|---|
| | | nursing administration and education. B Cur I et A | | | Dealing with transplants | | |
| 6 | Male | Diploma in general nursing and Diploma in trauma and emergency care | Nil | Tsonga | Trauma and emergency care unit | 25-30 | 5-10 yrs |

## 3.3 DATA COLLECTION

After informed consent was obtained from the respondents, arrangements were made to interview them. Unstructured interviews were conducted. The researcher asked the respondents the following central question:

**What is your perception of organ donation and transplantation?**

The researcher asked probing questions to gain more insight into issues raised. The interviews lasted about 45 minutes, and were tape-recorded and transcribed verbatim. Field notes were also taken during the interviews. Besides providing additional data, the notes also served as a guide and back up for the researcher when transcribing the data. Interviewing continued until data saturation had been reached.

## 3.4 DATA ANALYSIS

The data collected were carefully analysed and categorised into themes and categories, using content analysis. Content analysis is a qualitative analysis technique used to classify words in a text into themes and categories (Burns & Grove 2003:479). It is a systematic way of examining the content of messages or data. In this case, the content consisted of transcribed interviews.

## 3.5 RESULTS

Six themes with their categories were identified in this study (see table 3.2). The themes and categories are discussed in detail and linked to literature on similar or related issues. The themes provided a structure for detailing the various aspects of the study theme and highlighted most significant and problem areas. Table 3.2 lists the results (see section 3.6 for discussion).

**Table 3.2 Themes and categories in the respondents' perceptions of organ donation and transplantation**

| THEMES | | CATEGORIES | |
|---|---|---|---|
| 1 | Ethical and cultural issues | 1.1<br>1.2<br>1.3<br>1.4 | No respect for human feelings/dignity<br>Organ trafficking<br>Cultural shock<br>Beliefs and superstitions |
| 2 | Economic issues | 2.1<br>2.2 | Economic matters related to work<br>Cost effective |
| 3 | Information and education | 3.1<br>3.2 | Community awareness<br>Staff development |
| 4 | Experience of nurses | 4.1<br>4.2 | Positive feelings and experiences<br>Negative feelings and experiences |
| 5 | Perceptions of nurses of the experiences of patients and family members | 5.1<br>5.2 | Positive experiences<br>Negative experiences |
| 6 | Religious belief | 6.1 | Different views |

## 3.6 THEMES AND CATEGORIES

### 3.6.1 Ethical and cultural issues

*Ballière's Nurses' Dictionary* (1981:123) defines ethics as "a code of moral principles; the moral code governing a nurse's behaviour with her patients, their relatives and her colleagues".

Tjale and De Villiers (2004:217) point out "ethics is also related to and based on cultural principles. The question that should be asked is: right and good according to whom and in whose view?"

Regarding their experiences in organ donation and transplantation, the respondents referred to cultural and ethical issues. This indicated that for the respondents, cultural

and ethical issues were interwoven. The researcher therefore grouped the four related categories identified under the theme “cultural and ethical issues”.

Due to their cultural diversity and social background, most Blacks are not well informed about organ donation and transplantation. The respondents indicated that culture plays an important role in organ donation and transplantation. According to the respondents, some hear about organ donation when a family member is dying, and their hopes are raised that the patient will then be able to survive. They welcome this in a doubtful way, only to be told that the person they wish to see live can save someone else’s life. They have to let go in order to make another family happy, not theirs. According to one respondent:

> *Most of the Black community are culture orientated to such an extent that they believe if you are not related to that person, you are taking something that is not going to work because of the difference in cultural orientation. Maybe our ancestors will get angry or something terrible can happen because there are myths in our culture.*

In some cases, attitudes originate or are rooted in the culture. Pike et al (1993:93) found that public attitudes to organ donation were influenced by cultural beliefs as well as racial prejudices and superstitions in the South African context. Pike et al (1993:94) point out that although nothing prescribes that people need all their organs in order to join their ancestors, cultural beliefs are complex and cannot be overruled with scientific arguments.

#### *3.6.1.1 No respect for human feelings/dignity*

Regarding organ donation and transplantation, the respondents indicated that there was a lack of respect for human dignity in the procedure. They felt that it was not done in such a way that people still maintained their dignity. According to one respondent:

> *I was also involved in a situation where the patient had just died. And now there were all these sisters from the transplant unit, they were like falling all over the patient. For me, I felt it was inhuman. The person has to mourn for the lost child right now. Already we are coming up with a story that we need*

> *somebody to be opened up so that we can have the organs. Those are the situations that make me feel that I would rather let the patient die as he or she is.*

In a study on organ donation and transplantation within the Zulu culture, Bhengu (1995:67) found that the respondents stated that they must not be killed for their organs.

#### *3.6.1.2 Organ trafficking*

The respondents were of the opinion that organ donation could be a form of making money and not for therapeutic and other uses as stipulated in the Human Tissue Act, 65 of 1983, which governs the removal of tissue, blood or gametes from bodies of living persons. For example, in terms of the Act, tissue destined for transplantation may be removed only in a hospital or other authorised institution. According to a respondent:

> *We are being put in a situation where we have to be criminals, the people who are doing these operations and all that … Looking back there was some investigation being done where there was some organ trafficking going on. This was disclosed by the media to the public. That is when I felt rather let the patients have their own organs because what is happening is not honest. People are just making money out of the dead. I think it would be better if they leave the dead alone.*

An article published in the *Medical Chronicle* (Illegal kidney transplant: prominent surgeons and doctors 2005:1-2), supports these findings because in it, it is stated:

> *Prominent surgeons and doctors, including two professors, who participated in what the state says were illegal kidney transplant operations at Durban's St Augustine Hospital, have appeared in the Durban magistrate's court charged with fraud, assault and contravening the human tissue act.*
>
> *It is alleged that Brazilians were paid a few hundred dollars for their healthy kidneys, which were harvested at the Durban hospital and transplanted into Israeli patients who each paid the syndicate up to $120 000. In terms of the assault charges, it is alleged that the full implications were not properly explained to the donors and the operations were a serious assault on them.*

> *Contraventions of the Human Tissue Act relate to the alleged payments to the donors that took place here. Fraud charges relate to documentation, which misrepresented that the donors were relatives and that no money had exchanged hands.*

Amemiya, Suda, Khikawa and Fukuda (1992:2428) found that the majority of Hong Kong people had to go to Mainland China when organ donation and transplantation was needed. The donor sources were mainly from executed criminals. All recipients had to pay a substantial amount for a transplant, so these were basically for those who could afford it. The risk involved was not mentioned to any of the recipients. The first-year mortality was enormous; four times that of transplants done locally and there was a marked increase in morbidity related to chronic hepatitis, which was often acquired after the transplant. In Japan, the society for transplantation does not allow kidney transplants from non-related living donors, but transplantation of kidneys from spouses is sometimes allowed on condition that histo-compatibility and social problems are strictly considered (Amemiya et al 1992:2428).

#### *3.6.1.3 Cultural shock*

Culture is "the total of the inherited ideas, beliefs, values, and knowledge, which constitute the shared bases of social action; the total range of activities and ideas of a group of people with shared traditions, which are transmitted and reinforced by members of the group" (*Collins English Dictionary* 1991:387).

Bouwer, Dreyer, Herselman, Lock and Zeelie (1997:31) emphasise that culture is dynamic whatever way it is defined. It primarily provides guidelines for a way of life and is the result of the way that people have adapted to a particular environment.

In 1879, Tyler (cited in Andrews & Boyle 1995:10) wrote that culture is "the complex whole which includes knowledge, belief, art, morals, law, custom and any other capabilities acquired by man as a member of society. Culture represents a way of perceiving, behaving, and evaluating one's world." Cultural perceptions affect the way people are viewed and expected to act in various situations. A person's behaviour is determined by cultural influences as well as by personal characteristics (Andrews & Boyle 1995:9). Culture is learned not only through formal study but also through a

process of cultural osmosis in which the values, attitudes, roles and behaviours acceptable to and expected by the cultural group are absorbed.

The respondents affirmed the role of culture in people's perceptions of organ donation and transplantation. For example:

> *I believe culture plays a major role. Like in my culture, for instance, everybody would like to bury their relatives whole. They think if they take some organs then it means that the person is not whole. They always want to bury the person with everything, all the organs intact. With that kind of culture it is difficult to allow your family to donate an organ or to be an organ donor yourself. You believe that you have to go back to your maker whole like as you came to earth with all your organs intact. So I do think that culture plays a very important role.*

> *We always believe from the Xhosa background that what I have is mine and I cannot take somebody else's organ because we come from a different cultural background; for example, when a child is born, the family has to do some rituals.*

Some people think health problems are related to culture. Each culture ascribes a cause to a pathological condition and prescribes ways of diagnosing, preventing and treating mental and physical disorders. What is regarded as pathological in one society may be regarded as normal in another (Bouwer et al 1997:32).

South Africa has a pluralistic society with people of different cultures and diverse and conflicting values, beliefs and practices (Bhengu 1995: 16). These diversities are also reflected in people's attitudes towards organ donation and other health issues.

In a study among Afro-Americans and Hispanic Americans, Roark (1999:26) found that cultural differences did not play a major role when it came to organ donation. Most of the Afro-American and White respondents from rural and urban areas were willing to donate their organs. A minority of the respondents objected to donating relatives' organs when they were at the point of death or had passed away. According to these respondents, the decision to donate organs should have been made by the relatives when they were healthy. They stated that it was not up to them to decide for the dying relative. Others had a fear of donating eyes, saying that they would not be able to see

their ancestors in heaven. Furthermore, Roark asked the respondents specifically about the transplantation of an organ from another racial group. A minority stated that inter-racial donations should not be made because donations should be made to sustain a racial group (Roark 1999:26).

