# VIEWS OF COMMUNITIES REGARDING ORGAN DONATION IN SEKHUKHUNE DISTRICT OF LIMPOPO PROVINCE, SOUTH AFRICA

by

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DISSERTATION

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ln

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### **DECLARATION**

I MOKABANE DIKELEDI MASHEGO declare that this research report titled "Views of communities regarding organ donation in the Sekhukhune district of the Limpopo Province, South Africa" is my own work and that all the sources used have been indicated and acknowledged by means of complete references. This research report has not been previously submitted in full or in partial fulfilment of the requirements of an equivalent or higher qualification at any other recognized educational institution. This research report is submitted in full fulfilment of the requirements of the Master's in Nursing Science at the University of Limpopo, School of Health Sciences.

Signed:

Date 13/07/2020

# **DEDICATION**

The study is dedicated to my lovely family, my primary teacher Mrs Makate who taught me the value of education and to my patients suffering end stage organ failure.

#### **ACKNOWLEDGEMENTS**

Firstly, I would like to acknowledge and thank Almighty God for giving me the strength, wisdom and guidance throughout the research process.

I give thanks to my supervisor, Mr Mbombi MO. I really appreciate the continual and selfless support and motivation he has given me during the research study.

I would also like to acknowledge my siblings especially my brother Treasure for helping me during typing of the research process.

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It would be a mistake not to acknowledge University of Limpopo School of nursing lecturers for the orientation and foundation laid regarding conduction of a research study

The University of Limpopo (Turfloop Campus) Research Ethics Committee, for approval of the study;

I would also like the participation of Makhuduthamaga community members for their active participation in the research study, not forgetting King Madihlaba and Nduna Mabitla who allowed me to use their people as research participants.

### **ABSTRACT**

Introduction and background: There is an increase shortage of organs for donation to patients with end stage organ failure worldwide, including in African countries and South Africa as well. Regardless of the number of potential organ donors in South Africa organ availability remain scarce at communities are not actively involved in organ donation. Views of communities regarding organ donation among Sekhukhune communities has not being researched before, the purpose of the study is to explore views of Sekhukhune Community at Limpopo Province of South Africa regarding organ donation.

**Methodology:** Qualitative research method was used, applying descriptive and explorative research designs. The study site was Makhuduthamaga municipality of Sekhukhune district at Limpopo Province, targeting community members as research participants. Fifteen (15) participants were interviewed using semi-structured interviews until data saturation was reached. During data collection the researcher used an interview guide and the participants were audio recorded. Ethical principles were adhered to before and during conduction of the research study. Collected data was analysed using 8 steps of Tech's coding method.

**Results**: The study revealed that there are different views of community towards organ donation, which contribute to uncertainty, positivity and negativity towards organ donation. Knowledge and understanding of organ donation was found to be a factor that can influence improvement of organ donation among communities at Sekhukhune district. Other factors that were found to contribute the lack of organ donation among communities were religion, culture and stigma attached to organ donation.

**Conclusion:** Community members lack knowledge of organ donation and end up holding in to the myth regarding organ donation. Health awareness, workshop and education to the communities in schools and community facilities such as halls and meetings can improve knowledge on organ donation promoting involvement of community members.

#### **DEFINITION OF CONCEPTS**

#### Views

Views refer to a sight or prospect, typically of attractive natural scenery that can be taken in by the eye from a particular place (Deuter, Brandbery & Turnbull, 2015). In the study, views refer to perspective or ideas of the Makhuduthamaga community regarding organ donation.

# Community

Community refers to an open social system that is characterised by people in a place who have common goals (Maurer & Smith, 2013). In the study, community refers to the people living in Makhuduthamaga Municipality.

# **Strategies**

Strategies are the plans that are intended to achieve a particular purpose (Deuter et al., 2015). In the study, strategies mean the ways, which could be taken to improve organ donation in the Makhuduthamaga Municipality.

## **Organ donation**

The World Health Organization [WHO] (2018) defines organ donation as the gift of an individual's body parts after their death, for transplantation. In this study organ donation refers to the giving away of an organ to an individual in need of that particular organ.

# **LIST OF ABBREVIATIONS**

AN: Alaska Native

AI: American Indian

CVD: Cardiovascular Disease

CRD: Chronic Renal Disease

DD: Deceased Donor

ESOF: End Stage Organ Failure

ESRD: End Stage Renal Disease

FHDC: Faculty Higher Degrees Committee

HBM: Health Belief Model

ICU: Intensive Care Units

ODF: Organ Donor Foundation

SA: South Africa

TREC: Turfloop Research Ethics Committee

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#### CHAPTER 1

#### ORIENTATION TO THE STUDY

#### 1.1 INTRODUCTION AND BACKGROUND

Organ donation is the most preferred form of treatment for patients with End Stage Organ Failure (ESOF). Organ donations offers a chance for a better quality of life and has a better long-term survival benefits for a person receiving the organ (Bapat, Kedlaya & Gokulnath, 2010). However, the community members seem to lack knowledge about such benefits and or how to donate an organ. According to Organ Donor Foundation of South Africa (2017) any person who is healthy and below 70 years old can donate an organ. Balajee, Ramachandran and Subitha (2016) indicated that the success of the organ donation programme depends on the positive attitude, and knowledge of the public about organ donations.

Balajee et al. (2016) indicated that the primary hindrance to organ transplantation programmes worldwide is the shortage of organ donors. The availability of organs improves when the community has positive attitude towards, and knowledge about organ donation, as individuals tend to respond positively when they have an understanding. According to Derek (2014), the need for more organ donors in the United States of America (USA) is well recognised. Currently, more than 105,000 patients are waiting for a solid organ transplant in the USA. This is against the backdrop of the fact that over 6,500 patients will die each year before an organ becomes available (Derek, 2014).

Balajee et al. (2016) further identified India as another country having challenges regarding organ donations despite the human organ transplant legalisation published in 1994 by the Indian Government. The aforementioned authors noted that although India has high levels of awareness about eye and kidney donations, the awareness about the donation of other organs was said to be poor. Bapat et al. (2010) supported this by indicating that although the Indian public is accustomed to the idea of donating blood, donation of organs after death continues to be a problem, due to poor public awareness.

Naiker (2013) indicated that sub-Saharan Africa has a large population in need of organ donations. There is an increase in communicable diseases such as diabetes

mellitus and hypertension, which can cause the failure of organs such as the kidneys, heart and the liver. More donated kidneys are sourced from living donors than from deceased donors and the availability of organs remains a challenge in sub-Saharan Africa. According to Taha, Ahamed and Sabaee (2014), Egypt is one of the African countries with a high demand for organ donations. This is as a result of a high prevalence of chronic diseases such chronic liver disease and renal failure that can be best treated by organ transplantation. Taha et al. (2014) further noted that Egypt has a high mortality rate for patients on a waiting list for organ donors.

South Africa experiences the same challenge as other countries in Europe, Asia and Africa regarding organ donations. According to the Organ Donor Foundation of South Africa (2017), the need for donated life-saving organs is increasing much quicker than the available organs. On 4 August 2015, statistics from the Organ Donor Foundation of South Africa (ODFSA) indicated that there are about 4,300 South Africans awaiting life-saving organs and corneal transplants with only 0.2% of South Africans registered as donors.

Muller (2013), after studying a number of referrals made on donations from deceased donors at Groote Schuur Hospital in 2007, indicated that South Africa needs to triple the current number of 300 deceased donors per year. The referrals included patients with head injuries and neurosurgery disorders with a poor prognosis. Most suitable deceased donors had head trauma or a medical condition affecting the brain which resulted in the withdrawal of treatment, as the patients could not be saved. Against the backdrop of the demand, the numbers of organs available to be donated is declining.

Findings from Mpe, Klug, Sliva, Hitzeroth and Smith (2013) showed that cardiovascular diseases related to hypertension have been identified as a problem in South Africa, thereby increasing the demand for heart donations. Heart transplantation increases the survival rate, exercise capacity, quality of life and return to work of a patient compared to the conventional management of heart failure. The shortage of heart donors is a major challenge in South Africa, leading to increase in death rate of patients having end stage heart failure (Mpe et al., 2013).

In Limpopo Provincial Hospitals located in the Polokwane Mankweng Hospital Complex, cardiovascular disease (CVD) was identified among other diseases such as tuberculosis, HIV/AIDS and cancer, as being responsible for 61.2% of all deaths in the

Complex in 2010. There were 605 reported cases of CVD related deaths, including those referred from other hospitals in Limpopo (Malangu, Ntuli & Alberts, 2014). Some of the deceased patients were on a waiting list for organ transplants, illustrating the potential for an increase in the availability of organs to save lives. Polokwane Kidney and Dialysis Centre known as Clinix Renal Care Unit, is the only dialysis centre in Limpopo Province. The centre can only accommodate 80 patients on haemodialysis and 50 patients on peritoneal dialysis, at any one time, as stipulated by South African government policy. This centre work together with Fresenius to render service to the public. As a result of the escalating prevalence of ESRD in Limpopo, there is a significant demand on the centre's dialysis resources, which would be alleviated by a greater availability of donated kidneys. Patients travel for about 112,5 km daily or on alternate days to receive dialysis at this centre (Isla, Mapiye, Swanepoel, Rozumyk, Hubahib & Okpechi, 2014). This burden on the patient, the government's health system as well as on the dialysis centre can only be relieved by increased availability of donated kidneys. In this way, the quality of life of affected individuals will be improved.

By investigating the views of communities in the Sekhukhune district, a greater understanding of the reasons why organ donation are not prevalent in the communities across the country may be reached.

#### 1.2. RESEARCH PROBLEM

The researcher worked at Intensive Care Units (ICU) of different hospitals in Limpopo South Africa, both as a student nurse and a professional nurse. The researcher witnessed many patients who lost their lives whilst being on the waiting list for an organ transplant. Yet many brain-dead patients who were nursed until their death, were potential organ donors. The researcher was of the opinion that many lives could be saved in ICU if the community is knowledgeable about organ donation opportunities.

There has been no research done on the Sekhukhune District on the views or awareness of communities regarding organ donations. The researcher believed that exploring the views of these communities might play a role in reducing the mortality rate of patients with end stage organ failure (ESOF). Therefore, the study aims to explore the views of communities in Sekhukhune District of Limpopo Province, regarding organ donations.

#### 1.3. RESEARCH QUESTION

The research question was "What are the views of communities regarding organ donations in Sekhukhune district, Limpopo Province, South Africa?"

#### 1.4. AIM OF THE STUDY

The aim of the study was to determine the views of communities regarding organ donations in Sekhukhune District, Limpopo Province, South Africa.

### 1.5. OBJECTIVES OF THE STUDY

The objectives of the study were to:

- Explore the views of communities regarding organ donation in Sekhukhune
   District, Limpopo Province, South Africa;
- Describe the views of communities regarding organ donation in the Sekhukhune District, Limpopo Province, South Africa;
- To recommend measures to improve organ donation among Makhuduthamaga community at Sekhukhune District, South Africa.

#### 1.6. SUMMARY OF LITERATURE REVIEW

Literature relating to the research study as described above, has been found to be of importance in identifying the need for organ donations. Information regarding international, sub-Saharan African, and South African awareness of, and participation in organ donation is reviewed. A literature control was done at the end of the study, once the research had been done. Collected literature was divided into different themes, which are: organ donation demand, knowledge, attitudes of communities regarding organ donations, and beliefs, and religious influences within communities, on organ donation. The formulated sub-topics on the literature that includes organ donation demand, knowledge and attitude of communities regarding organ donations, and beliefs and religious influences within communities on organ donations is discussed in detail in Chapter 2.

#### 1.7. OVERVIEW OF RESEARCH METHODOLOGY

A qualitative research approach was used in the study, with explorative and descriptive research designs being adopted. The study took place within the Makhuduthamaga communities located in Makhuduthamaga Municipality that is a sub-district in Sekhukhune District at Limpopo Province, South Africa.

The sample population was exclusively made up of members of the Makhuduthamaga communities. Non-probability convenient sampling was used in the research study. Semi-structured interviews with the use of an interview guide was used to collect data. The researcher used Tech's coding method of analysis which involves eight steps of data analysis, as explained by Creswell & Poth (2018). The steps are explained in detail in Chapter 3.

# 1.8. MEASURES TO ENSURE TRUSTWORTHINESS

Trustworthiness is a determination that a qualitative study is rigorous and of high quality (Grove, Gray & Burns, 2015). Trustworthiness is ensured by the extent to which the qualitative study is credible, dependable, confirmable and transferable (Grove, Gray & Burns, 2015). The four measures to ensure trustworthiness are explained in full in Chapter 3.

#### 1.9. ETHICAL CONSIDERATIONS

The researcher obtained the necessary permission from the Faculty of Higher Degrees Committee (FHDC) to undertake the research. Turfloop Research Ethics Committee (TREC) granted the researcher ethical clearance. Permission to conduct the study from the clinics was requested from Department of Health prior the commencement of the study. Letters requesting permission to conduct the study within the Makhuduthamaga communities were sent to the Makhuduthamaga Ethical principles such as confidentiality, respect, autonomy, beneficence and maleficence and principle of justice were ensured in the study. Chapter 3 provides a detailed description of these ethical principles and strategies that were adhered to during the study.

#### 1.10. SIGNIFICANCE OF THE STUDY

The study might help the Department of Health in identifying communities not donating organs in South Africa. Prolonged conventional care might be shortened with the improved availability of organs, thus reducing costs related to care of patients with ESOF. This study might also result in the improvement in organ donation registration among Makhuduthamaga community members, and so improve the chances of survival of patients with end stage organ failure thereby reducing the mortality rate related to organ failure.

