

**PERCEPTIONS OF ORGAN DONATION BY ELDERLY COMMUNITY
MEMBERS IN A RURAL COMMUNITY OF SEKHUKHUNE DISTRICT,
LIMPOPO PROVINCE**

by

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DEDICATION

I dedicate this study to my mother, Thokgedi Kate Moropa (Mahlako), my late father (may his soul rest in peace), Madiseng Daniel Moropa (Phogole a' noge), my son, Madiseng Moropa, my siblings, Ntebo, Khutso, Itireleng and Motswako Moropa, for their enduring love, care and support for the past seven years of my studies. This dedication extends to my maternal grandmother, Kgolane Mokgwatsane (Mmeladi), and my nieces, Katlego, Lethabo and Omphile Moropa; your support will forever be wholeheartedly appreciated.

DECLARATION

I declare that **Perceptions of organ donation by elderly community members in a rural community of Sekhukhune District, Limpopo Province**, hereby submitted to the University of Limpopo for the award of the degree of Master of Arts in Clinical Psychology, has not previously been submitted by me for a degree at this or any other university; that is, it is my work in design and in execution, and that all material contained herein has been duly acknowledged.

Surname & Initials (Title)

Date

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GLOSSARY AND ABBREVIATIONS

Word or abbreviation	Definition/meaning
ODFSA	Organ Donor Foundation of South Africa
Umvelinqangi	One who appeared before all else, or if converted to Christianity, God, without question.
Zulu-speaking people	The people belonging to the Zulu tribe of South Africa.
Sepedi	A language spoken by the Pedi people of South Africa.
WHO	World Health Organisation

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ABSTRACT

Demographical factors affect the way people perceive, conceptualise and make meaning of their daily living experiences, which in turn influence their decision-making abilities in certain situations. Therefore, perceptions and conceptualisations, together with the associated attitudes to organ donation, were defined and understood in participants' socio-cultural context. A qualitative study was conducted among the African elderly community members of Madibaneng Village (Sekhukhune District), Limpopo Province (South Africa) to explore perceptions of organ donation. African elderly community members were selected using purposive sampling, after ethical clearance from the University and gate-keepers' permission from the Tswako-Lekentle traditional council had been obtained. Six (6) males and six (6) females were interviewed. Data was collected using semi-structured interviews and analysed using the thematic analysis method.

The following psychological themes and subthemes emerged from the study: African elderly community members' understanding and knowledge about organ donation (inadequate knowledge and lack of awareness); community members' feelings about organ donation; African elderly community members attitudes to organ donation (family dynamics relating to organ donation, culture and organ donation and psychological aspects of organ donation), and participants' perceptions of those living with donated organs.

The findings revealed that multiple demographical factors affect and influence people's perceptions of organ donation. The study revealed that 80% of the elderly community members expressed some positive perceptions about the process of organ donation; however, some of the participants expressed conflicting factors that might affect their ultimate decision about becoming donors, such as associated psychological aspects. Other participants portrayed a negative perception that was more likely to have been affected by cultural factors, their family dynamics, belief systems and other social factors in their context. The findings from the current study emphasise that there is a need for effective awareness campaigns to curb the levels of illiteracy and inadequacy in knowledge concerning the subject of organ donation and to incorporate the demographical factors of particular social contexts in the healthcare system and related policies.

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CHAPTER 1: INTRODUCTION

1.1 Background of the study

Organ donation is a phenomenon that continues to receive a lot of attention worldwide (World Health Organisation [WHO], 2017). This is attributable to the increasing need for more registered organ donors (Williamson, Reynolds-Tylus, Quick & Shuck, 2017), and the high demand for transplantable organs (Williamson et al., 2017). The limited supply of organs is a result of either medical failure or inability to obtain consent for donation (Muller, 2013). Furthermore, demographical and cultural factors have an impact on how people perceive organ donation (Morgan, 2011). For example, a study by Muller (2013) suggested that perceptions of and consent for organ donation are influenced by a range of factors that include people's religion, socio-economic status, ethnicity, cultural background and race.

Muller (2013) further articulated that the religious beliefs that people hold might interfere with their willingness to make donations. It was also provided that people of low-socio economic class are less likely to consider this process than those of high socio-economic status mainly because of limited information and knowledge by the former class. South Africa being a greatly diverse country with different cultural backgrounds, how people perceive organ donation is mostly influenced by their cultural beliefs (Muller, 2013). Since 1954 when the first kidney transplant was successfully performed, the demand for organs has escalated. This applies not only apply to kidney transplants, but also to solid organs such as the heart, liver and pancreas (Muller, 2011).

Across societies, religions and cultures, the body and its purpose are perceived differently after death, and these views ultimately influence people's decision to donate or not to donate certain organs (Bhengu & Uys, 2004; Sharp & Randhawa 2016). For example, in a study by Sharp and Randhawa (2016), the participants highlighted the need to say goodbye to a family member who has died. They felt that this process would be interfered with if they knew that the deceased's organ was alive in another person's body. Consequently, members of the family in such cultural contexts perceive organ donation as a way of depriving them of the opportunity for closure.

All cultures have a system of health beliefs that helps them to interpret and explain health problems and enables them to make informed decisions about their health (Udefi, 2014). People of African descent also have their own meanings, interpretations and significances when it comes to death. It is, therefore, imperative to uncover how these meanings and interpretations affect their views on organ donation (Makgahlela, 2016). It is vital for communities' beliefs to be understood through a broader description to uncover the interaction of multiple influences (Madu, 2015).

In psychology, the dominant Euro-American explanations and models are often perceived to be the only principled ways of understanding human and health-related behaviour (Chokwuokolo, 2009; Nwoye, 2015). As a result, indigenous African philosophy and perceptions of people of African descent are deemed inferior, unscientific and thus, are largely marginalised and ignored (Chokwuokolo, 2009). It is therefore imperative to explore organ donation from an African indigenous philosophy in order to understand the existential, cultural and spiritual factors involved in the processes of decision-making about major life decisions, specifically organ donation. Therefore, there is a need to trace African indigenous peoples' understanding of their reality and the world and how they make meaning, even on decisions about organ donation.

1.2 Research problem

Substantial research about perceptions of organ donation has been conducted in countries such as Greece (Symvoulakis et al., 2014), the United Kingdom (Sharp & Randhawa, 2016), the United States of America (Williamson et al., 2017) and the Middle East (Badrolhisam & Zakaria, 2014), and researchers have found that some people's decisions to donate are associated with ambivalent feelings. For example, there might be fear, altruism and uncertainty about the procedure of organ donation to others (Symvoulakis et al., 2014). Other studies found that cultural and religious factors and people's demographics play a vital role in decisions whether or not to become an organ donor (Badrolhisam & Zakaria, 2014; Sharp & Randhawa, 2016). Cultural death practices, perceptions of the body after death, life after death and socio-economic status are some of the predominant themes that emerge in most studies (Badrolhisam & Zakaria, 2014; Sharp & Randhawa, 2016; Williamson et al., 2017).

In South Africa, a study by Etheredge, Kahn and Turner (2014) on some urban South African populations' attitudes to organ donation found that the participants displayed positive perceptions of and attitudes to organ donation. The authors recommended that the study be conducted in rural populations across the country for a more objective understanding. Bhengu and Uys (2004) conducted a study about organ donation among Zulu-speaking people. This study was conducted in both urban and rural settings, with participants from the health sector, community members and other public sectors. The study results indicated that kinship, social factors, beliefs, ways of life and cultural factors influence decisions to donate or not to donate.

The limitation of a study by Etheredge et al. (2014) was that the participants came from urban areas, while the sample in Bhengu and Uys's (2004) study was not homogenous. It is these gaps in the above studies that have motivated the researcher to embark on the present study, which focuses on perceptions of organ donation by community members in some rural communities in Limpopo Province. The area is identified by the researcher because it is a stronghold for indigenous African elders. In African communities, elderly people are normally considered to be the conduits of accurate and authentic knowledge on health-related issues (White, 2015). Hence, the researcher in the study opted to focus on this segment of the population.

1.3 Aim of the study

The aim of the study was to explore perceptions of organ donation by African elderly community members in a rural community in Sekhukhune District, Limpopo Province.

1.4 Objectives of the study

The specific objectives of the present study were to:

- Determine elderly community members' understanding and knowledge about organ donation.
- Describe elderly community members' feelings about organ donation;
- Determine elderly community members' attitudes to organ donation; and
- Determine elderly community members' perceptions regarding those who are living with donated organs.

1.6 Operational definition of concepts

- **Organ donation:** In the context of the present study, organ donation will be understood to mean the act of giving one or more organs, without compensation, for transplantation to another person (WHO, 2017).
- **Perceptions:** In the context of the present study, perceptions will mean a way in which something is regarded, understood, or interpreted, often influenced by what we believe or our worldview. In the context of the present, perceptions carry the same meaning as above (Forges, 1992).

1.7 Significance of the study

The study is important in expanding our knowledge in terms of understanding the extent to which culture and people's demographics explain and affect health behaviour and how organ donation is perceived and understood in rural communities. Contribution to the emerging field of African psychology was another potential output of the study. The purpose of African psychology is to ensure that scholars and professionals, regardless of their demographics, are sufficiently cognisant of the African tradition despite being educated in the Eurocentric system. The study will further deepen researchers' understanding of the role of culture in explaining health behaviour. It is therefore hoped that this study will provide useful psychological insights into these culturally embedded experiences and perceptions, which will enable appropriate interventions in respect of organ donation and other health-related issues. This is to ensure that health practitioners acquire relevant cultural competency skills to become informed about African knowledge, tradition, ethics, culture and psychology, while being knowledgeable about the contributions of Western psychology (Nwoye, 2015).

1.9 Outline of the dissertation

Chapter 1 provides a brief summary of the study, the aim, objectives, research questions, operational definitions of terms used in the study and the significance of the study. Chapter 2 is a review of literature on the perceptions of organ donation starting from a global perspective and proceeding to the South African context. It also looks at various factors that have implications for people's perceptions of the organ donation process. It further outlines the theoretical frameworks adopted in the study. Chapter 3 provides a discussion on the research methodology that was used in this study.

Chapter 4 outlines the presentation of findings and the analysis of data. Chapter 5 discusses the results in the context of the existing literature. A summary of this study, its limitations, implications for theory and recommendations is presented in Chapter 6.

1.9 Summary

In this chapter, the researcher attempted to give a general overview of the study. Furthermore, the chapter focused on the background to the study, the research problem, aim, objectives, research questions and operational definitions of concepts, as well as the significance of the study. In Chapter 2, the literature pertaining to the field under investigation, including the theoretical framework used in the research will be presented.

CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

This chapter provides an overview of the literature and some of the theoretical perspectives adopted in this study. The chapter begins by giving a brief review of literature on international trends in organ donation, followed by a perspective on organ donation in the South African context. Other subtopics included in this chapter are the psychological aspects of organ donation, cultural and religious perspectives and family dynamics concerning organ donation. To enrich the literature review, the researcher has opted to include the ethical and legal issues relating to organ donation in South Africa. Lastly, theoretical perspectives (Afrocentric perspective and the health belief model - HBM) that were adopted to guide this study are presented.

2.2 International/global trends in organ donation

In recent years, technical, academic, political and public opinions in many countries across the world have steered efforts to come up with strategies to help promote organ donation and attract more people to becoming organ donors (Zúñiga-Fajuri, 2015). Alvarez et al. (2006) stated that international disparities in transplantation activities are recognised to be largely unrelated to the actual distribution of medical need associated with the resources available for healthcare provision. Alvarez et al. (2006) looked at the global diffusion of organ transplantation: trends, drivers and policy implications. The study used the Global Observatory on Donation and Transplantation, built in response to the World Health Assembly resolution summit, WHA57. The study found that provision for transplantation from deceased donors was closely associated with high levels of gross national income per capita in a country. Alvarez et al. (2006) stated that in previous studies of countries with established programmes of renal replacement therapy, the incidence of dialysis and kidney transplantation was found to be significantly associated with the country's economic status.

The alarming shortages of donors and transplantable organs put pressure on many states, leading them to reform their systems to increase the number of people registering and becoming donors (Zúñiga-Fajuri, 2015; Alvarez et al., 2006). However, countries use different approaches to resolve and deal with the issue of organ donation. Some of the commonly used approaches are an opt-out and opt-in system, hard consent and mandated consent. The opt-out laws have long been among the major and strong interventions used to increase the pool of potential donors in many

countries. Countries such as Austria, Belgium, the Czech Republic, Finland, France, Greece, Hungary, Israel, Italy, Luxembourg, Norway, Poland, Slovenia, Spain, Sweden, Turkey and recently Chile have joined the pool of opt-out law (Zúñiga-Fajuri, 2015; Etheredge, Penn & Watermeyer, 2017). It has been reported that countries with opt-out laws have 25 to 30% higher transplantation rate than countries requiring explicit consent or soft opt-in approaches, such as South Africa (Zúñiga-Fajuri, 2015). These countries have since seen substantial and positive outcomes because of this approach. In other countries, there is evidence that supports the association between hard consent and increased donation rates (Zúñiga-Fajuri, 2015).

2.3 Organ donation in South Africa

According to the Organ Donor Foundation for South Africa (ODFSA) (2016), the donation of organs, whether from a living or dead donor, is a free choice of the donor or the family of the deceased to donate organs and there is currently no financial compensation for the donor. South Africa, despite being one of the world leaders in the transplantation market, faces extreme challenges in engaging its citizens, especially in the public sector, to participate in organ donation programmes. In a recent comparison, consent rates in the private sector were between 80% and 100%, while in the state sector consent rates were as low as 30% (Muller, 2013). Despite an increasing waiting list of organ recipients, the number of donors to supply organs fails to meet the demands in South Africa (Muller, 2011). The ODFSA (2016) has made efforts to advocate organ donations among the public through campaigns and educational programmes, usually by using the phrase: "Give someone the gift of life". The metaphor of "the gift of life" helps and is often used in public awareness campaigns.

Muller (2011) states that the diversity of people present in the country with different belief systems is another factor contributing to the difficulty in addressing the subject of organ donation. South Africa has adopted the soft opt-in system to deal with deceased organ donation, which has been debated over the years. Some have advocated an opt-out system, in the belief that it would be more effective. Others have suggested that some form of remuneration, such as paying the funeral expenses of deceased donors, may also be beneficial and may in some way convince families of the deceased to donate (Muller, 2013; ODFSA, 2017).

According to Muller (2013), Gauteng Province and the Western Cape have so far been instrumental in the advocacy of organ donation, having been the only two provinces in South Africa with effective organ donation and transplantation programmes. However, Muller (2013) is of the view that most of the programmes have been focused on urban areas, while less attention is paid to organ donation in rural communities in South Africa. For example, a study by Etheredge et al. (2014) on the attitudes among some urban South African populations on organ donation indicated some positive results from the urban populations in relation to the subject. It was revealed in the study that more black people from urban areas are willing to donate their organs. The authors highlighted the need for studies in rural populations. In their view, most of the people in rural settings are deemed culturally conservative on issues of organ donation.