#### *3.5.1.4 Beliefs and superstitions*

The respondents perceived beliefs and superstitions as a contributing factor and the researcher identified it as a theme. *Collins English Dictionary* (1991:142) defines belief as "a principle, proposition, idea, etc, accepted as true; opinion, conviction; religious faith; trust or confidence, as in a person or a person's abilities, probity, etc." A superstition is an "irrational belief usually founded on ignorance or fear and characterised by obsessive reverence for omens, charms, etc.; a notion, act or ritual that derives from such belief; any irrational belief, esp. with regard to the unknown" (*Collins English Dictionary* 1991:1548). According to Bairds, Corkie and Grant (1991:3), superstitions are "non-evidenced information carried from generation to generation. A belief is a conviction of truth about the world and the life within it e.g. a person 's experience of sickness is strongly influenced by the belief held about that health problem, for instance, a health practitioner sees it as a biological phenomenon yet some patients experience sickness as a crisis of faith or a consequence of failed relationships including ancestral relationships." In indigenous health systems, "illness is more frequently believed to be caused intentionally and ascribed to supernatural (mystical) causes" (De Villiers in Bouwer et al 1997:34). According to the respondents:

> *If a person has received an organ they will think that the person is not living his/her life. He or she is living the life a person who has donated the organ. It is like they will be judging the recipient's movements; they will think that the donor is living his/her life in the recipient's body.*

> *I was involved in a situation where the patient had received an organ. He was a young man. Unfortunately, it was very traumatic because he was 30 years old and without children. He was very concerned that he is now going to live with somebody else's organ, he wanted clarification or to be counselled. Nurses did not see his concern; they felt that he did not appreciate it. I felt that we forget that people are individuals and they are unique, and that it was his right to raise it.*

The indigenous health belief systems in Southern Africa advance three main types of supernatural causes (Bouwer et al 1997:34):

- The activities of the ancestor spirits and associated supernatural beings, such as God and the river people among the Xhosa, and the *Molapo* spirits among the Pedi.
- The malevolent infliction of harm by a person perpetrating acts or witchcraft or sorcery known as *boloi* among the Sotho and *vhuloi* among the Vendas.
- The idea that illness may automatically follow an action such as the breach of a taboo.

According to Krige (1988:284), the traditional Zulus believe that man consists of:

- The body (*Umzimba*).
- The spirit or soul (*Indlozi* or *Ithongo*).
- The shadow or personality, which is hazily defined and is connected to the ancestral spirit in the Zulu mind. The shadow is that which ultimately becomes the ancestral spirit (*ithongo* or *indlozi*) when the body dies. *Amathongo* (ancestral spirits) live underground and occupy positions as they did while alive.

Although the ancestors are believed to be concerned about the interest and well-being of their descendants, if angered they may cause misfortune, of which illness is one form. Illness may also result when the duties owing to the ancestors, particularly at crucial times during the individual's life cycle, have been neglected. Some people feel the lifespan is predetermined by God therefore if the time for life to end has come, let it be rather than have an organ transplantation (Bhengu 1995:76).

Cadaver organ donation is less common among Afro-Americans for various reasons, including a lack of awareness about organ donation; mistrust of the medical community, and religious reasons. Anecdotal reports suggest that Afro-Americans do not donate organs because of cultural and religious barriers. Failure to adequately educate the Afro-American community about organ donation and a lack of sensitivity to racial issues

are among the main factors associated with poor participation in organ donation (Roark 1999:22).

From the above description it appears as if above cultural belief could play an important role. It seems as if donating an organ from the body may not threaten ancestral protection.

The availability of organs for transplantation is influenced by the attitudes of both the public at large and the medical community. Pike et al (1993:94) maintain that a shortage of organs shows a lack of knowledge and misconceptions. For example, in South Africa, some people argue that they can't donate their organs like corneas, as they need to see their ancestors in heaven when they die (Pike et al 1993:94).

In Japan, the most serious obstacle to transplantation is the lack of organ donation. The first heart transplant was performed in 1968 and a complaint of murder was lodged against the transplant surgeon who performed it, for the removal of the heart. This led to heart, lung, and liver transplantation being discontinued (Amemiya et al 1992:2427). A group of medical doctors also lodged a complaint of murder against the transplant surgeons who performed a combined pancreas-kidney transplantation using organs procured from a brain dead donor (Amemiya et al 1992:2428).

### 3.6.2 Economic issues

Economic matters involve money and are of concern to the patient awaiting organ transplantation of any kind. In this study, the respondents referred to money-related issues, and the economic advantages and benefits.

Medical consultation entails expense and poverty is one of the main problems for many Black South Africans. Although they may be treated as state patients at hospital and clinics, and therefore pay minimum fees or nothing at all, many are still faced with the high cost of transport. If they do not have money, they do not consult a practitioner or keep follow up consultations (Bouwer et al 1997:39). Proximity is important in consultation. Western medical facilities and practitioners are often removed from patients because of unequal distribution in South Africa. People in urban areas have an

advantage over rural people as regards the range of availability of facilities and access to them (Bouwer et al 1997:39).

Some of the respondents were very positive about the effect of organ transplantation, seeing it as something that saved money.

#### *3.6.2.1 Economic work advantage*

Some of the respondents maintained that patients receiving organs would benefit economically related to work or quality of life. As one respondent put it:

> *To me, organ donation is a very good thing. It is good for the recipient, to give him or her second chance in life. For those with kidney failure, haemodialysis is too expensive. When a person has received a kidney, it is going to be easy to manage his life and time. Less money will be spent on treatment. It will not be like going for dialysis three times a week. Even your life changes, you can do your own things at your own time, and are able to do a full day's job.*

Cerilli (1988:487) emphasises that the quality of life for successful transplant patients surpasses that of patients undergoing alternative therapies. Transplant patients are more likely to be working full time or still at school than are patients on alternative therapeutic regimens (Cerilli 1988:487).

A kidney transplant is considered the treatment of choice for the majority of patients suffering from end stage renal failure. The only viable treatment alternative is dialysis. However, from the patient's perspective, dialysis is time-consuming and severely affects quality of life and the way they look (Cerilli 1988:487).

#### *3.6.2.2 Cost effectiveness*

Some of the respondents had experience working in an environment where patients received dialysis. They emphasised the cost effectiveness of transplantation compared to dialysis treatment:

> *Organ transplantation is cost effective considering the fact that travelling to the hospital every alternate day is no longer necessary. This saves a lot of money and time. Time is money. Having time on your hands, you can do a lot of things, concentrate on your job or do some other business. You are able to make long-term plans about job-related issues.*

In 1988 funding for transplantation recipients who required immunosuppressive therapy after transplantation was initiated in the USA (Martinelli 1993:236). According to O'Dell, Brink, Robson and Kahn (1992:394), funding in South Africa for transplantation is not satisfactory, and the impression is that organ transplantation is an expensive procedure that can only benefit the rich and not the have-nots. The fact of the matter is that the results are comparable if not better than other forms of treatment. The surgical and intensive care costs of heart transplantation are no more expensive than those of other major cardiac procedures.

The annual cost of dialysis per patient in the UK is around three times higher than the annual cost for maintenance of a patient after kidney transplantation. Indeed since the procedure is now considered routine, the cost of the operation itself is low. Thus in economic terms, transplantation is the preferred option (Martinelli 1993:236).

### 3.6.3 Information and education

Health promotion information is distributed mostly through patient education. This also helps in community development and organisation, health advocacy and legislation. This increases the options available to people in making informed choices conducive to health. Furthermore, enhancing life skills facilitates the opportunities for people to exercise more control over their own health and their environment.

Community awareness and staff development were grouped under this theme.

#### *3.6.3.1 Community awareness*

The mass media, especially newspapers, radio and television, are powerful means to raise community awareness. However, media exposure does not occur equally across all social groups. People with higher formal education pay more attention to printed media, especially magazines, the news and information programmes on TV compared to people with lower educational levels (Koelen & Van Dan Ban 2005:115). According to the respondents:

> *I think education, lots of education. I said before that we can do this education in the media posters on the wall, newspaper, television, you can educate people. Have organ donation week.*

> *I believe the church leaders reach more people than the media can do, especially in rural areas. Almost everybody belongs to the some kind of church or religion. So all religious leaders can also be educated about organ donation and transplantation and they can take these messages to their followers that can also be an important place to start from.*

> *Children at an early age kind of pick up information easily, especially when they are in school and you teach them such things. It is very important because their beliefs are being formed at that young age. If they believe from that age that organ donation and transplantation is a good thing and will help the community, they will grow up believing it.*

According to Mailula (2005:3), a study funded by the US Agency for Healthcare Research and Quality (AHRQ) found that African communities need good information about the donation process. Africans often do not have all the information they need to make decisions about organ donation process.

The South African Organ Donor Foundation, a non-profit, non-government organisation (NGO) was established in 1988. Medic Alert and the Lions Club of South Africa initially started the foundation, and the objectives of the foundation are to:

- Address the critical shortage of donors in South Africa so that the number of organ transplantations can increase.

- Create awareness of organ donation to adults and children.
- Educate the public about the importance of organ donation and create an informed society who understands the issues surrounding the subject of organ donation (Organ Donor Foundation of Southern Africa 1992:1):

Intensive care nurses, operating room nurses and emergency room nurses often approach families of potential donors, namely brain dead patients. Due to lack of knowledge and experience, potential donors are not adequately referred to transplant experts, because nurses lose objectivity and become emotionally involved with them and the bereaved family, and therefore become reluctant to raise the issue of organ donation (Maher & Strong 1989:357).

Cadaver organ donation is less common in African-Americans for several reasons, including a lack of awareness about organ donation; mistrust of the medical community; religious reasons, as well as cultural and religious barriers. Failure to adequately educate the African-American community about organ donation and a lack of sensitivity to racial issues are the primary factors associated with poor participation in organ donation (Roark 1999:22).

#### *3.6.3.2 Staff development*

Some ignorance still exists among the nursing staff. When faced with a difficult situation and not equipped with knowledge, it becomes a problem because critical care nurses do not always know what to expect in their working environment. Some of the respondents pointed out:

> *I do not think nurses have enough information. Some of the ones I spoke to said they are not interested; others said in our culture we do not do this.*

> *I think, even myself, if I have the necessary information about organ donation and transplantation I can tell the community or educate them.*

> *We need information because, even myself, when I grew up, I grew up knowing that when you die you must go to heaven being complete. If you go to heaven*

*with one eye, you will have many questions to answer to God as to where the other eye is.*

Professional nurses face increasing demands. Thorough training has always been necessary in order to provide basic services. Health is part of a multisectoral approach to developing and meeting the basic needs of all people. Nurses are expected to act as leaders in the process of change and to coordinate multidimensional teamwork. Training is therefore necessary. Nurses will continue to play a key role in the health of the community (Bouwer et al 1997:12).

### 3.6.4 The respondents' experience

In the course of working with post-transplant patients, the respondents realised that patients were benefiting from this programme. They felt that it was beneficial to the patients, especially having seen the patients before and after transplantation (see annexure 3).

Accordingly, the theme of positive feelings and experiences emerged.

