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A programme for promoting the uptake of organ donation among Xhosa Community in the Eastern Cape Province

BY

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DECLARATION

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"I **TOBEKA MTISE**, student number 200025376 hereby declare that I am fully aware of the University of Fort Hare's policy on plagiarism, and I have taken every precaution to comply with the regulations.

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DEDICATION

To my late parents Mr N.J and Mrs G. N. Dondashe-Peter, I shall always be remarkably thankful to them for encouraging me to be a nurse who laid a foundation for my career pathing. Their unconditional love and encouragement have moulded me to become who I am today. With wisdom and patience for the present.

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CERTIFICATION

This thesis entitled **"A programme for promoting the uptake of organ donation among Xhosa Community in the Eastern Cape Province"** meet up the regulations leading to the award of the degree of Doctor Philosophy of the University of Fort Hare and is accepted for its contribution to scientific knowledge.

Signature of the Supervisor:_____ Date: 24 November 2024.

Signature of the Co-Supervisor:…… ___Date 24 November 2024.

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ABSTRACT

Currently, there exists a global shortage of viable organs that meet the high transplantation demands as treatment options. While there is an increasing need for organ transplantation, people are dying on a daily basis because they are not receiving the life-saving organs they require. Furthermore, while many South Africans rely on life-saving organ transplants, convincing rural black communities to donate organs is an arduous task because of their prevailing cultural beliefs.

Considering the above, the overall aim of this study was to develop a programme promoting the uptake of organ donation among the Xhosa community in the Eastern Cape Province by empowering them with the necessary knowledge and understanding of organ donation. Moreover, it sought to promote community discussion of and participation in organ donation. The researcher anticipated that by equipping communities and individuals with truth-based facts, more people would be willing to become organ donors, thereby addressing the severe shortage thereof.

The intervention mapping framework (IMF) was utilised to provide a coordinated process for the development of an evidence-based programme. The study was conducted in three phases, as follows:

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Phase 1 – Step1 (**Situational analysis)**

Research Methodology

Employed a qualitative approach and followed an ethno-nursing design.

The target population were four sub-groups of the Xhosa community, which included traditional leaders, traditional healers, ministers of religion, and general community members. To gain entry to the community, municipal and district leaders granted the researcher permission to conduct this study. At the same time, the coordinator of traditional health practitioners in the province facilitated access to conventional healers. Furthermore, the chairperson of the District Council of Churches (DCC) assisted the researcher in contacting religious ministers.

Purposive sampling was used to select traditional leaders, traditional healers and ministers of faith, and general community members who were willing to participate in the study. These individuals were based specifically in the rural districts of Oliver Reginald Tambo (ORTDM) and Chris Hani municipalities (CHDM) within the Eastern Cape Province of South Africa.

The method of data collection consisted of eight semi-structured individual interviews and ten focus group discussions.

Data was analysed utilising a four-phased ethno-nursing data analysis technique. The following themes emerged from the data analysis: lack of knowledge, information, and understanding of organ donation; secondly, the analysis established that the groups had both negative and positive views of organ donation; thirdly, all groups mentioned various relevant organ donation barriers. Lastly, participants suggested possible strategies to promote organ donation in their community. Phase 1 led to the development of the matrices in Phase 2.

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Phase 2 – Steps 2 & 3 **Development of Matrices and Theory Based Intervention**

This phase of the study collaborated with the stakeholders (Xhosa community and the planning group), using the findings from Phase 1 in developing an organ donation programme.

Step 2: Furthermore, it developed matrices of change objectives. Each matrix of change was linked with the behavioural determinants, the performance objectives, the change objectives, and the selected theories.

Step 3: In addition, Step 3 of this phase generated programme ideas with the planning group, theory-based intervention methods and practical applications that address change objectives were selected to complete the preliminary programme development.

Phase 3 – The Scope of the Programme

Step 4: The scope of the programme was described in Phase 3, Step 4, and the sequence is explained. Programme teaching and learning materials were selected and described. An expert panel was reviewed the programme. The results of the review prove that the programme is

meeting its objectives and could be implemented. Phase 4 is the implementation of the programme, and Phase 5 is the programme evaluation. However, this study ended in Phase 3.

Keywords: Uptake, Organ Donation, Programme Development, Xhosa Community

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ABBREVIATIONS

SA	South Africa
EC	Eastern Cape
ECP	Eastern Cape Province
DOH	Department of Health
WHOGP	World Health Organisation Guiding Principles
UK	United Kingdom
USA	United States of America
HIV	Human Immune Virus
ODF	Organ Donation Foundation
ODR	Organ Donation Register
ORTDM	Oliver Reginald Tambo District Municipality
CHDM	Chris Hani District Municipality
HWSETA	Health and Welfare Education Training Authority
NRF-I-A	National Research Foundation-Irish-Aid
UFH	University of Fort Hare
IMF	Intervention Mapping Framework
BIO	Biotechnology Innovation Organisation
PHC	Primary Health Care
MI	Motivational Interviewing
IMBSM	Information Motivation Behavioural Skills Model
SCogT	Social Cognitive Theory
HPT	Health Promotion Theory
SDT	Social Determination Theory

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CHAPTER 1: INTRODUCTION

1.1. INTRODUCTION AND BACKGROUND OF THE STUDY

Organ donation and transplantation are treatment options that can give many people a second chance at life. Organ donation is the removal of an organ, such as a heart, lung, or kidney. In contrast, tissue donation occurs when tissues in the body, such as skin, corneas, and bone, are removed from one person and transplanted into another person (Muco et al., 2021). While most donations occur after the donor has died, some donations are made by living donors. To promote the right to life in South Africa, according to its legislation, a close family member, such as a spouse, partner, biological child, parent, guardian, biological brother, or biological sister of the person in need of an organ, agrees to donate their organs in the case of brain-stem death (McQuoid-Mason, 2012:734). Currently, any organ or tissue donation in the country, whether from a living or a dead donor, is altruistic, meaning that it is the "free choice of the donor or the family of the deceased to donate organs" (Slabbert et al., 2011:261). Live donation takes place when a living person donates an organ, or a part of an organ, for transplantation to another person. Deceased donation is giving an organ, or a portion of an organ, at the time of the donor's death for transplantation to another person (Slabbert et al., 2011:261).