2.4 Psychological aspects of organ donation

Schulz and Kroencke (2015) conducted a review addressing the psychosocial challenges and relevant psychological aspects in the different phases of the transplant process in a general hospital. They argued that people undergoing the process of organ donation experience some psychological reactions, which are referred to as preoperative and postoperative reactions. The authors found that before the process of donation and transplantation, people experience emotional crises and destabilisation. Furthermore, depression, hopelessness and anxiety are among some reactions experienced by potential donors and recipients. Patients not only experienced reactions before the process, but afterwards identifiable symptoms of distress were evident in patients (Schulz & Kroencke, 2015).

Reactions in the perioperative period, where the focus is on the patient's physical recovery, related to possible rejection episodes and other medical complications causing anxiety and emotional strain (Schulz & Kroencke, 2015). Within the first days after transplantation, a postoperative delirium (acute organic brain syndrome) was a possibility, as stated by the authors. They pointed out that in view of the possibility of cognitive and emotional upheavals being experienced by patients during the process of donation and transplantation, extensive adjustments and considerable coping skills would be required. This would require interventions from various multidisciplinary stakeholders with the aim of helping prospective patients (Schulz & Kroencke, 2015).

In contrast to the emotional upheavals experienced by potential donors and patients undergoing transplantation, Engle (2001) argued that the psychological impact of a decision on organ donation on families should not be disregarded. Engle (2001) conducted a scoping review of literature on asking families to consent to organ donation. The scoping review of peer-reviewed literature included 168 articles published from January 2000 to February 2015 on the question of what constitutes an effective and efficient request. The factors that affect consent rates and family satisfaction with their decision and the process were examined (Engle, 2001).

One of the themes that emerged from the review was the effect of the donation decision on family well-being or the psychological impact of the decision to donate on the family. The negative psychological effects experienced were uncertainty, guilt and shame for having given up too early, grief and distress about the deceased's experience in the afterlife. The need to protect the family could limit requestors' efforts to overcome family reluctance if it were known that this could inflict psychological harm and emotional distress. As a result, both patients (donors and recipients) and the families of the deceased may require psychological interventions to help them cope with the distress and prevent further psychological harm (Engle, 2001; Schulz & Kroencke, 2015).

Sharp and Randhawa (2016) stated that people experience fears and concerns about the body being cut into and the concept of organ donation being unacceptable. The study indicates that not only people's desire to donate an organ may be influenced by personal, religious, cultural and other demographics; there are some psychological factors that people experience when considering the process of organ donation. Furthermore, it was indicated that for the improvement of patients, a variety of services should be provided. This will assist them in the process of facilitating decision-making and adherence, coping with uncertainty and stress reduction, processing of fear and grief, depression and aggression. Providing family counselling to the family of the deceased donors may be an appropriate psychological intervention to help people heal (Schulz & Kroencke, 2015; Sharp & Randhawa, 2016).

Engle (2001) stated that in some cases, the process of organ donation tends to comfort grieving families. On the other hand, those families who refused to donate had a greater tendency to regret their decisions. The authors indicated that behaviour that is

perceived as focused primarily on organ procurement may offend and distress families (Engle, 2001). A study conducted by Shepherd and O'Carroll (2013) on the psychological aspects of organ donation provided some psychological insights in terms of how people would feel and think about the concept of organ donation.

Sheppard and O'Carroll (2013) conducted a survey indicating that over 90% of the United Kingdom's general population agree that organ donation is a good thing, but only 31% are registered as potential organ donors. Among others, those who participated in the study indicated that the thought of contemplating the whole situation made them feel worried and sad. However, they would not face their own mortality by donating their own organs. It was therefore concluded that emotional factors such as fear, guilt and anxiety are important barriers to organ donation. However, general superstitious beliefs do not explain reluctance to becoming an organ donor (Shepherd and O'Carroll, 2013).

Spiers and Smith (2016) conducted a study exploring the psychological challenges experienced by people on the waiting list for a kidney transplant. The aim of the study was to provide clinicians with adequate information to support such people fully in the future. The themes related to the experience of waiting that emerged were adjustment to the uncertainty of waiting and thinking about receiving a kidney from a living donor. Existing literature in this area has found uncertainty to be of concern not only to those waiting, but also to those donating and receiving organs. Many of the participants interviewed in the study felt frustration because of their confusion. It was asserted that this was because they had no ability to control the situation (Spiers & Smith, 2015).

According to Boey (2002), when examining attitudes and perceptions about organ donation, both positive and negative dimensions should be taken into consideration. People may have humanitarian and charitable feelings about organ donation and feel the need to save lives, but at the same time, they also have fears and other negative psychological reactions. Bodily mutilation, being disfigured and fears of medical neglect and failure because of commitment to organ donation were the dominant themes that emerged.

2.5 Cultural practices in organ donation

The notion of organ donation raises issues and questions of life and death across different cultures. Life and death are socially, cultural and religiously constructed

(Sharp & Randhawa, 2016). Thus, cultural practices of death and rituals on the body after death vary. In most instances, these practices have an impact on the decision whether to donate or not. Kobryn, Modiba and Ndlovu (1998) conducted a study investigating the attitudes of black South Africans to organ donation. The study conducted in the then Ga-Rankuwa General Hospital indicated that 44 brain-dead potential donors were identified in 1998. The study indicated that 119 living potential donors showed a positive attitude to organ donation, primarily kidney donation, in the peri-urban area of Pretoria. For 20 of the 44 potential donors, consent could not be obtained, as relatives could not be traced. Of the remaining 24, only nine donors' relatives were willing to give consent; 15 refused, some basing their decisions on cultural beliefs, religion, the belief that organ donation was not an acceptable concept and others on the fact that they did not know the decision of the deceased (Kobryn et al., 1998).

Culture plays a vital role in the decision on organ donation; with many black South African communities believing that a person should be buried with the body complete (Buthelezi & Ross, 2011). A dominant belief is that the ancestors will not accept the person if he or she is buried with organs missing. There are other cultural beliefs and taboos within the South African diaspora concerning organ donation, such as a person not being allowed to have an open casket funeral after organ donation (Siminoff & Sturm, 2000; Buthelezi & Ross, 2011). It is argued that this belief is driven by individuals thinking that doctors cannot put the body back together. Other prevalent beliefs are that it is unethical to donate someone else's organs without their permission before their death and that organ donation can make one impotent or infertile (Buthelezi & Ross, 2011).

Bhengu and Uys (2004) stated that the Zulu-speaking people believe in the creator (*Umvelinqqangi*) or God, if converted to the Christian religion. They believe that they have no authority to donate their bodies or organs. The strong bond and interdependence that exist between the living and the dead (ancestors) among Zulu-speaking people contribute to the fear and anxiety to donate. This is because it is believed that if this bond is broken, the ancestors will show anger by visitation in the form of ill-health, misfortune or even death. The authors further indicated that ritual murders for human tissue or organs for use in witchcraft may aggravate this problem.

2.6 Religious perspectives on organ donation

According to Buthelezi and Ross (2011), religious beliefs and affiliations influence and contribute greatly to the complexity of how people perceive the issue of organ donation. Religions such as Christianity, Hinduism, Catholicism, Buddhism and Judaism support organ donation, but do not have policies regarding organ donation (Buthelezi & Ross, 2011). As a result, donation is perceived as a personal choice and is seen as a gesture of love, altruism and compassion towards a fellow human being. However, in the Islamic faith organ donation remains a highly debatable issue. The Islamic religion states that its members are forbidden by their faith to donate their organs. The Muslims believe that they are entrusted with their bodies by God and they cannot give away what is rightfully not theirs. It is further indicated that Muslims believe in the resurrection of the body, in which the soul must return to the body, which should be complete. Nevertheless, it has been emphasised that nowhere in the Koran is it stated that donating an organ to a terminally ill person is wrong (Buthelezi & Ross, 2011).

Sharp and Randhawa (2016) found that in other orthodox religions such as the Roman Catholic faith, there is strong superstition about death. These people believe, as indicated by one of the participants, that delaying the burial of the body may result in the deceased taking someone with them. The authors also found that Buddhists believed that the body should not be disturbed hours after death to preserve their belief of afterlife and immortality (Sharp & Randhawa, 2016). Therefore, the concept of organ donation is perceived to interfere with these people's beliefs. Thus, the decision to give consent for organ donation differs from one culture to another and from one religious perspective to another (Sharp & Randhawa, 2016).

According to Randhawa (1998), the Judaism religion encourages organ donation to save lives. This principle overrides the Jewish objections to any unnecessary interference with the body after death and the need for immediate burial. Families may be concerned that giving consent for donation may not be consistent with honour and respect for the dead. Judaism considers each case as different and recognises that any known wishes of the dead person may be valuable. However, even when the wishes of the dead person are known, it is widely recognised that families are entitled to decide for themselves. Families of the deceased will often consult their own experts

in Jewish law and tradition before making a final decision on donating organs or not (Randhawa, 1998; Shepherd and O'Carroll (2013).

Many religions teach that the human body is different from other material possessions or life forms in that it is a gift from a supernatural power, such as God and the ancestors. Therefore, these views call for a moral obligation to respect the human body. Christians, however, also believe in unselfishness and therefore regard organ donation as an act of generosity, care and love for another (Bhengu & Uys, 2004). Randhawa (1998) argued when exploring the attitudes of Asian people's religion to organ donation that most people's reason for not donating was that they did not know their religious stance on the issue of organ donation. Other participants had individual reasons, such as preferring the organs of people with whom they have biological and sociocultural bonds.

According to Randhawa (1998), for people's responses to be understood it is important to take into consideration the context of those people, especially when exploring organ donation. In the population studied, Randhawa (1998) indicated that religious perspectives were very important in deciding, especially among the Muslim group. One of the participants mentioned the need for a collective decision to be made rather than making an individual decision about consenting to organ donation. In this study, religion and culture were less important prohibitions when determining the level of consent to organ donation. However, the desire to be informed of their religious and cultural stance was still a much-needed factor. More people still wished to be informed of their own religious stance to make an informed decision, hence the passing on of knowledge by religious groups will certainly enhance people's awareness and facilitate the process of decision-making.

2.7 Family dynamics in organ donation

During the unfortunate events of deaths and critical illness, patients' families fulfil an additional essential role for patients who may be unconscious, unable to communicate or make decisions and those who may die as a result of their condition. Families not only provide vital support and care to their loved one, but also become the voice of the patient and the deceased (De Beer & Brysiewicz, 2016). This is no different when families are asked for consent to organ donation. Organ donation is part of end-of-life decisions that individuals and families make concerning what should happen to the body after death or even during critical illness. In the case of a deceased or critically

ill patient who is a potential donor, the family has the decisional right regarding whether the organs of their relatives may be donated after death (Sharp & Randhawa, 2016; Burr & West, 2002).

According to Burr and West (2002), the refusal of families is the most common reason why organs of medically suitable potential donors are not recovered. In their view, decisions about what to do with a body after death in families of the deceased are influenced by their worldviews, belief systems and in some cases the decision of the deceased. Burr and West (2002) conducted a study on family perspectives on donation of deceased's organs and a variety of themes emerged from the review, reflecting the need to respect the donor and family members' need for closure. However, respecting the deceased through preservation of the whole body was part of family decision-making (Burr & West, 2002). This means that the ultimate decision-making process lies with the family. In a similar vein, African communities believe that people must be buried properly to become ancestors (Bhengu & Uys, 2004). Thus, interfering with their body parts could be interfering with their journey to the unseen world.

According to Siminoff and Sturm (2000), a consistent finding from studies researching barriers to increasing the number of organs available for transplantation is that family members of the deceased are more likely to reject the idea of donating organs. This is most common when they do not know the deceased's preferences or wishes regarding organ donation. Engle (2001) identified a broad range of demographic and other characteristics of family decision makers with regard to deceased's organs.

The literature reviewed by the authors included the following characteristics of families as associated with consent or refusal to donate: ethnicity, culture, religion, values and beliefs. Further characteristics identified were psychological factors, gender, age, education, socioeconomic status, marital status, relationship to the deceased, and the number of family members present when the request is made (Engle, 2001). Further findings included not only those relating to the family of the deceased, but also those factors concerning the deceased that might have an impact on the decision, despite family consent. The characteristics of the deceased patient that have been identified as having possible associations with family willingness to consent were age, sex,

religion, medical insurance status, nature of the death (trauma, illness), marital status, and a previously expressed wish to donate (Engle, 2001).

Deaths and critical events often occur without any warning, giving patients and their families no time to prepare themselves socially, emotional and even psychologically (De Beer & Brysiewicz, 2016). De Beer and Brysiewicz (2016) conducted a study exploring the conceptualisation of family care during critical illnesses in KwaZulu-Natal, South Africa. Thirty-one participants from two private and public hospitals were interviewed. Findings of this study revealed that family care is conceptualised and conceived as togetherness, partnership, respect and dignity.

Sudden death or hospitalisation, especially into an intensive care unit, is unexpected and the family faces the possibility that their loved ones may die or be severely disabled (Brysiewicz & Bhengu, 2010). These psychological repercussions of death and critical illness may reduce families' ability to cope with the situation, which may lead to them failing to make informed decisions, especially when asked to donate organs (De Beer & Brysiewicz, 2016; Brysiewicz & Bhengu, 2010). It has been recommended that since families of patients are also affected during events of death and critical illness, support should be offered. Furthermore, practitioners should take the interests of the deceased families into consideration, because this is perceived as a vital role to be fulfilled. Health professionals should consequently act as pillars of strength, ensuring that families are not coerced but supported in making their decisions (De Beer & Brysiewicz, 2016).

The nature of discussions on organ donation by healthcare professionals with families also influences consent rates and family satisfaction. Matters such as the time of requesting the organs and the place where this is done are known to impede consent or to increase psychological harm to the family. Many families that consent report that they were requested for the organs in a good space and time and they were approached with respect, support and care. They also indicated that donation offered comfort for some, whereas others reported that their suffering was the same, regardless of donation (Engle, 2001). Studies of grief, post-traumatic stress and depression tend not to find significant differences between consenting and refusing families (Brysiewicz & Bhengu, 2010).

Engle (2001) indicated that in a small interview-based study of families from a range of cultural backgrounds, several positive effects of donation, such as feelings of peace and calm, spiritual achievement and a sense that the deceased is living on, were identified. Negative effects included uncertainty, guilt and shame for having given up too early, difficulty in accepting death, concerns about the deceased's experience in the afterlife and family dissension. The majority of both consenting and refusing families later reported satisfaction with their decisions or indicated they would make the same decision again. However, refusing families had a greater tendency to report that they regretted their decision (Engle, 2001; De Beer & Brysiewicz, 2016).