#### *3.6.4.1 Positive feelings and experiences*

Most recipients express their gratitude after organ transplantation and feel that they have been given a second chance in life. They see this as a gift of life. Organ transplantation changes their life for better. According to the respondents:

*I spoke to one of the liver recipients. He told me that before they did the transplant on him, when the children asked him to go out he could not, because he was always tired. He said now he is eager to go out and do all the things that he was not able to do.*

*The staff where I work were very excited. It was our first transplant since the nuns opened the hospital more than 50 years ago. The nurses were happy and excited with the success. We felt confident that we had managed to make a change. This will benefit the patient more. And we were also happy that we could make a difference.*

Changes are always not as fast as expected or informed. According to Dutton (1987:648-649), “What has been the impact on my life? Everyone said I would be back to normal in three months, but this did not happen, though I was eating normally (legally). Following this, life improved considerably, with the most significant benefit being the freedom conferred: freedom to visit friends, an awareness that there were no longer rigid time constraints to be imposed. As the fatigue diminished, the patterns of rest and activity associated with normal, everyday living could be resumed and there was a sense of being back in control of the new, independent life. However, I had been on haemodialysis for so long, that I had forgotten what the patterns of rest and activity associated with normal, everyday living were.”

### 3.6.5 Respondents’ perceptions of the experiences of patients and family members

The respondents described their perceptions of organ donation and transplantation. Positive as well as negative experiences were identified.

#### *3.6.5.1 Positive experiences*

According to most of the respondents:

> *It was a good move for the patient to accept that kidney because she was on the waiting list for so long that she was being dialysed maybe three times a week and came from a rural area.*

> *To me, organ donation, I think, is a very good thing. It is good for the recipient to be given a second chance in life, especially those who have kidney failure. Haemodialysis is very expensive. If you have a transplant, less money is needed for the management of the transplanted organ.*

> *The first one I observed was a family. The donor was the wife and the husband was a recipient. The husband was very excited. The wife was overweight by then, but she was so eager to donate for her husband that she managed to lose weight in no time, so that she was able to donate for her husband.*

When a patient is called in for a transplant, it is a worrying and an exciting time for both the recipient and the family. The wait could be anything from a few weeks to several years and it is probably the time when many patients have the most doubts.

#### *3.6.5.2 Negative experiences*

The respondents revealed different perceptions of the patients and their family. Some felt that patients' psychological, social and emotional needs should be addressed. The social and psychological impact varied. According to the respondents:

> *I think transplantation is very difficult and emotionally frustrating for the patient and the family. The patient thinks that now he or she is using somebody else' s organ, moreover that person died so that others could have those organs.*

> *My first experience regarding organ transplantation was scary because I was a student then. I did not expect that a recipient who had received an organ could reject it, and the recipient could be sick, compromising his or her health.*

Transplant patients need to be well informed regarding their condition to understand why most of the things regarding their condition were necessary, especially management of diet, medication, and so on.

Dutton (1987:644) emphasises that the psychological adjustment that takes place following transplantation should not be underestimated. Fears about rejection, side effects of the drugs, other complications and having to find employment are just some of the aspects with which the patient will need help. Occasionally, some patients remain in the sick role, putting extra stress on their family (Dutton 1987:644).

### 3.6.8 Religious belief

Religious views on organ donation differ. According to the respondents,

> *Yes, I strongly believe that religion plays an important role in organ donation and transplantation because some religions believe that you know what you came to earth with and it is what **you must** go to God with. As you are, so you*

*cannot receive anything from anyone else. With Jehovah's Witnesses, you cannot even receive blood transfusion. So I believe that religion plays a part. Traditional believers also do not want to donate any part of their body because they want to go to their Maker as they came to earth, so I think religion does play a part in organ donation and transplantation. As a medical person, I think that if you die there is no use for your body. Your soul is the only thing that matters, not your body. If you donate your body or organs to another person to have life or to a medical school so that they can study more on how to improve medical care, I think it is a good thing.*

*First of all, I believe in the fact that people are meant to go the way they came. For me, I would rather let people make their own decisions without feeling intimidated or guilty. If a person is dying, let the person go with all the organs that they came with. I think that is how it should be religiously.*

Among African-American women residing in a small Southern community, Wittig (2001:206) found that they "strongly believe that God would take care of them, regardless of their decisions relating to organ donation. They believe that God cures illnesses among the righteous and that organ donation is unnecessary for those who live right. The women who did not wish to be organ donors, all expressed this belief. Those who indicated that they would be donors expressed a similar belief that God would care for them until it was time 'to go home'."

Furthermore, regardless of their decision to donate or not to donate organs, they all made reference to God. According to Wittig (2001:206), they related health outcomes to "His Grace" and future health was frequently viewed as the result of possible divine intervention; "of course God takes care of me and he would if I needed a kidney or whatever"; "well, good people don't drink so as to need a liver"; "the Lord helps them that help themselves", and finally that "God intends for the wicked to suffer because he God says you reap what you sow".

## 3.7 CONCLUSION

This chapter discussed the results of the data analysis and interpretation, with reference to the literature review.

Chapter 4 concludes the study and makes recommendations for practice and further research.

# CHAPTER 4

# Conclusion and recommendations

## 4.1 INTRODUCTION

This chapter discusses the outcomes of the study and its limitations, and makes recommendations for practice and further research. Through the data analysis the researcher identified themes and categories related to the respondents' perceptions of organ donation and transplantation. The recommendations are based on the findings.

## 4.2 OUTCOMES OF THE STUDY

The objectives of the study were met as follows:

- The first objective was to determine Black critical care nurses' perceptions of organ donation and transplantation. This objective was met by collecting and analysing data, and formulating themes and categories (see chapters 2 and 3).
- The second objective was to explore and describe Black critical care nurses' perceptions of organ donation and transplantation. The results and the literature review achieved this objective.
- The last objective was to make recommendations in order to instil or strengthen positive attitudes in critical care nurses towards organ donation and transplantation. The recommendations are made in this chapter.

## 4.3 LIMITATIONS OF THE STUDY

The researcher identified the following limitations:

This study was limited to the perceptions of a sample of Black nurses practising in critical care units in Gauteng Province. Consequently, the findings cannot be

generalised to a larger population and were valid for this context only. Generalising findings from a purposive sample to the broader population can be very risky in most instances (Polit & Hungler 1997:230).

Most of the respondents felt that they did not know enough about organ donation and transplantation even though they had heard about it.

Most of the respondents were women. It was not possible to find a reasonable number of male nurses to participate in the study. Therefore it was not possible to determine whether male Black critical care nurses' perceptions would have differed.

## 4.4 RECOMMENDATIONS

Based on the results of the study, the researcher makes the following recommendations for practice and further research. The themes and categories provided a framework for structuring the recommendations.

### 4.4.1 Recommendations for practice

#### *4.4.1.1 Ethical and cultural issues*

The following recommendations are relevant to ethical and cultural issues.

- ***Respect for human feelings/dignity***

➢ It is recommended that nurses in the organ donation and transplantation field be made aware of how to show respect for people's feelings. Human dignity and how it could be held in high regard throughout harvesting as well as the transplantation process should be emphasised.

The donor, although brain dead, should not be handled just as a dead body but with respect/kindness. At the same time, the next of kin's feelings should be respected. They should be given a chance to say farewell, show sadness and not be forced into signing consent for donating organs of the deceased.

In the traditional African culture, there is a strong bond and interdependence between the living and the dead (ancestors) and it is important that this bond is respected. If this bond is not kept, the ancestors would show disapproval by visiting to their offspring in the form of ill health, misfortune, disease, and even death. This also applies to cultural aspects.

It is notoriously well known that in African communities, body parts and organs are used as *muti* (medicine) for witchcraft. Therefore this has a negative connotation and may affect people's attitudes towards organ donation and transplantation adversely. People might be hesitant to give away parts of the body and bury an incomplete person for fear of losing ancestral protection (Henning cited in Bhengu 1995:34). Shangase, Randeree and Schleubusch (1993:7) suggest sympathetic appreciation of cultural relativity as a prerequisite for success in work outside one's own community (see also recommendations on culture). Bhengu (1995:81) states that due to ancestor worship, it is normal in the Zulu culture to offer sacrifices to their ancestors and the respondents deemed it fit to include organ donation and transplantation among these rituals, like reporting organ donation and transplantation or to appease ancestors if it was done without the ancestors knowing. They would, for instance, slaughter a goat or burn incense. Bhengu (1995:91) points out that special attention should be paid to the traditional healers who reflect most misconceptions, yet are the most trusted members of the Zulu community and can, in turn, be utilised for educational campaigns on the topic.

➢ It is recommended that the principles of self-determination or autonomy be respected during organ donation.

The patient receiving an organ has the right to be informed of the following:

- The proposed treatment
- Risks attached
- What to expect in respect to pain, recovery, disfigurement and cost
- Other satisfactory options and success rates

➢ It is recommended that fairness in allocating organs should be observed at all times.

Harries and De Lone (1992:47) and McNatt (1992:343) identify the following inequities in the allocation of organs:

- More men than women receive organs for transplantation.
- More White than Black people receive organs for transplantation.
- More rich than poor people especially in "rewarded gifting" situations receive kidneys.
- More young than old people receive transplants.
- Black patients have a significantly longer waiting period compared to White patients.

McNatt (1992:343) maintains that minority groups must be made to feel that their group has equal access to transplantation thus excluding obstacles like age, money, celebrity, race, physical handicap, or geography in the allocation of organs.

➢ It is recommended that people be made aware of the criteria followed when selecting recipients and donors. Shade (cited in Wittig 2001:203) indicates that Non-Whites wait about twice as long as Whites because of the difficulty in finding a suitable donor.

The following criteria apply in one of KwaZulu-Natal's hospitals for selection for the transplantation programme:

- Psychosocial stability with an adequate support system
- Good communication with health care centre
- Safe water supply

The criterion of a safe water supply means that some patients living in rural areas or informal settlements would not have an equal opportunity for selection (Bhengu 1995:37).

- ***Organ trafficking and legal aspects***

➢ It is recommended that nurses be made aware of all the regulations on organ donation and transplantation as contained in the *Human Tissue Act* (Act 65 of 1983).

Regarding the removal of tissue, blood or gametes from bodies of living persons for therapeutic and other uses, the following aspects must be adhered to:

- Tissue destined for transplantation may be removed only in a hospital or other authorised institution.
- The Medical Superintendent of the hospital or institution must provide written authorisation and may not carry out the transplantation himself.
- Removal of tissue may only be effected with the consent of the donor; in the case of a minor, the consent of the parents or guardian should be given in writing.
- In the case of donors of 14 years or older, who are mentally competent, no parental consent (or guardian) is required before removal of replaceable tissue like bone.
- The donor must have met the criteria for brainstem dead certification before being declared brain dead in case of a cadaver donor.
- Two doctors, one of whom must have been practising for at least 5 years, must establish death. The two doctors may not be members of the transplantation team.
- Tissue removed in order to save a person's life (as the organ was threatening the person's life or the organ was detached from the body and cannot be saved, e.g. bone from an amputated leg after an accident) may be used for any of the above-mentioned purposes.