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According to research by Muller (2013), the practice of donating deceased individuals' organs is well-established in South Africa, being underpinned by adequate legislation and supported by well-founded transplant units. However, donor numbers are decreasing and living donations outnumber deceased donations in some areas of the country. Muller (2013) further notes the declining deceased donations because of more aggressive treatment of head injuries and other neurosurgical patients with a good prognosis. Additionally, donor referral patterns have changed over time, with a notable increase in medical and extended criteria. Despite the increase in possible and eligible donors, the consent rate has declined (du Toit, Manning, Thomson, McCurdie & Muller, 2020). This fact emphasises the urgent need for more programmes in South Africa that promote the uptake and increase of organ donation.

Section 2 of the Human Tissue Act No 65 of 1983 (SA, 1983) stipulates that "anyone competent to make a will (16 years of age, or older) may donate an organ by signing a document attested to by two competent witnesses (aged 14, or older), or by indicating the wish through a clause in a will, or orally before two competent witnesses". In other words, an individual must decide

to become a donor while still alive and having full control of the mind, with the actual donation only taking place after their death. South Africa currently only recognises living organ donations if donors are related to or are the spouses of the patients. Consequently, a friend or an altruistic donor (living donation to a stranger) who chooses to donate an organ must apply to the Department of Health (DoH) which will then examine the request thoroughly to determine whether it is a non-financial gain since section 60 of the National Health Act No. 61 of 2003 specifically prohibits any payment for donated human organs. More recently, sections 61 and 62 of the National Health Act 2003 (SA, 2003) encompass the same obligation for an organ donation in the case of a deceased donor as the Human Tissue Act, 65 of 1983. Notably, the only difference is that section 1 of the new Act acknowledges 'brain-death' as death. People of all ages can become organ donors in South Africa, although their age determines the process. If they are under the age of 18 (a minor), a parent or a guardian must consent to their decision to donate. However, someone is over the age of 18 is seen as an adult, meaning they can register themselves as a donor and must simply sign a donor card (Department of Health, 2015:8-9).

Brain death is the complete stopping of all brain function and cannot be reversed (National Kidney Foundation, 2024). Brainstem death is characterised by the cessation of all functions of the brainstem – midbrain, pons and medulla (Cowan & Miles, 2024:382). However, according to Spears et al. (2023:651), in their study of eight protocols, two (25%) required assessment for loss of function of the whole brain, three (37,5%) only required assessment for loss of function of the brainstem and three (37,5%) were ambiguous about whether loss of function of the higher brain was required to declare death. The overall agreement between raters was 94%. During assessment of brain death, an individual is ventilatory supported as the brain can no longer send signals telling the body to breathe. Once the diagnosis of brain death is made, an individual is pronounced legally dead, and a healthcare professional converse with the family about certain decisions to be made, which include the possibility of organ and/or tissue donation (National Kidney Foundation, 2024).

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According to Rudgel, Matesanz, Delmonico and Chapman (2012:2) regarding international organ donation practices, "the pressure to increase the number of organs is felt worldwide, while many countries have introduced systematic programmes to increase donation". Conversely, settings in various countries have developed unethical, illegal, and unacceptable practices, resulting in intense activity driven by political and professional organisations (Rudgel et al., 2012:8).

The best matches for Black people require the same tissue typing and blood group concerning organ donation and transplantation (About Donation, 2020). Western Cape Government, SA (2019) emphasise that family members can be potential organ donors as every person inherits the genotype from their parents. Ethnicity does contribute towards organ donation. According to Sharif (2013:347), ethnic minorities make up 10.8% of the UK population but are more on organ waiting lists (24%) than on the country's Organ Donation Register (ODR). Relatives of other race groups are also less likely than Whites to consent to organ donation of loved ones who have died in appropriate circumstances for organ donation (30.3% v 68.5%) for organ donation after brain death (Sharif, 2013:347). For these reasons, *ethnic* minority people have longer average waiting times for organs because of biological differences between ethnic groups and of dissimilar frequencies of different blood groups and particular combinations of alleles for human leucocyte antigen (HLA) found in members of other ethnic communities (Sharif 2013:347). "In the context of transplantation, HLA molecules are polymorphic antigens that comprise an immunodominant alloreactive trigger for the immune response, resulting in rejection of the transplantable organ" (Montgomery, Tatapudi, Leffel & Zachary, 2018:558). However, noteworthy advances in knowledge and technology in the field of immunogenetics have significantly enhanced the safety of transplantation. Live donations, such as kidney transplants, are often performed among family members. The blood groups and tissue types are more compatible, ensuring a high success rate (Organ Donation in South Africa, Western Cape Government, 2019).

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In South Africa, the Xhosa population from the same ethnic group are more likely to be a close match to each other (Yang, Abrams, Smolinski and Nathan, 1993:2487). Additionally, in USA, an increased representation of ethnic groups within existing unrelated donor registries will increase the likelihood of finding a suitable donor. This is particularly important, as the greatest contribution comes from donors within shared ethnic groups (Pidala et al., 2013). People with rare tissue types may only get an organ from someone of the same ethnic group, as stated in Sharif (2013:347). Therefore, it is essential that people from all ethnic backgrounds donate organs. Organ transplantation was once considered an experimental procedure with a low survival rate, but now is a routine (Tinley, 2003). The medical team transformed transplant surgery from risky to routine; hence, now it is the treatment of choice for patients with end-stage organ disease (Tinley, 2003).

Research by Morgan, Hooper, Mayblin and Jones (2006:229) in the United Kingdom (UK) has indicated that many respondents were aware of the possibility of living kidney donation. Ethnic minorities were more aware of the urgent need but did not wish to become donors. These minorities believed that their organs would be used for medical research; they tended to distrust medical teams to save them as donors on retrieval of an organ and did not want to wear a donor bracelet, regarding organ donation as against their religious beliefs and wish to have an intact body when they are buried.