In another study by Boey (2002), families who were initially unsure of their desire to donate eventually consented to donation when healthcare professionals favoured it. It was also reported that healthcare professionals' attitudes may affect the family's decision to consent to organ donation. Boey (2002) further indicated that a study on a group of rural critical care professionals concluded that increased knowledge and positive attitudes are important when providing support to families and care for potential donors. Therefore, there is a need to inform the families fully before they make their decision.

2.8 Ethical dilemmas and legal issues associated with organ donation

According to Ahmadian, Rahimi, and Khaleghi (2017), the ethical responsibility of care, emotional and social support by healthcare professional should be directed at primarily the families. This can be done during the pre- and post-donation process of the deceased. These families usually find themselves deciding to donate while they are in difficult, complex, and traumatic conditions. Besides this, deciding to consent to donation is not the end to families' distress. Strong post-decision support is needed to ease their distress and enhance their emotional and psychological stability. In fact, the need for post-decision support highlights the ethical responsibility of healthcare professionals and organ procurement systems. Respect for persons, non-maleficence and fidelity are the basic principles of ethical practice in the field of organ donation.

Hawkins (2017) believes that families have an ethical obligation of responsibility to the suffering member of the community who needs an organ even if that person is unknown to them. This obligation is grounded in the concept of the mutual benefit of reciprocal relationships that we establish as members of the community or society.

The duty and altruism to the unknown person evinced by the family of the deceased or patients in a critical condition such as being brain-dead ought to be weighed up against any perceived duties to the deceased person.

The healthcare professionals who care for the dying person and those treating the patient in organ failure also hold certain ethical responsibilities to the patient, his family and the potential recipients of the organs. The patient's autonomy, which entails being able to choose freely, is seen as valuable in many areas of life, as this increases people's capacity to satisfy their wants and gives them greater control over their lives. The right to make choices in the context of organ donation is an ethical responsibility that should be afforded to families and patients (donors and recipients) (Hawkins, 2017).

The legal aspects of organ donation and transplants in South Africa are regulated by the National Health Act, 61 of 2003 (South Africa, 2003), which came into effect on 2 May 2005. Section 93(1) of this Act repeals the entire Human Tissue Act, 65 of 1983 (amended in 2003). It is thus necessary to look at both these acts concerning organ transplantation. The Human Tissue Act, 65 of 1983 (amended in 2003) made provision in section 2 for anyone who was able to make a will (16 years or older) to donate an organ by signing a document authenticated by two competent witnesses (14 years or older), or by stipulating this wish through a clause in a will, or verbally before two competent witnesses. In other words, it was up to the individual to indicate his/her wish to be an organ donor (Slabbert, Mnyongani & Goolam, 2011).

This had to be done while donors were still alive and had full control of their minds, whereas the actual donation would occur only after death. In the absence of a donation made by a deceased before death, the Act stipulated that the deceased's spouse, major child, parent, guardian, major brother or major sister might donate usable organs of the deceased after death (S2(2)(a)). The National Health Act, 61 of 2003 Section 62 (South Africa, 2003) generally has the same requirements for an organ donation in the case of a deceased donor as the Human Tissue Act, 65 of 1983. The only difference of any note is that the new Act in section 1 acknowledges "brain death" as death. Section 55 addresses organ donations by living donors (Slabbert et al., 2011).

In the early 1980s the South African government made provisions under the National Organ Transplant Act that outlawed the buying and selling of organs. This legislation

led to a sharp decline in the number of potential organ donors. According to Buthelezi and Ross (2011), an increase in the number of “grey areas” when it comes to organ donation has been substantial because of this legislation. Because of the long waiting lists in both private and public medical facilities, individuals have now resorted to solicitation of donors and the use of health insurance. Solicitation of organs raises concerns of ethical responsibility and considerations that conflict with people’s constitutional rights, such as the right to life and equality. For example, solicitation is viewed as jumping the queue or waiting list and therefore violating the principles of organ donation, even though it can be viewed as acceptable if the deceased had allocated his/her organs to a family member before death. Furthermore, solicitation may result in the victimisation of vulnerable populations, such as the socio-economically disadvantaged, psychologically unstable and mentally impaired (Buthelezi & Ross, 2011).

Buthelezi and Ross (2011) argue that solicitation of a living donor for a specific recipient does not desecrate any available existing national policies. This is in line with these policies when there is no payment or compensation for the organ and this form of donation is not dispensed by any organisation. However, a relevant factor is that solicitation may lead to unethical and illegal practices. Because of these unethical and illegal practices, clear policies and provisions about the pre-existing relationship between the potential donor and recipient need to be implemented. The authors suggested that solicitation would relieve organ shortage, if donors were allowed the autonomy and integrity to sell or receive some form of compensation for their own body parts. This would be economically beneficial to the donor and family and would economically benefit society, leading to less dialysis and more transplants.

2.9 Theoretical framework

In the present study, the researcher opted to use both the Afrocentric perspective and the HBM as the theoretical lenses through which the phenomenon of organ donation would be understood. The Afrocentric perspective was chosen because it allowed participants to examine the topic through the eye of African people, subject to their own cultural, religious, indigenous and historical experiences. Asante (2014) stated that the Afrocentric perspective seeks to relocate the African person as an agent in human history in an effort to eliminate the illusion of the fringes. On the other hand, the HBM was found appropriate for the study because the beliefs that people have about organ donation, its benefits, barriers and self-efficacy explain and determine whether they will engage in this health-related behaviour.

2.9.1 The Afrocentric perspective

The current study adopted the Afrocentric perspective as part of its theoretical framework. Afrocentricity is a paradigmatic intellectual perspective that privileges African agency in the context of African history and culture trans-continently (Asante, 2007). The Afrocentric framework is described as an approach that prioritises the cultural perspective of Africans in the investigation and rationalisation of mental illness, as explained by Africans (Mkhize, 2004). The Afrocentric idea rests on the assertion of the primacy of the African experience for African people, with the primary aim of giving Africans their consciousness back.

According to Mkhize (2004), the African worldview refers to the way in which Africans perceive their world, which in turn influences their ways of knowing and doing. Afrocentricity looks at existence from the point of view of cultures and social structures that make up communities and create an environment of holism (Asante, 2007). Primarily, this approach seeks to restore the African sense of identity (Asante, 2007) and to reconstruct hidden parts of the African historical self-formation. The Afrocentric perspective emphasises the significance of African cultural influences in the process of understanding and describing health issues among Africans (Asante, 2007). It is an intellectual theory and the study of ideas and events from the standpoint of Africans as the key players rather than victims (Mazama, 2001). Afrocentricity asserts that African indigenous cultural traditions, mythology and history may be understood as a body of knowledge dealing with the social world and as an alternative system of knowledge informed by African people's histories and experiences.

According to Mazama (2001), health-related issues are common to all human societies. However, the types of health issues that occur and the ways in which they are diagnosed, treated and approached depend on how people regard them. According to him this varies from one society to another. This signifies the essence of Afrocentricity, where it aims to reconstruct in a critical manner the missing, hidden and unresolved parts of African history and self-formation. Primarily the approach seeks to restore the African sense of identity. Furthermore, this emerging school of thought seeks to critically reconstruct and restore the missing and hidden parts of African historical self-formation (Asante, 2007).

Afrocentricity is therefore considered the most suitable framework for this study, since the philosophic and theoretical paradigm underlying Afrocentricity is consistent with the African worldview (Asante, 2014). This theoretical approach will enable the researcher and participants to engage and outline the hidden and conservative meanings that people of the rural community have about organ donation. Thus, this will assist in understanding the perceptions the Pedi-speaking people of rural communities have of organ donation.

2.9.2 Health belief model

In the present study, the researcher utilised the HBM as one of the theoretical frameworks. The HBM (Rosenstock, Strecher & Becker, 1950) was developed to understand why people did or did not use services offered by public health departments. Over the years, because of research, the model evolved to articulating health behaviour, addressing lifestyle behaviours and understanding individual perceptions. The HBM attempts to engage health-related behaviour and problems by accounting for individual differences in beliefs and attitudes (Williamson et al., 2017; Rosenstock et al., 1950). Currently, the HBM is one of the most commonly used theories in health promotion and education, mostly in the health sector. Predominantly the formulation of the HBM consists of six constructs, which include (a) perceived susceptibility, (b) perceived severity, (c) perceived benefits, (d) perceived barriers, (e) self-efficacy, and (f) cues to action (Rosenstock et al., 1950). In the context of the present study, each HBM construct will be defined individually and related to the subject.

Perceived susceptibility is defined as individuals' perception of their personal risk of experiencing an adverse health effect. This dimension refers to people's subjective perception of the risk of allowing their bodies to be subjected to surgery to harvest one organ. In the case of organ donation, if one becomes an organ donor, it means that the person will retain only one organ, which may induce feelings of fear of exposing oneself to personal risk and the extent of effects that the person might experience. Thus, the combination of perceived susceptibility and severity has become labelled perceived threat.

Perceived severity refers to an individual's beliefs about the seriousness of the adverse health outcome (Rosenstock et al., 1950). This also refers to the feelings concerning the seriousness of contracting a disease or of leaving it untreated. These include evaluations of both medical and clinical consequences (e.g., death, disability, and pain) and possible social consequences (such as the effects of the conditions on work, family life and social relations). Perceived severity may be thought of as individuals' more general understanding of the need for organ donors (Rosenstock et al., 1950). In the context of organ donation, people who are supposed to be living donors may feel scared of the procedure that they have to go through.

Perceived benefits refer to a person's beliefs about the value or usefulness of a certain form of behaviour. While acceptance of personal susceptibility to a condition that is also believed to be serious (perceived threat) produces a force leading to behaviour, the course of action taken depends upon beliefs regarding the effectiveness of the various available actions in reducing the disease threat, termed the *perceived benefits* of taking health action. Other factors include non-health-related benefits (e.g., quitting smoking to save money, having a mammogram to please a family member). Thus, an individual who exhibits an optimal (high) level of beliefs in susceptibility and severity would not be expected to accept any recommended health action unless that action was perceived as potentially efficacious. Perceived benefit in this regard is the view of helping other people. Most people view organ donation as an opportunity not only to save and extend other people's lives or as an act of love, but also to afford people a better life (Williamson et al. 2017; Rosenstock et al., 1950).

Perceived barriers, on the other hand, refer to individuals' perceptions of the various barriers to acting in a certain way, as well as the negative circumstances related to behavioural espousal. The potential negative aspects of a health action, or the

perceived barriers, may act as impediments to undertaking the recommended behaviour. A non-conscious cost-benefit analysis occurs in which the individual weighs the expected effectiveness of the action against perceptions that it may be expensive, dangerous (having negative side effects), unpleasant (painful, difficult, upsetting), inconvenient, time-consuming, and so forth. Significant barriers to donor donation, for example, are the erroneous cultural and religious beliefs that people hold about the significance of the body after death and during critical illnesses, which ultimately have an impact on their decision to donate (Williamson et al. 2017; Rosenstock et al., 1950).

Self-efficacy was another component added to the HBM to explain individual differences in health behaviour better. Self-efficacy refers to individuals' perception of their competence to perform a behaviour successfully (Bandura & Wessels, 1997). Bandura and Wessels (1997) hypothesised that efficacy is not only about competence in performing a behaviour, but also the effort sustained in the face of obstacles and adverse experiences. Successful management depends on the person believing that the behaviour change will improve the situation (outcome expectancy) and that he or she can make the behaviour change (self-efficacy expectance). People's behaviour is strongly influenced by their confidence in their ability to perform it. Self-efficacy beliefs can influence choices of activities, preparation for an activity, effort expended during performance, as well as thought patterns and emotional reactions (Rosenstock et al., 1950). In relation to organ donation, confidence and belief in one's ability to effect change in outcomes by donating organs to other people and saving their lives is a key component of health behaviour change. This also involves the belief in the experience of organ donation being a safe procedure, which ultimately induces self-efficacy.

Finally, with regard to **cues for action**, the HBM advocates mass media campaigns, advice from healthcare professionals, furthering public awareness through posters and newspapers and magazines as cues to action that will influence people to become donors. The illness of family members and friends may be another instrumental way in which people ultimately become donors (Rosenstock et al., 1950; Williamson et al., 2017).

2.9 Summary

The chapter attempted to provide a general overview of the literature used in the study with regard to most commonly debated topics concerning organ donation. Furthermore, it provided the theoretical frameworks that guided the study. The theoretical frameworks that were used are the Afrocentric perspective and HBM.

CHAPTER 3: RESEARCH METHODOLOGY

3.1 Introduction

This chapter focuses on the research methodology used in the study. It provides an outline of the research design, the sampling process that was adopted, the procedure that was followed and the process of data collection and analysis. Issues concerning quality criteria, together with the ethical considerations that were adhered to during the process of data collection, were also discussed.

3.2 Research design

In this study, a qualitative research design was used. According to Kobus (2010), a qualitative research design in research is based on a naturalistic approach that seeks to understand phenomena in context. This was also supported by Neuman (2006), who pointed out that an exploratory research design is used to investigate problems that are not clearly outlined. It enables researchers to have better understanding and knowledge of existing problems; however, it does not provide conclusive results. An exploratory research design is used to increase the researcher's awareness of a phenomenon and provides valuable information for further investigation (Allen & Babbie, 2008). Qualitative research is acknowledged as a reasonable way to gather knowledge that might not be easily accessed by other methods and to provide extensive and intensive data on how people perceive, interpret and act upon certain phenomena (De Vos, Strydom, Fouche & Delpont, 2011). Since the aim of the study was to explore perceptions, meanings and interpretations of participants, the exploratory research design was found to be appropriate.

3.3 Area of study

The study was conducted in Madibaneng village, situated in Sekhukhune District, Limpopo Province, South Africa. The researcher chose Madibaneng village because it is his home village, stronghold for elderly people and literature on organ donation is limited, especially about people residing in rural areas. Below is a map illustrating the geographical location of Madibaneng Village.



Figure 1: Map of Madibaneng

3.4 Sampling

A sample in a qualitative study consists of cases or units of elements that will be examined and are elected from a defined research population (Patton, 2002). The sample for the study was drawn from elderly community members in Madibaneng village, Sekhukhune District, Limpopo Province. The participants were selected through purposive sampling after the village traditional authority council and gate-keepers had been requested for approval of the study. Only elderly people between the ages of 50 to 80 were sampled. However, sampling depended not only on availability and willingness to participate, but also on the applicability and suitability of certain participants, based on particular characteristics, for example age (Terre Blanche, Durrheim & Painter, 2006). Through this sampling process 12 elderly community members participated in the present study.