#### 1.11. OUTLINE OF THE STUDY

Chapter 1: Overview of the study

Chapter 2: Literature Review

Chapter 3: Research methodology

Chapter 4: Discussion of research results

Chapter 5: Integration of results with theoretical framework

Chapter 6: Summary of the study, recommendation, limitations, and conclusion

#### 1.12. CONCLUSION

In this chapter, the researcher outlined the need for organ donations, against the backdrop of a lack of organs that are donated from an international and a local perspective. The aims and objectives, as well as the importance of undertaking the research study in communities within the Sekhukhune District was explained. Literature related to the study was introduced with a detailed review of the literature presented in chapter 2. Reference was made to the qualitative nature of the research including the explorative and descriptive designs used to conduct the research study. For legal considerations, the researcher was granted permission from the TREC, Department of Health, and the relevant royal authorities in the areas identified for the research, to undertake the study. In introducing the chapter, there is a need for the research on organ donation in Sekhukhune district to find the root of the problem regarding organ donation.

#### **CHAPTER 2**

#### LITERATURE REVIEW

#### 2.1. INTRODUCTION

In this chapter the researcher discusses the literature found in relation to the proposed research study on the views of communities regarding organ donations in the Sekhukhune District, Limpopo Province, South Africa. During the review of international, sub-Saharan African and national literature, the headings discussed below were developed. The theoretical framework is also explained in detail as, along with the literature review, it guides the researcher through the entire research process.

# 2.2. ORGAN DONATION (BASIC BACKGROUND)

Organ donation is defined as a process of surgically removing an organ or a tissue from one person (a donor) and placing it into another person (the recipient) (WHO, 2018). According to Lindel, 2009 organ donation and transplantation has dramatically progressed from clinical experience to routine reliable therapeutic and lifesaving practice. Organ donation is also seen as a cost effective action in medicine. From the first kidney transplant performed in 1967 at Middle East, organ donors where limited regardless of religious approval (Ghods, 2014).

Initially organ donation and transplantation was among relatives, kidney transplantation from unrelated donor was adopted by Iranian ministry of Health for kidney transplant in 1988. Dr Fazel recognised brain death and obtained approval of deceased donor transplants of organs including liver and heart (Ghods, 2014). In Canada, euthanasia was approved by the state in 2016, involving mainly brain dead patients and independed voluntary death of patients with cancer. Regardless of negativity in attitude of the community and the sensitivity of the matter, voluntary organ donation and euthanasia is performed. With increasing rates, the estimation is that 2000 euthanasia related organ donations would be performed in Canada (Takita, 2020).

Relating to the scarcity of organs for transplantation, Israel passed a law in 2008 in which closed relatives where prioritized to receive organs from the dying. Registration for organ donors was encouraged with incentive promised to registered donors (Stoler, Kesser & Ashkenazi, 2016). In Netherlands negative attitudes and poor respond of

communities towards organ donation was related to lack of or insufficient knowledge. The state of Netherlands then decided to introduce education of organ donation at school from primarily level with facilitated family and teachers support (Siebelink, Verhage & Roodbol, 2017). The scarcity of minority donors, especially among African Americans was identified in Washington DC in 1978. A program was also introduce to improve community education and empowerment. Education on organ donation was introduces at schools as well and improvement in organ donation was evident years later (Callende & Miles, 2010).

The first organ to be donated and transplanted in South Africa was a kidney in 1966 at Johannesburg. These was followed by the first successful heart transplant in the world performed at Cape Town at 1967 by Doctor Christiaan Barnaard and his team (ODSF, 2017). South African community displayed positive attitude towards organ donation thou registration of organ donors is limited. There is dramatic increase in waiting list of patients in need of organ transplantation with few donors available (Etheredge, Tuner & Kahn, 2014).

South African legislature permits deceased organ donation, after two doctors have performed a brain function test with one of them being of five years' experience and above. Family concern is required even when the dying was a registered donor. Rate of organ donation in South Africa remain low with deceased donation of less than 3% (Thomson, 2017). Muller, 2013 define South Africa as a country with higher renal failure incidents with over 5000 patient with end stage renal failure of which 2500 awaits kidney transplants increasing organ shortage. Other organs such as liver, and heart are also in high demand. There is a shared list of patients in need of organs on both private and public sector increasing the waiting period (Muller, 2013).

#### 2.3. ORGAN DONATION DEMAND

Organ donations are referred to as the most effective way of saving lives during End Stage Organ Failure (Abdulrahman, Ahmed & Muatasim, 2015). With the increase in the prevalence of chronic diseases causing organ failure, the need for the donation of organs increases. There is decreased in the number of organ donations worldwide, which has led to a discrepancy between the availability of organs and the demand for organs. This shortage of organs has become a hindrance in the management of those

patients diagnosed with End Stage Organ Failure (Abdulrahman et al., 2015; Balajee, Ramachandran & Subitha, 2016).

In Africa, research by Oluyombo, Fewale and Ojewola (2016), agreed with the international and national findings that thousands of lives could be saved by organ transplantation, if there were more organs available. The promotion of organ donations has become a necessity since organs are very scarce. The government has shown a lack of support for organ donations, even though there is a significant shortage (Oluyombo et al., 2016; Taha *et al*, 2014).

According to a document released by Western Cape Provincial Government in 2017, more than 500 000 people die in South Africa every year of which 12% are due to violence, motor vehicle accidents and unnatural head injuries. By comparison less than 300 organ transplants are performed annually, which is a lot less than the possible demand. The Organ Donor Foundation of South Africa (2017) described the organ donation registration process as a simple choice that cost nothing, yet very few South Africans register to form part of organ donor community.

Muller (2013) explained that South Africa has one of highest incidents of renal failure in Africa. It is estimated that the country now has more than 5000 patients with end stage renal failure, and more than 2500 of these patients are awaiting organ transplants. Kidney transplantation is more cost-effective, and provides a much better quality of life for the affected patients than dialysis. In South Africa over and above kidney transplantation, heart, liver and other vital organ transplantations also take place across the country. Muller (2013) further indicated that in most regions, the state and the private sector share waiting lists for patients requiring donated organs. The declining number of donors is a big problem in South Africa. Despite the increased in the number of patients on the waiting lists, actual transplants remain constant due to organ shortages. Living donors remain a source of organs in most centres were relatives help their loved one, whilst donations from deceased donors are declining.

# 2.4. KNOWLEDGE AND ATTITUDE OF COMMUNITIES REGARDING ORGAN DONATIONS

Common sources of information regarding organ donations for community members include the media and the internet (Vinay, Beena, Sachin & Praveen, 2016; Michelle, Allison, Stephens & Alan, 2012). Internationally, studies revealed that knowledge

about organ donations could help people make informed decision regarding the donation of organs. Michelle et al (2012) established that with the increased awareness of organ donations, individuals are more likely to respond positively to donate organs. A positive attitude is also mostly seen in individuals who are more knowledgeable about organ donations. In addition, Vincent and Logan, (2012) reported that lack of knowledge as a barrier for organ donations in the United Kingdom.

Knowledge of the potential donors' prior consent or their expressed views and wishes was reflected as a key issue for participation in organ donations (Michelle & Allison, 2012). Therefore, it is important to understand why people do or do not offer to donate their organs and then to initiate discussions with their families in order to improve participation of communities in organ donations (Vincent & Logan, 2012).

Ralph, Alyami, Allen, Howard, Craig, Chadban, Irving and Tong (2016) conducted a study in Australia in which they identified that there was decrease in knowledge about organ donations in Arabian speaking population. The lack of awareness was considered a big contributor to lack of support for the donation of organ, and that if there was greater awareness, especially when a donation of an organ would be of assistance to a community member, there would be greater support. According to Balajee, Ramachandran and Subitha (2016), a lack of knowledge relating to organ donations contributes to a negative attitude. The study also suggested that people above age of fifty view the donation of organ donation negatively.

According to Derek (2014), fear and lack of information are commonly cited as barriers to organ donations amongst African Americans. Common fears as potential donors that were expressed included a financial burden to the family, failure to get a proper burial and their body being disfigured in the donation process. Addressing these fear-inducing misconceptions are an important part of informative organ donation educational campaigns. Information was the most common facilitator in securing organ donors, and lack of information was the most common barrier to becoming a registered organ donor (Derek, 2014).

In relation to organ donation knowledge in Africa, urban inhabitants were found to be more knowledgeable than those in rural areas (Oluyombo et al., 2016). Taha et al. (2014) reported that television and radio represent the main source of information regarding organ donations, which mirrors international trends. In this study in Egypt,

of the 60% who expressed of knowledge about organ donations, only 30% were willing to donate organs after death, due to religious reasons. In another study, it was found that people were more willing to donate organ such as kidneys to close relatives than to strangers (Zulbairu & Isa, 2014).

Fabian, Sparaco, Wadee, Gottlich, and Sideris (2014), in the study on renal replacement among South Africans, reported that the participants who had knowledge were mostly those who had a family member with renal failure, while those not exposed were found to be less knowledgeable in the matter. The process of registration an organ donor is not clear to most of the participants in the study, whilst those who were registered reported the process to be long and complicated. The negative attitudes and lack of knowledge among health care workers has also been identified as a barrier that needs to be addressed to ensure successful organ donations from communities (Oluyombo et al., 2016). The shortage of organs in South Africa is due to several factors including lack of knowledge as well as a lack of a network of active transplant programmes (Byrne, Eksteen & Crickmore, 2016). Numerous strategies have been employed in an attempt to address this problem, including promotions and advertisements in the lay media, as well as education programmes at schools and other institutions. Despite these efforts, the overall number of organ transplants performed each year has decreased. The consent rate among the families of brain-dead patients who could be potential donors, decreased from 55% in 1991 to 32% in 2001 (Etheredge, Turner & Kahn, 2014).

Van der Merwe (2015), in a newsletter on UNISA's website, indicates that one of the biggest reasons for the shortage of organ and tissue for transplant is a lack of knowledge about organ donation among South Africans. Van der Merwe (2015) also indicated that the issue of not donating organs is not necessarily a cultural or religious one. Their research has proven that the main obstacle is ignorance, which is then referred to as cultural issue. It was proven in the same research that there is greater acceptance of organ donation where there has been explanation. Lack of knowledge about organ donations in South Africa is also found among medical practitioners, as organ donations are not part of medical training. According to Van der Merwe (2015), even in the legal profession, knowledge of the law on organ donation is limited

# 2.5. BELIEFS AND RELIGIOUS INFLUENCES WITHIN COMMUNITIES ON ORGAN DONATIONS

According to Lopez (2012), in Spain there are differences in opinion regarding the donation of organs based on religious beliefs, social integration and information about organ donation and transplantation. These opinions are seen in people from across different geographical origins and religious beliefs, and are linked to relationships with additional socio-demographic, social integration, and information variables. In turn, the relationship between religious beliefs and the attitude toward donations varies as a function of the degree of social integration.

Jernigan and Fahrenwald (2013), found the rates of consent for donations from deceased individuals to be also lower than general population in India. The above mentioned also suggested that culturally targeted education has the potential to improve organ donation and transplantation rates in the minority communities. This targeted education needs to take into account the unique cultural and spiritual beliefs of many American Indians and Alaska Native, including the importance of keeping the body intact for burial (Jernigan & Fahrenwald, 2013).

Similarly, there has been a decrease in the desire for donations from deceased patients among Islamic groups in Australia, where the paying of respect and abiding to family and community culture and traditions were cited as reasons. The study also found that Christians and Muslims supported the donation of organs. The difference in religious belief patterns has influenced communities differently depending on their respective views of life and death. Some of the participants in the study were willing to be organ donor but afraid of disrespecting family values (Ralph et al., 2016).

Muller (2013) indicated that the decrease in organ donations in South Africa is influenced by religion, socio-economic status and race. Consent rates for organ donation in the private sector, dominated by people with a higher socio-economic status, is better than in the public sector. The consent rate for donation in private sector was found to be about 80%, whilst in public sector is less than 30% (Muller, 2013).

#### 2.6. THEORETICAL FRAMEWORK

Theories are formulated to explain, predict and understand phenomena and sometimes to challenge existing knowledge (Terry, 2015). The use of a theory assisted the researcher in data analysis, as the researcher explored and described the views of Makhuduthamaga community regarding organ donations. This study uses the Health Belief Model to ground and support the research. The Health Belief Model (HBM) is a psychological model that attempts to explain and predict health behaviours. This is done by focusing on the attitudes and beliefs of individuals. The HBM model was first developed in the 1950s by social psychologists Hochbaum, Rosenstock and Kegels working in the United States Public Health Services (Baum, Newman, Weinman, West & McManus, 1997).

Perceived Susceptibility is defined as one's opinion of the chances of getting a condition (Baum et al., 1997). In the study, the community members who believed that they might in future be in need of organs or were exposed to a condition that may lead to organ failure and therefor a demand for an organ, displayed positive views towards organ donation.

Perceived Severity is defined as one's opinion of how serious a condition and its consequences are (Baum et al., 1997). In the study, participants who took the issue of organ donation shortage as a serious gap, or effect on health, were more willing to participate in organ donations than those who do not see the seriousness of the matter. The views of the community on organ donations depend on the perceived knowledge.

Perceived Benefits is defined as one's belief in the efficacy of the advised action to reduce risk or seriousness of impact (Baum et al., 1997). The community was likely to view organ donations positively when they believed that it will be beneficial to the community and may relieve the health burden. The behaviour and attitude depend on the positive expected outcome of the behaviour.

Perceived Barriers is related to one's opinion of the tangible and psychological costs of the advised action (Baum et al., 1997). In the study, the views of the community on organ donations depended on the emotional impact it has in relation to their belief system and what is perceived as right. Support, reassurance and incentives might promote positive attitudes and views related to the matter.