This supports the research among African Americans that identified various barriers to organ donation, including a lack of awareness, distrust of the medical fraternity, and even racially based reasons for not wanting to participate in organ donation, whether as recipients of or donors to other ethnic groups (Shilling, Norman, Chavin, Hildebrand, Lunsford, Martin, Milton, Smalls & Baliga, 2006:834). Similarly, a study by Morgan et al. (2006:226) found that the number of organ donations among Black Africans and ethnic minorities is much lower than that of White populations. While ethnic minorities account for 8% of the UK population, only 2% are organ donors. Additionally, Siminoff, Lawrence and Arnold (2003:146) in Pennsylvania and North Ohio revealed that the number of Black families involved in organ donation is considerably lower than that of White families. Soylar and Kadioğlu (2018) assert that many factors, such as age, gender, educational level and religion, influence public perception of organ donation. Misconceptions and a lack of knowledge regarding brain death, as well as religious and legal aspects of organ donation, are among the most significant factors for Turkey's low deceased donation rate (Soylar & Kadioğlu, 2018).

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The lack of available donors presents a significant obstacle to organ transplantation in Nigeria, as do cultural and religious considerations, inadequate infrastructure, a lack of staff and the high cost of care leading to patients travelling to Malaysia and India for treatment (Abdullahi, Garba & Abubakar, 2018).

In South Africa, "Xhosa groups in both the urban and the rural surveys were to some extent more willing to donate organs than Blacks in any other groups, while the Sotho group were willing to donate their organs, but to donate those of a close relative" (Pike, Odell & Kahn, 1993:94). One significant factor linked to this reluctance among African population groups appears to be a lack of knowledge concerning brain-death, the organ donation process and transplantation, while their unwillingness to donate organs of a close relative reflects a lack of

communication within the familial sphere (Pike, Odell & Kahn, 1993:94). Naude, Nel and Uys (2012), in their study on attitude and knowledge of nurses in South Africa regarding organ donation, indicated a detrimental problem that exist between the role players in the organ transplant process which led to non-referral of potential organ donors. Many Black families do not know the wishes of the deceased relative and hence refuse to give consent to donate their deceased's organs (Pike et al., 1993:91; Dimo, 2018:71). As a result, South Africa has about 15 000 people whose kidney problems cannot be treated due to a lack of organ donations, insufficient dialysis machines, and exclusion from other diseases (Health System Trust, 2015). Muller (2013) has estimated that there are more than 5000 patients with end-stage renal failure, with over 2500 individuals waiting for available and matching donor organs. The researcher further asserts that transplantation outcomes are associated with fewer costs and a better quality of life for recipients than those of haemodialysis.

In an endeavour to address the shortage, various countries, including Spain, Croatia, and Portugal, have embraced international approaches or models to improve organ donation according to different time frames. Comparisons across countries in implementing the guidelines regarding the progress made in improving the uptake of organ donation are difficult due to differences in healthcare systems, population size, community attitudes, and their relative starting points (Organ and Tissue Authority, 2013). The sustainability of each approach requires critical people who share a similar vision, as exemplified by the above-mentioned three countries. This was achieved by forming a sustained network of donation specialists before a concerted effort was made to change clinical practice (Organ and Tissue Authority, 2013).

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Furthermore, staff members who were knowledgeable about organ donation were assigned to individual hospitals. As a result, Spain, Croatia, and Portugal have managed to systematically change their clinical practices across their relevant intensive care units, critical care, and hospital governance to successfully increase their national organ donation outcomes (Organ and Tissue Authority, 2013). Australia also adopted an international approach to organ donation reform, which has shown promising growth in donation and transplantation outcomes; public education and awareness of the importance of family discussions added to the Australian organ donation growth (Australia, 2021). The Australian Government is implementing a nationally coordinated, culturally, and linguistically diverse audience communication and engagement plan. Saudi Arabia has a well-established deceased donation programme to

increase donor numbers yearly, several studies indicated that previous knowledge and awareness of the different aspects of organ donation are all important factors that influence people's willingness to consent to organ donation (Shaheen & Souqiyyeh et al., 2009).

While the issue of organ donation is widely known, there are very few programmes that promote the uptake of organ donation other than international approaches to organ donation reform (Organ and Tissue Authority, 2013). Several countries have responded to the global organ shortage by adopting approaches aimed at increasing organ and tissue donation and this has led to them having well-recognised reform models (Rudgel et al., 2012:4). Similarly, many governments and professional bodies have formulated the structure for ethical and clinical reform models for fairness, value, and safety of organ and tissue donation for transplantation, which has resulted in the development of the World Health Organization Guiding Principles (WHOGP) on human cell, tissue, and organ transplantation (Organ and Tissue Authority, 2013).

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Improving organ donor numbers has been identified and explored worldwide, including in South Africa, using marginal donors, meaning patients with pre-existing medical conditions are used as donors (Muller, 2013:220). As a country, South Africa has a large HIV-positive population, and it was for this reason that an HIV-positive-to-positive transplant was considered and successfully completed in 2008 (Muller, 2013:221). Donation after cardiac arrest has been explored as a way forward for South Africa as it is already practiced in European and North American countries. This initiative was implemented after the families agreed to donate organs (Muller, 2013) in SA. Although Xhosa people are widely spread throughout the country and are exposed to organ donation in major urban cities, the majority, residing in the Eastern Cape, do not have the same exposure to such discourses; therefore, an organ donation programme might facilitate learning and understanding of organ donation and improve uptake of organ donation. There are no programmes in the Eastern Cape Province that promote the uptake of organ donation except the placement of organ donor transplant coordinators who identify potential organ donors and refer them to tertiary hospitals in other provinces (larger urban cities) in South Africa. South Africa does not have an accredited national training programme for transplant coordinators (Organ and Tissue Donation, A National Strategy Roadmap, 2019). Transplantation rates are low in the private and public sectors and lowest in Mthatha. A large public sector Kidney Replacement Therapy provision gap exists in the Eastern Cape and needs to be addressed urgently (Mtingi-Nkonzombi et al., 2023). This is an

indication of low organ donation in the province.