According to the *Human Tissue Act* (Act 65 of 1983), consent is a prerequisite, except for medico-legal autopsy and can be given under the following circumstances:

- By a deceased person **prior** to his death in a will or any document attested by two competent witnesses.
- The person giving consent must be 14 years and older.

- Consent can also be a verbal statement in the presence of at least two witnesses. The prospective donor may wear an identity tag. The consent may be revoked by the donor prior to his death but not by a relative.
- A spouse, any major child, any parent, guardian, any major brother or sister of the deceased can give consent after death only if the deceased has not forbidden it.

If none of the above can be traced and provided the deceased had not given contrary instructions prior to death, the Director General: National Health and Population Development or someone authorised by him can give consent. The purpose must be to save someone's life and the official concerned must be convinced that all reasonable steps have been taken to trace the relatives if the deceased is unidentified.

Some countries, especially members of the World Health Organization, prohibit the sale of organs by law and no form of incentive other than altruism and volunteerism is allowed for organ donation (Bhengu 1995:40).

Strong and Strong (1985:239) maintain that shortage of organs has forced some countries to allow the sale of organs, e.g. some developing countries like Long Island. In some countries children are sold and sacrificed for their organs (Pike 1992:14). In the Philippines, the family of a brain dead person is promised payment of hospital bills and funeral costs in return for organs (Pike 1992:14).

Martinelli (1993:245) found that rewarded gifting is practised in India, where the recipient

- pays the cost of donor selection
- pays for immediate follow-up
- lifelong health insurance for the donor

In South Africa, hospital fees are waived from the time of brain stem death certification. However, McNatt (1992:341-343) proposes some financial incentives to balance organ transplantation and organ donor supply, such as

- providing funeral expenses
- reducing estate taxes for families of cadaver donors
- government regulated incentives, e.g. medical care to be free
- brokered donation

In the USA, Harries and De Lone (1992:49) emphasise that the privileged have an advantage of multiple listing, by booking an organ in more than one state to shorten their waiting period. Harries and De Lone (1992:49) strongly criticise the commercialisation of human organs on the basis that it puts those who have the means at an advantage and may lead to financial exploitation of the vulnerable, like the poor, especially in the context of gross economic hardship.

Martinelli (1993:241) refers to the 1983 Gallup Society survey finding that married Blacks with higher incomes were more willing to consider organ donation than single Blacks with lower incomes.

South Africa practises the required consent or opt in approach in which consent is either requested from the next of kin or indicated by the donor before death in the form of Medic Alert discs, donor cards or bracelets (McNatt 1992:341; Pike et al 1993:261).

According to Matthewman (1993:45), the advantage of required consent is volunteerism and donor autonomy. In addition, education about newer laws and not the law itself was responsible for the increase in the number of organ donors.

The disadvantage is that this approach does not normally lead to an increase in donation of organs unless the community concerned is well informed and altruistic to give informed consent, and the health care personnel are well motivated to approach families (McNatt 1992:341; Pike et al 1993:264).
Belgium, Austria and other European countries practise the presumed consent or opt out approach, which gives the physician the legal right to remove organs from brain dead individuals without the consent of the patient or family unless the patient or the family have indicated objection to organ donation previously (Pike et al 1993:264). Presumed consent has dramatically increased the availability of organs for transplantation in countries where it is implemented. Ward (1993:44) maintains that

presumed consent removes the burden of having to make an important decision at the traumatic time of bereavement. Moreover, it relieves the hospital staff of the unenviable task of approaching the relatives for permission to remove organs. However, McNatt (1992:342) maintains that the presumed consent approach violates the principle of autonomy and volunteerism on the part of the donor. This approach may change attitudes towards the deceased; for example, regarding them as "spare parts" rather than deceased persons.

Matthewman (1993:45) claims that the presumed consent approach can alienate people and cause them to lose trust in health professions, making it even more difficult to discuss organ donation. Presumed consent is not yet lawful in South Africa therefore it is good to be knowledgeable about it but also to know that it is not done this way in South Africa.

- ***Cultural shock***

➢ It is recommended that it be recognised that organ donation can lead to cultural shock. Therefore, the importance of cultural sensitivity and recognising different cultures in this nursing context is important (also see beliefs and superstitions below).

Cultural sensitivity programmes should be made available for professionals working in the field of organ donation and transplantation.

- ***Beliefs and superstitions***

➢ It is recommended that the beliefs and superstitions of nurses working with organ donation and transplantation patients be addressed. In addition, that it be recognised that patients come from different backgrounds with certain beliefs and superstitions, and this should be taken into consideration and handled sensitively.

Professionals working in this field should read up on the beliefs and superstitions of other cultures.

#### *4.4.1.2 Economic factors*

The following recommendations are relevant to economic factors.

- ***Saving money***

➢ It is recommended that potential donors as well as recipients of organs be made aware of the money that can be saved after organ transplantation. For example, the financial strain of haemodialysis could motivate potential donors to donate organs.

Bhengu (1995:76) found that in one case the members of a congregation were motivated to donate organs because of the experience of a person in financial difficulty from haemodialysis and the church members' efforts to collect funds.

- ***Cost effectiveness***

➢ It is recommended that the cost effectiveness of organ donation be emphasised to donors as well as recipients.

After organ transplantation, the recipient saves money on the trip to renal dialysis three times per week and that time could be allocated for something else. The recipient can do a full day's work after a successful transplant therefore he or she will be an economically active member of society.

#### *4.4.1.3 Information and education*

The following recommendations are relevant to providing information to the community and educating professionals.

- ***Community awareness***

➢ It is recommended that serious efforts be made to eliminate the following obstacles to knowledge about organ donation and transplantation:

- Language differences preventing communication between families and health care workers.
- Public mistrust of health care personnel, which is not necessarily confined to Blacks (Yang, Abrams, Smolinski & Nathan 1993:2487).
- Misconceptions about brain stem death criteria; for example, premature declaration of death for the purpose of organ retrieval.
- Inappropriate timing of the request for organs, such as during the traumatic time of bereavement when the family is not in a position to grasp the concept.

➢ It is recommended that **public awareness campaigns** be launched to motivate individuals to donate organs and to accept the idea of transplantation. People themselves would give consent voluntarily while still alive (Bhengu 1995:92).

➢ It is recommended that the **content of educational campaigns** be attended to as follows:

- The content of education to be given should be designed to meet the needs of the particular community.
- Basic anatomy and physiology principles should be explained to avoid confusion about organs and their functions. Bhengu (1995:72) refers to the confusion of not being able to differentiate between reproductive organs and renal function; the fear of reproducing a different offspring, change of gender, or getting sexually transmitted infections.

- The organs that can be donated need to be specified when explaining the concepts in anatomy and physiology.
- How individuals should indicate that they want to donate their organs should be explained. Bhengu (1995:89) and Simmons (1995:316) emphasise direct contact during discussion of organ donation and transplantation rather than the use of remote mass media programmes.
- Legal aspects of communicating the wish to donate organs should be explained. If the deceased expressed a wish to donate organs, the family or next of kin's decision will be taken as final. If they decide that they do not want the organs to be donated, their decision cannot be overruled.

➢ Regarding the **implementation of educational campaigns**, it is recommended that the following be considered:

- The campaigns must be run throughout the year while the communities are being familiarised with the idea of organ donation and transplantation.
- It would be of benefit to the community if organ donation campaigns can be run throughout the year rather than during the organ donor month only (Simmons 1995:315; Coupe 1990:35).
- Direct contact is preferred. Therefore community health nurses should be asked to include organ donation and transplantation in their existing health education programmes in community health centres (CHCs) and primary health care (PHC) services. Due to the need of information and demand for organs, there is a great need for awareness.
- Health workers of the same culture should be used where possible, because they understand their clients' worldview (e.g., ancestor worship). The language barrier is also an obstacle as 99.9% of transplant coordinators are English-speaking South Africans and not conversant with African languages or African communities' background. Thus it is difficult for them to make them understand or to understand their cultural background and make it easier for them to understand. Bundezi (1992) (cited in Bhengu 1995:89) emphasises that the translator should be conversant not just with the language but also with the patient's culture. Shangase et al (1993:7) point out that the Zulu language has no

terminology to explain concepts like loss of renal function and electrolyte imbalance. This stresses the need that language that is more or next to the people concerned should be used to create a better understanding and to be able to clarify the subjects being explained.

- With regard to the use of the media, the most widely used media and the highest listener or viewing times when families are together should be assessed to trigger discussions.
- People who know the subject and have experience in the field should conduct discussions in the media. They should also be able to answer people's questions appropriately and anticipate people's concerns about organ donation and transplantation.
- Open days should be organised and individuals from the community invited to see the purpose of haemodialysis and transplantation units. This would allow them to compare the expenses involved with these procedures.
- The Organ Donor Foundation of Southern Africa is involved in educational campaigns (e.g., talks in churches, service organisations, women's groups, armed forces and schools). These talks are given by transplant co-coordinators and transplant recipients and the foundation's campaign should be promoted.
- The appointment of Black transplant coordinators may help improve communication (Pike et al 1993:267).

➢ It is recommended that **target populations** be identified for educational campaigns, including the following:

- Nurses working in non-transplant intensive care units, operating rooms, casualty and surgical units (Bhengu 1996:43).
- Law enforcement officers as well as members of the local fire department and other individuals who may be instrumental in organ procurement (Coupe 1990:34).
- Community health nurses for their close contact with the community and because often they are of the same culture as the community.

- Religious leaders to clear their religious aspects and provide Scriptural verses relevant to extension of life on organ donation and transplantation.
- Clergy and ministers could indicate that medical and advanced technological resources used to provide organ transplants and sustain life are acceptable practices in the Church. The introjections of ideas such as the notion that God gave us the abilities to perform these procedures could be beneficial (Wittig 2001:209).
- Staff of the same culture in the transplant unit should use their terminology and phraseology to clarify and explain concepts to patients and their relatives.
- Transplanted and live donors should discuss the effect of transplantation and organ donation, respectively.
- Community organisations, such as burial clubs, as they are already engaged in activities of preparing for death.

- ***Staff development***

➢ It is recommended that the entire health team be equipped with information on organ donation and transplantation to enable and facilitate knowledge transfer in the workplace, when the need arises, as well as to provide good care, when necessary.

There is a need for staff development programmes to be implemented to maintain the standard. Theory and skills taught in the classroom should be followed through into the workplace and established in actual practice. Theory and practica must be integrated so that people realise that it is not just theory that does not exist in the real world.