Cues to Action is defined as the strategies to activate readiness (Baum et al., 1997). The views and behaviour of the community were explored in relation to the strategies

and information in place to promote organ donations in the community. Scarcity in awareness and sources of information regarding organ donations impacts negatively on how organ donations are viewed by the community.

Self-Efficacy is the confidence in one's ability to take action (Baum et al., 1997). The community is likely to engage actively and be positive about organ donations if they have a sense of confidence that they can take part correctly and fairly. Provision of training and guidance in relation to organ donation may promote positivity.

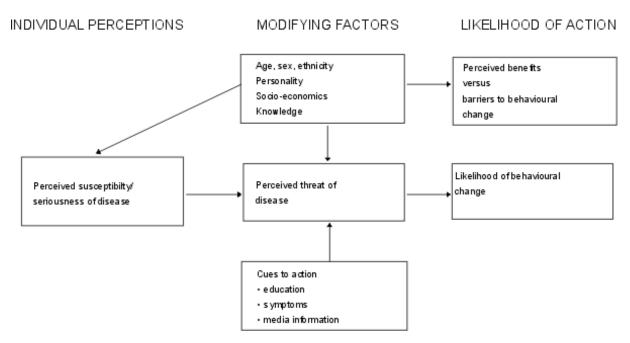


Figure 1. Health Belief Model (adopted from Baum et al., 1997)

#### 2.7. CONCLUSION

In this Chapter the researcher provided international and national literature that relates to the study. The gathered international, sub-Saharan African and national information agreed with the fact that there is shortage of donor organs in communities. The literature revealed factors such as organ donation demand, knowledge and attitudes regarding organ donation, and beliefs and religious influences to impact on the views of different communities. The Health Belief Model was described as a theory that grounded the study. The Chapter that follows will discuss the research methodology used to address the research problem and answer the research question. In the reviewed literature, there is an agreement that there is shortage of organs globally, thou there is different views affecting individuals and response of communities to

organ donation. These views are the ones motivating and discouraging community involvement in organ donation.

# CHAPTER 3 RESEARCH METHODOLOGY

#### 3.1. INTRODUCTION

The previous Chapter provided a literature review relating to the research problem. This Chapter explains the detailed research methods used to answer the research question. The Chapter will clarify the designs selected for the study in an attempt to answer the research aim and research objective. The participants for the study were selected from community members that were available and willing, from Sekhukhune District. The steps implemented to achieve the data collection from community members are also discussed in detailed in this Chapter. Furthermore, the Chapter provides a detailed method of data analysis for the data collected from interviews from community members. Lastly, the Chapter provides a detailed discussion on principles and strategies used to ensure ethical compliance and trustworthiness of the study.

#### 3.2. RESEARCH APPROACH

Qualitative research attempts to understand a phenomenon in its entirety, rather than focusing on specific concepts (Brink, Van der Walt & Van Rensburg, 2012). A qualitative research approach was chosen because its purpose is to seek in-depth description and understanding of people's beliefs, actions and events in all their complexity (Brink et al., 2012). Creswell and Poth (2018) indicate that in a qualitative research process, the researcher keeps a focus on learning the meaning that the participants hold, about the problem or an issue. Therefore, in order for the researcher to achieve the goal of describing and understanding communities' perspectives of organ donations, a qualitative research approach was found to be necessary (Burns & Grove, 2013). This approach was used in the study, to determine the views of Makhuduthamaga community at Sekhukhune District, Limpopo Province, South Africa regarding organ donations.

#### 3.3. RESEARCH DESIGNS

Research design is the overall plan for gathering data in a research study (Brink *et al*, 2012). The study employed explorative and descriptive designs of a qualitative research approach to achieve the objectives and these designs are discussed below.

# 3.3.1. Explorative design

Explorative design is defined as research designs that explores the full nature of a phenomenon, the manner in which it is manifested and the factors related to the phenomenon under study. Explorative design sheds light on the different ways in which the phenomenon manifests. This also helps in explaining the underlying processes and mechanisms related to phenomenon under study (Polit & Beck, 2012).

The researcher chose this design because of the need to explore the views that the Makhuduthamaga community has regarding organ donations. The intention was to reveal different views within the community, which might prevent the community members from forming part of an organ donor community or participating in organ donations. This included other factors that might affect Makhuduthamaga communities' behaviour or involvement in the act of donating organs. The underlying factors and issues related to views of communities in the Sekhukhune District regarding organ donations were not ignored.

# 3.3.2. Descriptive design

Descriptive design is described as research design that describes phenomena as they occur without focusing on culture or social process (Botma, Greeff, Mulaudzi & Wright, 2015). This descriptive feature involves an accurate way that clearly shows the characteristics of the phenomenon of interest in real life situations. The intention is to discover the phenomena in their natural settings (Burns & Grove, 2013).

The participants were describing their views as community members with regard to organ donations. These views were based on their knowledge and understanding of organ donations. The process took place within the participants' own context and their views were not influenced by the researcher.

## 3.4. RESEARCH METHODS

Research methods are techniques applied systematically during the course of a research process to obtain information relating to the research problem (Ponelis, 2015). The qualitative research methods used in the study included population identification, and sampling, data collection that was done by means of interviews, and the analysis of the data using specific tools, as explained below.

# 3.4.1. Population and Sampling

The population of a study is all the elements (individuals, objects or substances) or aggregations that meet certain criteria for inclusion in a given universe in which the researcher is interested (Botma et al., 2015). Burns and Grove (2013) describe population as particular type of individuals who are of interest to the research study. The population in the study was made up of all community members from Makhuduthamaga Municipality at Sekhukhune District, Limpopo Province, South Africa.

# Sampling method

Sampling is a process of selecting a portion or subset of the designated population to represent the entire population (LoBiondo-Wood & Haber, 2014). According to Burns and Grove (2013), sampling defines the process of selecting the group of people to be included in the research project. This study used non-probability convenient sampling to select the sample used in the research study. Non-probability sampling is used when the researcher is unable to locate the entire population (Botma et al., 2015). In this regard, the Sekhukhune District is a large geographical area with five municipalities. It was impossible for the researcher to reach all the municipalities, so the researcher chose one municipality from which the participants were selected.

The researcher selected Makhuduthamaga Municipality, as it was closer to where the researcher lives and is the area in which she was working, which made the community more accessible. King Madihlaba's and Nduna Mabitla's communities of Makhuthamaga manucipality, was selected by the researcher as the location for data collection due to their geographical location and accessibility to the researcher. The researcher worked at St Ritas hospital at Makhuduthamaga manucipality, which is located at Glen Cowie under the leadership of King Madihlaba. Nduna Mabitla was also a leader of a neighbouring community at Makhuduthamaga. Those areas were selected as they were close to the researchers work place and it was easy to locate, gain access to the leaders for permission for conduction of research from the leaders, and it was cost effective. Community members were accessed during the community meetings, which are being held monthly in two selected royal households of King Madihlaba and Nduna Mabitla of the Makhuduthamaga community. Convenient sampling is the use of the most readily accessible persons (LoBiondo-Wood & Haber,

2014). Convenient sampling was used in this study as participants were selected at the aforementioned gatherings because the researcher found the method to be the easiest and most appropriate for use in the study.

#### • Selection criteria

Participants were selected from Makhuduthamaga community members who were available at the monthly royal meeting at the King Madihlaba and Nduna Mabitla royal households and also agreed to participate in the study. Participants were selected because they were readily available at the research settings during data collection. The participants selected were eighteen years of age and older, were not suffering from chronic organ failure such as renal failure and heart failure.

#### Exclusion criteria

Community members who were members of the health care team - such as nurses, doctors and psychologists – were excluded as their encounter with patients with organ failure may influence their views. In addition, community members who already had experience of organ failure such as those on dialysis, were also excluded, as they are directly affected by the topic under study.

## Sample size

Participants were selected from community members who attended the monthly meeting at the Madihlaba and Mabitla royal households during the dates at which the researcher was available at the meeting. The total number of participants from all four sites were 15. Participants from Nduna Mabitla's community were 7 and from King Madihlaba community were 8, adding to the total of 15 participants. The researcher ceased interviews after there was no new data emerging from the participants' regarding their views on organ donations.

### 3.4.2. Data Collection

Data collection is defined as a process of obtaining pieces of information or facts collected during a research study (Brink *et al*, 2012). Polit and Beck (2014) define data collection as the gathering of information to address a research problem. The researcher collected data from community members regarding their views about organ donations. The data helps to make relevant conclusions in answer to the research

question. Each interview session took approximately 30 minutes to complete. The interview sessions took place in a comfortable space, with minimal movement and controlled noise as selected by the researcher, to ensure that disturbances were minimised

# Preparation for data collection

According to Brink et al. (2012), preparation for data collection is guided by the kind of data required in line with the research topic. Consideration is given to how to collect the required data, the measures or instruments to be used in collecting data, from whom to collect data, where to locate participants for the study, and when to collect data. The places used by community members, and where they often gather was found to be the clinics and community meetings.

No data collection could be undertaken until the research proposal was submitted by the researcher, was approved by the TREC. Letters were written to the King Madihlaba and Nduna Mabitla royal households, informing them of the research and requesting permission to sample attendees of monthly community meetings.

The researcher visited the data collection areas requesting for spaces to be used for participants' interviews. The spaces provided were assessed for comfortability and conduciveness for the interview sessions. King Madihlaba spokesperson and Nduna Mabitla provided information regarding the most suitable days for interviews and arrangements were made regarding suitable times. The royal households also provided information regarding the dates on which community meetings would take place and the researcher was given time at the end of the meetings.

The researcher collected narrative data using interviews.

# • Interview method

An interview is defined as method of data collection where the data collector asks participants to narratively respond to a set of open-ended questions (LoBiondo-Wood & Haber, 2014). The researcher chose interviews as they allowed for a collection of varied and in-depth information, with flexibility. Interviews were also used as it allowed all community members to form part of the study regardless of their educational level. Participants did not have to be able to read or write (Burns & Grove, 2013). A semi-structured interview format with the use of an interview guide (see Annexure 1) was

used to collect data. In semi-structured interviews, the researcher prepares a written guide, which includes specific questions to be covered with each participant (Polit & Beck, 2012). Due to the nature of the research, face-to-face semi-structured interviews were selected for data collection to ensure that the researcher obtained the required information without leaving out specific areas.

Semi-structured interviews involve the interviewer asking a central question, followed by additional probes using open-ended questions (Brink et al., 2012). The central question posed to all participants during the interview session was "How do you view organ donations?" The follow ups questions were guided by the interview guide and the participants' responses. The interviewer also had the freedom to probe and explore additional questions in response to participants' replies. All interviews were face-to-face, and audio recordings and the writing of field notes assisted the researcher to capture all data, including behaviours and mannerism during the interview sessions.

#### Data collection tool

The researcher used a voice recorder to record the participants during interview sessions. A voice recorder is a digital handheld device that records and store conversation and sounds (Deuter et al., 2015). Each interview session was recorded on a voice recorder with the knowledge and consent of the participants. A voice recorder was chosen so that the researcher could go back to the interview sessions and listen repeatedly as needed in order to provide meaning to the interview session. In addition, the voice recordings were used by the researcher when transcribing the interviews verbatim. The recordings could also be used for future reference.

Field notes were written for each interview with notes taken related to gestures, mannerism and the individual's behaviour. Field notes refer to qualitative notes recorded by researchers in the course of field research during and after their observation of a specific phenomenon under study (Gibbs, 2019). The researcher held a notebook and pen, reflecting the participants' facial expressions, tone of a voice and mannerisms during and after the interview session. These helped the researcher in explaining the moods and unsaid feelings of the participants as they express their views concerning organ donations.

# Skills used to enhance quality for data collection

The researcher as a principal investigator used reflective, summarising and probing skills to reflect back on the participants' responses. Additional probes were used to ask the participants to provide a clear meaning for some of the responses provided.

#### • Data Saturation

Data saturation means that no additional data trends are being found by the researcher (Creswell & Poth, 2018). Data was collected until data saturation was reached as recommended by Brink et al., 2012. Data saturation assisted the researcher in concluding the total number of participants in the study, and the point of data collection cessation. This implies that researcher has marked the beginning of data analysis process as described below. Data saturation was reached after interviewing 15 participants.

# 3.4.3. Data analysis

Data analysis refers to the technique used to reduce, organise and give meaning to data (Burns & Groove, 2013). Qualitative data is dense and rich, requiring steps to analyse different forms of data collected. The intention of data analysis is to make sense out of the text and image the data. By segmenting the data and putting it back together, it gives meaning to it. (Creswell & Poth, 2018). The researcher used Tech's Coding Method of analysis to analyse the collected data. The strength of the Tech's method lies in its stringent methodological control and systematic analysis of information (Creswell & Poth, 2018). The eight steps followed in this method of data analysis were:

- During organisation and preparation of data, the researcher listened to the
  audiotapes, and then transcribed the interviews verbatim (see Annexure J for
  an example of transcript). The transcripts, together with the field notes, were
  carefully read by the researcher, while writing down ideas as they come into the
  researcher's mind. Collected data was sorted and arranged into different types
  depending on the age groups, gender, similarity of ideas and location.
- The researcher carefully read the most interesting individual transcripts several times with an aim of making general sense of the information. The ideas of the participants were reflected considering the tone and expressions shown during

interview sessions. The researcher tried to understand the contents of the transcripts, separating the common ideas or expected ideas from the more interesting and unusual findings. General thoughts about the findings were written down.