The Sunrise Model resembles a rising sun where each ray signifies a different aspect of culture affecting healthcare, such as cultural values, religious beliefs and practices, economic factors, political history and social structure (George, 2002:491). **Religion** is a cultural universal, but its substance may differ across cultures; it forms the basis of some people's lives, thus becoming a way of life (Leininger, 1991). This model is a comprehensive visual tool that allows to envision how culture and religion impact health care. **Culture** refers to "learned, shared, and transmitted values, beliefs, norms, and lifeways to a specific individual or group that guide their thinking, decisions, actions, and patterned ways of living" (George, 2002). The model assists in the assessment and the study of cultural data for nursing diagnosis, planning and delivery of cultural care. Level two, after worldview (level 1), represents a multi-faceted person affected by different factors, which include technological, religious, economic and educational factors. The Sunrise Model shows that a person is a product of a complex environment, which in turn forms a person's culture and influences the person's way of thinking. In the context of organ donation and transplantation, given that campaigns are still ongoing, Cheung and Wolbring, (2015:74) suggest that the campaigns themselves must reflect changes that would include education on scientific and technological developments by writing foresight bulletins to alert people and get people involved in the governance of emerging scientific and technological developments towards organ donation. Currently, newspaper coverage is not linking scientific and technological developments to organ donation and transplantation (Cheung & Wolbring, 2015:74). Therefore, campaigns could include social media sites where technological development updates are posted.

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1.2. PROBLEM STATEMENT

Literature shows both cultural, religious, and other several factors contribute towards the low and decreasing numbers of organ donation on international, national, and local levels (Irving et al., 2012:2526; Cantarovich, 2005:22). Several factors accounted for the decision to be an organ donor. An earlier systematic review study demonstrates that relational ties, religious beliefs, culture, mistrust of the medical sector in terms of the validity of brain death and fear of early organ retrieval all influence an individual's decision to donate. The study further highlights personal knowledge of the donation process and the associated significant reservations about it, even in those who support organ donation as influencers of organ

donation (Irving et al. 2011:1). There are several reasons for this resistance to donating cadaver organs which include a lack of awareness, religious uncertainties, distrust of medicine, hostility to new ideas, and misinformation (Cantarovich, 2005). Irving et al. (2012:2526) further recommended culturally appropriate strategies to engage minority groups, primarily religious or cultural leaders, and more comprehensive information about the donation process and its positive outcomes. Xhosa people are a minority cultural and ethnic group affected by the abovementioned factors. The fact that there is no programme in South Africa relevant to this community means that they experience certain previously mentioned problems, which are associated with various factors.

1.2.1. The Decline in Organ Transplants Among the Xhosa Community

Organ donation rates in South Africa are among the worst globally, despite the country's constitution that outlines brain death and inventive heart transplant history. According to Organ and Tissue Donation, A National Strategy Roadmap (2019), National deceased donation statistics (2018), out of 59 622 350 population, donors per million population (pmp) 1.62 with annual deaths of 446 544. Eastern Cape deceased donation statistics (2018), out of 6 734 001population, donors 0.61 pmp with annual deaths of 65 162. National deceased donation statistics (2017), out of 59 622 350 population, donors pmp 1.62 with annual deaths of 446 544. Eastern Cape deceased donation statistics (2017), out of 6 734 001population, donors 0.76 pmp with annual deaths of 65 162. According to Du Toit et al. (2020:132) in a study conducted over a 10-year period, 861 possible organ donors were referred, with a steady increase in the number of referrals over time. Five hundred and fourteen [514] (59.7%) were eligible for a donation of at least one solid organ. Of the 508 families that were approached for consent to donation, 342 declined to consent for a variety of reasons, resulting in a consent rate of 32.7%. Ultimately, at least one solid organ was obtained from 159 of the 166 consented donors. Despite the increasing number of possible and eligible donors, a statistically significant decline in consent rate was observed over time (p trend=0.023) (Du Toit et al., 2020:132). The average citizen has little understanding of patients' dilemmas with end-stage organ failure. Accordingly, there is a knowledge deficit about organ donation (Etheredge et al., 2013; Bengu & Uys, 2004; Ndlovu, Kobryn & Modiba, 1998). While published literature suggests that attitudes towards organ donation in South Africa are positive, there has been a decline in the actual number of transplants taking place annually, which contradicts this finding. Etheredge et al. (2013) and Ndlovu et al. (1998:241) highlight that among Black African populations, altruistic motivations

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significantly contribute to the likelihood of securing consent for organ donation. Etheredge et al. (2013 noted that both IsiZulu and IsiXhosa-speaking populations were less likely to have heard of organ donation than their English, Afrikaans, or Setswana counterparts. These researchers also indicated that the former two groups, namely Xhosas and Zulus, are not adequately targeted by advertising.

1.2.2. Cultural Beliefs That Discourage Xhosa People from Donating

Black African culture is known to influence decision-making regarding consenting to organ donation (Bengu & Uys, 2004; Etheredge et al., 2013; Ndlovu, 1998). Traditional community members and healers living in the South African province of the Eastern Cape have mentioned that removing the organs of a deceased person is a cultural taboo since it is believed that their spirits will not be accepted by their ancestors and will be doomed to roam the earth; this means that the bodies of the deceased must be treated with respect. Consequently, donating their bodies for studies or to recipients contradicts and undermines these cultural beliefs (Zikali, 2018).

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1.2.3. Religious Beliefs Regarding Organ Donation

De Gamal, Bhengu and Satyapal (2018) conducted a study that revealed a notably low proportion of Black African undergraduate students (14.7%) are willing to self-donate, primarily due to the perceived necessity of such donations for anatomical education. Religious beliefs were the main reason for this unwillingness. In addition, a low percentage of these students reflected that their religious (8.7 %) and cultural (4.1 %) beliefs permitted whole-body donation. Lastly, research by Dimo (2019) established that most South African Blacks are not registered organ donors due to a lack of awareness or education, religious and cultural backgrounds, and myths regarding organ donation prevent Black South Africans from registering and donating their organs.

1.2.4. Lack of Education Regarding Organ Donation

Numerous strategies, such as promotion, advertising in the lay media, and education programmes, have been implemented to overcome the barriers to organ donation but have only shown slight improvement, and participants gained some knowledge after reading the educational packages (Buthelezi & Ross, 2011:752). This is despite the fewer number of studies that are available among ethnic groups of Black South Africans. In a study conducted

among the Zulu culture, Bhengu and Uys (2004:31) reported a knowledge deficit due to numerous factors, resulting in a minor uptake of organ donation among this demographic. Consequently, it is crucial to understand the underlying reasons for any ethnic group's refusal to consider organ donation as a treatment option. Therefore, the fears expressed by the Xhosa people and their level of knowledge on the benefits of organ donation are crucial in informing clinical health decisions.