3.5 Data collection

In this study, data were collected using semi-structured, one-to-one interviews conducted at a suitable location that was convenient for the participants. De Vos et al. (2005) stated that the approach of semi-structured one-to-one interviews affords both the researcher and participants more flexibility and openness. This led to new ideas being introduced and allowed the researcher to take an interest where an issue was controversial or personal. It was also desirable, since the researcher was particularly interested in the complexity of certain issues that developed in the process. Open-

ended interviews were conducted in Sepedi – the language preferred by the participants – to gain an informed description of the participant's perceptions about the research topic and the interviews were translated by two different translators. Tape recorders and written notes were used to capture data. According to De Vos et al. (2005), a tape recorder provides a broad and much fuller record and information than notes taken during the interview.

3.6 Data analysis

Thematic analysis (TA) was used to analyse data. Thematic analysis involves breaking down or sorting information into themes, as defined by Preacher and Hayes and (2008). Hsieh and Shannon (2005) defined TA as an analysis technique for the subjective interpretation of the content of text data through the systematic classification process of coding and identifying themes or patterns. Braun and Clarke (2006) further elaborated that TA is a method for identifying, analysing and reporting patterns within data. This approach is also used to elaborate on themes through interpretation of the in-depth experience of participants. To support valid and reliable inferences, TA involves a set of systematic and transparent procedures for processing data (De Vos et al., 2005). Thematic analysis was conducted following the steps stipulated below.

3.6.1 Familiarisation with the data

This phase required the researcher to familiarise himself with the data. This was done by reading the data set repeatedly while searching for patterns. It was significant to read the overall data set at least once or twice before beginning to code, as ideas and identification of possible patterns were shaped as the data were read. Then the data were transcribed into written form (Braun & Clark, 2006).

3.6.2 Generating initial codes

After familiarisation with the data had taken place, a list of ideas was generated from the data set. After generating the ideas, the next step was the production of initial codes from the data. The codes identified a feature of the data that appeared interesting to the analyst and referred to the most basic elements of the raw data. All actual data extracts were coded and collated within each code (Braun & Clarke, 2006).

3.6.3 Searching for themes

After all the data had been coded and collated, the different codes were sorted and identified into emerging themes. Collation of all the relevant coded data extracts within the identified themes was then undertaken. The researcher analysed the codes and considered how different codes could be merged to form an all-embracing theme. The themes were then arranged into themes and subthemes. For ease of referencing and identification of themes and subthemes, these were numbered. (Please see Chapter 4 on results and analysis.)

3.6.4 Reviewing themes

After the potential themes had been identified from the data, the analyst reviewed and refined them to ensure that they told a compelling and convincing story. All collated extracts for each theme were read and considered to determine whether they appeared to form a coherent pattern.

3.6.5 Defining and naming themes

Themes were defined, refined and further named. Defining and refining refer to identifying the essence of what each theme is about and determining what aspect of the data each theme captured.

3.6.6 Writing report

Finally, the researcher made a final analysis and wrote the report. The researcher provided a concise, coherent, logical, non-repetitive, and interesting account of the story of the data, within and across the themes. The report was in written form, which remained the primary mode for reporting the results of the research.

3.7 Pre-testing

The current study was pre-tested by interviewing two African elderly community members in the identified area using the semi-structure interview guide. This was done prior to the actual collection of data to determine the effectiveness and efficiency of the research questions, the extent to which they were appropriate and the extent of information they would yield concerning the process of organ donation. It was also done to ensure that cultural and religious sensitivities are observed and to avoid any emotional or psychological harm. Pre-testing is a procedure that assist researchers to determine which questions need clarity, rephrase or refinement prior to the main study to elicit relevant responds to the objective of the study. The research questions in the

study did not need any modification or refinement because they were pre-tested before the main study was done. It also emerged that the questions were aligned to the objectives of the study and the ethical principles (Hsieh & Shannon, 2005).

3.8 Quality criteria

Qualitative approaches have been widely recommended for studies of this nature. However, these have often been criticised for not possessing some level of rigour and accuracy. Thus, for a qualitative study, trustworthiness becomes important. Shenton (2004) states that for a qualitative study to be trustworthy, it should satisfy the quality criteria of credibility, transferability, dependability and confirmability. In the current study these qualities were observed to ensure the quality and validity of the current process and findings.

3.8.1 Credibility

Denscombe (2009) states that this is an alternative to internal validity where the goal is to demonstrate that the study was conducted in such a manner as to ensure that the sample was accurately identified and described and that no other factors explain the results except the inquiry itself. In the present study, to ensure credibility, the researcher adopted well-recognised research methods, debriefed participants and described the phenomenon under scrutiny (Shenton, 2004).

3.8.2 Transferability

Transferability is the provision of sufficient accounts to allow readers to appreciate if insights from one setting can be transferred to other settings and is the alternative to eternal validity or generalisability (Lincoln & Guba, 2010). In the present study, the researcher provided sufficient detail of the context of the study for a reader to be able to decide whether the prevailing environment is similar to another situation with which he or she is familiar.

3.8.3 Dependability

Dependability ensures that the research findings are consistent and could be repeated (Lincoln & Guba, 1985). The researcher in the present study ensured this by audio-recording the interviews as well as taking field notes during the entire data collection process. This was also ensured by clearly stating the steps followed in the present study; the researcher sought to provide a measure of dependability.

3.8.4 Conformability

The concept of confirmability captures the traditional concept of objectivity as applied in qualitative research. This emphasises the need to ask whether the findings of the study could be confirmed by another researcher. Confirmability questions how the research findings are supported by the data collected (Lincoln & Guba, 1985). In the present study, confirmability was ensured by approaching 12 different elderly community members. These elderly village members may not have had similar perceptions, though they were talking about the same phenomenon, namely organ donation.

3.9 Ethical considerations

The following are the most important ethical issues that were considered in this research:

3.9.1 Permission to conduct the study

The researcher sought and obtained permission from the University of Limpopo Research and Ethics Committee before the study was undertaken (see Appendix E1: Ethical clearance). The researcher also approached the Tswako-Lekentle Traditional Council to obtain gate-keeper permission to interview the participants (see Appendix E2: Letter of permission from gatekeeper).

3.9.2 Informed consent

Informed consent is a norm ensuring that subjects participate in the study voluntarily with full understanding of the possible risks involved and are entitled to be informed of the aims, reasons and purpose of the study (Allen & Babbie, 2008; Dyer, 1996). In line with this ethical principle, the researcher explained the significance of the study before conducting it. The participants were given a consent form that was explained to them in a language they could understand before it was signed by both the participants and the researcher. In this study, the participants were fully informed about the details of the study and their consent was obtained.

3.9.3 Privacy, anonymity and confidentiality

Privacy, anonymity and confidentiality were maintained and adhered to throughout the study, taking into consideration the best interest of the participants. No personal information was required from participants. The tape recordings and notes taken

during the interview were accessed only by the supervisor and the researcher. The researcher assured the participants that in all the documents numbers would be used rather than names to ensure anonymity, privacy and confidentiality.

3.9.4 Respect for persons

The researcher ensured that the dignity and integrity of the participants were ensured throughout the study, and it was explained to the participants that their participation was neither intended to violate them nor to use them to achieve the researcher's goals; the intention was to learn from them and their perceptions informed by their demographics could contribute to the development of the health system. For the purpose of confidentiality of the study, pseudo-names were used.

3.9.5 Avoidance of harm to participants

To avoid subjecting participants to harm, the researcher assumed the responsibility for looking for subtle dangers and guarding against them (Babbie & Allen, 2008). The researcher considered these when undertaking the study. The researcher and supervisor's names and contact details were given to participants so that if they felt anxious or uncomfortable after the interviews, they could contact them and be referred to an appropriate professional for intervention if necessary.

CHAPTER 4: RESULTS

4.1 Introduction

In this chapter results from the recorded interviews are presented and analysed. The term *participant* is used instead of the real identity of the individuals participating in the research. To ensure that participants can be easily recognised in the research, they are given numbers to protect their identity. Biographical information of participants is given so that their social context can be understood. In the present chapter, the researcher first presents the demographic profile of the participants. This is followed by TA of the data and protocols obtained from the participants so as to extract the themes and subthemes that emerged from the data.

4.2 Demographic profile of participants

Table 4.1: Demographic details

Participant's no	Age	Gender	Home language	Marital status	Residential area	Educational level
1	75	Female	Sepedi	Married	Madibaneng (Ga-Mphakane)	None
2	51	Female	Sepedi	Unmarried	Madibaneng (Ledingwe)	Tertiary level
3	59	Female	Sepedi	Unmarried	Madibaneng (Ga-Mphakane)	High school level
4	67	Male	Sepedi	Married	Madibaneng (Mototolong)	Primary level
5	55	Female	Sepedi	Married	Madibaneng (Sefateng)	High school level
6	60	Male	Sepedi	Married	Madibaneng (Ga-Mphakane)	Primary level
7	65	Male	Sepedi	Married	Madibaneng (Nokaneng)	Tertiary level

8	53	Male	Sepedi	Married	Madibaneng (Ledingwe)	None
9	58	Female	Sepedi	Married	Madibaneng (Lehlabile)	Primary
10	78	Female	Sepedi	Widow	Madibaneng (Ga- Mohlala)	None
11	71	Male	Sepedi	Widower	Madibaneng (Madimeng)	None
12	59	Male	Sepedi	Married	Madibaneng (Ga- Mphakane)	Primary

The sample of this study comprised 12 participants who are elderly community members of Madibaneng village (Sekhukhune District) belonging to the Tswako-Lekentle Traditional Council. There were six males (50 %) and six females (50%). Fifty percent of the participants were over the age of 60 and 50% between the ages of 50 and 60. This was consistent with the purpose of the study, to interview elderly community members of the community concerned rather than the young generation. Four (33%) of the participants never went to a formal school, whereas six (50%) attended school but terminated their education while still in the lower and higher grades (that is, between Grade 1 and Grade 12). Two managed to attend tertiary education, one being a school teacher and the other a retired factory worker. The majority of the participants (80%) were married and were staying with grandchildren, as their own children had moved out to stay with their own families. Only two (16%) community members who participated in the study were single and never married. The other two (16%) participants were a widower and a widow. The diversity of the sample was beneficial and enriching for the study because of the vast amount of data, knowledge and literature from different perspectives that was obtained.

4.3 Emerging themes

The emerging themes and subthemes are presented in tabular form, as reflected in Table 2 below. A detailed narrative presentation of each theme and subtheme will also be given.

Table 2: Themes and subthemes

Theme number	Major theme	Subtheme
1.	Elderly members' understanding and knowledge about organ donation (4.3.1)	Level of knowledge (4.3.1) Awareness about organ donation (4.3.1.2)
2.	Elderly community members' feelings about organ donation (4.3.2)	
3.	Elderly community members' attitudes to organ donation (4.3.3.)	Family dynamics in respect of organ donation (4.3.3.1) Cultural factors and organ donation (4.3.3.2) Psychological aspects of organ donation (4.3.3.3)
4.	Participant's perceptions of others living with donated organs (4.3.4)	

The chapter will be concluded by giving a summary of the results of the study.

4.3 Thematic analysis of the data

4.3.1 Elderly community members' understanding and knowledge about organ donation

4.3.1.1 Level of knowledge

Participants were asked to give their understanding of organ donation to ensure that they had a true understanding of what the research was about. This understanding was instrumental in deducing their level of knowledge of the subject. It was also evident from their responses that some had good understanding of the subject under study, while other had no knowledge and understanding. Their responses are noted as follows:

Participant 1: *"I have a little understanding about organ donation, but what I know is that in the past when traditional healers passed away, other traditional healers would approach the family to ask for certain organs of the deceased. In cases where the family refused the request they would compensate people to exhume the body and then harvest the organs ..."*

"I am a little startled about whether someone who donates a heart to someone else will carry all the characteristics and behavioural traits of another person with them ..."

Participant 2: *"I think when one is talking about organ donation it refers to when an organ is taken from one person to another through an operation ..."*

Participant 3: *"Organ donation has been happening for years and I have heard about it. It is done when one of your family members needs a particular organ or blood; they will then source a family member who will help with that organ or blood ..."*

Participant 5: *"I have heard about it but I do not have much knowledge about the process and I do not know how it is done. What I have knowledge about is blood donation; where are people in need of blood, family members donate to those people ..."*

Participant 7: *"I have heard of it this procedure and how it works. Personally, I do not have a positive attitude to it ..."*

Participant 8: *"What I understand about organ donation is that when people experience organ failure requiring organ transplant, other people can donate their organs to help those people ..."*

Participant 10: *“I understand that the donation of organs is when someone’s organ is no longer functional, other people may be able to donate their organs to people in need. They can donate when they are alive or dead; however, it depends on the type of organ you donate. I do not think you can donate a heart when you still alive; maybe a kidney will be more appropriate ...”*

Participant 12: *“I think it is when your organs are given to people who need them after you die but with the consent of your family members. Mainly, it is done to help people who are sick and in need of organs, just like when donating blood to help people with insufficient blood in their body ...”*

It is apparent, and it can be deduced from the above statements or data, that all the participants did not have the same knowledge and understanding about organ donation. Sixty percent (60%) of the participants had good understanding and knowledge about the process of organ donation. This shows that the level of adequacy in terms of knowledge is limited and culturally constructed regarding the organ donation process in this setting.

4.3.1.2 Awareness about organ donation

The participants displayed no knowledge of the process. This resulted from a lack of awareness that was prevalent among the participants concerning organ donation. This is indicated by the quotations below:

Participant 4: *“I have no knowledge of organ donation that you are talking about and I have never heard of it before. What I know about is blood donation to family members.”*

Participant 6: *“I do not have much knowledge of organ donation; what I know about is blood donation. I have my own personal experience of donating blood to a close family member who had insufficient blood in his body ...”*

Participant 9: *“I do not know what you are talking about. I have never heard of it. Because organ donation that I know about cannot be construed as donation for the greater good because normally people will steal other people’s organs for their own personal use and save their own lives ...”*

Participant 11: *“I have heard of this process you are talking about but I do not have much knowledge about it and how it works. What I know is that it is possible for*

someone to donate a kidney to someone else, but what perplexes me is that what will happen to that person if the person's only kidney that is left becomes dysfunctional during the course of his life. Would he want his kidney back because he would be dying?"

A few of the participants in the study did not have any prior knowledge of organ donation but showed knowledge of blood donation. This was evident from the above quotations where participants were unable to show any level of understanding and knowledge. Overall, only four of the participants displayed informed knowledge about organ donation. The process of organ donation and eventual transplantation is undertaken by a team of multidisciplinary health professionals. The donor should provide express written consent before the donation process and in the case of a deceased donor, the onus is on the family to give such consent.

4.3.2 Community members' feelings about organ donation

Participants expressed ambivalent feelings about organ donations. Most of the participants had positive feelings, but some had negative feelings. These feelings were influenced by many demographical factors within which individuals function. The feelings of participants were subject to their systems of functioning. The following extracts illustrate this causal explanation:

Participant 1: *"I would enlist my name on the registry but in that case, I would prefer and feel positive if the organs or donation would be for a family member. It is always preferable to help a family member first rather than any other people and I think enlisting my name will help many of my close family members to come ..."*

"Again, I do believe that even if it happens, the organ doesn't work properly like that person's original organ ..."