- The researcher wrote down different topics that emerged during analysis process. This was done after a couple of interviews were read. The segmented data and general ideas developed were clustered according to their similarities.
   The clustered topics were put in different columns including the most dominating ideas, unique ideas and unexpected ideas.
- After clustering the topics, the researcher went back to the collected data and
  wrote different letters close to each developed topic. The codes were developed
  by abbreviating the topics and writing them next to the appropriate section of
  the text. The researcher assessed this organising scheme to see whether new
  categories or codes emerged.
- Each topic was given the most descriptive word, and categories were formed. The topics were read again and grouped together according to how the information related to one another and included the similarities of data in the topic, to reduce the list of categories. The interrelationship of the categories was shown by drawing of a line between those categories.
- The researcher made final decision on the abbreviation for each category and wrote the developed codes alphabetically.
- After alphabetising the codes, the researcher assembled the data material belonging to each category in one place.
- The recoding of the existing data was done at the end of the steps.

# 3.5. MEASURES TO ENSURE TRUSTWORTHINESS

Trustworthiness is a determination that the study is of high quality. Credibility, dependability, confirmability and transferability were used as criteria to ensure the quality of a study (Grove et al., 2015).

# 3.5.1. Credibility

Credibility refers to confidence of the reader about the extent to which researchers have produced results that reflect the views of the participants (Grove et al. 2015).

This refers to the extent to which the study findings are trustworthy and believable to the readers (Polit & Beck, 2014). Credibility was ensured by prolonged engagement by the researcher, who stayed in the field until data saturation had been reached. Data was collected for a month to capture the essence of the community views. The researcher visited the research settings a couple of times to interview the participants in order to seek full explanations and clarification to gain an in-depth understanding of the phenomenon under study. Debriefing was also used in participants were informed about the intention of the research study before taking part in the project.

# 3.5.2. Dependability

Dependability refers to the stability of data over time and over conditions (Polit & Beck, 2014). The researcher collected data until no new themes emerges, as data saturation had been reached. The research method was systematically explained in detail in Chapter 3 of this thesis. To ensure data stability the researcher was open to new information from the participants and was flexible with regards the research topic to ensure a good level of understanding of the participants during data collection. Collected data was re-examined throughout the research process for new emerging insights. Data was continually analysed to inform the researcher about the need of further data collection.

# 3.5.3. Confirmability

Confirmability refers to the objectivity that is the potential for congruence between two or more independent people about data accuracy, relevance or meaning (Polit & Beck, 2014). In this study to ensure objectivity or neutrality of the data, the records used to collect data have been kept and they will be made available for future reference, scrutiny, confirmation and auditing purposes. The researcher and the supervisor reached an agreement on the meaning and relevance of collected data before interpretation. The whole research process was explained in the research report including the motives of the researcher at each stage of the research process. The literature review was conducted during the writing of the research proposal providing guidance to the researcher on that sort of data that might need to be collected. Literature control was also conducted during data analysis in order to relate the study findings with the available literature. The researcher did not allow personal points of view regarding organ donations to affect study findings.

# 3.5.4. Transferability

Transferability refers to the potential for extrapolation, the extent to which qualitative findings can be transferred to or have applicability in other settings or groups (Polit & Beck, 2012). Transferability was ensured in this study by the literature control process during data analysis, relating the study findings with the existing literature from a different setting. Thick description was done, in which the researcher discussed the finding of the study in detail, providing meaning to the emerging themes and context.

## 3.6. ETHICAL CONSIDERATIONS

The ethical considerations of the study are discussed according to the following research strategy and ethical principles:

#### 3.6.1. Permission

The researcher obtained permission from the Faculty Higher Degrees Committee (FHDC) to do the research through the approval of the research topic (see Annexure C). Turfloop Research Ethics Committee (TREC) (see Annexure H) also granted the researcher ethical clearance. Permission to conduct the study at the departmental clinics was obtained from Department of Health before the research study commenced. Permission to conduct the study at monthly community meetings was granted by the King Madihlaba and Nduna Mabitla royal households.

## 3.6.2. Informed consent

Informed consent ensures that the ethical principle of voluntary participation, the right of respect of human dignity, the right of self-determination and full disclosure are adhered to (Polit & Beck, 2014). Participants were informed about the purpose, objectives and significance of the study in the language they understand. The researcher explained to the participants that participation in the study was voluntary. The participants were notified of their freewill to participate in the study, and that they could withdraw at any time during the study even if they had previously given consent (Brink *et al*, 2012). Written informed consent was obtained from every participant (see Annexure K for an example of signed consent).

# 3.6.3. Principle of Anonymity

To ensure anonymity, participants' information is not linked with the collected data, even by the researcher (Grove et al., 2015). The participants' names were not used during data collection and data analysis. Participants, together with the researcher, developed codes that consist of numbers and letters. The codes were used during the interview sessions instead of participants' real names. The researcher tried not to link the collected data with the participants' information, even during data analysis (Grove et al., 2015).

#### 3.6.4. Principle of Confidentiality and Privacy

Confidentiality occurs when the researcher cannot link the participant information with the collected data, and privacy ensures that the researcher is not more intrusive in participants' lives than s/he needs to be (Polit & Beck, 2012). Participant information, together with the interview records, were kept locked in the researcher's personal locker and there was no any unauthorised person who had access to them. There was no need to share participants' information with other stakeholders other than the research team, and this was done with the participants' authorisation.

The participants were assured that the information provided would not be used against them in anyway whatsoever (Grove et al., 2015). Privacy was ensured by using a private room with a "no disturbance sign" on the door, when collecting data. Names of the participants were not used during data collection and interpretations, and the participants' information is not linked to the participant in any way (Brink et al., 2012).

#### 3.6.5. Principle of beneficence and non-maleficence

The principle on beneficence and non-maleficence is grounded in the premises that a person has a right to be protected from harm and discomfort and that one should do good and no harm (Botma et al., 2015). In the study, the researcher ensured that an interview was stopped immediately when a case of discomfort arose, providing reassurance where necessary and participants who required psychological support were referred to a psychologist. There was no economic harm to the participants, as they were not requested to use their money in any way. There was also no physical impact related to their participation in the research study. The study might improve health awareness in the community regarding the issue of organ donations.

#### 3.6.6. Principle of justice

Principle of justice refers to the participants' right to fair selection and treatment (Brink et al., 2012). The researcher was fair in selecting participants from the study population. The reason for selection was in relation to the purpose of the study, not due to manipulation or vulnerability. Participants were provided with clarity and explanations whenever they were requested from the researcher, regardless of their geographical location (Brink et al., 2012). The researcher treated the participants equally at all times, and shared information equally among them.

#### 3.7. BIAS

Bias is an influence that produces a distortion or error in the study results (Polit & Beck, 2012). To minimise bias in the study, the researcher did not communicate her expectations regarding organ donations with the participants before conducting the interviews, to avoid bias behaviour or disclosure. The participants were selected conveniently from the target population of the Makhuduthamaga community, to avoid engaging only one group of community members who may not represent the whole population (Polit & Beck, 2012). After literature has been reviewed, the researcher undertook a process of bracketing in which, the preconceived ideas about the community views regarding organ donations was put aside, and the researcher focused on exploring the views of Makhuduthamaga community, as explained by the community members themselves.

#### 3.8. CONCLUSION

In this Chapter, the researcher discussed in detailed the research approach used in the study to answer the research question. The researcher used a qualitative approach, with explorative and descriptive research designs, to describe and explore the views of communities of Sekhukhune District regarding organ donations. Semi-structures face-to-face interviews were conducted in which the researcher recorded the participants using an audio tape recorder whilst also writing field notes. Qualitative research approach with explorative and descriptive designs has helped in clear understanding of the research problem. The participants, who were eighteen years old and above, were located in the Sekhukhune District and resided in the Makhuduthamaga community, Turfloop Research Ethics Committee (TREC) approved the study and permission to conduct the study was obtained from Limpopo Department of Health and the royal households of King Madihlaba and Nduna Mabitla

at the Makhuduthamaga tribal offices. Measures to ensure the principle of anonymity, self-determination and confidentiality were also discussed in detail. Truth-value of the study was also maintained through dependability, confirmability, transferability and credibility. Maintaining ethical issues promoted the participants comfort and openness and allowed the researcher to collect relevant data until data saturation was reached. Data was analysed using the Tech's open coding method of data analysis.

The following Chapter discusses the results of the study and includes a discussion of the findings with regard to the community's views on organ donations.

#### CHAPTER 4

#### **RESULTS AND DISCUSSION OF FINDINGS**

#### 4.1. INTRODUCTION

In the previous Chapter the researcher discussed in detailed the research methodology used to answer the research question. In this Chapter the findings of the study on the views of communities regarding organ donations in the Sekhukhune District, Limpopo Province, South Africa, is discussed. Semi-structured face-to-face interviews were used to collect data from community participants. The recorded interviews were transcribed verbatim to enhance the analysis process that generated the themes and sub-themes of the study. Themes and sub-themes emerged during the coding method of the data analysis and they are discussed together with the demographic profile of community participants.

#### 4.2. DEMOGRAPHIC DATA

The demographic profile of community participants is presented in Table 4.1 below:

**Table 4.1:** Characteristics of participants

| Characteristics      | Participants |
|----------------------|--------------|
| Gender               |              |
| Females              | 6            |
| Males                | 9            |
| Language             |              |
| Sepedi               | 10           |
| Ndebele              | 5            |
| Age                  |              |
| Between 20 & 30years | 5            |
| Between 30 & 50years | 6            |
| Above 50years        | 4            |
| Educational level    |              |
| Never went to school | 1            |
| Grade 1 to 7         | 2            |
| Grade 10 and above   | 12           |

| TOTAL | 15 |
|-------|----|
|       |    |

The study sample consisted of 15 community members of Sekhukhune District, located within the Makhuduthamaga Municipality. All participants were above 18 years of age. Five participants were Ndebele, and ten were Sepedi speaking. Etheredge et al. (2014) has shown that among black Africans there is an unwillingness to donate organs of their loved ones regardless of their difference in cultural beliefs. During the interview sessions, one isiNdebele speaking used English as his language of preference as he did not understand Sepedi well. Three isiNdebele speakers understood Sepedi but mixed Sepedi with isiNdebele in their responses. In both Sepedi and isiNdebele speaking participants, culture and religion were found as a dominating factor influencing their views towards organ donations. All of the other eleven participants used Sepedi during interview. There were nine male and six female participants in the study. One participant was illiterate, two did not complete primary school level and the remaining twelve participants were literate, with a grade ten and above. According to Krupic, Westin, Hagelberg, Skoldenberg and Samuelsson (2018), positive attitudes, understanding of organ donations and a willingness to donate organs was found among those participants who have acquired higher education than the illiterate.

Five of the participants were youth between ages 20 and 30 years, six were adults between 30 and 50 years, and four were above 50 years old. The results show that it was easier for the participants between 18 and 20 years to accept the idea of organ donations and showed more understanding and willingness to donate compared to the older participants. In a study of attitudes to organ donations among urban South African population, there were some differing attitudes relating to organ donations depending on the age of those interviewed, with an increased unwillingness to donate organs among the older black Africans (Ertheredge, Turner & Kahn, 2014). In the same study, it was also found that there was a variation in attitudes of different genters, with females being more receptive to the idea of organ donation (Ertheredge et al., 2014).

#### 4.3. RESULTS AND DISCUSSION OF FINDINGS

The results of the study are discussed below according to the themes and sub-themes as outlined in Table 4.2. The discussion of the themes and sub-themes is supported by quotes from participants. Furthermore, the findings of the study are compared and contrasted to both the national and international literature. However, before discussion of the results, the results of the study are summarised in a table format below.

Table 4.2: Summary of the main findings

| Themes                 | Sub-themes   |
|------------------------|--|
| Theme 1: Participants  | Sub-theme 1.1: Existence of knowledge versus lack  |
| express multifaceted   | of knowledge related to organ donation and         |
| perceptions concerning | its importance by community members.               |
| organ donations        | Sub-theme 1.2: An explanation that organ donation  |
|                        | idea is acceptable versus the idea being           |
|                        | unacceptable amongst community members.            |
|                        | Sub-theme 1.3: Existing diverse interpretations of |
|                        | organ donations by community members are           |
|                        | difficult to comprehend.                           |
|                        | Sub-theme 1.4: The existence of a strong view that |
|                        | organ donations should be considered for           |
|                        | close family members only but not for              |
|                        | strangers.   |
|                        | Sub-theme 1.5: An opinion that community           |
|                        | members hold an understanding that organ           |
|                        | donations are focused on saving other              |
|                        | people's lives.                                    |
|                        | Sub-theme 1.6: Existing view that organ donations  |
|                        | has both negative and positive outcomes.           |
|                        | Sub-theme 1.7: The existence of a stigma related   |
|                        | to organ donations in the communities              |
|                        | outlined.  |

|                             | Sub-theme 1.8: An explanation that educating          |
|-----------------------------|---|
|                             | community members about organ donations               |
|                             | is viewed as violation of their cultural rights       |
| Theme 2: Participants       | Sub-theme 2.1: The description that acceptance of     |
| expressed reasons towards   | donating an organ or receiving a donated              |
| •                           |   |
| rejection or acceptance of  | organ depends on the religious, cultural,             |
| the idea of organ donations | personality and health status of an individual.       |
|                             | Sub-theme 2.2: An explanation that the willingness    |
|                             | to donate organ is based on health                    |
|                             | experiences and the need to survive.                  |
|                             | Sub-theme 2.3: A belief that receiving other people's |
|                             | organs is viewed as inheriting other families'        |
|                             | bad luck  |
|                             | Sub-theme 2.4: An explanation that a person is        |
|                             | viewed complete if they have all their organs,        |
|                             | therefore the donation of organs is not an            |
|                             | option.   |
|                             | Sub-theme 2.5: Existing cultural myths related to     |
|                             | organ donations.                                      |
| Theme 3: Participants'      | Sub-theme 3.1: Only pure Christians should be         |
| suggestions on how to       | considered for organ donations.                       |
| improve the understanding   | Sub-theme 3.2: Implementation of community            |
| of organ donations          | health education and health awareness                 |
|                             | programmes on organ donations.                        |
|                             | Sub-theme 3.3: A health assessment must be            |
|                             | carried out prior to an organ donation with           |
|                             | assurances provided to both the donor and             |
|                             | recipient.  |
|                             |   |
|                             |   |

Theme 1: Participants express multifaceted views concerning organ donation

The participants expressed different views on organ donations from which eight subthemes emerged. Some participants reflected lack of knowledge while others had some existing knowledge related to organ donations and the importance thereof. There was both a level of acceptance and rejection of organ donations among community members depending on how organ donations are interpreted. The subthemes are discussed below.