Orientation programmes on organ donation and transplantation are essential. Urden, Stacy and Lough (2006:6) state that sufficient inquisitive practitioners who strive for best practices in order to provide optimal care need to be employed to care for the rapidly growing population of critically ill patients (potential donors should be identified, referred properly and proper nursing care be continued).

Lack of knowledge makes people less confident and unable to render total quality nursing care. Coupe (1990:28) maintains that nurses do not refer potential donors adequately due to lack of knowledge and experience of organ donation and transplantation. Monett (1992:34) claims that nurses become emotionally involved with the patient and the bereaved family, thus become reluctant to raise the question of organ donation, feeling that "the family has had enough". Coupe (1990:36) contends that health care personnel have both knowledge and interpersonal problems regarding the following aspects of organ donation and transplantation and staff development could focus on these aspects:

- Legal and medical aspects of organ donation and transplantation, like criteria for transplants and legislation such as the *Human Tissue Act* (Act 65 of 1983) (South Africa (Republic) 1983).
- Relationship of brain stem death and organ donation.
- Interpersonal and communication skills to approach a grieving family and a family of a different language.
- Hospital policies regarding procurement and allocation of organs.
- Assertiveness, to act as the patient's advocate.
- Knowledge of referral units or hospitals and procedures for referral.
- Donor maintenance.

Some of the respondents stated that they needed to be educated, as the last time they had heard about organ donation and transplantation was during their training and most of the information did not make sense to them as they thought it was something very rare. In-service training would help keep them well informed and up to date.

Awareness and development programmes to enhance organ donation and transplantation should be implemented and promoted, in a way that would create a mind shift in the nursing profession.

➢ It is recommended that the following methods be used to promote awareness of organ donation and transplantation:

- Seminars
- Panel discussions
- Conferences

The study concluded that most of the respondents did not have enough information on organ donation and transplantation, therefore, it is recommended that the above be used to equip them with the required information. Wittig (2001:203) maintains that although some explanation for low organ donation rates has been addressed, there is still much that is not understood.

#### *4.4.1.4 Recommendations for nurses' experiences*

The following recommendations are relevant for nurses' experiences.

- ***Positive feelings and experiences***

➢ It is recommended that if nurses feel good about the results achieved (successful organ transplantation), the results should be spread to the community so that they can see the benefit of it.

Word of mouth is a powerful method of spreading a message, as first-hand information is the best because is not altered. The results of organ donation and transplantation are seldom made known.

- ***Negative feelings***

➢ It is recommended that nurses with negative feelings about organ donation and transplantation be counselled, educated and supported in the process of nursing donors or recipients of organs. Programmes that will help them to understand the need of saving a life through organ donation and transplantation should be free. Strategies like values clarification could be used.

#### *4.4.1.5 Nurses' perceptions of the experiences of patients and family members*

The following recommendations are made for nurses' perceptions of the experiences of the patients and family members.

- ***Positive experiences***

➢ It is recommended that positive experiences of organ donation and transplantation be shared. Facilitate and encourage the spread of positive information. Good working relationships between the coordinators and the nurses looking after the recipient and the donors should be spoken about.

- ***Negative experiences***

➢ It is recommended that family and patients be educated about organ donation and transplantation, including the side effects of medication and the complications. They should be aware that sometimes healing could take months. The chances of rejection should also be explained as this devastates them most.

#### *4.4.1.6 Religious and philosophical factors*

➢ It is recommended that different religious and life-view backgrounds be respected. This also plays an important role, as we live in an open society where human rights are respected.

Organ donation is seen as a good deed in religious terms. To the researcher coercion seems to be a problem among husbands who coerce their wives into donating organs to them such as kidneys. This problem may be related to the traditionally imposed social standing of women as subordinate to men and men as providers of social position and the good things in life.

➢ It is recommended that information on different religions related to religious practices be made available, such as the following:

- *Christianity*

  Organ donation and transplantation is a modern concept. The Bible does not directly address this question, but the researcher, as a Christian, is of the opinion that a decision of this nature can only be made between a person, their family, and God. A guideline could be that a person should prayerfully consider what God would want them to do in regard to donating their organs upon death because in James 1:5 the message is "if anyone of you lacks wisdom let him ask God who gives to everyone without reserve and without reproach" (The Holy Bible 1983:900), which is considered the light of life for guidance. "If you feel led to donate organs, then there is no reason you should not. If you do not feel led to do so, you should not feel guilty about it and you should not allow yourself to be coerced by someone" (Mailula 2005).

  Donation and transplantation are strongly encouraged by Seventh Day Adventists who are also a sub-group within the Christian faith. They have many transplant hospitals, including Loma Linda in California. Loma Linda specialises in paediatric heart transplantation (Mailula 2005).

- *Buddhism*

  Buddhists believe that organ donation is a matter of individual conscience and place a high value on acts of compassion. Mailula (2005) stated that Gyomay Masao, president and founder of the Buddhist Temple of Chicago indicated that they honor those who donate their bodies and organs to the advancement of medical science and to saving lives. The importance of letting loved ones' know your wishes is stressed.

- *Hinduism*

  Mailula (2005) also indicated that the Hinduism Temple Society of North America does not prohibit Hindus from donating their organs. This act is an individual decision. Trivedi (cited in Mailula 2005) in this *Transplantation Proceedings* article states that "Hindu mythology has stories in which parts

of the human body are used for the benefit of other humans and society. There is nothing in the Hindu religion indicating that parts of humans, dead or alive, cannot be used to alleviate the suffering of other humans."

- *Islam*

  The religion of Islam believes in the principle of saving human lives. According to Sachedina (1990) (cited in Mailula 2005) in his Transplantation Proceedings' article, *Views on Organ Transplantation*, "the majority of Muslim scholars belonging to various schools of Islamic law have invoked the principle of the priority of saving human life and have permitted organ transplant as a necessity to procure that noble end" (Mailula 2005).

- *Jehovah's Witness*

  Mailula (2005) indicated that according to the Watch Tower Society, Jehovah's Witnesses believe organ donation is a matter of individual decision. Jehovah's Witnesses are often assumed to be opposed to donation because of their belief against blood transfusion. However, this merely means that blood must be removed from the organs and tissue before being transplanted. This would make transplantation impossible.

- *Judaism*

  According to Mailula (2005), all branches of Judaism (Orthodox, Conservative Reform and Reconstructionist) support and encourage organ donation. In 1999, the Rabbinical Court of America (Orthodox) approved organ donation as permissible, and even required from brain-dead patients.

### 4.4.2 Recommendations for further research

There is a need for research in the critical care environment in order to foster high-level patient care, especially in the field of organ donation and transplantation. There is a great need for organs. Every year, thousands of people die while waiting for organ

transplantation. The researcher therefore makes the following recommendations for further research:

- A quantitative study of critical care nurses' perceptions of organ donation and transplantation over a wider area could be done.
- A qualitative study of community perceptions of organ donation and transplantation in rural and urban areas should be done.
- The general public's perceptions and understanding of organ donation and transplantation should be investigated.
- A comparative study should be done of critical care nurses' perceptions of organ donation and transplantation in South Africa and those of other countries.

## 4.5 REFLECTION OF THIS STUDY

The study emanated from the researcher's own experience working in a level 1 trauma unit and trauma ICU prior to working in a general ICU where patients were admitted post-operatively following organ transplantation.

The researcher realised that there was a lot of uncertainty and no system or programme in place to help nurses to deal with the family of the potential donor when coordinators introduced the subject of organ donation and transplantation.

The researcher found prevailing specific problems related to critical care nurses' perceptions of organ donation and transplantation in the nursing clinical environment. The study was undertaken to understand their perceptions of organ donation and transplantation. Among the nurses, some were totally comfortable with organ donation and transplantation while others were completely against it.

## 4.6 CONCLUSION

The researcher ventured on a journey into Black critical care nurses' perceptions of organ donation transplantation. The entry point was from a position of realising a lack of information and misunderstanding among the nursing staff on organ donation and transplantation. The study indicated that there is a need for education on the subject.

The consequent recommendations for nursing education, cultural and ethical issues, kinship and social factors, and implementation of educational programmes should benefit transplant units and the community at large.

## BIBLIOGRAPHY

Amemiya, OH, Suda, ZN, Khikawa, JM & Fukuda, EA. 1992. Knowledge and attitude about organ donation. *Transplantation Proceedings*, 23(2):2427-2428.

Andrews, MM & Boyle, J. 1995. *Transcultural concepts in nursing management care*. 2nd edition. Philadelphia: Lippincott.

Aston-Prior, P. 2000. The greatest gift of all. *South African Medical Journal*, 90(1):57-59.

Babbie, E & Mouton, J. 2001. *The practice of social research*. Cape Town: Oxford University Press.

Bairds, MC, Corkie, RD & Grant, M (eds). 1991. *Cultural systems*. Philadelphia: Saunders.

*Ballière's Nurses' Dictionary*. 1981. 19th edition. London: Cassell.

Beck, CT. 2006. *Nursing research: principles and methods*. 7th edition. Philadelphia: Lippincott, Williams & Wilkins.

Bhengu, BR. 1995. Organ donation and transplantation within the Zulu culture. Unpublished master's dissertation. Johannesburg: Rand Afrikaans University.

Booysens, SW. 1996. *Introduction to health service management*. Cape Town: Juta.

Bouwer, M, Dreyer,S, Herselman, M, Lock, M & Zeelie, S. 1997. *Contemporary trends in community nursing*. Johannesburg: Thomson.

Brammer, LM, Shostram, EL & Abrego, PJ. 1993. *Therapeutic psychology: fundamentals of counseling and psychotherapy*. 6th edition. Englewood Cliffs, NJ: Prentice Hall.

Brink, HIL. 1996. *Fundamentals of research methodology for health care professionals*. Cape Town: Juta.

Burns, N & Grove, SK. 2003. *Understanding nursing research*. Philadelphia: Saunders.

Cerilli, GJ. 1988. *Organ transplantation and replacement*. Philadelphia: JB Lippincott.

Clochesy, JM, Breu, C, Cardin, S, Rudy, EB & Whittaker, AA. 1993. *Critical care nursing*. Philadelphia: Saunders.

*Collins English Dictionary*. 1991. 3rd edition. Glasgow: HarperCollins.

Cormack, D. 2000. *The research process in nursing*. 4th edition. London: Blackwell Science.

Coupe, D. 1990. Donation dilemmas. *Nursing Times*, 86(27):34-36.

Creswell, JW. 1998. *Qualitative inquiry and research design: choosing among five traditions*. Thousand Oaks: Sage.