1.2.5. Attitude and Knowledge of Nurses Regarding Organ Donation in South Africa

Lomero et al. (2017) agree with Crymble et al. (2017) about the attitude and knowledge of nurses in South Africa regarding organ donation. These authors indicated an urgent need to clarify nurses' roles in the process of organ donor referral. Although nurses display a positive attitude towards organ donation, nurses expressed uncertainties about referring potential donors, and the non-referral of potential donors creates a detrimental problem which leads to low uptake of organ donation (Crymble et al., 2017; Lomero et al., 2012).

1.3. AIM OF THE STUDY

Against the backdrop of the above, the overall aim of the study was to investigate, analyse and develop a programme to promote the uptake of organ donation among the Xhosa community in the Eastern Cape to improve their comprehension of and commitment to organ donation. As a result, the following objectives were formulated:

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1.4. RESEARCH OBJECTIVES

Three main objectives are identified and set out below, namely:

- To explore and describe the barriers contributing to the low uptake of organ donation among the Xhosa community.
- To develop matrices of change objectives and theory-based interventions to inform the programme development for organ donation among the Xhosa community.
- Lastly, to develop a programme that will promote uptake of organ donation among the Xhosa community.

1.5. RESEARCH QUESTIONS

To achieve the above objectives, the researcher formulated three main research questions, namely:

- What barriers contribute to the low uptake of organ donation among the Xhosa community?
- What matrices of change objectives and theoretical-based interventions would be suitable to inform a programme development that promotes the uptake of organ donation among this community?
- What is the nature of a programme to aid and increase the uptake of organ donation among this community?

1.6. OPERATIONAL DEFINITION OF KEY TERMS

Development: Development is a concept that can be defined as "a process rather than an outcome: it is dynamic in that it involves a change from one state or condition to another. Ideally, such a change is a positive one" (Israel, 2018). In this study, development is used to constitute a new stage in changing the state of mind of the Xhosa community to consider organ donation as a treatment option for organ failure.

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Programme: A programme can be defined as a series of actions designed to achieve blueprint actions, including creating a matrix of proximal programme objectives from the needs assessments, selection of theory-based intervention methods, and practical strategies (Bartholomew, Parcel and Kok (1998). In this study, the programme was a planning aid to increase the awareness of organ donation processes to improve its uptake among the Xhosa community.

Promotion: Lexico Oxford Dictionary (2020) defines promotion as "An activity that supports or provides active encouragement to further a cause, venture or the aim". Actively promoting or "active promotion" means regularly undertaking specific identifiable actions that encourage greater participation in an activity or make an activity more visible and accessible (Lexico Oxford Dictionary, 2020). In the study, promotion means publicising organ donation to increase public awareness. According to WHO (2016), people must obtain the knowledge, skills, and information that help them to make healthy choices in life. Deciding to donate one's organs is a difficult decision. However, ultimately, it will empower the Xhosa community

within their specific context, ease their conscience, and assist them in making such decisions with more confidence. Consequently, the promotion of such a programme aims to encourage the Xhosa community to purposefully take part in organ donation by giving them the reasons why they should commit to organ donation and the benefits of donating an organ. This study, therefore, intends to increase awareness and create interest in organ donation uptake among the Xhosa community.

Organ donation: Organ donation is the act of donating one's organ/s to another person through an organ transplant (Definitions and Translations, 2021). Within the context of this study, organ donation refers to the action by a person who signs a will allowing their family members to donate their organs in case of confirmed brain-stem death. An organ donor is registered with an organ donor foundation and indicates their wishes to donate their organs; furthermore, they are deemed to have made an informed decision to donate organs while still alive in the case of kidneys.

Uptake: The definition of uptake can be summed up as follows: "quick to understand, learn, mental grasp, capacity for understanding" (Definitions and Translations, 2021). In this study, this term refers to the Xhosa community's capacity for knowledge, comprehension and commitment to organ donation.

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The Xhosa community: Xhosa people are members of native communities inhabiting the Eastern Cape Province of South Africa, with their primary language being isiXhosa. Since a community is defined as a social group determined by geographic boundaries, the Xhosa community are defined as the central subgroup with its own distinct but related heritages (Pauw, 2018). This community is the target population of interest in the study because the survey was conducted in their community.

1.7. PHILOSOPHICAL FOUNDATIONS

The framework chosen for this study was identified and outlined before the survey was conducted. In their 2007 research, Creswell and Clark (2007:21) argue that every kind of research should be based on a worldview or paradigm and philosophical assumptions. Considering this, the researcher identified the paradigm that best fits the identified research

problem, and the methodology that followed was based on it. The researcher further ensured a logical and coherent fit between the selected paradigm and the research design.

This study employed the social constructivism worldview as a guide since it emphasises human-centred approaches, values the subjectivity of experiences and the multiple voices of individuals (Gergen, 2001; Muller, 2003; Maree, 2007). Social constructivism is typically used as an approach to qualitative research and examines the subjectivity of experience and seeks to deconstruct and uncover new meanings and interpretations of experiences (Maree, 2007). Moreover, it encourages a comprehensive and holistic approach to deal with a phenomenon, while also acknowledging the complexity of life (Shaw, 2001; Maree, 2007). The study sought to interpret those perceptions and uncover new meanings regarding organ donation among the Xhosa ethnic group community. For the aim of social constructivism, researchers focus their attention on the specific context in which people live and work to understand the historical and cultural setting of the participants (Creswell, 2014:8).

There are no fixed criteria for evaluating the validity of the research endeavour other than respect for subjectivity and feeling. To understand reality, constructivists must assume that each response is someone's reality. By reading a variety of responses, a researcher gains insight into the reality of social injustice.