## Sub-theme 1.1 Existence of knowledge versus lack of knowledge related to organ donation and its importance by community members.

The study findings revealed that among community members, there were those who were found knowledgeable about organ donations. The knowledgeable community members had positive attitudes towards organ donations. The source of information was said to be books, media and secondary information from fellow citizens. Yet there were some community members who appeared to be less knowledgeable about organ donations. The quotes below support the findings:

- Participant 4: "...we [community members] need to be taught because we don't know anything about this organ donation, especially in rural areas".
- **Participant 5**: "I know that you can donate...you donate (rolling eyes) ...with blood or with organs like the kidneys to help someone".
- **Participant 9:** "ah, i don't know it that much i just hear people saying organ donation organ donation".

Participant 12: "eh, the issue of organ donation? I have just heard about it on media".

The study findings were found to be similar to those conducted in rural Kerala, in India, by Manojan, Ramiz, Vincy, et al (2014) who indicated that among participants some were knowledgeable while others had no clear knowledge on organ donations. Most of those who had knowledge were the ones who were directly involved or affected by organ donation. In Nigeria, knowledgeable participants regarding organ donations had more positive attitudes towards organ donations than participants who were less knowledgeable (Oluyombo et al., 2016). Therefore, there is agreement between the literature and the findings of the study, indicating the relationship between knowledge and respond to organ donation.

## Sub-theme 1.2: An explanation that organ donation idea is acceptable versus the idea being unacceptable amongst community members

The study findings indicated mixed feelings about accepting organ donations. There were community members who saw organ donations as a good initiative and acceptable. Those community members explained organ donations as the right thing to do to others during ESOF. At the other hand, some community members were negative about the organ donation idea and could not accept donating organs to other human beings. The study revealed that it was easier for community members to agree to organ donations from those deceased than to accept the organs from people still living. This is because participants regarded organ donations as a sacrifice not worthy to make, especially as it contradicts their belief and religion. The quotes below support the findings:

- Participant 12: "Is a very important thing because a person... as a person you should consider that at the end of the day on your body there is a certain part of your body that can save a person".
- Participant 13: "I don't see why you can't give your brethren a lung or any part if his is damaged and you have a well-functioning one and you are his match... I can receive an organ without hesitation when I need it".
- Participant 11: "I don't think I will ever donate, unless someone signs for it when am late you see. I can't live with parts that God did not give to me".
- Participant 10: "Must someone sacrifice for me and loose an organ while i do not believe in those things? I will not receive any organ, i just will not agree".

Similar findings were found in Denmark, where the participants displayed different reactions towards the idea organ donations and transplantation. In that country, younger participants were found to be more positive and willing to donate than elders, regardless of religious belief (Nordfalk, Olejaz, Jenzen, Skovgaard & Hoeyer, 2016). Similarly, there was an increased positivity in response to organ donations after death or if one was brain dead compared to live donations. Diversity of organ donation

acceptance or rejection was also reflected among Arabian speaking population in Australia (Ralph et al., 2016).

## Sub-theme 1.3: Existing diverse interpretations of organ donations by community members who find it difficult to comprehend

The idea of organ donations was a challenge to community members in that they found the concept difficult to comprehend. The study results have shown that they could not clearly express their views regarding organ donations. They were unsure of whether it is a good or bad thing, finding it a difficult decision to make and finding discussion about organ donations unusual. The findings are supported by the quotes below:

**Participant 3**: "Eish (scratching head), it is difficult for me unless if doing it when am already dead".

Participant 14: "Yes, it [organ donation] is really difficult. Is like those things [organs] are taken from (Paused) I don't know... dead people"

**Participant 15:** "It is just not that easy to think about organ donation"

The study also focused on decision making regarding the donation of organs of the loved one who are confirmed brain dead. Families explained decision making as being a dilemma and provoking a feeling that the deceased's rights might be violated. Families further explained that they felt incompetent to make such decisions and seemed to struggle with decision making (De Groot, Van Hoek, Hoendemaekers, Hoitsma & Smeets, 2015). Therefore, the literature reflected the study findings although the literature focused on the donation of the body parts of deceased people.

## Sub-theme 1.4: The existence of a strong view that organ donations should be considered for close family members only but not for strangers

The study findings revealed that there were community members who agreed that it is good to donate organs and save lives, but that this should only be done among family members, as there is a shared genetic bond. Community members showed discomfort and an unwillingness to share organs with strangers. The idea of giving organs away to, or receiving organs from, strangers just did not seem to be right as indicated in the following quotes:

**Participant 1:** "Ya in the family you can donate, because you are already in that particular family, right in that setup".

**Participant 2:** "No, not to donate for a relative per say, but to a wife, my children and siblings, i mean close relatives"

Participant 4: "No, I won't take my body and give it to the person I don't know"

Participant 3: "For me, ere (scratching head) organ donation is right for a family"

Etheredge et al. (2014) found attitudes to organ donations among the urban South African population in which respondents were found to be positive with a clear understanding if the concept of organ donations. Similarly, most of the respondents were willing to donate to relatives and were uncertain about donating an organ to a stranger. Cusumano, Garcia-Garcia, Gouzale-Bedat, Marinovich et al. (2013) indicated that families of kidney failure patients were more willing to donate than strangers. In agreement with the study results, the study on public awareness and attitudes towards organ donations, showed public willingness to donate patients known to or related to them rather than to unknown recipients, with kidney donations being preferred organs to be donated (Tong, Chapman, Wong, Josephson & Craig, 2013).

## Sub-theme 1.5. An outline that community members hold an understanding that organ donation focus on saving other people's lives

During the analysis of the collected data, there was a collective understanding among community members that organ donations are aimed at the promotion of health and saving other people's lives. Regardless of the participants' willingness to take part in organ donations or not, the participants still agree that the donation of organs does save lives. The idea that organ donations aim at saving lives was shared in all community members of different cultural beliefs, age and gender as supported by the quotes below:

**Participant 5:** "I see it [organ donation] being important you know. Yes is important because you can help a human recover from illness, you see."

Participant 7: "It [organ donation] is a good thought because it really saves people's lives in life"

**Participant 11:** "...at least you will be doing the right thing. You will be saving people, you will be saving people's lives and I think is a good thing".

According to Abdulrahman et al. (2015), and in support of the current study findings, organ donations are often the only preferable treatment for end-stage organ disease, which results in a long-term survival benefit with positive quality of life improvement for the recipient. In contrast to the idea that organ donation saves life, it was established that organ donation could be a futile act, as it cannot be established before the procedure whether the recipient of an organ will accept or reject the transplanted organ. Organ donations have been described as taking a chance in which one can survive if it is successful, or die in the case of organ rejection (Moorlock, Ive & Draper, 2014).

## Sub-theme 1.6. Existing view that organ donations have both negative and positive outcomes

Although organ donations were seen as having a positive impact and a life-saving tool, community members believed that it can have a negative impact on the lives of the donors. Community members raised the fear of donating a body part and suffer the effects without getting any help. Some members indicated that donations from deceased individuals is better as the donor will no longer need the donated organ. The community also believed that the donation of an organ could shorten the donor's life. The findings are evidenced by the following quotes:

Participant 8: "I can donate and save life then find that in future I have dysfunctioning of the same part and I fail to get the same help that which I have given to another person".

Participant 2: "Ayi, organ donation is ok but sometimes it is not okay..."

**Participant 3:** "it is good when am dead, when you are still alive you just think that you are reducing your days of living".

Similarly, the public has verbalised some perceived benefits, concerns and barriers related to organ donations from living individuals rather than from those who are brain dead (Tong et al., 2013). The public believed that donors would gain a sense of reward and satisfaction in helping others through organ donation. The fear of surgical

procedures and health risk related to organ donations was mentioned as a barrier and concern to donors (Tong et al., 2013).

## Sub-theme 1.7: The existence of a stigma related to organ donations in the communities outlined

One of the effects that the study findings has revealed on views of communities regarding organ donations, is the stigma that the community hold on the issue of organ donations. Members of the community verbalised that as a receiver of a donated organ they would always be identified within the community as some who is alive because they have a donated organ. That was identified as a discomfort and that they would be belittled. The following statements support the findings:

Participant 2: "So the issue of organs is a stigma even in the community."

**Participant 9:** "It just doesn't feel right to be pointed at saying you have other person's organ."

Contrary to the finding of the study on community members' views regarding organ donation in the Sekhukhune District, Kumar and Mattoo (2015) reported that organ donations were defined by organ recipients' as having improved their physical health. The recipients of organs described the process as challenging and associated with emotional stress due to lifestyle changes. Anxiety and depression were found to be common among recipients, other than stigma (Kumar & Mattoo, 2015).

## Sub-theme 1.8. An explanation that educating community members about organ donation is viewed as a violation of their cultural rights

Culture was found to be of great influence on the views of communities regarding organ donations. In the current study findings, communities expressed their view of organ donations as a Western idea, which is against African culture. Communities further indicated that educating Africans about organ donations is in fact a violation of black African culture. The findings are supported by the following quotes:

**Participant 14:** "you are not supposed to tell them because is not cultural and you are going to scare people"

**Participant 2:** "If you are trying to educate me about it, i can even tell you that you are violating my traditional rights"

**Participant 8:** "I don't wish for it to improve, it must stay standard, those who get he will and those who can't be helped. Just don't tell people to improve on it"

Salim, Ley, Berry, Schulman, et al (2014) encouraged community education regarding organ donations in schools, churches and local communities. Education focused on the promotion of life through organ donations has resulted in positivity as the community members understood the concept of organ donations and made informed decisions in this regard. Education to communities is seen as the way to provide clarity regarding the subject and not a violation of rights.

## Theme 2: Participants expressed reasons towards rejection or acceptance of the idea of organ donations

In the findings of this study, the respondents expressed different reasons contributing to their rejection or acceptance of organ donations. Five sub-themes that emerged from this theme are explained in detail below. The sub-themes include reasons such as religious, cultural and personal influences, and as well as health experiences and myths held by communities.

# Sub-theme 2.1: The description that acceptance of donating an organ or receiving a donated organ depends on the religious, cultural, personality, and health status of an individual

Religious identification or value belief systems have a marked influence in decision-making in the studied community. There were respondents who identified with certain religious groups that do not believe in organ donation. It was articulated that organ donations were believed to be against God and interfering with His will regarding people's lives. Organ donations were also described as something not aligning with black African culture, whilst some community members expressed organ donations as a personal issue, guided by ones feelings and emotions. The statement is supported by the quotes below:

Participant 13: "Is just that our people...our culture doesn't agree with it. The culture does not agree that you can take your organ and give it to another person"

- Participant 2: "I, according to myself am saying; as an African man i believe that when each an every person leaves this earth must leave with all his organs."
- Participant 8: "I think is against eh... let me say Christianity like you see. To give with parts of your body is against it because God cannot create what he does not know. In my religion we don't donate, not even with blood".
- **Participant 9:** "No man, my part is my part. I don't know about others. But for me at my side no even blood I can't"

Even though there was no religion that was found to formally forbid organ donations, objections were made by Native Americans, Roma Gypsies and some South Asian Muslims, indicating that the body is a gift from God that should not be desecrated following death (Michelle & Allison, 2012). Michelle and Allison (2012) further indicated that the idea of not desecrating the body was different from the Christian faith which strongly encourages organ donation among its congregants.

## Sub-theme 2.2: An explanation that the willingness to donate is based on health experiences and the need to survive

The point of view of some community members was influenced by personal health experiences such as the loss of a loved one due to organ failure, or a loved one suffering with organ failure. In that case, community members were positive about organ donation and expressed a willingness to donate. The current study also reflected that it was easier for community members to agree to accepting organs in order to survive, than to be a donor. Participants who had seen family members recover from critical conditions, when the predictions were negative about their survival, started trusting the health system and the idea of organ donations.

- Participant 15: "There are different kinds of illnesses, which may require one to be given organs. My aunt had a heart problem and died as she needed such help you see and I think there are many other people who need organs".
- Participant 2: "Even my sister was once being said to be paraplegic, it was confirmed that she will never walk. She was in coma hearing them... listening.

  They even showed us the x rays, nature worked at its own way"

Participant 3: "...Because when I refuse with the organ, but then when that happens to me that means I will need it, isn't that I will be feeling pain and I need to be well." In contrast to the current study findings, Jernigan, Fahrenhend, Harries and Tsosie, (2014) discovered that health experiences increase knowledge and understanding of organ donations but does not necessarily impact on the acceptance and willingness to donate. Amongst the participants of the same study by Jernigan et al. (2014), greater knowledge was found in the participants who had relatives with diabetes or who were suffering from diseases like end stage renal failure, compared to participants with no related health problem. Abdulrahman et al. (2016) stated that regardless of the amount of knowledge that people had, organ donations were described as complicated and that the willingness to donate was influenced by attitudes and beliefs toward the idea.

## Sub-theme 2.3: A believe that receiving other people's organ is viewed as inheriting other families' bad luck

There was an emerged belief that blood and body organs contain either a generational blessing or a curse. It is believed by some community members that such curses can also be inherited through the donation of organs. If one receives such organs, he/she will inherit curses of the family that he/she received the organ from. The quotes below support this statement:

Participant 1: "I mean, if for instance, I receive a donor or an organ from someone (hesitating). I will inherit the curses of that particular family"

Participant 7: "We need to stop the thought that having other people's organ is like sharing their lives or their ways of living."