Participant 2: *"I can enlist my name on the transplant registry for donation when I am dead because I believe people can benefit from my organs and live a longer life. I do not have any reservation; besides, I will be dead ..."*

Participant 3: *"I feel as if the situation now is a bit complicated because of the widespread nature of diseases. People are now afraid to donate their blood and organs. However, I still have mixed feelings about the thought that it is possible for one's organs to be transplanted into other people and that those people will live a healthy life ..."*

“I would enlist my name on the organ donation registry, but this will have to be a decision that involves the whole family. Because when you are dead the family is responsible for your body and they are the ones to take decisions about what should happen to your body ...”

Participant 4: *“I will only enlist my name if my family agrees to it. I cannot make a decision involving my life and not include my children and wife; remember when I am dead they are the ones to decide on my body ...”*

Participant 5: *“The problem is that I can agree, and my kids may prevent the process. But if my family agrees to it then I can donate because it is not going to be used for witchcraft or devil possession; however, the onus rests on the family to support my decision ...”*

“I also feel that people’s decisions to refrain from donating is because they are not thoroughly informed about these processes ...”

Participant 6: *“I can enlist on that registry to donate my organs. I do not think it is of any importance to keep organs once I am dead. However, when am still alive I can only donate my blood, not my organs ...”*

“I also feel that people do not take care of their own bodies. They consume too many substances that tamper with the functions of their organs and afterwards they come seeking help from us who take care of our own bodies ...”

Participant 7: *“That one will have to be a decision that will need a family discussion and be made on common grounds as a family ...”*

“I do not know how to say what I feel about it; what I know is that there has to be a family intervention ...”

Participant 8: *“I can enlist my name on the organ registry because I know I would be helping other people. I think it’s better if people benefit from others and again helping others is one of the fundamental principles of being a Christian ...”*

Participant 9: *“I would enlist my name on the organ registry when I am dead, not when am alive. Even when I am dead I would like my family members to be the only recipients of my organs, not strangers. This is because I think it would not cause any familial issues or bring me into conflict with my culture and ancestors ...”*

Participant 10: *“Provided that the only people receiving my organ are my close relatives or my children are the recipients of my organs, I do not have a problem with donating. I do not prefer that anyone who is not a family member should be a recipient of my organs ...”*

Participant 11: *“I will enlist my name for my organs to be donated when am dead; besides I will dead by that time. However, my family will have to guide me in making such a decision. I will have to consult my family because I do not want to cause any problems when I am dead ...”*

Participant 12: *“I want to be buried with no missing organs; if a person is buried with a missing body part, she/he will not rest. Those people mostly appear in dreams and trouble their family members, instructing them to find their body parts and bury them with them. So, I do not want my family to struggle because of angry ancestors. However, an exception can be made in a case of a dead person where another family member needs the organ. The family will then have to perform a ritual to cleanse the dead and the recipient of the organ ...”*

The above extracts illustrate the ambivalent feelings that participants had when asked about their feelings on the subject. The most prevalent dynamic that affected people’s decision-making capacity was the family system. Participants expressed the need to include family members in decision-making on whether to enlist their names or not. Some participants preferred to become donors only when they were dead, not when they were alive, even if a family member was in need of the organ. It can also be deduced that some participant’s feelings were affected by uncertainty about the process. It is therefore suggested that information about the organ donation process be disseminated to people across the country, primarily those in rural communities. About 80% of the participants expressed positive feelings about the process; however, they cited their families as vital in decision-making, which would ultimately influence their feelings about organ donation.

4.3.3 Elderly community members’ attitudes to organ donation

4.3.3.1 Family dynamics and organ donation

Most participants’ attitudes conflicted with how they felt about the process of organ donation. It appeared that almost 90% of the participants portrayed positive attitudes

to organ donation, yet participants indicated some family implications of decision-making on actually becoming donors. This is illustrated by the following extracts:

Participant 1: *“I think it is much preferable and better when saving a family member. This is because if the procedure does not go well at least you would have died or become disabled for a family member ...”*

“It is always preferable to help a family member first rather than any other person.”

Participant 3: *“It’s easy to endanger your life for a family member and this will be easy when I am old, not when I am still young and healthy ...”*

“This has to be a decision that involves the whole family. Because in our culture when you are dead the family is responsible for your body and they are the ones to take decisions about what should happen to your body. In many cases we can be a family but have different beliefs, attitudes, views about something, so involving the family can be a positive route to take ...”

“I think regarding this organ donation processes, it is always advisable to include your close family members in decision-making so that they become aware of your wishes. Because in many cases conflicts arise in families after the passing on of people who made a major decision without involving their close family members ...”

Participant 4: *“I think it’s better to go through the process for a close family member rather than for someone who is not a family member. Because you never know the outcomes of this new medical procedures; they can be uncertain sometimes and go wrong ...”*

“The decision that they took, I believe their families were very much involved in it. What I am trying to say is that family is very important in this kind of process ...”

“I will only enlist my name if my family agrees to it.”

Participant 5: *“My objection is when I am expected to donate to a stranger; I can only donate to a family member. However, this will be determined by many factors, such as my age and what the cause of that person’s organ failure was. Again, I do not think even my family can agree for me to donate to someone who is not a family member ...”*

“The problem is that I can agree, and my kids may refuse the process. But if my family agrees to it, then I can donate because it is not going to be used for witchcraft or devil possession; however, the onus rests on the family to support my decision ...”

Participant 7: *“My family and I in this case would have to make a decision because in our culture decisions like these are made collectively as a family, not in isolation ...”*

“I do not have a problem with them because that might have been a decision made by them and their families ...”

“That one will have to be a decision that will need a family discussion and be made on common grounds as a family. I cannot make that decision alone; when I am dead my family will have power over my body, so I do not want to cause conflict, that’s cultural. But as a family we agreed upon about it, therefore I do not have any reservation ...”

“I think and believe that a family intervention in making a decision will be significant in this regard ...”

Participant 9: *“Even when I am dead I would like my family members to be the only recipients of my organs, not strangers. This is because I think it would not cause any familial issues or bring me into conflict with my culture and ancestors ...”*

Participant 10: *“This should be done primarily for a family member, not a stranger ...”*

Participant 11: *“More favourable will be donating to a family member because one of my own will be saved, and continue to grow our family in my absence ...”*

“My family will have to guide me in making such a decision. I will have to consult with my family because I do not want to cause any problems when I am dead ...”

Participant 12: *“If the organs belong to their family member or a relative, it will not be a problem to their ancestors ...”*

From the above quotations one can deduce that people’s attitudes to the subject are affected by their family, culture and their individual feelings. More than 90% of the participants illustrated the importance of the process and conveyed a positive attitude; however, the family dynamics highlighted by the participants showed that it would be more favourable if a family member was the one benefiting from the process, not an outsider or stranger to the family. About 80% of the participants did not have a negative attitude to other people with donated organs, as illustrated by the above quotations.

However, some participants still portrayed a negative attitude to the procedure owing to various cultural and traditional reasons.

The family system plays a vital role in influencing the actions and attitudes of people when taking major life decisions, despite their own personal perspectives or attitudes. Most of the participants in this study preferred to include the family dynamics and accept how these dynamics continue to influence their lives. The family system determines the activities, choices of life and actions that individuals decide to take. The significance of the family system was mentioned by most participants concerning the subject of organ donation.

4.3.3.2 Cultural factors and organ donation

There seems to be a variety of cultural factors that influence the perceptions of participants in the current study on the subject of organ donation. The cultural dynamics are different for different participants; however, some appear to be common. Participants referred to factors that were based on individual reasons, familial and societal norms and values. This is illustrated by the quotations below:

Participant 1: *“Many people within the Pedi culture do donate organs, but not for a donation process to the organ donor registry. It is done for traditional reasons, such as donating to sangomas for medicinal harvests; however, it is always kept secret across many families ...”*

“Historically, traditional healers would recommend meat from the monkey to help people who had organ failures. Another approach would be poison from a snake to help heal organ failures and other non-communicable diseases and this proved to be effective ...”

Participant 3: *“In our Pedi culture it not acceptable to donate organs because they believe in burying the complete body of a person. This was evident in the olden days when they didn't take the deceased to funeral parlours because they knew that funeral parlours had a tendency of harvesting human organs. Old people would just cover the body in a blanket and bury the deceased ...”*

“Old people believed that if a person is buried incomplete, the living will incur consequences such as misfortunes and many deaths within the primary family ...”

“In many sections of the Pedi culture there is still a prominent belief that sangomas and traditional healers would approach some family members of the deceased and request some organs that they can harvest, and they would compensate the family ...”

“When sangomas and traditional healers die, even now many of them are not taken to funeral parlours. It is said that other sangomas harvest some parts from the deceased healers and use these for medicinal processes and the families of those sangomas do not have a problem with it; it is a normal tradition for them ...”

Participant 4: *“Sometimes this organ donation thing may interfere with the tradition within the Pedi culture. In the Pedi culture when someone dies from an illness that is suspected of being brought upon the deceased through evil possession, the family will require the complete body to perform rituals aimed at investigating who killed the deceased and I think in that regard organ donation will interfere with that process ...”*

Participant 5: *“In our culture the system of family is very important and major decisions are not taken in isolation; the family has to be involved ...”*

Participant 7: *“Because in our culture decisions like these are made collectively as a family, not in isolation. However, personally I do not think I would allow it ...”*

“I think it defies our culture and what it means to be human. However, because of recent advancements we have to move on and help other people ...”

Participant 8: *“I do not think it helps to be buried with your organs that can still help other people, despite what your culture or religion says ...”*

“However, culture does play an important role and it is a good thing that people will make decisions adhering to their own cultural beliefs ...”

Participants 9: *“Our cultural beliefs can sometimes be altered if the whole community is fully informed about things like these ...”*

Participant 10: *“It will be against the culture to give your blood to someone who is not a family member and let that person carry your family blood with them; then that will make the ancestors angry, consequently incurring misfortunes in the family ...”*

“I think that my culture would support this only if I am not donating to a stranger. Ancestral spirits play an integral role in our lives, so any decision that we take we must be cautious to refrain from incurring misfortunes from them. I think if you donate to a

stranger, it is like disconnecting yourself from the whole family system and ancestral spirits ...”

Participant 11: *“Traditionally we believe that when a person is ill, and we have done all we could to heal the person and nothing worked out, we know it was time for that person to be our ancestor and let him/her go, rather donating his/her organs or implanting some other person’s organ into him/her ...”*

Participant 12: *“In our culture it is believed that if you donate your organs, your ancestors will not recognise you and it will cause unnecessary fights in the family, accusing one another of murder and selling your organs ...”*

Based on the above quotations, it can be deduced that many community members do not have a problem with the process of organ donation; however, they attach great importance to cultural dynamics. Many participants highlighted the family system as the cultural domain that would sometimes interfere with this process of organ donation. They based their perceptions of becoming actual donors as something to be a collective decision made by the family system. Participants perceived themselves as not having the individual capacity to decide on becoming organ donors. Some participants revealed the significance of ancestors in terms of the role that they play in respect of the whole body of the person while alive and dead and the consequences that may result from defying the ancestral spirits. Others believed some of the traditional beliefs and practices within the Pedi culture included the process of donating organs, but this was done for traditional reasons.

4.3.3.3 Psychological aspects of organ donation

Participants in this study mentioned psychological aspects concerning the subject of organ donation. Most participants’ feelings, attitudes and decisions were greatly influenced by psychological aspects that had an impact on their perceptions of becoming organ donors. These aspects further led to participants developing ambivalent feelings. Most participants had some positive attitudes to organ donation, but the uncertainty about the process made them develop psychological barriers. The following quotations illustrate the above subtheme:

Participant 1: *“I do believe that even if it happens, the organ doesn’t work properly like that person’s original organ ...” (Uncertainty and lack of hope).*

Participant 2: *“In case where it is required that I donate while I am still alive I do not think I will and be separated from my organ ...” (Fear and uncertainty).*

*“What worries me is the eye tissue transplant, where it is visible that it has been transplanted. I think this will cause **some esteem issues, confidence problems, social isolation and withdrawals** from other people, as I know of some people who are experiencing such problems with eye tissue transplants ...”*

Participant 3: *“For me it will be difficult to donate while I am still not that old and still healthy. Only when am old and dead will I be able to donate to family members ...” (Anxiety).*

“It is easy to endanger your life for a family member ...” (Uncertainty).

“I do not believe those people live a healthy life ...” (Lack of confidence in the procedures).

“This has to be a decision that involves the whole family ...” (Social cohesion).

Participant 4: *“I think it’s better to go through the process for a close family member rather than for someone who is not a family member. Because you never know the outcomes of these new medical procedures; they can be uncertain sometimes and go wrong ...” (Uncertainty and fear).*

Participant 5: *“My objection is when I am expected to donate to a stranger; I can only donate to a family member ...” (Fear and uncertainty).*

Participant 6: *“I do not think it is of any importance to keep organs when I am dead. However, when am still alive I can only donate my blood, not my organs ...” (Uncertainty).*

“Again, many people refrain from this process because of fear, worry about the success of the procedure and family circumstances ...”

Participant 7: *“I think and believe that a family intervention in making a decision will be significant in this regard ...” (Social cohesion).*

Participant 8: *“This will help in eliminating all the worries, fears, uncertainties about their lives and enhance their personal and psychological well-being ...”*

“Others hold back from donating because of guilt and shame that they will incur from sharing their organs ...”

Participant 9: *“This sounds like a risky procedure and doing it while alive - if anything goes wrong I will be dead ...”*

“I would enlist my name on the organ registry when I am dead, not when I am alive. I do not really have confidence in this procedure ...”

Participant 10: *“I think they live a hard life; imagine possessing blood that doesn’t belong to you, and dealing with the fact of living with someone’s organ ...”*

Participant 12: *“... for example the Jehovah’s witnesses believe in denial of eternal life in the afterlife; even myself I am personally against it ...” (Denial)*

Based on the above explanations, it can be suggested that community members perceive organ donation positively; however, there are multiple psychological aspects associated with how they perceive this subject. More than 90% of the participants appeared to be uncertain about the whole process being a success or even being possible. They expressed fear, lack of hope, anxiety, esteem issues and the need for social cohesion, among other psychological factors. These factors seemed to play an important role in influencing people to become organ donors. It was therefore observed that participants might have developed these views because they were not fully informed about how the process operates and the dynamics involved. Therefore, it is argued that lack of knowledge might have played an integral part in the development of psychological attitudes.

4.3.4 Participants’ perceptions of those living with donated organs

Participants’ responses towards other people living with donated organs were more often positive than negative. This is substantiated by the quotations from participants below.