Denzin, NK & Lincoln, YS. 2002. *A handbook of qualitative research*. Thousand Oaks: Sage.

De Vos, AS (ed). 2002. *Research at grass roots: a primer for the caring professions*. 2nd edition. Pretoria: Van Schaik.

Dutton, M. 1987. Chronic renal failure: a personal account of life before and after transplantation. *Renal Nursing*, 17:646-649.

Evans, MM. 1993. Moral costs. *Nursing Times*, 89(37):34-35.

Gillies, DA. 1982. *Nursing management: a systems approach*. Philadelphia: Saunders.

Green, C. 1983. *Organ transplantation*. London: Oxford.

Guba, EG. 1989. *Criteria for assessing the trustworthiness of naturalistic inquiries.* Educational Resources Information Centre Annual Review Paper No 29:75-91. London: Sage.

Hawker, FH. 2002. *Liver transplantation*. 4th edition. London: Butterworth.

Harries, JS & De Lone, PA. 1992. Allocation of cadaver kidneys. *ANNA Journal*, 19(1):47-49.

Henning, E, Van Rensburg, W & Smit, B. 2004. *Finding your way in qualitative research*. Pretoria: Van Schaik.

Henning, W. 1992. Traditional healers: hocus pocus or the way to health? *Sunday Times Magazine*, 40:32-36.

Holloway, I & Wheeler, S. 1996. *Qualitative research for nurses*. Oxford: Blackwell Science.

Illegal kidney transplant: prominent surgeons and doctors. 2005. *Medical Chronicle*:1-2.

Koelen, MA & Van Dan Ban, AW 2005. *Health education and health promotion*. Wageningan: Wageningan Academic.

Krefting, L. 1991. Rigor in qualitative research: the assessment of trustworthiness. *American Journal of Occupational Therapy*, 45(3):214-222.

Krige, EJ. 1998. *The social systems of the Zulus*. Pietermaritzburg: Shuter and Shooter.

Kvale, S. 1996. *Interviews: an introduction to qualitative research interviewing*. Thousand Oaks: Sage.

Laing, R. 2004. Accompaniment needs of nursing students related to the dying patient. Unpublished master's dissertation. Port Elizabeth: University of Port Elizabeth.

Leininger, MM. 1991. *Culture diversity and universality: a theory of nursing*. New York: National League for Nursing.

Lynch, J. 1990. Approaching organ donation in the African-American family: a case for understanding expectations. *Contemporary Dialysis and Nephrology:*21.

MacKenzie, D. 1992. Donor of death. *YOU*, April 1992:18-19.

*MacMillan English Dictionary for Advanced Learners*. 2002. Oxford: Bloomsbury.

Maher, ME & Strong, S. 1989. Organ donation: a nursing perspective. *Journal of Neuroscience Nursing*, 21(6):357-360.

Mailula, ML. *Correspondence*, 14 October. Pretoria University.

Manganyi, NC. 1974. Health and disease: some topical problems of socio-cultural transitions. *SA Medical Journal*, 48:922-924.

Martinelli, AM. 1993. Organ donation: barriers, religious aspects. *AORN*, 58(2):236-251.

Matshikwe, NB. 2001. Critical care nursing specialists' experience of their work environment. Unpublished master's dissertation. Port Elizabeth: University of Port Elizabeth.

Matthewman, E. 1993. Opting out. *Nursing Times*, 89(2):44-46.

McCurdie, F, Donald, D & Kahn, D. 1992. Suicide and organ donation. *Verpleging RSA Nursing*, 7(6):43-46.

McNatt, G. 1992. Testimony: controversy in organ donation. *ANNA Journal*, 19(4):341-343.

Monett, R. 1992. *Applied social research tool for the human services*. Menlopark: Addison Wesley.

Morse, JM & Field, PA. 2002. *Nursing research: the application of qualitative approaches*. 2nd edition. London: Chapman and Hall.

Mouton, J. 2001. *How to succeed in your master's and doctoral studies: a South African guide and resource book*. Pretoria: Van Schaik.

Munhall, PL. 2001. *Nursing research*. 3rd edition. Sudbury: Jones & Bartlett.

Ngubane, H. 1997. Body and mind in Zulu medicine: an ethnography of health and disease in nursing. San Francisco: Academic Press.

O'Dell, JA & Brink, JG. 1992. Heart transplantation in South Africa: a critical appraisal. *South African Medical Journal*, 82:394-396.

O'Dell, JA, Brink, JG, Robson, S & Kahn, D. 1992. Transplantation of solid organs in South Africa. *South African Medical Journal*, 82:427-431.

Oh, JE. 2002. *Design and organization of critical care units*. Intensive care manual. 4th edition. London: Butterworth.

Organ Donor Foundation of Southern Africa. 1992. Annual report. Cape Town: Juta.

Pike, RE. 1992. Organ donour in developing countries. *Nursing SA Verpleging*, 7(10):2-14.

Pike, RE, O'Dell, JA & Kahn, D. 1993. Public attitudes to organ donation in South Africa. *South African Medical Journal*, 83(2):91-94.

Polit, DF & Beck, CT. 2004. *Nursing research: principles and methods*. 7th edition. Philadelphia: Lippincott.

Polit, DF & Hungler, BP. 1997. *Essentials of nursing research*. 4th edition. Philadelphia: Lippincott-Raven.

Polit, DF, Hungler, BP & Beck, CT. 2001. *Essentials of nursing research*. 4th edition. Philadelphia: Lippincott-Ravan.

Prograf Tacrolimus Product Monograph. [Sa]. *Efficacy in kidney transplantation*. Johannesburg: Adcock Ingram.

Roark, D. 1999. The need for increasing organ donation among African-Americans and Hispanic Americans. *Journal of Emergency Nursing*, 25(1):21-27.

Rossouw, D. 2003. *Intellectual tools: skills for the human sciences*. 2nd edition. Pretoria: Van Schaik.

Schlebusch, L, Bruwer, MM & Bosman, EA. 1991. Interspouse donor decisions in renal transplant. *Membrane* 11(1):7-9.

Searle, C. 1987. *Professional practice: a South African nursing perspective*. Durban: Butterworths.

Sells, RA. 1992. Some ethical issues in organ retrieval. *Transplantation Proceedings*, 24(6):2401-2403.

Shangase, GS, Randeree, IGH & Schleubusch, L. 1993. Traditional beliefs and practices versus modern health care. *Membrane*, 11(1):6-7.

Simmons, DE. 1995. Significance of increasing organ donation by African-Americans and implications for nursing practice. *ANNA Journal,* 22(3):313-317.

South African Dialysis and Transplantation Registry. 1992. *Combined report on maintenance dialysis and transplantation in the Republic of South Africa*. Cape Town: Juta.

South Africa (Republic). 1978. *Nursing Act (*Act 50 of 1978, as amended*)*. Pretoria: Government Printer.

South Africa (Republic). 1983. *Human Tissue Act* (Act 65 of 1983). Pretoria: Government Printer.

South Africa (Republic). 2005. *Nursing Act* (Act 33 of 2005, as amended). Pretoria: Government Printer.

South African Nursing Council (SANC). 1998. *Standard for nursing practice*. Pretoria: Government Printer.

South African Society of Nursing Researchers. 1996. Ethical standards for nurse researcher. *Curationis*, 19(1):74-75.

Strauss, SA. 1992. *Legal handbook for nurses and health personnel*. 7th edition. Cape Town: King Edward VII Trust.

Strong, M & Strong, C. 1985. The shortage of organs for transplantation. *ANNA Journal*, 12(4):239.

Tesch, R. 1990. *Research design: qualitative and quantitative approaches*. Thousand Oaks: Sage.

Terre Blanche, M & Durrheim, K. 1999. *Research in practice*. Cape Town: Oxford University Press.

The Holy Bible. 1983. *National bible press for the Gideons International*. South Africa.

Tjale, A & De Villiers, L. 2004. *Cultural issues in health and health care*. Cape Town: Juta.

Tyler, P. 1985. African tribal medicine and its role in modern nephrology. *EDTNA Journal*, V:35-40.

Urden, LD, Stacy, KM & Lough, ME. 2006. *Thelan's critical care nursing: diagnosis and management*. St Louis: Mosby/Elsevier.

Van Heerden, M. 2005. The perceptions of accident and emergency nurses regarding a structured debriefing programme in a private hospital in Gauteng. Unpublished master's dissertation. Pretoria: University of Pretoria.

Ward, E. 1993. Opting out. *Nursing Times*, 89(A20):44-46.

Wilson, HS. 1989. *Introducing research in nursing*. 2nd edition. Menlo Park: Addison-Wesley.

Wingate, P. 1976. *The Penguin Medical Encyclopaedia*. 2nd edition. Hammondsworth: Penguin Books.

Wittig, DR. 2001. Organ donation beliefs of African-American women residing in a small Southern community. *Journal of Transcultural Nursing*, 2:203-210.

Yang, SL, Abrams, J, Smolinski, S & Nathan, H. 1993. Organ donation and referrals among Black Americans. *Transplant Proceedings*, 25(4):2487-2488.

# ANNEXURE 1

## Letter: Informed consent

# PARTICIPANT INFORMATION LETTER AND INFORMED CONSENT

## TITLE: BLACK CRITICAL CARE NURSE'S PERCEPTION OF ORGAN DONATION AND ORGAN TRANSPLANTATION

### INTRODUCTION

You are invited to volunteer for this research study. This information letter is to help you decide if you would like to participate. Before you agree to take part in this study, you should fully understand what is involved. If you have any questions, which are not fully explained, do not hesitate to ask questions.

### AIM AND OBJECTIVES OF THE STUDY

The aim of this study is to determine the perceptions of black critical care nurses, working in the critical care environment regarding bereavement organ donation and organ transplantation.

### WHAT IS EXPECTED OF YOU DURING THIS RESEARCH STUDY?

You will have to give some of your time in order to participate in an unstructured interview and share your perceptions regarding the research topic.

### HAS THE STUDY RECEIVED ETHICAL APPROVAL?

This study protocol was submitted to the Research Ethics Committee of the University of Pretoria, Faculty of Health Sciences. The committee has granted written approval (see annexure 2)

### WHAT ARE MY RIGHTS AS A PARTICIPANT IN THIS STUDY?

Your participation in this study is entirely voluntary and you can refuse to participate or stop at any time without stating any reason.

### CONFIDENTIALTY

All information obtained during the course of this study is strictly confidential. Data that might be reported in scientific journals will not include any information that identifies you as a participant in this study.