Organ donations are seen as a blessing to the participants, which provides hope for the improvement of health that patients with end stage organ failure rarely find (Moritsugu, 2013). Organ donations are also seen as a good thing to do among Christians, as it is a way of giving love to other human beings (Michelle & Allison, 2012). There was no specific literature found on sharing of blessings or curses through organ donation.

## Sub-theme 2.4: An explanation that a person is viewed complete if having all organs, therefore the donation of organs is not an option

The study findings revealed that respondents define their completeness based on their body organs. There was a revealed belief that there is life after death and that ancestors must receive one in that complete form in the life after death. Members of the community also indicated that there will be rapture (biblically meaning the second coming of Jesus to transport mankind to heaven), and if one donates an organ, one will rise from the dead as an incomplete being. It is in respect to God that humans should die in the same form that God created them, without other people's organs in their bodies or by missing organs through organ donations. These was evidenced by the following quotes:

- Participant 2: "We are African you know. We don't believe in such things. We believe that when a person dies must die with all his or her organs being complete. There is no such thing as giving someone another person's kidney, no no."
- Participant 10: "Me, according to my believe it is not right. In my belief when a person passes from this earth she must pass being whole. Why should I die incomplete while I was born complete."
- Participant 12: "Our problem as black people is...there is this myth that says if a person dies having half of some part, even the day of rapture you will wake up with the half part but that one will".

Similarly, religious and cultural beliefs were cited as being among factors that contribute to the lack or shortage of donor organs amongst South Africans (Etheredge et al., 2014). Most black African participants were concerned about keeping their bodies intact for burial, and organ donations were perceived as damage to the body (Etheredge et al., 2014). The study by Wong and Chow (2016) provided insight into promoting the donation of organs, and revealed one of the hindrances to organ donations as the concern for keeping the body intact.

#### Sub-theme 2.5: Existing myths related to organ donation outlined

The study findings have discovered some strongly held opinions regarding organ donations amongst community members that are not necessarily true. With the increased prevalence in chronic diseases in the South Africa, communities hold a myth that organs can be transmitters of illnesses. The other myth revealed was that when

you have shared an organ with a person, you will also inherit their genes. Community members articulated a belief in the idea that when one is a registered organ donor, one can be killed for ones organs. Fear of rejection by the ancestors was found to be a myth share among participants. The quotes from participants listed below, support these statements:

- **Participant 1:** "Ya, organs have blood and genes relating to a particular family, when organ is donated the genes and blood are automatically shared"
- **Participant 5:** "You find that people are afraid that maybe you can be infected by that people's illness".
- Participant 13: "Our culture is against it because there is a belief that when a person can die having lost some parts he will do... he will be able to lie well with the ancestors".
- Participant 14: "Yes, so even with organ donation it must be that way, not for us to register. Signing a paper is another thing, is like you are saying they can take your part anytime, so they will kill you".

There was also a common myth that there might be a possibility that brain-dead patients might somehow still be alive having been misdiagnosed by medical practitioners and that by donating with their organs they will be killed. That myth was described as an emotional provoking of barriers that was held among individuals, leading to a negative attitude and perspective of organ donation (Miller, Currie & O'Carroll, 2019).

## Theme 3: Participants' suggestions on improving the understanding of organ donation

Participants had different opinions and reactions relating to organ donations. During this study, community members pointed out that organ donations are not common amongst blacks people and the concept is not fully understood, especially in rural areas. The need to improve the understanding of organ donations was revealed and members made some suggestions on how to improve the number of organ donations in the Sekhukhune District. This theme explained the suggestions on improving the understanding of organ donation, through the five sub-themes that emerged, which are explained in detail below.

### Sub-theme 3.1: Only pure Christians should be considered for organ donations

A suggestion that only pure Christians should be considered for organ donations was outlined by the community members. A participant indicated that purity can be achieved through being born again and getting deliverance from curses that may be contained in blood and the organs of humans. The statement is supported by the quote below:

**Participant 1:** "people must be born again, then be delivered from generational curses before they can be encouraged to donate".

Religion was found to be most influential belief within communities relating to organ donations (Jernigan et al., 2013; Michelle & Allison, 2012; Ralph et al., 2016). No study was found supporting the idea that only pure Christians should donate organs. However, Oliver, Ahmed and Woywodt (2012) indicated that Christians were supportive of the idea of organ donations and were more willing to register as organ donors based on their faith. The opposition to organ donations was dominant among Muslim and Hindu respondents citing the need to honour God's creation as the reason for their opposition (Oliver et al., 2012).

## Sub-theme 3.2: Implementation of community health education and health awareness programmes on organ donations

Participants suggested that educating communities in the form of health awareness and workshops might be helpful in promoting the understanding of organ donations and improve the communities' participation in the issue under study. The quotes below support this statement:

- Participant 4: "We can help our community members with that... with workshops because some of them knows nothing about organ donation"
- Participant 7: "By talking to the nation making they understand the way organ donation is important. We need to stop the thought that having other people organ is like sharing their lives or their ways of living."

Participant 15: "... by just meeting with people and holding workshops in communities and providing guidance about organ donation as it is not that famous to people."

Participant 13: "People must be taught. Yes, there must be ways to give people health talks about organ donation."

Miller et al. (2019) suggested that holding campaigns within communities to explain the concept of organ donations, helps in clearing the myths regarding the process and promotes insight regarding organ donations in the communities. The study findings are in agreement with Miller et al. (2019), Naiker (2013) and Jernigan et al. (2013) who indicated in their studies that the distribution of information to community members increase awareness and promotes a positive response towards the idea of organ donations. Jernigan et al. (2013) further emphasised that it is easier to make informed decision when the information about organ donations has been fully explained. Knowledge and understanding about organ donations boosted confidence in communities to participate in an organ donation programme. Therefore, the study findings are similar to the gathered literature.

## Sub-theme 3.3: A health assessment must be carried out prior to an organ donation with assurances provided to both the donor and recipient.

The responses from participants suggested that prior to organ donations, a health assessment must be carried out and there must be an assurance of the survival of both the donor and the recipient. The participants believed that intensive screening and health assessment are necessary before organ donations. The participants further indicated that transparency to both the donor and recipient of an organ on the outcome of the health assessment was required before an organ can be donated. Community members also required an assurance of the quality of life for the organ donor and the recipient prior to the performance of the procedures. The quotes that follow support the statement:

**Participant 3:** "I say maybe, if maybe the health status of the donors can be thoroughly checked before donation".

Participant 5: "I think they can be satisfied by seeing that they [the organs] have been checked, before donated to them so that they can be sure the organ is free from diseases.

Participant 11: "... if there is assurance that both me [as an organ donor] and the one
I am giving an organ will live, yes... surely I will donate but we must
both be assured to live..."

The assurance of survival of both the donor and the recipient of an organ could not be given as it depends on the recovery of the patient and the acceptance of the body receiving the donated organ of the new organ (Moorlock, Ive & Draper, 2014). The ODFSA (2017) explained that prior to the procedure, the donor and recipient of an organ are thoroughly screened for possible infections that may compromise health and increase risk related to the organ donation. ODFSA (2017) also indicated that psychological support and pre-counselling are provided when the risks and benefits of the organ donation are explained, in order to prepare both the donor and recipient of an organ.

#### 4.4. CONCLUSION

In this Chapter, the study findings were discussed using the themes and sub-themes that the researcher identified and emerged during the exploration and description of the communities' views regarding organ donations. Community members in the Sekhukhune District displayed different views regarding organ donations. The concept was viewed as a complex issue with multiple violations to culture, religion and humanity. Some community members did not agree with the idea of donating organs to improve health because it was viewed to be against God's will. However, there were other members who suggested that education, proper screening, and the involvement of family and community can help in improving organ donation opportunities. There was some positivity and negativity regarding organ donations regardless of the common insight that organ donations aim to save lives. A literature control was done and related to the findings of the study.

#### CHAPTER 5

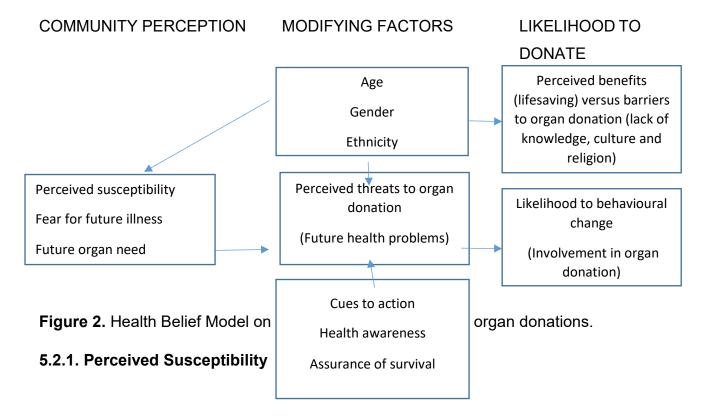
#### INTEGRATION OF THE RESULTS WITH THE THEORETICAL FRAMEWORK

#### 5.1 INTRODUCTION

In the previous Chapter, the study findings were discussed regarding the views of community members regarding organ donations at Sekhukhune District of the Limpopo Province. Literature control was also done to verify, contrast and compare the study findings. This Chapter focuses on the theoretical framework in relation to the study findings.

#### **5.2. THE HEALTH BELIEF MODEL**

The Health Belief Model (HBM) is a psychological model that attempts to explain and predict health behaviours. The focus of this model is on the attitudes and beliefs of individuals that may contribute to a particular behaviour (Baum et al., 1997). The HBM is explanatory and descriptive in nature and explains the likelihood of displaying certain behaviour towards health-related issues as perceived by individuals but does not suggest strategies for changing health related actions (Glanz, Rimer & Viswanath, 2015). The HBM is divided into perceived susceptibility, perceived severity, perceived benefits, perceived barriers, cues to action and self-efficacy (Baum et al., 1997). The above dimensions are discussed in this Chapter, including how they have affected the views of members of the communities surveyed in the Sekhukhune District, regarding organ donations.



Perceived susceptibility is one's opinion of the chances of getting a condition (Baum et al., 1997). Glanz et al. (2015) explained perceived susceptibility as a strong predictor of preventive health behaviour in which an individual feels vulnerable or exposed to a need or illness. Perceived susceptibility is explained as a subjective belief that a person may acquire a disease or may enter into a harmful state of health due to a particular behaviour (Kasmaei, Shokravi, Hidarnia & Montazeri, 2014). Community members felt that receiving a donated organ might exposed them to the illnesses of the donor. In this study, the community members who believed that they might in future be in need of organs displayed positive views towards the idea of organ donations. As outlined by Glanz et al. (2015), the community members showed greater support for the donation of organs to family members and close relatives as this was perceived to reduce the chances of contracting chronic illness from different genetic groups.

#### Concluding remark on perceived susceptibility

Community members who have suffered the pain of watching a relative suffer from organ failure believed that they were also exposed to suffering. Those same community members were positive about organ donations and supported its promotion within the community, as they believed that organ donations save lives. On the other hand, members of the community who believed that their healthy lives would be compromised by organ donations, viewed it as risky and showed an unwillingness to promote it.

#### 5.2.2. Perceived severity

Perceived severity is defined as one's opinion of how serious a condition is and its consequences are (Baum et al., 1997). Perceived severity is the belief in the extend of harm that can be related to a particular behaviour or occur because of that particular behaviour. It is related to the personal feeling one might have of the seriousness of the medical effect that a behaviour may inflict (Kasmaei et al., 2014).

The study findings revealed that participants who perceived organ donations as a dangerous procedure were not willing to donate themselves and displayed negativity towards the idea. Some of the participants indicated that donating an organ might compromise their future state of health. Individuals who believe that the condition will causes a disability or results in death, are likely to avoid the risk of exposure (Glanz et

al., 2015). In the study the community members who believed that organ donations pose a danger to the donor did not shown interest in getting involved in organ donations.

#### Concluding remark on perceived severity

The community members displayed fear regarding the health status of the donor of an organ. They believed that with a missing organ their bodies would not function as normal. They described organ donations as a dangerous act. Some community members expressed fear that should they donate an organ (like a kidney) and that they themselves needed to replace the said organ ( the other kidney) which was not forthcoming, this would be a problem.

#### 5.2.3. Perceived benefits

Perceived benefits are defined as one's belief in the efficacy of the advised action to reduce the risk or seriousness of impact (Baum et al., 1997). Perceived benefits reflect one belief in the positive features or advantages of an advised action to reduce threat. The act is considered beneficial to oneself or to the next person, as it is described as an act of justice (Glanz et al., 2015).

The findings of the study showed that people in the community view organ donations positively when they believed that it will be beneficial to the community and may relieve the health burden. The behaviour and attitude depend on the positive expected outcome of the behaviour (Glanz et al., 2015). There were community members who shared a common view that organ donations are important in saving lives of patients in ESOF and showed interest in participating in organ donations. These community members took the issue of organ donations seriously and understand its impact on health. The positive views of the community regarding organ donations were influenced by the health benefits associated to it.

#### Concluding remarks on perceived benefits

In the shared understanding among community members of the Sekhukhune District that organ donations are aimed at saving lives, organ donations were seen as a good thing to be done and a way to promote health. The community also indicated that organ donations are a way of helping other humans in need, to recover from illness and live a healthy life. The perceived benefit of donating an organ, enabled community

members to have a positive view and attitude towards organ donations and which made them willing to be organ donors, if the need arose.