Participant 1: *“I do not have a problem with someone living with donated organs. This is because I know of someone who was living with an organ which was not the person’s, but in that case, it was an eye tissue transplant ...”*

Participant 2: *“I do not have a problem with them because it is not visible for other people to see. What worries me is the eye tissue transplant, where it is visible that it has been transplanted ...”*

Participant 3: *“In as much as I do not have a problem with that, I do not believe those people live a healthy life. It is as if you are begging to live by living off other people’s organs ...”*

Participant 4: *“I do not have a problem with those people if they were helped and they can still live their lives. The decision that they took, I believe their families were very much involved ...”*

Participant 5: *“The thing is that you cannot see that these people are the recipients of an organ, thus there is no problem. I think they too deserve to live because people are helped by others; you cannot ever survive on your own ...”*

Participant 6: *“I do not have a problem with those people, since they have a second chance in life again. As people we are guided by our Christian principles and we are not supposed to judge other people ...”*

Participant 7: *“I do not have a problem with them because that might have been a decision made by them and their families who agreed to it. If it helped them to heal and live a longer life that is by God’s grace and I will wish them well too ...”*

Participant 8: *“I think it is a good thing and I do not have a problem, as it helps extend those people’s life. This will help in eliminating all the worries, fears, uncertainties about their life and enhance their personal and psychological well-being ...”*

Participant 9: *“I do not have a problem with them since they have been granted the opportunity to live longer. I do believe that their families are happy that they received help ...”*

Participant 10: *“I think they live a hard life; imagine possessing blood that doesn’t belong to you, and dealing with the fact of living with someone’s organ. However, if the procedure is done properly they can live a healthy life, especially if they have support from their own family and close friends ...”*

“I can donate to a family member, because there is a stronger blood tie between us. Furthermore, I do not think our ancestors will have a problem with it when the organ is being donated within the same blood line. It will be against our culture to give your blood to someone who is not a family member and let that person carry your family blood with them, then that will make the ancestors angry, consequently incurring misfortunes in the family ...”

Participant 11: *“I do not really have a problem with them, but I do not think they live a healthy life, because of all the medication I presume that they have to drink every day and the check-ups that they undergo on a recurrent basis ...”*

“I will, I mean there is no need for me to be buried with functional organs that can be used to help other people. More favourable will be donating to a family member because one of my own will be saved, and continue to grow our family in my absence ...”

Participant 12: *“If the organs belong to their family member or a relative, it will not be a problem to their ancestors, but there are many beliefs against this whole organ donation thing. For example the Jehovah’s witnesses believe in denial of eternal life in the afterlife; me too, personally I am against it ...”*

From the above quotations one can deduce that most participants’ perceptions of other people living with donated organs were not negative. About 80% of participants pointed out that they did not have a problem with those people, because they might have had their own personal reasons for accepting organs from other people. It was also detected that cultural, familial and religious dynamics played a vital role in influencing the organ donation process. Participants based their decisions on their belief system and also acknowledged that other people’s decisions were determined by their own systems, hence most participants did not express negative perceptions of to those living with donated organs. However, a portion of participants still displayed some conservative views about those living with donated organs, as illustrated in the extracts, basing their reasons on mistrust of the whole process.

4.4 Summary of findings

The present study found that participants (elderly community members) seemed to hold varying perceptions regarding the subject of organ donation. Their levels of understanding and knowledge appeared to vary. It was clear from the findings that some participants had good understanding and knowledge about the process of organ donation. Some appeared to be informed, whereas others were not informed at all and did not have any prior knowledge about organ donation. The prior knowledge that dominated the data concerning donation was of blood donation. Many of the participants stated having prior knowledge of what blood donation entailed and a few of them had experience of being blood donors. Some indicated that they had a prior

knowledge of traditional healers, *sangomas* and families donating organs for medicinal purposes.

Participants who displayed knowledge and understanding of organ donation construed it as a process where someone's organ is no longer functional and other people are able to donate their organs to people in need. They can donate organs when they are alive or dead, depending on the type of organ. Participants highlighted the fact that one cannot donate a heart when one is still alive; "*maybe a kidney would be more appropriate*". The process is undertaken by a team of multidisciplinary health professionals. The donor should provide express written consent before the donation process and in the case of deceased donors, the onus is on families to give such consent.

About 80% of the participants expressed positive feelings about the process; however, they cited their families as playing a vital part in decision-making, which would ultimately influence their feelings about organ donation. Participants expressed ambivalent feelings when asked about their feelings on the subject. The most prevalent dynamic that affected people's decision-making capacity was the family system. Participants stated that they did not have the individual capacity to make decisions on their own.

They indicated that their families played an integral part, especially when making major decisions such as deciding to become an organ donor and enlisting their names on the organ donor registry. Some participants preferred to become donors only when they were dead, not when they were still alive, even if it was a family member in need of the organ. It was also extracted from the findings that some participants' feelings were affected by the uncertainty of the process.

Community members' attitudes to the subject were affected by multiple factors. Through the analysis of the findings concerning the attitudes, four subthemes emerged. These themes included family dynamics, cultural factors, psychological aspects or factors elicited from participants concerning the organ donation process and how participants viewed or perceived people living with donated organs. About 80% of the participants illustrated the importance of the process and conveyed a positive attitude; however, the family dynamic highlighted was that they would like family members to be the ones benefitting. One participant was quoted as saying, "*I*

think it is much preferable and better when saving a family member. This is because if the procedure does not go well at least you would have died or become disabled for a family member.” This highlights how most of the participants’ portrayed a positive attitude, albeit restricted to the family system. The cultural factors influencing people’s attitude rather concerned conserving the family lineage and maintaining their own blood ties. This was mentioned as supporting statement to why they would love to donate, but within their own family lineage.

Some participants illustrated the importance of family in making such decisions to avoid conflicts at a later stage. Participants indicated that they did not have the individual capacity to make such decisions, but if their families agreed to it they would not have a problem with becoming organ donors. In addition, it was highlighted that cultural dynamics and ancestors would not be a problem if the process should be constrained within the family system, maintaining the same blood ties. It was also stated that community members perceived organ donation positively; however, there were cultural factors associated with how they perceived this subject.

They based their perceptions of becoming actual donors on consent as something to be a collective decision taken by the family system. The consequences that some of them would suffer from defying their traditional and cultural beliefs, consistent with tampering with their own bodies, was one of the worries expressed by some the participants. Some participants indicated that their families would suffer death and many misfortunes brought upon them by the ancestors if they defied them.

However, sacrifices would be made if the organ donation was done for a close family member. In such cases rituals would be performed, though this was not always the case, because some would still insist on burying the whole body. Participants revealed the significance of ancestors in terms of the role that they play in respect of the whole body of the person while alive or dead. Others believed in some of the traditional beliefs and practices within the Pedi culture, including the process of donating organs, but this was done for traditional reasons.

Many participants referred to some psychological aspects and factors that would sometimes interfere with the process of organ donation. More than 80% of the participants appeared to be uncertain about the whole process being a success or even being possible. They expressed fear, lack of hope, anxiety, esteem issues and

the need for social cohesion, among other psychological factors. These factors seemed to play an important role in influencing people to become organ donors. In addition, other participants' responses indicated that they did not have a problem with the process of organ donation; however they attached a lot of significance to cultural factors.

About 80% of the participants did not have a negative attitude to people living with donated organs, as illustrated by the extracts from the data. However, some participants still portrayed a negative attitude to the procedure because of various cultural and traditional reasons. The family and the cultural system play a vital role in influencing the actions and attitudes of people when taking major life decisions, despite their own personal perspectives or attitudes. More than 90% of the participants indicated that the procedure would be much more favourable if one donated an organ to a family member. It was perceived that saving a family member was better, because if the procedure did not go well, it would be better to have endangered oneself for a family member.

These findings from the study suggest that participants' views were more likely to be dominated by their lack of knowledge and understanding about the process of organ donation. However, this would have been expected to apply to those who reflected a negative or conservative view, despite being informed about the process. Furthermore, it is argued that community members' cultural values, traditions and norms are integral to their decision-making and as a family system.

CHAPTER 5: DISCUSSION OF FINDINGS

5.1 Introduction

The purpose of the study was to explore perceptions of organ donation held by elderly community members in a rural community in Sekhukhune District, Limpopo Province. This chapter presents and discusses the findings of the study in relation to the information gathered and the literature reviewed. These findings will be discussed according to the emerging themes and subthemes identified in the previous chapter.

5.2 Emerging themes

5.2.1 Elderly community members' understanding of and knowledge about organ donation

(a) Level of knowledge and awareness about organ donation

It emerged from the present study that elderly community members hold varying perceptions of the subject of organ donation. These perceptions are highly likely to be influenced by their level of understanding and knowledge of the subject. Badrolhisam and Zakaria (2012) found that motivation to donate an organ has been shown to have a relationship with knowledge and awareness of organ donation. Another study by Mossialos, Costa-Font and Rudisill (2008) in the European Union found that being more educated and younger, as well as expressing some sort of political affiliation, determined the level of understanding and knowledge of the issue, willingness to donate one's own organs and consent to the donation of those of a relative.

Badrolhisam and Zakaria (2012) explained that to examine respondents' understanding of the definition of organ donation in their study, they provided a questionnaire with three different but correct definitions of organ donation and another option that combined all three definitions for respondents. From these definitions, participants' knowledge and understanding were further associated with their level of education, awareness and their age. They found that the older the participants were, the more deficient their knowledge about organ donation. The current findings were consistent with those of Badrolhisam and Zakaria (2012).

The findings of the study showed that some participants had good understanding and knowledge about the process of organ donation, whereas others appeared to be informed and others quite uninformed, with no prior knowledge about organ donation. The prior knowledge that dominated the data on donation was related to blood

donation. The variety of knowledge and understanding was observed to be associated with participants' previous and current level of education, awareness and their age.

In the current study participants who had tertiary education displayed informed knowledge, whereas those with primary and secondary education had some understanding of the subject. Those who had no level of education had no understanding and knowledge of organ donation. Vijayalakshmi et al. (2016) stated that relatively higher percentages of people with insufficient education were more likely to lack awareness and knowledge of organ donation. The authors further analysed the interdependency relationship between knowledge, level of education and shortage of organ donors. The analysis indicated a significant difference in the level of knowledge of organ donation and the motivation to become a donor, which is related to people's level of education.

Etheredge et al. (2014) argue that in South Africa, primarily among the black population, there is still hugely insufficient awareness of organ donation. They recommend that extensive research and campaigning about organ donation be done in those areas to stimulate awareness, which may have some implications for people's attitudes to the subject. Research by these authors suggests that television advertising may be one of the most effective ways of communicating information about organ donation among the South African public.

Etheredge et al.'s (2014) study was supported by the findings of the current study that in the black community, the level of awareness and knowledge about organ donation is still limited. This calls for an extended effort from the government to disseminate information regarding organ donation extensively to all corners of the country. This may assist in increasing the number of people in the organ registry and improving consent rates, as relatives will not feel they are deciding on behalf of their loved ones without knowing their preferences.

5.2.2 Community members' feelings about organ donation

The study findings indicated that participants expressed ambivalent feelings about organ donation. Such feelings ranged from mistrust of the medical system, feelings of altruism, concern about whether ancestors will have a problem with it, the fear associated with the process and reactions from the family. These feelings were

influenced by a variety of factors, which included familial, social, traditional and individual reasons. This was evident because about 80% of the participants expressed positive feelings about organ donation, but cited their families as playing a vital part in decision-making, which would ultimately influence their feelings about the whole organ donation process.

Nizza, Britton and Smith (2016) studied how organ donation can trigger difficult thoughts and how the family can be used to explain not having signed up. In their study, they found that all participants expressed the intention to sign up. However, the participants judged themselves harshly for not signing up earlier, but also gave clear reasons to explain why they had not signed up. Dominant reasons for not signing up for organ donation was the need to maintain bodily integrity or mistrust of the medical system, which has been recorded in the documented literature. Discomfort with donation is an initial reaction that for most people dissolves when weighed up against pro-donation arguments. This is consistent with the findings of the current study, in which participants perceived the process positively in general but had their own individual reasons for not becoming donors (Nizza, Britton & Smith, 2016). The feelings of discomfort and mistrust were some of the considerations influencing their perceptions. The process of organ donation also implied difficult thoughts for the participants, primarily because it requires one's own mortality to be taken into consideration.

D'Alessandro, Peltier and Dahl (2012) believe strategies to avoid thinking about death, such as avoidance and displacement, can be described and enacted during the interview. The anxiety caused by the awareness of being mortal can trigger avoidance strategies, but can also motivate prosocial behaviour. However, this does not extend to organ donation, since the salience of death can become so overwhelming that a self-protecting instinct prevails over the altruistic desire. This explains why death-related thoughts may act as concrete obstacles for many participants in organ donation explorations.

The participants seemed to feel a need to explain why they were against individual decisions to become an organ donor. The family turned out to play an important role in the way in which most participants related to organ donation, to the extent that one could say the family was used as a reason for making their final decisions and deciding how they perceived the subject. This is supported by the study of Nizza, Britton and

Smith (2016), which states that families are directly or indirectly used as an opportunity to put off a decision that is difficult to make. However, in African communities families are construed as the embodiment of individuals, which influences their decisions in many aspects of their lives (Mazama, 2001). In the current study, the family seems to be used as a shield to protect the person from dealing with the difficult feelings arising from the conflict between what one feels one ought to do and what one feels like doing.

5.2.2 Elderly community members' attitudes to organ donation

The present study found that community members' attitudes to the subject resulted in multiple subthemes emerging from the data under the above theme. Subthemes that emerged included family dynamics, cultural factors and psychological aspects associated with organ donation. Subthemes identified are discussed below:

(a) Family dynamics in organ donation

The present study found that elderly community members perceived that donating organs to family members is more favourable than donating to someone who is not a family member. This was because they argued that if the procedure did not go well, it would be better to have endangered or disabled oneself for a family member. It was also discovered that participants emphasised the importance of family in making such decisions to avoid conflicts at a later stage. Participants indicated that they did not have the individual capacity to make such decisions; only if their families agreed to it, would they have no problem with becoming organ donors. Other participants highlighted that their families' religious and cultural beliefs and social attitudes would not allow them to consent and they would not support the idea of organ donation.

Hawkins (2017) states that the reason why individuals would cite their families when talking about organ donation is that families have authority over them when they have passed on. This is because despite the deceased's wishes, the family sometimes makes the ultimate decision. Yan, Wang, Shao & Yuan (2018) articulate that the family plays a vital role in decision-making and the whole life of the person, hence there is a need for people to be considered in the context of their families. This is consistent with the findings from the current study, in which participants stated the dire need for family involvement in their decision-making, especially about organ donation.