## SOURCE OF ADDITIONAL INFORMATION

If you have any questions during this study please do not hesitate to contact me or my supervisor on the following numbers:

Researcher: Nancy Shubane
011 824 0806/7
078 1087 627

Supervisor: Dr.A.D.H. Botha
012 429 8814

## INFORMED CONSENT

I hereby confirm that I have informed by the student researcher Nancy Shubane about the nature and conduct of the study. I have also received, read and understood the above written information (Participant Information Letter and Informed Consent) regarding the study.

I am aware that the results of the study, including personal details will be anonymously processed into the study report.

I may, at any stage, without prejudice, withdraw my consent and participation in the study. I have had sufficient opportunity to ask questions and (of my own free will) declare myself.

Participant's name: _____

Participant's surname: _____

Participant's signature: _____

Date: _____

I, Nancy Shubane, herewith confirm that he above participant has been informed fully about the nature conduct and risks of the above study.

Researcher's name: _____

Researcher' signature: _____

Date: _____

# ANNEXURE 2

## Permission obtained from the Research Ethics Committee (University of Pretoria)

University of Pretoria
Faculty of Health Sciences Research Ethics Committee
University of Pretoria
Tel (012) 339 8619 Fax (012) 339 8687
E Mail deepeka.behari@up.ac.za
Soutpansberg Road Private Bag x 385
MRC-Building Pretoria
Level 2, Room 20 0001

**Date: 21/07/2004**

**Number** : **S105/2004**

**Title** : Black critical care nurses' perceptions of organ donation and organ transplantation

**Investigator** : Nancy Shubane, Dept of Nursing Science, University of Pretoria
(SUPERVISORS: MS I COETZEE / DR A D H BOTHA)

**Sponsor** : **None**

**Study Degree** : **M Cur (Clinical)**

**This Student Protocol has been considered by the Faculty of Health Sciences Research Ethics Committee, University of Pretoria on 20/07/2004 and found to be acceptable.**

| | |
|---|---|
| Prof P Carstens | BLC LLB LLD (Pret) Faculty of Law |
| Prof S.V. Grey | (female) BSc (Hons); MSc; DSc: Deputy Dean |
| Prof V.O.L. Karusseit | MBChB; MFGP (SA); M.Med (Chir); FCS (SA): Surgeon |
| Dr M E Kenoshi | MB,CHB; DTM & H (Wits); C.E.O. of the Pretoria Academic Hospital |
| Prof M Kruger | (female) MB.ChB.(Pret); Mmed.Paed.(Pret); PhDd. (Leuven) |
| Dr N K Likibi | MB.BCh.; Med.Adviser (Gauteng Dept. of Health) |
| Dr F M Mulaudzi | (female) Department of Nursing |
| Miss B Mullins | (female) BscHons; Teachers Diploma |
| Snr Sr J. Phatoli | (female) BCur (Et.Al) Senior Nursing-Sister |
| Prof H.W. Pretorius | MBChB; M.Med (Psych) MD: Psychiatrist |
| Reverend PDG Richards | B.Th. (UNISA), M.Sc. (Applied Biology) (Knights), M.Sc (Med) (Wits), TechRMS, DipRMS |
| Dr L Schoeman | (female) Bpharm, BA Hons (Psy), PhD |
| Dr C F Slabber | BSc (Med) MB BCh, FCP (SA) Acting Head; Dept Medical Oncology |
| Prof J.R. Snyman | MBChB, M.Pharm.Med: MD: Pharmacologist |
| Dr R Sommers | (female) MBChB; M.Med (Int); MPhar.Med |
| Dr TJP Swart | BChD, MSc (Odont), MChD (Oral Path) Senior Specialist; Oral Pathology |
| Prof C W van Staden | MBChB; Mmed (Psych); MD; FTCL; UPLM; Dept of Psychiatry |

**Student Ethics Sub-Committee**

| | |
|---|---|
| Mrs E Ahrens | (female)B.Cur |
| Dr L Schoeman | (female) Bpharm, BA Hons (Psy), PhD |
| Dr R Sommers | SECRETARIAT (female) MBChB; M.Med (Int); MPharMed |
| Dr S.J.C. van der Walt | (female) B Art et Scien (PU for CHE),M Soc Sc (UFS), M Ed (UFS), D.Cur (RAU) |
| Mrs N Lizamore | (female) BSc(Stell), BSc (Hons) (Pret),MSc (Pret) DHETP (Pret) |
| Prof R S K Apatu | MBChB(Legon); PhD(Cambridge) |
| Advocate A G Nienaber | (female) BA(Hons) (Wits); LLB; LLM (UP); Dipl Datametrics (UNISA) |
| Dr S I Cronje | DD (UP) – Old Testament Theology |
| Dr M M Geyser | (female) BSc; MBChB; BSc HONS (Pharm); Dip PEC; MpraxMed |

PROF J R SNYMAN
MBChB, M.Pharm.Med: MD: Pharmacologist
CHAIRPERSON of the Faculty of Health Sciences Research
Main Ethics Committee - University of Pretoria

DR L SCHOEMAN
Bpharm, BA Hons (Psy), PhD
CHAIRPERSON of the Faculty of Health Sciences Research
Students Ethics Committee – University of Pretoria

# ANNEXURE 3

## Sample: Copy of data collected

**TRANSCRIBED UNSTRUCTURED GUIDED AUDIOTAPED INTERVIEW**

**Researcher**: I promise that confidentiality and anonymity will be maintained throughout the study. So feel free to express your perceptions on organ donation and transplantation.

**Researcher**: As a critical care nurse what are your perceptions on organ donation and transplantation?

**Participant:** I think organ donation is a good thing. If there is someone who is about to die, although it is very unfortunate it is best to donate their organs to somebody who need it to live. I think it is a very good thing. I think it is fine.

**Researcher:** Have you ever been involved in a situation where an organ was transplanted?

**Participant:** Yes, I have nursed patients who have been transplanted, liver, kidney and simultaneous kidney and pancreas.

**Researcher:** How did you feel about that?

**Participant:** I think it is emotionally straining and very difficult for the family sometimes. Even the patient because now the patient feels that they have got somebody else's organ and especially that he /she died so that they can get an organ. I think emotionally and even psychologically for the patient it is quite very difficult and they need to be prepared before transplant can be performed with organs from other people.

**Researcher:** Does that also affect the nursing staff especially those who are delegated to look after the patient who had a transplant?

**Participant**: Yes, sometimes if you hear who died or what happened to the donor, it quite touches you. I have had quite a few of them where a patient had to receive an organ from a person who committed suicide so such stories kind of linger in your mind as you nurse the patient it does affect one at some stage or another.

**Researcher**: Do the recipients know where the organs are coming from?

**Participant:** No, they do not know. In all areas where I rendered my services, the patients do not know where they got organs from. They just know that the person is deceased.

**Researcher:** If they happen to ask you do you think you might be tempted to tell them?

**Participant:** No, I do not think it is ethical to tell them where they got the organs from because they will feel guilty that a person had to die for them to get an organ so I do not think it is fair for the patient to tell them.

**Researcher:** How does the recipient cope with the organs that they have received especially if they do not know where they came from and the background of the person?

**Participant:** From my experience most of them just leave it, they are grateful that they got an organ and if the organ is functioning well they are very happy and thankful to the staff and to the person whose organ they have got and they just keep on going. They try their best to take care of the organ so that it does not fail. Yes, this is my experience and what I know.

**Researcher:** In your experience do you sometimes come across patients who have been emotionally affected especially after receiving an organ?

**Participant:** Yes, quite a few of them they talk a lot about the donor. They say they do not even know who the donor was, but they appreciate and they are very grateful that they got an organ. So they keep saying such things and you realize that emotionally it is affecting them, that they got somebody‘s organ and the person had to die in order for them to get an organ so they don’t talk a lot about it. That is why I think psychological preparation is very important, so that they know that even if they were not going to receive an organ the person would have died. They should know that they are not depriving anyone of life so that they can have life.

**Researcher:** Do you think culture has an effect on organ donation and transplantation?

**Participant:** I believe culture plays a major role. Like in my culture for instance. Everybody wants to bury his or her relatives’ whole. They think if they take some organs then it means that the person is not whole. They always want to bury the person with everything all the organs intact. Therefore, with that kind of culture it is difficult to allow your family to donate an organ or to be an organ donor yourself. You believe that you have to go back to your maker whole like as you came to earth with all your organs intact. Therefore, I do think that culture plays a very important role. I think education can help with that kind of perception

**Researcher:** Do you think there is enough awareness about organ donation and transplantation?

**Participant:** No, I do not think so because most of the time if you hear about organ donors they are mostly white people because they are informed mostly they know what it is. White people donate more in comparison to black people because of the perception of our black community and lack of education; they think they must die with all their body parts intact, as I have said.

**Researcher**: How can information reach them?

**Participant:** Mostly through the media, because almost everybody in these era have access to a television set, radio or something of that sort. I think the media will play a very important role and in hospitals as well as educational programmes. Once in a while, educate people who come to hospital, because lot of people go to hospital and they wait in the waiting room, there must be people educating them, yes I think also in the media it is very important.

**Researcher:** Your colleques, do you think they are well informed about organ donation and transplantation?

**Participant:** No, I do not think we are well informed because sometimes we do not know. I personally do not know about the legal issues involved in organ donation and transplantation. I do not have enough insight about the human tissue act. I may know a bit and pieces but I don't know the whole thing about the organ tissue act what to do and not what to do and the kind of information to obtain from patients who want to donate an organ. I do not know, I think also it is because we have people who specialize in that field. Transplant co-ordinators specialize in that field and they know about all of it. So we are just there to nurse the patient post organ transplant, we do not involve ourselves in the legal part. I do not think we have enough information. I personally do not have enough information.

**Researcher**: Before you, started working as a nurse were you aware of the importance of organ donation and transplantation?

**Participant:** Yes I have had that you could make a will that you want to donate your organs or your whole body to the medical school for studying but then I don't think that a that point I could have a made up my mind what to do because I didn't know what it was all about. I just heard that you could donate your organs if you want to be a donor you can sign up to be a donor. That is all I heard about organ donation before joining nursing.

**Researcher:** Now that you know about organ donation and transplantation, do you think you can donate an organ to a person?

**Participant:** I have not quite made that decision yet. Nevertheless, I think if it is a close family relative, maybe children I am sure I will consider it but currently I am

not even considering it, maybe because I am not in a situation that demand donating an organ. I do not know, I may consider it.

**Researcher:** Your parents and siblings do you think they know about organ donation and transplantation?

**Participant:** No, no they do not. They have heard about it. As I was growing up we all knew that you could sign up to donate an organ but there was no convincing like you are convinced that you could sign up to donate an organ so they might have heard about it but they don't know what it involves. I do not know. Nevertheless, I do not think they know what it involves.