#### 5.2.4. Perceived barriers

Perceived barriers are related to one's opinion of the tangible and psychological costs of the advised action (Baum et al., 1997). It is a belief concerning the actual and imagined costs of engaging in a suggested behaviour. Perceived barriers are the obstacles to taking or being involved in, an action. They are negative ideas that prevent the desire to participate in a behaviour (Kasmaei et al., 2014).

In the study, the views of the community on organ donations depended on the emotional impact it had in relation to a belief system, and what was perceived as right. The Sekhukhune Community perceived culture and religion as a shared barrier to the idea of organ donations. Some of the community members described organ donation as a violation of African culture. It was considered a stigma to live with other peoples' organs in you for the rest of your life. There was a significant lack of knowledge and understanding of organ donations amongst Sekhukhune community members that also added a barrier to the idea of organ donations. The belief that there is life after physical death contributed to negativity towards organ donations as community members feared that they would not be accepted by ancestors, or they would wake up incomplete during the rapture, should they donate organs. Community members were also afraid of contracting infections through organ donations and wished for the assurance that their lives would be saved and that there would be no harmful effects on the donors. Support, reassurance, and incentives might promote positive attitudes and views related to the matter.

#### Concluding remarks on perceived barriers

Community members expressed that the issue of culture and religion were the reasons for not agreeing with organ donations. The donation of organs is viewed as a Western construct, and contrary to African culture. Misunderstanding and a lack of knowledge or information regarding organ donations also added to the lack of participation in organ donations and added to the negativity around organ donations. Uncertainty regarding the safety of the procedure, added to the perceived barriers regarding organ donations.

#### 5.2.5. Cues to actions

Cues to actions are defined as the internal or external triggers that are necessary for engagement in health promoting behaviour. They are the strategies to activate readiness (Glanz et al., 2015).

The community members had some suggestions on how organ donations can be promoted in the Sekhukhune communities. There was agreement that there is a lack of knowledge about organ donations. The community members suggested that the establishment of workshops and health awareness programmes about organ donations could help in promoting knowledge as well as impact positively on how people view organ donations. Some community members needed assurance that organ donations can save lives without causing harm to either the donor or the recipient of an organ. Screening with proper health checks, social status and lifestyle checks was considered one of the ways that could promote confidence in organ donations and encourage community participation. Scarcity in awareness and sources of information regarding organ donations impacted negatively on how organ donations were viewed by the community.

#### Concluding remarks on cues to actions

In the study, the suggested way to improve the communities' understanding of organ donations is through the use of cues to action. The cues to action are external forces that promote a positive view of organ donations. With improved knowledge through the hosting of workshops and health awareness programmes about organ donations, community members will be able to make informed decision regarding whether to take part or not. The more the community hears about organ donations, and the need for donated organs for the promotion of health the better informed they will be. Transparency regarding the organ donation procedure, including screening and measures to prevent complication, will promote a positive view of organ donations among community members.

#### 5.2.6. Self-efficacy

Self-efficacy is explained as a personal judgement of one's ability to execute courses of actions required to deal with a prospective situation (Maddux & Kleiman, 2016). Maddux and Kleiman (201), further explained that self-efficacy as not just a perceived skill or a belief about one's ability to perform an act but focuses on self-esteem with belief that skill and ability can be coordinated to change a challenging situation. It entails the confidence in one's ability to take action (Baum et al., 1997).

In the study findings, community members indicated that they would only donate when they were sure that the donors are screened before donating. They also felt more able to donate to relatives or close family members than to strangers. Community members also agreed that they would donate organs more readily if there were measures assuring them of their survival after donating organs. Community members also indicated that an improvement in the perception of organ donations would result when information workshops were hosted in communities.

#### Concluding remarks on self-efficacy

The community is likely to engage actively and positively regarding organ donations, if they have the confidence to take part correctly and fairly. Provision of training and guidance in relation to organ donations may promote this positivity.

#### 5.3. CONCLUSION

In this Chapter the researcher has discussed the views of the Sekhukhune community regarding organ donations using the Health Belief Model. The model is divided into six dimensions, which are used to explain the findings of the study. The communities' view on organ donations depends on their perceived susceptibility, perceived severity, and perceived benefit towards the act of organ donations. For example, community members avoided organ donations when they believed it was a way of contracting illnesses and that organ donation could lead to future health problems, such as the failure of a donated organ. The barriers explained included religion, culture and a lack of knowledge about organ donations. The measures which promote the idea of organ donations as suggested by the community was discussed under cues to action.

#### **CHAPTER 6**

#### SUMMARY, RECOMMENDATIONS, LIMITATIONS AND CONCLUSION

#### **6.1. INTRODUCTION**

This Chapter of the research study on views of community members regarding organ donations in the Sekhukhune District, Limpopo Province summarises the research that was done and provides recommendations for the improvement of community members' views regarding organ donations. The limitation of the research study as well as the conclusions that are drawn from the research, are discussed.

#### 6.2. SUMMARY OF THE STUDY

#### 6.2.1. Aim of the study

The main aim of the study was to determine the views of community members of the in Sekhukhune District, Limpopo Province, South Africa regarding organ donations.

This aim was achieved by exploring and describing community members views through intensive face-to-face semi-structured interviews of 15 community members of the Sekhukhune District. Data was analysed in all the stages of data collection to direct the needs of the researcher to ensure that all possible views were able to be harvested.

#### 6.2.2. Objectives of the study

The objectives of the study were to:

- Explore the views of communities regarding organ donation in Sekhukhune District, Limpopo Province, South Africa.
- Describe the views of communities regarding organ donation in the Sekhukhune District, Limpopo Province, South Africa.
- To recommend measures to improve organ donation among Makhuduthamaga community in the Sekhukhune District, South Africa

Insight into the views of community members in the Sekhukhune District relating to organ donations was explored by allowing community members to explain their understanding of organ donations. The community members were encouraged to describe their views, attitudes, beliefs and reactions to the idea of organ donations. The researcher collected data until no new concerns emerges and interpreted data scientifically, giving meaning to the gathered information. The suggestions made by

the community members on how to improve organ donations in Sekhukhune District were used in collaboration to the findings of the study, to develop recommendations to promote the idea of organ donations.

#### 6.2.3. Research question

The research question was "What are the views of communities regarding organ donations in the Sekhukhune District, Limpopo Province, South Africa?"

This research question was answered by describing and analysing the views of the Sekhukhune community as shared by the community members in their own context and according to their level of understanding of the procedure.

#### 6.2.4. Research methodology

The research study originated from the problem of increased death rates of patients suffering from ESOF in critical care units of hospitals in the Limpopo Province. Despite the increase in accidents causing patients to become brain dead, or neurological trauma resulting in brain damage, there were no organs donated to patients in ESOF.

To explore and address the root problem, a qualitative research method was applied using explorative and descriptive designs to answer the research question and achieve the objectives of the study. The researcher selected participants from the Makhuduthamaga communities of the Sekhukhune District using non-probability convenient sampling from different locations. Ethical clearance was granted from Faculty of Health Sciences, and the Turf loop Research Committee, whilst permission to conduct the research was obtained from the Limpopo Department of Health and the royal households of King Madihlaba and Nduna Mabitla in the Makhuduthamaga community. Data was collected from participants using semi-structured face-to-face interviews with the use of an interview guide. Informed consent was obtained before the interview sessions took place, with a full explanation of the research and the assurance of privacy and confidentiality. All interviews were recorded. Data was analysed using Tech's Eight Coding Step Method after data saturation was reached. The number of interviewed participants were fifteen, consisting of six males and nine females.

#### 6.2.5. Findings of the study

During analysis, three themes emerged where participants expressed multifaceted perceptions concerning organ donations, reasons the rejection or acceptance of organ donations and participants' suggestions on how to improve the understanding of organ donation. From each theme, multiple sub-themes also emerged and were explained in detail in Chapter 4.

The community members were given a chance to make suggestions on how to improve views of organ donations. Among the participants, there were those who did not support organ donation, as they believed it to be against religion and African culture. Other community members proposed the implementation of community health education and health awareness programmes about organ donations. In addition, health assessments prior to donations, with the assurance of survival of both the donor and the recipient, as well as an assessment of the social aspects of the donor that might affect the recipient's health were viewed as measures to improve attitudes regarding organ donations. The study findings were compared, contrasted and verified with the literature from both national and international publications.

#### 6.3. RECOMMENDATIONS FROM THE STUDY

- There should be pamphlets and flyers shared in public places such as malls, schools and churches to promote awareness within communities regarding organ donations and those materials need to be translated in the languages used around the area before distribution
- Strengthening of social media and television programmes addressing the issue of organ donations should be used to ensure that knowledge is shared to a broader network of society.
- The Government should actively engage with the ODFSA to promote the idea of organ donations.
- Organ donations should be strengthened in the programme of health sciences studies to ensure that health professionals are fully informed about the practice and can provide education in this regard, to communities.
- The development of organ donation centres in rural areas where community members can access the information and register as donors.

- The ODFSA should liaise with local communities to arrange public workshops and awareness programmes regarding organ donations.
- Additional research in different communities in South Africa would help to identify
  the gaps in knowledge and understanding of organ donations and ways to
  promote it.
- Involve cultural and religious leaders in the implementation of organ donations in the Limpopo Province to encourage members of the community to consider organ donations.

#### 6.4. LIMITATIONS OF THE STUDY

- The study was conducted with community members at Sekhukhune District only, and the reason for this was a lack of funding and a limited study period.
   Therefore, the study findings cannot be generalised to other districts within and outside the Limpopo Province of South African.
- Furthermore, the study used qualitative research approach to determine the views of community members, and as such, the findings cannot be generalised to other studies which used quantitative or mixed method research approach.
- Due to the limited period of study and qualitative nature of the study, pilot study was not done

#### 6.5. CONCLUSION

This Chapter outlined the summary, recommendations, limitations and conclusion of the study. Communities displayed multifaceted views regarding organ donations, and community members generally found it a difficult and unusual thing to think about. Organ donations were found not to be a common topic among rural communities. Some of the community members explained organ donations as a taboo subject as it violates cultural and religious rights. Community members showed preference to donating organs to close family members, rather than to strangers. Even though community members agreed that the aim of organ donations is to save lives, there was a discrepancy regarding knowledge and understanding of organ donations. In all those different views regarding organ donations, some members of community showed an interest in, and willingness to, donate if they were given the opportunity to do so. The major recommendations for the promotion of organ donations was education among community members concerning organ donations.

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| ANNEXURE A: Interview guide |
|-----------------------------|
| Age:                        |
| Sex:                        |
| Ethnicity:                  |
| Religion:                   |
|                             |

Questions

| Question: What do you understand about organ donation?   |  |  |  |  |  |  |  |
|--|--|--|--|--|--|--|--|
| Question: What are your views about organ donation?  |  |  |  |  |  |  |  |
| Question: what can you suggest for community members to understand the concept of organ donation |  |  |  |  |  |  |  |
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| ANNEXURE B: Translated interview guide   |  |  |  |  |  |  |  |
| Mengwaga:  |  |  |  |  |  |  |  |
| Bong:  |  |  |  |  |  |  |  |
| Tumelo:  |  |  |  |  |  |  |  |
| Dipotšišo  |  |  |  |  |  |  |  |

O kwišiša eng ka go fana ga ditho tša mmele?

Ana mmono wa gago ke ofe mabapi le go fan aka ditho tša mmele?

O ka akanya gore go dirweng gore badudi ba motse ba kgone go kwišiša ka ga go fana ga ditho tša mmele ga batho?

#### **ANNEXTURE C**



## University of Limpopo Faculty of Health Sciences

Executive Dean

Private Bag X1106, Sovenga, 0727, South Africa Tel: (015) 268 2149, Fax: (015) 268 2685, Email:kgakgabi.letsoalo@ul.ac.za

DATE: 04 FEBRUARY 2019

NAME OF STUDENT:

STUDENT NUMBER:

MAKOBANE DM 200520344 NURSING

DEPARTMENT: SCHOOL:

HEALTH CARE SCIENCE

QUALIFICATION:

MNURS

Dear Student

#### FACULTY APPROVAL OF PROPOSAL (PROPOSAL NO. FHDC2019/)

I have pleasure in informing you that your MNURS proposal served at the Faculty Higher Degrees Meeting on the 04 February 2019 and your title was approved as follows:

Approved Title: "Views of communities regarding organ donation in Sekhukhune district of Limpopo Province".

#### Note the following:

| Ethical Clearance  |   |  |
|--|---|--|
| Requires no ethical clearance  |   |  |
| Proceed with the study   |   |  |
| Requires ethical clearance (TREC) (apply online)                           |   |  |
| Proceed with the study only after receipt of ethical clearance certificate | √ |  |

ours faithfully

MR K. Letsoalo

Charperson

CC: Supervisor: Mr M.O Mbombi

UNIVERSITY OF LIMPOPO

FACULTY OF
HEALTH SCIENCES

2019 -02- 0 4

PRIVATE BAG X1106
SOVENGA 0727

Finding solutions for Africa

# ANNEXTURE D. CONSENT TO PARTICIPATE IN RESEARCH STUDY

You are herein invited to take part in a research study, on "views of communities regarding organ donation in Sekhukhune District of Limpopo Province, South Africa'

The researcher has discovered that patient die often in intensive care units waiting for organ transplant yet there is shortage of organ as donors are not available. The researcher would like to conduct a study on the above mentioned topic. The study aims to develop strategies to improve organ donation among Makhuduthamaga community at Sekhukhune district, Limpopo province, South Africa. The study might help in reduction of deaths caused by organ failure among South Africans.

There will be no risks and discomfort in sharing the information. The interview session will not take more than 30 minutes of your time. The information obtained will not be provided to any person except the researcher, supervisor and research stakeholders Your name will not appear on the interview records or transcripts and the data collected will not be linked to your name.

Your participation is voluntary, you have the right to withdraw at any time without penalty even if you have given consent. If you have any questions or you need clarity on anything regarding the study, feel free to contact the following researchers.