In a study by Sharp and Randhawa (2016) it was found that the family must decide on whether to donate or not, either to a relative or any other person. It was further

indicated that sometimes families found themselves in an emotionally charged state where their capacity to make an informed decision became impaired and they would approach the whole process negatively. It has also been demonstrated that social, cultural and social norms play a vital role in the perception of organ donation and death. The findings in the present study also elicited the fact that ancestors of the family concerned would not have a problem if the process was constrained within the family system and the same blood ties. The participants also mentioned that it would be more favourable for the ancestors if the donation happened through the family system. This would protect them from any form of ancestral misfortunes being visited upon them.

Chirozva, Mubaya and Mukamuri (2005) argue that in the African context, the concept of the African traditional family is premised on an expansive kinship network. Traditionally, the family is an organisation based on descent groups. In an African context, material co-operation is expected between members and decision-making is done collectively. This collective action is envisaged to bring about positive reciprocity, which is important in maintaining equilibrium in the institution. This was apparent in the present study in terms of how the participants maintained the importance of including their family members in decision-making about becoming an organ donor. This was because the family embodied their own culture, values and norms, which described their identity.

Furthermore, the present study's findings indicate the involvement of families in deciding to donate and whether they coherently have common ground. However, some participants highlighted that given the broad spectrum of beliefs that may exist within a single family system, it is difficult to reach common agreement, where they all agree to donate. This would in most cases lead to disagreement about donating. This was supported by the study of Vijayalakshmi et al. (2016), which found that participants felt that it was important to discuss their wishes about what would happen after death with their families. This was because traditionally, the family took care of its members even when they were ill. Hence, the consent of the family was mandatory for the organ donation process. The authors further stated that participants felt that after their death it was important to know their family's wishes. However, as in the present study, despite a person's wishes, the family may have to take the final decision (Reynolds, Lecker, Giardino & Takooshian, 2012).

(b) Cultural factors and organ donation

In the study it was found that cultural factors offer perceived opposition to organ donation, since participants indicated the need not to defy the ancestral spirits and to maintain bodily integrity for the afterlife. Many participants highlighted the family system as the cultural domain that would sometimes interfere with this process of organ donation. They based their perceptions of becoming actual donors or consent as something to be a coherent decision taken by the family system. Some participants revealed the significance of ancestors in terms of the role that they played in terms of the whole body of the person while alive or dead and the consequences that may result from defying the ancestral spirits. Others believed some of the traditional beliefs and practices within the *Pedi* culture included the process of donating organs, but this was done for traditional reasons.

Bojuwoye and Sodi (2010) pointed out that different societies have their own way of understanding and describing various health-related issues. In Africa, people interact with one another not based on how things are, but how they perceive them. Africans believe existence to have material, moral, supernatural and pre-natural causes, which can be maintained by staying in contact with ancestors through periodical performance of rituals and avoiding practices that would bring them into conflict with their ancestral spirits. In the current study participants emphasised the concerns that ancestors and the whole family system might have about the process of organ donation. This was because participants' cultural beliefs viewed the body of a human being differently, both when alive and when dead.

In the current study, participants pointed out that respecting their ancestral spirits prevented them from incurring misfortunes that may result from opting to become a donor or sign up for organ donation. This was supported by Sharp and Randhawa's (2016) study, which suggested that many people mention bodily concerns, which are influenced by cultural traditions intertwined with religious scripture. The authors further articulated that cultural factors hindering organ donation are the sacredness that people attach to their own bodies and the importance of burial customs in a particular cultural monarchy. Some participants highlighted the fact that they did not want to think of death, because of the difficulty of talking and thinking about it. Sharp and Randhawa (2016) further pointed out that the cultural beliefs of the individuals belonging to certain systems have an impact on their attitudes to organ donation. The need for body totality

could also influence individuals' decisions to become donors or how people react to the matter. They furthermore articulated that the sociocultural and religious norms that regulate people in many societies view the body of a human being through an embodiment lens, by which the body and the self are not separated, hence influencing people's reactions to the subject of organ donation, as was apparent in the context of the current study.

According to Bhengu and Uys (2004), the Zulu-speaking people believe in a creator (*Umvelinqangi*, one who appeared before all else) or, if converted to Christianity, God, without question. Therefore, they may believe that they have no authority to donate their bodies or organs. The strong bond and interdependence between the living and the dead (the ancestors) among Zulu-speaking people add to the fear, as it is believed that if this bond is broken, the ancestors will show anger by visitation in the form of ill-health, misfortune or even death. In the current study participants also believed organ donation dehumanises the body and their own cultural beliefs. One participant was quoted as saying, "*In our culture it is believed that if you donate your organs, your ancestors will not recognise you and it will cause unnecessary fights in the family, accusing one another of murder and selling your organs.*"

(c) Psychological aspects of organ donation

More than 90% of the participants discussed a variety of psychological aspects both positive and negative about the whole process of organ donation. Most participants' feelings, attitudes and decisions were greatly influenced by psychological aspects that had an impact on their perceptions of organ donation and organ donors. These aspects further led to participants showing ambivalent feelings. Most participants had some positive attitudes to organ donation, but uncertainty about the process made them harbour contradicting views.

Participants appeared to be quite concerned about whether the process of organ donation can be successful. The problem was mistrust of the medical system or whether the organ would work, because it was perceived as a dangerous and life-threatening process. Manicom (2015) believes there is a very real human need for the donor and the families of both the donor and the recipient to trust the medical system. They have to trust that the bodies will be handled respectfully and with great care by the healthcare professionals undertaking proper medical procedures. Any level of

uncertainty about this induces fear and anxiety in the people concerned and influences their ultimate decision to donate.

Participants in the current study also displayed some level of anxiety when the topic of organ donation was discussed. The participants indicated that they did not believe that the procedure was possible and that made them feel anxious about the whole discussion. The researcher believes that lack of knowledge was related to the level of anxiety displayed by some of the participants. Ríos et al. (2018) highlighted that multiple psychological factors may be associated with how people react to the whole process. Gidimisana (2016) was also of the opinion that potential donors are sometimes startled by the sudden approach from health professionals asking them to become organ donors. Kaye, Dame, Lehman and Sexton (1999) indicated that prospective candidates are sometimes caught by surprise, mostly because of their low level of awareness and knowledge. Consequently, they often experience some psychological impressions that would ultimately affect them negatively in their decisions to become organ donors.

The present study found that it was not only the uncertainty associated with the process and their lack of awareness that caused some psychological upheavals, but also the influence of the family, which has extreme implications. Participants highlighted that there is a need to make such a decision collectively as a family and they feared making such vital decisions alone. This indicated the importance of social cohesion, which appeared central to the rural community members of Madibaneng. This indicates the effect that people's families have on their decision-making capabilities (Kometsi, 1998) and signals the importance of healthcare practitioners and policy makers not considering individuals in isolation, but in the context of their functioning. This is consistent with the findings of Chirozva et al. (2005), who stated that in an African context, co-operation is expected between members and decision-making is done collectively. This collective action is envisaged to bring about positive reciprocity, which is important in maintaining equilibrium in the institutions.

Engle (2001) argued that the psychological impact of organ donation on families should not be avoided. The author believed not only potential organ donors had to consider psychological aspects, but also their family members who sometimes found themselves in an extreme situation where they had to make decisions on behalf of the

deceased or in consultation with people on becoming organ donors. In African societies, as highlighted by Chirozva et al. (2005), the problem of a single individual becomes a family problem, therefore the same implications faced by the donor also affect other families. However, Engle (2001) further indicated that in some cases, the process of organ donation tends to comfort grieving families. On the other hand, those families who refused to donate had a greater tendency to regret their decisions. This was consistent with the findings of the current study, in that some participants expressed some positive attitudes and the promotion of psychological health, in that individuals receiving organs and donating may have a sense of happiness, eliminating the anxieties and fears that people had about their lives.

Boey (2002) stated that when examining attitudes and perceptions about organ donation, both positive and negative dimensions should be taken into consideration. In the author's view, people may have humanitarian and charitable feelings about organ donation and feel the need to save lives, but at the same time, they also have fears and other negative psychological reactions. Boey's (2002) explication was supported by the findings of the study in that some participants' positive attitudes were influenced by their sense of altruism that made them want to contribute to saving lives and helping those in need. However, they still had reservations related to fears, lack of hope and confidence in the whole process.

In summary, the findings of the study indicated that elderly community members perceived organ donation both positively and negatively, and in that process took cognisance of multiple psychological aspects. Participants alluded to fear, lack of hope, anxiety, esteem issues and the need for social cohesion, among other psychological factors. These factors seemed to play an important role in influencing participants to become organ donors. It was therefore hypothesised that participants might have developed these views because they were not fully informed about how the process operates and about the dynamics involved. However, some held these views because of demographical factors such as the influence of family.

5.2.4 Participants' perceptions of those living with donated organs

Participants' perceptions of people living with donated organs were both positive and negative. About 80% of participants had a positive perception, while only about 20% displayed a negative attitude. Participants highlighted their own personal reasons for displaying a specific reaction to people with donated organs. The current study

findings were that most participants or those displaying a positive attitude to people living with donated organs associated the process with altruism as the fundamental principle of organ donation. Manicom (2015) defined altruism as referring to both motivation and action/practice. The distinction between the two is the difference between what motivates an action, behaviour or practice and the actual outcome of that action, behaviour or practice. Participants believed people living with donated organs were helped by those driven by their own religious principles and desires to help other people in need.

Mbeje (2013) states that insufficient knowledge and understanding of the perceptions of people usually lead to stereotyping, discrimination, prejudices, racism and biases. Increasingly, health is influenced by social and economic circumstances. The author further indicated that how people primarily react and perceive those living with donated organs depends on the levels of awareness and knowledge of organ donation. The study deduced that some participants had a negative or stereotypic attitude to those living with donated organs. One of the participants was quoted as saying, "*I think they live a hard life; imagine possessing blood that doesn't belong to you, and dealing with the fact of living with someone's organ.*" This quotation illustrates that some people's views may appear stereotypic to other people; however, this is assumed or indicated to be influenced by people's belief systems and their own personal dynamics.

According to Farhenwald and Stabnow (2005), traditional beliefs about the body having to remain intact to enter the spirit world have been cited as a barrier to the concept of kidney donation. In the current study, participants indicated that their personal beliefs about organ donation, together with their traditional beliefs, do have some implications for how they perceive people with donated organs. This indicates how beliefs system not only influence people's decision to donate, but also how they perceive others. The potential conflict between individuals' intent to donate and their family's difficulty with honouring that request because of their personal beliefs is apparent. This conflict ultimately affects how people perceive those living with donated organs (Mbeje, 2014).

Participants who appeared to have a negative attitude were also preoccupied with the medical procedures and treatments that donors would have to go through after a transplant. They perceived this as a tedious process that would impair an individual's

normal functioning. This was found to be consistent with the findings of the study by Clegg et al. (2005) which stated that participants believed that as much as organ donation successfully prolongs the survival of patients with organ failures, patients must cope with frequent changes in their health and life situation, as well as shortened survival. The authors further stated that beliefs have a great impact on organ donation and cannot be ignored and therefore organ donation coordinators need to be sensitive and well-informed.

From the current study findings, it was also deduced that cultural, familial, religious and other demographics play a vital role in influencing the organ donation process. Participants' perceptions were based on their belief system and the proceedings incorporating the whole process of organ donation. Hence participants had different perceptions of those living with donated organs. The researcher noted with interest that the inadequate knowledge of many participants could have had implications for how they perceived other people, despite some indicating demographical factors as their main reasons for such views.

CHAPTER 6: SUMMARY AND CONCLUSIONS

6.1 Summary

The aim of the study was to explore perceptions of organ donation by African elderly community members in a rural community in Sekhukhune District, Limpopo Province.

The specific objectives of the present study were to:

- Determine elderly community members' understanding and knowledge about organ donation.
- Describe elderly community members' feelings about organ donation;
- Determine elderly community members' attitudes to organ donation; and
- Determine elderly community members' views regarding those who are living with donated organs.

Based on the findings of the study, the following four themes emerged: a) Elderly members' understanding and knowledge about organ donation; b) Elderly community members' feelings about organ donation; c) Elderly community members' attitudes to organ donation; and d) Participants' perceptions of others living with donated organs.

The four themes were further broken down into subthemes. The results are discussed in the context of the emerging field of African psychology. This calls for recognition and inclusion of people from all spheres of demographics in healthcare provision and policies in developing countries such as South Africa.

From the findings of this study it does appear that elderly community members perceive the subject of organ donation differently because of multiple factors, family dynamics being the main issue influencing their perceptions. The process of deciding about organ donation appeared to be highly centralised in the family and the integral role it plays in influencing participants' attitudes to organ donation. Some participants were assuming that their families would share or be sympathetic to their views, which is a very risky assumption to make. The decision to donate a loved one's organs depends on many factors and the attributed desires of the deceased is only one of them. In addition, lack of faith in the medical system and the procedure itself seemed to be influential in the attitudes that participants had about organ donation.

Participants in the study also highlighted factors such as knowledge and awareness, feelings participants attach to the subject, cultural factors, perceptions participants had about people living with donated organs and psychological factors associated with the

subject. This study also discovered significant associations between the age, education, economic status and background of the participants and their intentions to donate their organs. It was found that the younger group among the elderly community members, who were between the ages of 50 and 60, had a positive attitude to the subject and some level of knowledge of it; however, they were less likely to become donors in the future than participants who were 65 years and above. The psychological aspects that were found to be influential in the study were uncertainty, fear, anxiety, social cohesion, denial, esteem issues and guilt.

Participants who are 65 years and older indicated cultural factors that may interfere with their decision to donate, hence such issues needed careful consideration. In the cultural domain, the ancestral consideration was a major concern, which may have certain implications for the family concerned. This suggests that organ donation is conceptualised in the context of the systems in which participants found themselves. However, factors that had a positive effect on a decision to donate by the participants in the study include the altruism associated with donation and a utilitarian view of the body. Some participants in the study acknowledged the importance and usefulness of organs for donation, especially in the light of scientific progress.

South Africa works on an opt-in system of organ donation. This means that the organs of a deceased individual may not be donated without the informed consent of their next of kin. This applies even when the individual is a registered organ donor. This approach was taken considering the South African multiculturalism and the vast diversity that exist. The findings in the study support that idea that the South African organ donation system has been constructed with due consideration of people's diverse beliefs and cultures and their particular family system, together with their dynamics.

6.2 Limitations of the study

The researcher is aware of the considerable limitations of this study. The following were some of the limitations of the present study:

- Firstly, the study was conducted in only a few rural sections of Madibaneng Village in the Sekhukhune District, Limpopo Province. The current findings may therefore not be generalisable beyond the places where the study was conducted. The study dealt with the issues of perceptions about organ

donation among the elderly community members in the Pedi culture. Therefore, the current data are limited, and cannot shed light on how other groups of people in the Pedi culture and other cultural groups perceive the subject of organ donation in South Africa and elsewhere.