**Researcher:** You mentioned ethical issues and human tissue act. Do you think the legal aspects are being adhered to considering the little information that you are having?

**Participant:** I think so, sometimes not. You sometimes come across patients that you don't think are related or you think are not related but they still donate organs to each other. That is our own perceptions, because we think that if they are related there must be more going on, like families visiting each other visiting the donor and the recipient. They come in, visit one of them, and go away without seeing both of them but just that, makes you wander. Then you have the perception that they might not be related. Otherwise, the transplant co-ordinators bring the file from the transplant unit. We do not even know what is happening or what is in the file and mostly I do not even worry about the legal aspects. I rather leave it to the expert. Therefore, I do not quite involve myself in the legal part of it although sometimes, I think some of the things are not done legally. Yes, that is true but the consent form and all these other documents; we do not have access to them in the ICU. If one wants to do an investigation to see if the transplant was done legally or illegally and if you go to the transplant unit to ask for them, they will ask you why you need them. Therefore, the only thing is to think of leaving it to those whom you think are expert and if there are any.

**Researcher:** Do you think religion has an effect on organ donation and transplantation?

**Participant:** Yes, I believe strongly that religion plays an important role in organ donation and transplantation because mostly some religions believe that you know what you came to earth with is and what you must go to GOD with (as you are). Therefore, you cannot receive anything from anybody as with Jehovah's Witness that you cannot even receive blood transfusion. I believe that religion does play a part. Traditional believers also do not want to donate any part of their body to anybody because they want to go to their maker as they came on earth so I think religion does play a part on organ donation and transplantation.

**Researcher:** Coming back to that earlier on you spoke about the legal issues. It says that when a patient is a minor the law can overrule that decision of the patient's parents or guardian if it is not in favor of the patient's benefit. In case of Jehovah's witness where they are not suppose to receive any blood and blood products. The superintendent of the hospital can ask for a court interdict and overrule it. Do you think it is ok in that instance because those are the parents but the minor is considered young to make a responsible decision?

**Participant:** I think it is ok because the child must have his or her right protected. If the parents are saying the child does not have rights or old enough to make or to know what is good for him or her, I think it is only fair that superintendent of that hospital get a court order for that child, because we are suppose to advocate for people who cannot speak for themselves. I think it is right for the hospital to get a court order.

**Researcher:** Have you ever been involved in a situation where an organ was donated?

**Participant:** Yes, sorry I do not quite get that.

**Researcher:** Have you ever been involved in a situation where an organ was donated?

**Participant:** No, the only thing I have seen was a family, they decided to donate the body of their father to a medical school for medical studies and further research, but often organs. I have never seen witnessed it but I have heard about it.

**Researcher:** What was your reaction on that?

**Participant:** As a medical person, I think that if you die there is no use to your body. Even religiously maybe your soul is the only thing that matters not your body. If you donate your body or organs to another person to have life or to a medical school so that they can study more on how to improve medical care. I think it is a good thing to do. I would not mind donating any organ but as I have already said, I have not given it a thought. I am not in that situation but I think people who do it are very brave and are not selfish they give off themselves to other people. Therefore, I think the person who decides to donate his body to the medical school did a noble job. I believe so.

**Researcher:** Your colleques, do you think are well informed about organ donation and transplantation?

**Participant:** Transplantation maybe, because we nurse quite a lot post transplants. However, as to organ donation I do not think so because I have

never had anybody coming in to our unit and educating or give an in-service training about organ donation although we nurse quite a lot post transplant I have never had that kind of education before. I am not well informed and I do not know about my colleque maybe they have had enough education about organ donation and transplantation.

**Researcher:** Who do you think is the ideal person to talk to the family of the potential donor about organ donation?

**Participant:** I think it should be the transplant co-coordinators and a psychologist, because at that point, the family is in such a grief. Therefore, to talk them, about donating an organ of their relative, it must be very hard. I think it must be somebody with enough information, to be able to break such news or to discuss such things at such a crucial time in a family's life. It must be a psychologist and somebody who is well versed with organ donation and transplantation.

**Researcher:** If it happens that they ask you to be part of the team where they would like to ask the family to donate an organ do you think you can agree to do that?

**Participant:** Personally wow… no, because I am quite an emotional person and I think at that point it will be very difficult for me to approach the family and ask them to donate an organ of their relative. From the personal point of view, I think I am too emotional for that, it will be very stressful for me and I would not do it.

**Researcher**: If you are looking after the patient who is considered to be a potential donor and the family has confidence in you as a caregiver, they ask you for your opinion how do you think you can comment on that?

**Participant:** I will tell them it is a matter of choice what they want to do at that point. I will support them whatever decision they decide to take, because at that point your family or relative is dying. It is one of the most difficult times that you are going through so my opinion will be, they must decide on what they think will make them comfortable. If you tell them they must and then they do it later they go home and they start feeling guilty about the decision they took. I believe it is a matter of choice. It is their choice, either donate or do not donate. I will support them no matter what decision they are making. Nevertheless, I still think and feel that they need help of the psychologist for such a decision. I would not support whether to donate or not to donate.

**Researcher:** Going back to what you said earlier about your family you said you are not sure, if they are well informed about organ donation and transplantation. If you are involved in a situation, where a family member is on chronic dialysis and you can see that this person is taking a lot of strain emotionally and

something can be done which can bring this to an end, financially they are also struggling due to time wasted when going for dialysis. Can you encourage one of them to donate for that person?

**Participant:** I do not think encouraging is the thing to do, because this is quite a personal decision. To donate or not to donate is a personal decision. I will explain that, this Is what it involves. You will go through this and this is how your relative is going to benefit. I will leave the decision to them to decide. Whether to donate or not to donate but to encourage them, I do not think I will, but I will explain to them to the best level of my knowledge, that this is what it involves, this is how you recover and everything that I know. I will tell them about it and that they will decide whether they want to donate or not. I think this is what I will do personally.

**Researcher:** If they ask you, “what will you do if you were in our position?” what do you think you can tell them?

**Participant:** Yes for me if I see my family suffering and I think they need an organ and I am comfortable I will discuss it with my husband I think. Because know as the bible says the two of you are one. I will discuss this with him if he thinks it is fine and he agrees he is giving me a go-ahead I will go for it at all, donating to somebody.

**Researcher:** Have you ever been involved in a situation where the recipient’s body was rejecting an organ?

**Participant:** Yes, I have come across quite a few patients, who come into our unit rejecting an organ. Even immediately after transplant sometimes, they get acute tubular necrosis that is quite disturbing. They sometimes do not pass urine and they think the organs are not functioning. Therefore, I do encounter some of those patients and those who have chronic rejection some do also come into our unit. I have had contact with quite a few.

**Researcher:** How was the general feeling of the family?

**Participant:** They have a feeling of lost. It is like having lost something that you value so much. It is quite a trying time for the family thinking what a patient has gone through “major operations” getting an organ after waiting for a long time and all of a sudden, the body is rejecting the organ. It is a feeling of lost and grief. It is not easy to watch patients go through that kind of thing.

**Researcher:** What is the success rate of transplant in your department?

**Participant:** Post operatively I think all of our patients do well. I think most of our patients do well. Then since there is no follow up, we do not have the records we do not have any follow up data to show the percentage that did well and to check later or those who get chronic rejection. I cannot prove statistically, from the nursing point in the unit they recover and go home or to the ward but most of them do recover. About the follow up, I cannot tell whether long term is successful or not.

**Researcher:** Do you have follow up of the donors?

**Participant:** I do not know may be the transplant unit but from our unit I do not know of follow-ups

**Researcher:** How can organ donation and transplantation change one's life?

**Participant:** I think it gives you another chance to live because if you are a chronic renal failure person you may be terminal and end up dying in a few years. Therefore, I think a healthy organ gives you a better quality of life it gives you another chance to live. Gives you your life back. I think that this is what it does.

**Researcher:** Does it also change their financial situation?

**Participant:** I think it does considering the fact that with renal failure you go for dialysis like every second day. Sometimes every day. That will save one a lot of money and time. Time is money. Having time in your hands, you can do many things, concentrating of your job or doing some other business.

**Researcher:** What do you think could be done to enlighten people or make awareness on organ donation and transplantation?

**Participant:** Education, lots of education. I think I said before that we could do this education in the media, posters on the wall, newspapers and television you can educate people. Have organ donation week. I think they do have something like that in which they educate people and ask them their opinion and try to educate them. I think that will be important, that should be the way to get people to educate them, as they do with HIV when educating. Nevertheless, I think education.

**Researcher:** People in the rural areas, do you think they have access to information about organ donation and transplantation compare to people in urban areas?

**Participant:** No, I think because the media is more widespread in the urban areas than it is in the rural areas. Therefore, they can incorporate clinics where

the patients go for medical attention. If they have people who educate them about organ donation and transplantation.

**Researcher:** The prominent people in the community, like church leaders, do you think they can play an important role in educating people especially if they are taught?

**Participant:** I believe those churches reach more people mostly, because almost everybody belongs to some kind of religion or church. So all religious leaders can also be educated about organ donation and transplantation and they can take these messages to their followers. Therefore, that can also be an important place to start to.

**Researcher**: If children get taught at an early age, about organ donation and transplantation do you think that will benefit them as a society in the end?

**Participant:** Yes, I think that is going to benefit the community because children at an early age kind of pick things quickly and when they are in schools and you teach them such things. It is very important because their beliefs are being developed at that age. If they believe from an early age that organ donation and transplantation is a good thing and will help the community, they will grow up believing it. Knowledgeable children from young age will be very beneficial to the community.

**Researcher:** Is there any thing that you would like to add or say that we did not get a chance to talk about or I did not ask you about?

**Participant:** No, for know I think I do not have anything to add.

**Researcher:** Thank you very much, for your time and co-operation.

# ANNEXURE 4

## Guiding questions

**GUIDING QUESTIONS**

As a critical care nurse what is your perceptions on organ donation and transplantation?

Have you ever been involved in a situation where an organ was transplanted?

Do you think culture has an effect on organ donation and transplantation?

-transplantation?

Do you think your colleques are well informed about organ donation and transplantation?

Do you think religion has an effect on organ donation and transplantation?

Have you ever been involved in a situation where an organ was transplanted?

Have you ever been involved in a situation where an organ was donated?

Who do you think should be the ideal person to talk to the family about organ donation?

Have you ever been involved in a situation where the recipient was having signs and symptoms of rejection?

What is the success rate of organ transplant in your department?

How can organ donation change one's life?

Do you think people in the rural areas have access to the information about organ donation and transplantation?