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1.7.1. Paradigm Perspective

Paradigms are worldviews, or a set of beliefs about the social world that guide a research action or an investigation (Lincoln & Guba, 1994 in Kivunja & Kuyini, 2017). It defined what was studied, determined questions asked by the participants, how questions were asked, and the rules followed in interpreting results (Babbie & Mouton, 1998). It influences research method by facilitating the rationale behind the design chosen. Paradigms were distinguished by how they responded to fundamental philosophical questions using the following dimensions: meta-theoretical assumption, ontology, epistemology, axiological and methodological technical assumptions (Terre Blanche, Durrheim & Painter, 2006:6). The paradigmatic perspective of this study included meta-theoretical assumptions, which consisted of the ontological, epistemological, axiological, and methodological technical assumptions that provided direction for the research.

1.7.2. Theoretical Conceptual Assumption

Dervin (2003:136) has defined meta-theory as assumptions that provide general ways of looking at the world based on the nature of reality and human beings (ontology), the nature of knowing (epistemology), values and ethics (axiology), and the nature of power (ideology). The meta-theoretical assumption or meta-paradigm assumption guided the study's research decisions throughout and served as a framework for making theoretical statements (Botes, 1995). The theory further denotes an obligation to or belief in the truth theories and laws in terms of a constructed paradigm (Yamauchi, Ponte, Ratliffe & Traynor, 2017:11).

Meta-theoretical assumptions in the study include: – reinforcing knowledge about organ donation; encouraging family debates; preparing healthcare professionals, including students; launching an organ donation incentive system; and applying appropriate legislation that can positively change public attitudes (Shumin, Woo & Lei, 2014). These meta-theoretical assumptions could be applicable in South Africa. In addition, qualitative researchers are mainly concerned with knowledge and the meanings inherent in studied phenomena, which, in this study, was the uptake of organ donation among the Xhosa community. Participants can explain how they arrive at their meanings and how they influence their daily lives (Denzin & Lincoln in Streubert & Carpenter, 2011:4). According to Leininger's theory, the assumption is that although the Xhosa community are culturally and religiously sensitive, they have the right to culturally congruent quality care (George, 2002: 491).

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1.7.3. Ontological Beliefs of Social Constructivism

Ontology is a social context where the research is being conducted and the participants' interpretation is understood (Mouton & Marais, 1999). Ontological assumptions are implicit understanding of human nature, society, the status of mental entities, the meaning of obstacles, causality, and intentionality in human behaviour (Kloppers, 2011:16). Constructivists believe that factors are mentally constructed. Consequently, the present study seeks to find those realities which has been built during the socialisation process and aims to interpret them (co-construct the meaning). In addition, it aims to find out how the participants are orientated to organ donation during the socialisation process. Ontological assumptions in the study were based on the Xhosa community's views, perceptions, and understanding of organ donation. The researcher was aware of the diverse range of ideas, perceptions, attitudes, experiences, and thoughts within the Xhosa community regarding the reality of organ donation uptake.

Leininger's theory (George, 2002:491) posits that culture is a complex interplay of values, beliefs, and traditions that are unique to a specific group of people and are transmitted from one generation to the next.

1.7.4. Epistemological Beliefs of Social Constructivism

"A way of understanding and explaining how we know what we know" (Crotty, 2003:3). Knowledge is based not only on observable phenomena but also on subjective beliefs, values, reasons, understanding, and justified belief. Individuals derive significance from their experiences, which extends beyond their tangible creations. The researcher engaged with participants to explore the nature of their understanding concerning organ donation, the sources of this knowledge, and the processes through which they constructed meaning from their responses. The research acquired knowledge, participants' views, and perceptions of the Xhosa community regarding uptake of organ donation in Phase 1 and their recommendations on programme development in Phase 3.

1.7.5. Axiological assumption

Axiology is defined as the "branch of philosophy that studies judgements about the value" (Saunders, Lewis & Thornhill, 2012). Research is value-bound, and since the researcher is part of what is being researched, he/she is subjective in qualitative studies. Axiology is the study of being and influences the way people view themselves in their relationships with others. In this regard, values play an essential role (Polit & Beck, 2017). A value is an idea shared by society about what is good and evil, right and wrong, desirable and undesirable. Accordingly, values shape the ideas and goals of a society (Saunders, Lewis & Thornhill, 2012). The study adhered to ethical considerations by following the research protocol of the University of Fort Hare (UFH) and the research policy of the DoH in the EP, South Africa. Community protocols through community leaders. Abiding by research protocol and ethical standards, the following obligations and steps were considered: participants were respected for privacy, confidentiality, anonymity, and the right to withdraw from the study. Ethical aspects of the research project were explained to the participants before they signed their consent and the commencement of the study.

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1.7.6. Methodological and Technical Assumption

According to Guba and Lincoln (1998) and Creswell (2013), methodological and technical assumptions define the nature of the research process and the most appropriate methods for carrying out the research study. This research study followed a qualitative approach and ethno-nursing design (from ethnography) of an explorative, descriptive, and contextual nature. The methods it employed allowed the researcher to interact with the Xhosa community in their natural environment to better understand their stories regarding the uptake of organ donation, applying semi-structured interviews and focus group discussions. Inductive reasoning applied throughout the study, including data collection, and analysis. The views of the participants regarding the uptake of organ donation were interpreted by the researcher inductively. Inductive reasoning is developing or creating a theory from the observations and general statements of empirical reality (Aliyu, Singhry, Adamu & Abubakar, 2015).

1.8. THEORETICAL PARADIGM ASSUMPTION

The study is built upon the assumptions of the information-motivation-behavioural skills model, social cognitive theory, health-promotion theory, theory of culture care diversity, universality, self-determination theory of motivation, practice-orientated theory, Knowles's andragogy theory of adult learning and determinants of behaviour, such as self-efficacy. The theoretical paradigm and assumption are a means of creating a specific way of looking at a particular phenomenon that guides the study's process, allowing the researcher to link the results of the study to the existing body of knowledge (Burns & Grove, 2009:126).

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1.8.1. Information-Motivation-Behavioural Skills Model

Information-Motivation-Behavioural Skills Model (IBM) (Fisher & Fisher, 1992;1993; 1999; 2000) conceptualises determinants of the performance of behaviours that have the capacity to impair or improve health status. This model focuses comprehensively on the set of information, motivation, behavioural skills and factors that are conceptually associated with the performance of health-related behaviour, but which are often dealt with in isolation from one another in both conceptual and health-promotion intervention efforts (Fisher & Fisher, 1993) that may be used for translating the IBM approach into health-promotion interventions.