- Secondly, the researcher acknowledges that pretesting was not conducted and this is one of the limitations of the study.
- Thirdly, the researcher acknowledges the limitations associated with translation of information from one language to another. It is thus possible that the translation of the interview data from Sepedi into English before perceptual explications had been done may have led to omissions or inappropriate substitutions of the original material provided by the participants. This process may have resulted in some of the cultural nuances that are embedded in language being lost in the process of transforming the data from one language to another.

6.3 Implications for theory

Dlamini (2006) pointed out that the South African healthcare system is such that it encompasses various healing systems, namely the Western system based on science, the traditional healing system based on indigenous knowledge systems, and a holistic approach to healthcare. This is because of the broad spectrum of diversity that is present in the country. This diversity brings about different cultural beliefs, religions, and traditions that influence people's perceptions, attitudes and behaviour. The present study was guided by the Afrocentric theoretical framework. The Afrocentric perspective examines topics through the eye of African people as subjects of cultural and historical experiences. It seeks to relocate the African person as an agent in human history in an effort to eliminate the illusion of the fringes (Asante, 2007).

The perspective views the worldview of African people as influenced by their own culture, norms and values. People of African descent's decision-making processes and behaviours are influenced by their traditions transferred through generations (Mabunda, 2001). This was evident in the study in terms of how their cultural and familial dynamics played a significant role in their perception of the process of organ donation. Based on the results of this study, it can be suggested that some participants tend to perceive organ donation as an integrated process that involves their ancestors,

culture, family and all other important role players in their existence. This was further supported by Bojuwoye and Sodi (2010), who pointed out that different societies have their own way of understanding and describing various health-related issues. In Africa, people interact with one another not on the basis of how things are, but how they perceive them.

According to Ezeabasili (1977), Africans believe health-related behaviour to have material, moral, supernatural and pre-natural causes that can be determined by both physical observation and divination. According to the results of this study, some participants indicated that decisions on organ donation without consulting with family members or ancestors would result in misfortune and ill health of the living.

In addition, the researcher used the HBM to outline the extent to which beliefs about health affect the ability of people to seek help with health-related issues. Rosenstock et al., (1950) were interested in understanding why people did or did not use services offered by the public health departments. This model attempts to engage health-related behaviour and problems by accounting for individual differences in beliefs and attitudes. Participants in the study highlighted a variety of reasons why they might opt for engaging in organ donation, while others were against the process.

Those against the process mentioned various reasons influenced by their different cultures. This was because of the beliefs that those cultures have an effect on processes such as organ donation. This was supported by Sharp and Randhawa's (2016) study, which suggested that many people raise bodily concerns that are influenced by cultural traditions intertwined with religious scripture. The authors further articulated that cultural factors hindering organ donation are the sacredness that people attach to their own bodies and the importance of burial customs in a particular cultural monarchy.

6.4 Recommendations

- From the findings of the current study, it is evident that community members draw from different demographical factors and their influences in forming perceptions of organ donation. It is therefore important for future studies and for researchers to understand and appreciate the critical role that people's demographical factors such as age, socio-economic status, cultural factors,

religion, level of education or literacy, ethnicity and other factors play in their lives.

- The findings of the current study could be applied to clinical settings to improve the cultural awareness that healthcare practitioners have regarding people's attitudes to the concept of organ donation.
- The current study suggests that extensive public awareness campaigns are still needed. These may take the form of television advertising and community awareness campaigns because this is perceived as the most effective form of communicating information about organ donation to the public.
- Cultural and religious leaders need to be included in any awareness campaigns, explaining the stance of religion and culture about organ donation.
- It is also recommended that organisations advocating the donation of organs consider family communication regarding preferences for donation as a message that must widely be distributed. This may help in improving consent rates, as relatives will not feel they are deciding on behalf of their family members without knowing their decisions.
- It is further recommended, because of the findings from the current study, that further research be conducted among other ethnical, racial and cultural groups across South Africa. This will enable policy developers to take into consideration coherent views from different perspectives.

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APPENDICES

APPENDIX A1: Interview guide (English version)

Objective	Interview questions
1. Determine elderly community members' understanding and knowledge about organ donation	a. What do you understand about organ donation?
2. Describe the elderly community members' feelings about organ donation.	b. Would you enlist your name on the list to donate any of your organs when you are dead? Why or why not?
3. Determine the elderly community members' attitudes to organ donation.	c. In your opinion, is it necessary to donate one's organs? Why or why not?
	d. Would you donate your organ to your family member who could benefit from it when you are dead? Why or why not?
4. Determine the elderly community members' views about those who are living with donated organs.	e. What do you think of people living with donated organs?
	f. Is there any other issue you would like to tell us about organ donation that we did not ask you about?

APPENDIX A2: Interview guide (Sepedi version)

Maikemišetšo	Dipotšišo tša tlhahlo
13.1 Go lekola kwišišo le tsebo yeo batho ba naleng yona mabapi kabo ya ditho	(a) O kwišiša eng ka kabo ya ditho?
13.2 Go Hlaloša maikutlo a batho ba bagolo mabapi le kabo ya ditho	(a) Ka kgopolo ya gago, go bohlokwa gore motho a abelane ka setho sa gagwe? ge o dumela e kaba lebaka ke eng? ge o ganetja e kaba lebaka ke eng?
13.3 Go lekola mokgwa o batho ba bagolo ba bonang temana ye ya kabo ya ditho	(a) O ka ngwadiša leina la gago gore ge o hlokofala ditho tša gago ba abelane ka tšona?
	(b) O ka abela o mongwe wa leloko la geno yeo setho sa gago gore a thušege ge o hlokofetše? ge o dumela e kaba lebaka ke eng? ge le ganetja e kaba lebaka ke eng?
13.4 Go lekola maikutlo le pono ya batho ba bagolo kgahlanong le batho bao ba phelang ka ditho tšso ba abetšwego tšona	(a) E kaba go nale se sengwe seo le ka ratago gore botša mabapi le taba ye ya kabo ya ditho se resa botšišago ka sona?
	(b) Le bona bjang batho bao ba bephelang ka ditho/setho tšeo ba a betšwego ke batho ba bangwe?

APPENDIX B1: Informed consent letter and form (English version)

Department of
Psychology
University of Limpopo
Private Bag x1106
Sovenga
0727
Date

Dear participant

Thank you for your interest in the study that focuses on the perceptions of organ donation by elderly community members in a rural community in Sekhukhune District, Limpopo Province.

Your responses to this individual interview will be kept strictly confidential. Your anonymity as a participant is ensured. The information obtained in this study will be useful in forming part of knowledge about the issue under study, and the findings of the study will be compiled in the research report that will be submitted to the University of Limpopo.

Kindly respond to all questions as honestly as possible. Your participation in the research is not compulsory but voluntary and important. You may withdraw at any point of the study if you feel uncomfortable.

Thank you for your time.

Yours sincerely

Moropa M (Masters Student)

Date

APPENDIX B2: Informed consent (English version)

I, _____ hereby give consent to take part in this study that aims to explore the perceptions of organ donation by elderly community members in a rural community of Sekhukhune District, Limpopo Province.

The researcher has provided me with adequate information concerning the nature and purpose of the study, and a chance to ask questions before participating in the study. I fully understand what will be requested of me and I am aware that I reserve my right to withdraw at any point during the study without any penalty.

I understand that this is a research project whose purpose is not necessarily to benefit me or anyone else personally. I understand that any information regarding my participation will remain confidential.

I hereby give consent to participate in the study.

Participant's signature

Date

APPENDIX C1: Informed consent letter and form (Sepedi version)

Department of Psychology
University of Limpopo
Turfloop Campus
Private Bag x1106
Sovenga
0727
Date

Motšeakarolo

Ke leboga ge le bontšhitše kgahlego go tšeya karolo lesolong le la thuto le ikemišeditšego go tseba ka “Pono mabapi le kabo ya ditho mo bathong ba bagolo setšhabeng sa Sekhukhune profentsheng ya Limpopo”

Dikarabo tša lena go dipotšišo tse di tla tshwarwa ka mokgwa wa sephiri. Go se tsebagale ga lena bjale ka motšea karalo gwa tshepiswa. Dikarabo tše di tla ba di etswa mo nyakisisong goba lesolong le di tlilo oketša tsebo mabapi le thuto le gona ditla iswa yunibesithing ya Limpopo, ka lefapeng la thuto ya maikutlo le menagano.

Lekgopelwa go araba dipotšišo tse ka botshephegi bjo bogolo. Go tšeeng karolo ga lena ga se kgapeletšo, ke boikgethelo eupša go bohloka. Gafao le nale tokelo ya go tlogela go tšea karolo nako efe go ba efe.

Walena

Moithuti (Moropa M)

Tšatšikgwedi

APPENDIX C2: Informed consent (Sepedi version)

Nna _____ ke dumela go tšea karolo lesolong goba nyakišisong ye ya thuto ye ikemišeditšego go tseba ka “Pono mabapi le kabo ya ditho mo bathong ba bagolo setšhabeng sa Sekhukhune provenseng ya Limpopo”

Monyakišiše o nhlaloseditše ka botlalo mabapi le nyakišišo ye ka ga mohola le maikemišetšo a yona. Monyakišiše o mfele le sekgoba sa go botšiša dipotsiso mabapi le go tšea karolo pele ke thoma. Ka fao ke kwišiša seo se nyakegang go nna gape ke fahlološitšwe gore ke nale tokelo yago tlogela go tšea karolo nako efe kapa efe, gafao ga gona kotlo.

Kea kwišiša gore nyakišišo ye mohola wa yona a se thusa nna goba monyakisise. Gape kea kwisisa gore tshedimošo mabapi le karolo yaka e tla ba ka mokgwa sephiri.

Ka fao ke dumela go tšea karolo mo nyakišiong.

Mosaeni wa mo tšea karolo

Date

APPENDIX D1: Letter requesting permission Madibaneng (English version)

Department of
Psychology
University of Limpopo
Turfloop Campus
Private Bag x1106
Sovenga
0727
Date

Dear Sir/Madam

RE: Permission to conduct research on perceptions of organ donation by elderly community members in Madibaneng village, Sekhukhune District.

I, Moropa Monareng (student no 201312177), am currently a registered master's student at the University of Limpopo, Turfloop Campus. I hereby request permission to conduct a research study among traditional healers at Madibaneng village as a requirement for the master's degree in the Department of Psychology.

My research title is "Perceptions of organ donation by elderly community members in a rural community of Sekhukhune District, Limpopo Province".

Should you require any further information, please do not hesitate to contact me or my supervisor. Our contact details are as follows: Mr M. Moropa (student) - 0796675718 and Dr JP Mokwena (supervisor) – 015 268 2322.

Your positive response will be greatly appreciated.

Yours faithfully

Mr M. Moropa
Masters student

Dr Mokwena J.P
Supervisor

APPENDIX D2: Letter requesting permission Madibaneng (Sepedi version)

Department of
Psychology
University of Limpopo
Turfloop Campus
Private Bag x1106
Sovenga
0727
Date

Morena Mohumagadi yo a ratego

RE: Kgopelo ya tumelelo yago dira nyakišišo mabapi le “Pono mabapi le kabo ya ditho mo bathong ba bagolo setšhabeng sa Sekhukhune provenseng ya Limpopo”motseng wa Madiabaneng.

Nna, Moropa Monareng (nomoro ya moithuti, 201312177) ke moithuti wa masters ka yunibesithing ya Limpopo, go la Turfloop. Ke ngwala lengwalo le go kgopela tumelelo ya lena go dira dinyakišišo tšaka tša thuto maagareng ga di ngaka tša setšo sa Sepedi mo motseng wa lena wa Madibanneng bjalo ka senyakwa sa ka sa master’s degree lefapeng la tša menagano le maikutlo.

Tabakgolo ya nyakišišo yaka ke “Pono mabapi le kabo ya ditho setšhabeng sa Sekhukhune provenseng ya Limpopo”

Ge leka rata go tseba tshedimošo yenngwe le seke la lakalela gore leletša mo megaleng yeo e latelago. Mr Moropa M (moithuti)-0796675718 le Dr. Mokwena JP (mofahlodi) – 015 268 2322

Thušo ya lena eka atlega

Wa lena

Mr. M Moropa
Moithuti

Dr. JP Mokwena
Mofahlodi

APPENDIX E1: Ethical clearance from the University of Limpopo



University of Limpopo
Department of Research Administration and Development
Private Bag X1106, Sovenga, 0727, South Africa
Tel: (015) 268 3935, Fax: (015) 268 2306, Email: Anastasia.Ngobe@ul.ac.za

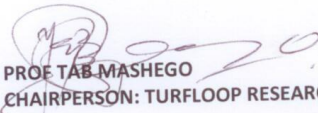
TURFLOOP RESEARCH ETHICS COMMITTEE CLEARANCE CERTIFICATE

MEETING: 15 May 2018

PROJECT NUMBER: TREC/106/2018: PG

PROJECT:

Title: Perceptions of organ donation by elderly community members in a rural community of Sekhukhune District, Limpopo Province.
Researcher: M Moropa
Supervisor: Dr JP Mokwena
Co-Supervisors: Prof T Sodi
School: Social Sciences
Degree: Master of Arts Clinical Psychology


PROF TAB MASHEGO
CHAIRPERSON: TURFLOOP RESEARCH ETHICS COMMITTEE

The Turfloop Research Ethics Committee (TREC) is registered with the National Health Research Ethics Council, Registration Number: REC-0310111-031

Note:

- i) Should any departure be contemplated from the research procedure as approved, the researcher(s) must re-submit the protocol to the committee.
- ii) The budget for the research will be considered separately from the protocol.
PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES.

APPENDIX E2: Letter of permission from gate-keepers

TSWAKO-LEKENTLE TRADITIONAL COUNCIL

Ref : Traditional Council
Enq: Seraga M.J
Cell: 083 371 3146



P O Box 160
SEKHUKHUNE
1124

Limpopo, Department of Co-operative Governance, Human Settlement & Traditional Affairs, Sekhukhune, Makhuduthamaga, Madibaneng

REF NO : CH 11/5/3/3/5 -178 / 1

ENQ : SERAGA M.J

TEL NO. 078 943 7740 / 082 354 1252

The head

Department of Psychology

UNIVERSITY OF LIMPOPO

SOVENGA

0727

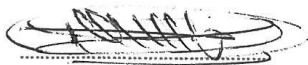
Sir / Madam

RE : LETTER OF PERMISSION TO CONDUCT RESEARCH BY ELDERLY MEMBERS AT MADIBANENG VILLAGE SEKHUKHUNE DISTRICT

This letter serves to confirm that Mr Moropa Monareng student no. **201312177** has been given a permission to conduct a research by the elderly community members at the area of our jurisdiction (Madibaneng village under **TSWAKO LEKENTLE TRADITIONAL COUNCIL**.

The office has no objection

Regards



ADMINISTRATIVE OFFICER