NAME

CELL NUMBER

MOKABANE DM 0837745336

Marke 15.1119

I hereby agree to participate in the study.

Signature of participant

Date 15-11-2019

Signature of witness

#### ANNEXURE E: Translated consent form

#### Tumelelano ya go tšea karolo nyakišišong

O laletšwa go tšea karolo go nyakišišo ya "ditsela tša go kaonafatša phano ya ditho tša mmele motseng wa Makhuduthamaga, seleteng saSekhukhune, Profenseng ya Limpopo, Afrika Borwa."

#### Statamente sa go tšea karolo nyakišišong

Monyakišiši o lemogile gore go nale balwetši ba bantšhi bao ba hlokofalago maokelong ba emetše go fiwa ditho tša mmele, mme go nale tlhaelelo ya tšona ditho tšeo ka ge go se baneedi. Nyakišo e, e diretšwe go ka tšweletša mekgwa e ka dirišwago go kaonafatša go neelana goba go fana ka ditho tša mmele go badudi ba Makhuduthamaga, seleteng sa Sekhukhune, Limpopo Province, Afrika Borwa. Seo se ka thuša le go fokotša mahu ao a hlolago ke go se šome botse ga ditho tša mmele magareng ga Ma-Afrika borwa.

Go boledišana le rena ga gago, go ka se go bee kotseng goba go go hlolela go se dudišege. Potšišo poledišano y arena, e ka se tšee lebaka la go feta metsotso e 30. Tšeo o di tšweleditšego go monyakišiši, di ka se fiwe motho e mongwe, ga ese bao ba amegago nyakišišong e. leina la gago le ka se tšweletšwe dingwalong ka moka tša go amana le nyakišišo e.

Go boledišana le rena gag ago ga se kgapeletšo. O nale tokelo ya go tlogela poledišano le ge o kabe o dumelelane le monyakišiši gore o tlo tšea karalo. Ge o nale potšišo efe goba efe mabapi le nyakišišo e, o ka e kgokaganya le monyakišiši o lokologile.

| LEINA   | NOMORO YA MOGALA |      |      | TSHAENO      | LET  | TŠATŠIKGWEDI |     |  |  |  |
|---|------------------|------|------|--------------|------|--------------|-----|--|--|--|
| MOKABANE DM                                     | 083774           | 5336 |      |              |      |              | ••• |  |  |  |
| Ke dumelelana le go tšea karolo nyakišišong ye. |                  |      |      |              |      |              |     |  |  |  |
| Tshaeno ya motšea                               | karolo           | Date | Tsha | aeno ya Tlha | itse | Date         |     |  |  |  |
|   |                  |      |      |              |      |              |     |  |  |  |

### **ANNEXURE F: Approval from Turfloop Research Committe**



#### 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

#### ETHICS CLEARANCE CERTIFICATE

MEETING: 14 May 2019

PROJECT NUMBER: TREC/117/2019:PG

PROJECT:

Title: Views of Communities Regarding Organ Donation in Sekhukhune District

of Limpopo Province, South Africa.

**Researcher:** DM Mokabane **Supervisor:** Mr MO Mbombi

Co-Supervisor/s: N/A

School: Health Care Sciences

Degree: Master of Nursing Science

PROF MASOKO

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) This Ethics Clearance Certificate will be valid for one (1) year, as from the abovementioned date. Application for annual renewal (or annual review) need to be received by TREC one month before lapse of this period.
- ii) Should any departure be contemplated from the research procedure as approved, the researcher(s) must re-submit the protocol to the committee, together with the Application for Amendment form.
- iii) PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES.

# **ANNEXURE G: Approval from department of health**



# DEPARTMENT OF HEALTH

Ref .

LP\_201907\_013 Letseparela K

Enquires Tel

015-293 6028

Email

Kurhula.Hlomane@dhsd.limpopo.gov.za

#### Dikeledi Mokabane

# PERMISSION TO CONDUCT RESEARCH IN DEPARTMENTAL FACILITIES

Your Study Topic as indicated below;

Views of Communities Regarding Organ Donation in Sekhukhune District of Limpopo Province, South Africa

- 1. Permission to conduct research study as per your research proposal is hereby Granted.
- Kindly note the following:
  - a. Present this letter of permission to the institution supervisor/s a week before the study is conducted.
  - b. In the course of your study, there should be no action that disrupts the routine services, or incur any cost on the Department.
  - c. After completion of study, it is mandatory that the findings should be submitted to the Department to serve as a resource.
  - d. The researcher should be prepared to assist in the interpretation and implementation of the study recommendation where possible.
  - e. The approval is only valid for a 1-year period.
  - f. If the proposal has been amended, a new approval should be sought from the Department of Health
  - g. Kindly note that, the Department can withdraw the approval at any time.

Your cooperation will be highly appreciated

Mead of Department

Daté



# Kwena - Madihlaba Traditional Authority

P O BOX 28, GLEN-COWIE, 1061

Enq: Madihlaba R.C Cell: 083 3310 802

TO WHOM IT MAY CONCERN

SIR/MADAM

TO BOX 28 GLENCOVIE

AO BOX 28 GLENCOVIE

1061

EXHINHUNE DISTRICT SUSPORT CENTRE

# RE: APPROVAL OF RESEARCH PROJECT FOR MOKABANE DIKELEDI MASHEGO

- 1. THE ABOVE MATTER BEAR REFERENCES
- 2. THE UNDERSIGNED CONFIRMS THAT MISS MOKABANE DIKELEDI MASHEGO ,ID NO 850813091186 FROM THE DEPARTMENT OF HEALTH [ST.RITAS HOSPITAL],HAS BEEN APPROVED TO DO RESEARCH AROUND GA- MADIHLABA VILLAGE, FOR COMMUNITY VIEWS REGARDING ORGAN DONATION ,WHICH IS UNDER THE JURISDICTION OF KGOSHI MADIHLABA.
- 3. THE COUNCIL HAS NO OBJECTION WITH THAT APPROVAL

YOU ARE REQUESTED TO ASSIST THE BEARER IN THE SERVICES SHE MIGHT NEED.

THANK YOU!

ADMIN OFFICER

KIND REGARDS

**ANNEXURE I: Permission letter to Royal offices** 

PO BOX 4154

**GROBLERSDAL** 

0470

22 January 2018

MAKHUDUTHAMAGA ROYAL OFFICES

NDUNA MABITLA L.R.

**PO BOX 185** 

**NFBO** 

1059

RE:\_Request to conduct a research study for masters in nursing science degree at Glen Cowie Gate way clinic and Phaahla clinic of Makhuduthamaga Municipality community, Sekhukhune District Limpopo Province, South Africa

The researcher is Postgraduate Student of Masters in Nursing Science, at University of Limpopo (Turf loop Campus).

As a requirement for Master's degree in Nursing Science to complete the research study, the researcher has identified a gap during provision of health care at Sekhukhune District, Makhuduthamaga municipality. Request is hereby made to conduct a study in the mentioned area.

The research topic: "Strategies to improve organ donation at Makhuduthamaga community, Sekhukhune district, Limpopo province South Africa.

The study will contribute to the community by encouraging provision of knowledge to its members regarding organ donation. This may also help in promoting active participation of the matter of organ donation and saving lives of fellow South Africans where necessary.

The researcher undertake to observe ail ethical principles which include confidentiality anonymity and privacy.

Hoping that this application will be considered

Yours faithfully

NAME OF RESEARCHER

MOKABANE D.M.

DATE 12/06/2019

SIGNATURES

This retter was received by Habraha and approved that Motasque D. or can do the mentioned fescare

Date 13/06/2019.

NOUNA · MABITLAL POUR VIERFONTEIN

1 - 00 - 2019

VILLAGE NEBO 1058

ABITLAL POUR SON 185 NEBO 1058

ANNEXURE J: EXAMPLE OF INTERVIEW TRANSCRIPT

Participant no 2

Researcher: how are you mr

Participant: Ahh, i am ok, am fine

Researcher: How do you view organ donation?

Participant: Yes?

Researcher: I am saying, what is your view concerning organ donation

Participant: No,no,no eish

Researcher: Ao, then you just say ao eish.... what is it? Talk to me

Participant: Ayi, organ donation is ok but sometimes it is not okay, because as for us sometimes ... we are African you know. We don't believe in such things. We believe that when a person dies must die with all his or her organs being complete. There is no such thing as giving someone another person's kidney, no no. For instance, let me give an example with amputation. Most of Africans don't believe in cutting of parts, they believe that when a person dies must die with all his organs

Researcher: Yes...

Participant: Yes.

Researcher: Then what is okay with it because you said it is either okay or not okay?

Participant: No what am telling you is that, i mean it is okay when it favours you as you are the one in need. Because mostly when a person is in need of organs, even when he knows that such a thing is not allowed because finding an organ from another person will make him survive, he will agree with that. But for him to give to another person (shook head)

Researcher: You said even thou he knows that such is not allowed, do you believe is

not allowed

Participant: Yes, it is not allowed

Researcher: Why are you saying it is not allowed?

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Participant: Me, according to myself am saying; as an African man I believe that when each an every person leaves this earth must leave with all his organs. You see

Researcher: Okay

Participant: Yes, you see. Then at the other side when i need an organ let me say a

kidney; being told that to survive I must have it then yes.

Researcher: Meaning you can receive that kidney, when you are the one in need

Participant: Yes, but if someone close to me need it. Yes i can donate

Researcher: Close to you as in like a relative?

Participant: No, not the relative per say, a wife, my children and siblings

Researcher: Owo, close not the extended family or friend

Participant: No, not extended

Researcher: (Laughs), then what about the person you do not know

Participant: Ayi (shaking head)

Researcher: But then can you receive an organ from a stranger?

Participant: It is that greediness when you need help. Sometimes you check, you can become greedy like becoming really greedy but when you are the one in trouble you can accept anything that can help you survive

Researcher: Neh...

Participant: Yes. Even a thief when you have pointed it with a gun, it will beg you to leave him so that he can leave

Researcher: Yah?

Participant: (continuing) But when he is the one pointing you with a gun he can injure you anyhow and do anything until he gets what he wants. So, the issue of organs is a stigma even in the community. Just image the talk being that I am alive because my sister gave me a kidney such things. Like when i go up and down it will be said that if it wasn't because of her i wouldn't be like this

Researcher: Then my person, lets say is wife and has registered as an organ donor then is a critical situation where the doctors are saying there is nothing left of her, she cannot be helped. Can you give a concern for donation of her organs?

Participant: No ways

Researcher: So you just violate her desire

Participant: I will violate it life, in my believe my wife can wake up

Researcher: So you can't give away her organs even....

Participant: No, i won't. What if I say take one kidney then the person recovers, then

the kidney that i took becomes a problem

Researcher: Do you believe in miracles?

Participant: No, that is not a miracle is nature?

Researcher: Is nature that any person can recover regardless of medical findings?

Participant: Yes, is nature. It is the way. In life we go through a lot of things you understand. What if that is just a temporary thing that one must go through it, the tunnel for that short period of time

Researcher: Even when it has being explained to you that the person is brain dead there is absolutely nothing that we can help her with, but the organs are fine

Participant: I don't believe in that, see, just understand this i know that nature works in this way that's the way nature is. There are a lot of people who has been in coma and has been written off. Even my sister was once being said to be paraplegic, it was confirmed that she will never walk. She was in coma hearing them... listening. They even showed us the x rays

Researcher: So you are saying mistakes can happen

Participant: Yes, nature can work at its own way

Researcher: But as for how can organ donation be improved among us blacks, so that we can also donate

Participant: For them to donate, eish. It is very difficult because you cannot change

other people's culture, norms, and customs or believes. You can't just change them

over night

Researcher: But then what can be tried?

Participant: Eish, this thing. If you are trying to educate me about it, i can even tell you

that you are violating my traditional rights because you will be trying to change what i

believe in so that i can believe in your western way, no no

Researcher: Ao, now is western for the whites?

Participant: Yes, let me tell you something even if you can find an old woman she will

tell you. I can find an old woman will tell you that in our culture there is nothing such

as a woman and a man can't make a baby, she will not agree in your western ways

there is always an African way of dealing with things

Researcher: So what are we saying, we just do not have to donate

Participant: As for me, according to the African way and the situations i have heard of.

African's parts belong to them

Researcher: So we don't have to address it in our communities

Participant: No, you can address it. There are people who have been programmed in

a western way, understand. But some are truly African like me you can't change them.

We can't be buried from this earth without some of our organs. You can try to get their

perspectives and provide education based on their ideas. An African can even refuse

to be amputated regardless of the fact that he has severe pain on a leg or a limb and

say i cant be buried without my leg.

Researcher: so you are saying on improvements plants regarding organ donation you

have nothing.

Participant: It being part of learning?

Researcher: no, being something to be implemented in the community

Participant: You can try to convince people

Researcher: how?

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Participant: you can have a panel... not necessarily to go house to house. You can even gather people even when they have visited hospitals and get their own perspective evaluating on how they stand on that issue. You can't just say you teach people not knowing how they understand i... this is a very difficult thing, especially to us blacks.

Researcher: Okay, thank you for your time

Participant: Sure



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Date: 17 June 2020

#### To Whom it May Concern

I hereby confirm that I have proof-read the document entitled: "Views of Communities Regarding Organ Donation in the Sekhukhune District of the Limpopo Province, South Africa" authored by Dikeledi Mashego Mokabane and have suggested a number of changes which the author may or may not accept, at her discretion.

Each of us has our own unique voice as far as both spoken and written language is concerned. In my role as proof-reader I try not to let my own "written voice" overshadow the voice of the author, while at the same time attempting to ensure a readable document.

Please refer any queries to me.

Andrew Scholtz