1.8.1.1. Assumption of the IBM Model

The IBM model asserts that health-related information, motivation, and behavioural skills are fundamental determinants of the performance of health behaviours. If individuals are well-informed, motivated to act, and possess the requisite behavioural skills for effective action, they are likelier to initiate and maintain health-promoting behaviours and experience positive health outcomes. The model further specifies that motivation is an additional determinant of the performance of health-related behaviour and influences whether even well-informed individuals would be inclined to undertake health-promotion actions. According to this, personal motivation (attitudes towards the unique performance of health-promotion behaviours) and social motivation (social support for enactment of health-promotion behaviours) are critical influences on the performance of health-related behaviours. In the uptake of organ donation domain, for example, personal attitudes to organ donation uptake and the perception of social support are strongly predictive of whether someone would register for organ donation.

1.8.2. Self-Determination Theory of Motivation

Self-determination theory (SDT) is an active part of emotional well-being, regulating one's purpose. It applies to anyone striving for a more fulfilling life. It motivates people to act, especially when they believe their actions will influence the outcome (Ackerman, 2019). Once the Xhosa community becomes motivated, their drive will help them make decisions to donate organs, especially when they realise that both the donor and the recipient survive through organ donation and transplantation as the treatment option. The SDT suggests that people can become self-determined when their need for competence, connection, and autonomy is fulfilled (Legault, 2017). Xhosa community members could decide to donate when given sufficient information on organ donation and transplantation; the wisdom of the ability to take direct action will result in real change that plays a significant role in helping people feel in control.

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1.8.3. Social Cognitive Theory

Social cognitive theory is a theoretical perspective that focuses on learning by observing others. Social cognitive theory favours a causation model involving triadic reciprocal determinism (Bandura, 1989). In this model, behaviour, cognition, and other personal factors, as well as environmental influences, all operate as interacting determinants that influence each other or are bidirectional (Bandura, 2001). According to Bandura (1986), what people think, believe,

and feel affects their behaviour, e.g., what the Xhosa community thinks, believes, and feels about organ donation. Several basic assumptions are grounded in the social cognitive theory. For the purposes of this study, they include (Berzonsky, 2004; Nabavi, 2012; La Rose & Eastin, 2004):

- Learning can be done by observing others – simply watching the model (by demonstrating a behaviour to someone else/meeting face-to-face with a person who donated or received an organ)
- Learning is an internal process that may or may not lead to a behaviour – learning may occur immediately or may take time (reinforcement and motivation is essential to acquiring a behaviour).
- People and their environment mutually influence each other (social and community support).
- Goal-directed behaviour – individuals can influence/amend their conduct in the environment in a goal-targeted way (Bandura, 2001).
- Behaviour eventually becomes self-regulated – behaviour learnt by individuals becomes self-regulated.

Health behaviour change theories are identified as forecasters of conduct in the study.

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1.8.4. Health-Promotion Theories

Effective programme development needs comprehensive interventions. Considering psychological, organisational, cultural, community level, political, and policy-driven factors is essential to encourage healthy behaviour. There are many determinants towards a behaviour; therefore, interventions that focus on multiple factors are more likely to be effective (Raingruber, 2014). Health-promotion theories are needed for multilevel interventions to accomplish desired outcomes. Health-promotion theories provide a roadmap and a systematic summary of which factors to consider when developing a health-promotion programme. It is essential to have a theoretical understanding of why people behave the way they do if a health professional planning to assist a person, family, a group, or a community to improve their health status should have such a theoretical understanding. Health-promotion theories are applied to explain why an intervention is necessary and how to intervene (Glanz & Rimer,

2005). As a result, the study examined behavioural theories and intervention-based models (Raingruber, 2014).

1.8.5. Culture Care Diversity and Universality

The theory of cultural care diversity and universality is recognised as a leading nursing theory. Knowledge of culture/s has become central and of unique importance in nursing to know and assist diverse cultural groups (Leininger, 1978; 1991 in George, 2014:430). The theory has guided nurses meaningfully and stimulated their understanding of diverse cultures in nursing practices and research (Leininger, 1991). Leininger's approach is suitable in conducting the study to develop a programme in promoting the uptake of organ donation among the Xhosa community.

This theory (George, 2002:491) postulate that human beings belong to a cultural group in which they live and practice their cultural values and norms. People of each culture determine the traditions they understand and observe in their nursing care world and integrate these traditions and observations into their general health beliefs and practices. Based on this principle, nursing care should be established within the cultural context in which it is rendered (George, 2014: 430). Xhosa communities are bound by culturally based care factors, which are recognised by Leininger (1978; 1991) in George (2014:430) as influences on human care expressions, beliefs, and practices related to health, illness, well-being, or to facing death and disabilities.

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Leininger further asserts that human care is central to nursing as a discipline and profession. Her belief is that cultural care should be preserved (George, 2002:491). Culture has health practices specific to one culture and dominant forms common to other cultures; hence, the theory is termed culture care diversity and universality. One of the barriers that contributes to the limited uptake of organ donation among the Xhosa community is their cultural belief system. The drive beyond this theory, which is derived from the sunrise model, seeks to assist in the study regarding how the components of the idea impact the health status and care of individuals, families, groups, communities, and institutions within a culture and to decide upon the most appropriate nursing care and activities to accomplish culturally congruent care (George, 2014:430).

The nurses need to look at their clients' worldview and environmental backgrounds to render culturally sensitive care regarding organ donation, particularly around cultural and social components that might negatively affect attitudes to donation and transplantation. Cultural and social structure factors are important considerations in this theory. These are broad in nature, interrelated, and influence the behaviour of an individual or group. The Xhosa community, as a cultural group, is influenced by cultural and social factors when making decisions regarding organ donation. These factors include religion (spirituality), kinship (social ties); politics; legal issues; education; economics, technology; political factors; philosophy of life; and cultural beliefs and values, and gender and class differences.

1.8.5.1. Technological Factors

A Xhosa person prefers cultural rituals and limits the use of high technology tools and instruments (George, 2002:492); instead, in the studies conducted in USA and UK, the participants expressed a lack of confidence in medical teams that retrieve the organs for transplant, confirming limited understanding of brain-death (Shilling et al., 2006:839; Morgan et al., 2006:233).

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1.8.5.2. Religious and Philosophical Factors

Most religions believe that the human body is a temple of God and needs to be pure and intact, and it should return to heaven intact. Because of this, grieving relatives often hope for recovery and cannot accept the reality of brain death; thus, they do not understand that organ donation is a religious sacrifice. This belief contributes to the insufficient uptake of organ donation (Bhengu & Uys, 2004:29).

1.8.5.3. Ethical Factors

Ethical considerations are strongly emphasised regarding organ donation, as it is a culturally sensitive issue. Any donation-related decisions must be examined as an outcome of people's attitudes to donation, and their consent should be influenced by their prior knowledge of the deceased individual wishes (Radecki & Jaccard, 1997:183). Vincent and Logan (2012:80) state that the consent rate can be improved by requesting at the right time, in an appropriate setting, providing emotional support, and imparting specific knowledge regarding the nature of brain death.

1.8.5.4. Kinship and Social Factors

Bhengu and Uys (2004:30) report that male family members still had the upper hand in decision-making regarding organ donation in the Zulu culture. The transplant coordinator revealed that men do not donate organs for their wives; instead, their wives donate them. Feelings for the person affect organ donation, as many mothers donate organs for their children.

1.8.5.5. Economic Factors

Results of a study conducted in America reported financial concerns regarding organ donation. A live donor incurs costs for travelling and loss of work time, which are reasons for insufficient uptake of organ donation (Shilling et al., 2006:837). However, South African hospitals or states cover all the medical expenses regarding organ donation and transplant (Organ Donation Foundation, 2013).

1.8.5.6. Educational Factors

Misconceptions regarding organ donation identified by Bhengu and Uys (2004: 30) were mainly knowledge deficits and communication barriers in terms of Zulu speaking people, such as not accepting an organ from a female if one is a male. The language also became a problem for the transplant coordinator with Zulu speaking people. Etheredge et al. (2013:140) assert that campaigns to promote organ donation awareness should focus on languages other than English and Afrikaans. Mass media publications in other languages could encourage organ donation, thus improving understanding among more diverse groups of people. To mitigate culturally congruent care, alongside the general nature of human beings as caring beings, the ethnic values, beliefs, and practices of a particular culture provide bases for the patterns, conditions, and actions associated with human care. Knowledge of these offers a base for three action-decision care modes identified by Leininger in George (2014:430), all of which need the collaboration of a nurse and the client (Xhosa community member).

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1.8.5.7. Culture Care Preservation/Maintenance

"Those assistive, supportive, facilitative or enabling professional acts or decisions that help cultures to retain, preserve, or maintain beneficial care beliefs and values to face health disabilities and death" (Leininger, 2006 in George, 2014:432). Leininger suggests that culture need not be changed; instead, continuous education and awareness campaigns that will change

the mind set will yield a more positive attitude to the uptake of organ donation among the Xhosa community.

1.8.5.8. Culture Care Accommodation/Negotiation

"Those assistive, accommodating, facilitative, or enabling creative provider care actions or decisions that help cultures to adapt or negotiate with others for culturally congruent, safe, and effective care for their health, well-being or to deal with illness or to die" (Leininger, 2006 in George, 2014:432). Leininger (2006) suggests that culture need not be changed but should instead be negotiated by looking at the options that can satisfy both the health professional and community members to promote the uptake of organ donation effectively.

1.8.5.9. Culture Care Patterning/Restructuring

"Those assistive, supportive, facilitative, or enabling professional action and mutual decisions that would help people to reorder, change, modify or restructure their lifeways and institutions for better health care patterns, practices, or outcomes" (Leininger, 2006 in George, 2014:432). The essence of this is to reorder, change, or modify the cultural belief, as culture is dynamic and can change with times or circumstances beyond control. For example, the high costs of a funeral and the sudden, painful loss can push some Black families to abandon their traditional burial rituals (Kwamilele, 2011) and opt for cremation; the notion of being buried incomplete falls off, resulting in the promotion of organ donation uptake.

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1.8.6. Practice-Oriented Theory

For this study, Dickoff, James and Wiedenbach's (1968) practice-orientated theory was applied to conceptualise the results from the situational analysis. The aspects of the programme activities were aligned with the six ways or questions of looking at one entity. The reasoning map of practice-orientated theory asks the following five questions:

- Who or what performs the activity?
- Who or what is the recipient of the activity?
- In what context is the activity performed?
- What is the endpoint of the activity?
- What is the guiding procedure, technique, or protocol of the activity?

(Conceptualisation is briefly explained in Chapter 2 and discussed in Chapter 4)

1.8.7. Knowles's Andragogy Theory of Adult Learning

The developed programme promoting the uptake of organ donation among the Xhosa community will be educational to change the behaviours. Therefore, principles of teaching and learning were applied. These principles directed the programme from its developmental stage to its evaluation. The principles of adult learning by Knowles (1968) and other appropriate teaching methods in health education were applied during the development of the programme content. Andragogy is a term that refers to a theory of knowledge explaining how adults learn. Adults have a habit of becoming more self-directed, internally motivated, and ready to learn (Palis & Quiros, 2014). Therefore, instructors can draw on concepts of andragogy to increase the effectiveness of adult education.

1.9. RESEARCH METHODOLOGY

A research paradigm fundamentally reflects the researcher's worldview (Kivinja & Kuyini, 2017:26). A paradigm comprises four assumptions, namely ontology (nature of the belief about reality), epistemology (nature of knowledge and the process by which the knowledge is acquired and validated), methodology (articulates the reasoning and flow of the systematic process followed in guiding a research project to gain knowledge about the research problem, and axiology (ethical issues that need to be considered when planning a research project) (Kivunja & Kuyini, 2017:27; Rehman & Alharthi, 2016:52). The nature of reality demonstrates the validity of information (worldview as interpreted by the Xhosa community regarding promotion of organ donation uptake) and generated knowledge (brought by the Xhosa community in promoting the uptake of organ donation). The study uses a qualitative approach to develop a programme that will follow the steps of the Intervention Mapping Framework (Bartholomew et al., 2011).

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1.9.1. Research Design and Methods

This study's research design is qualitative, developmental, and ethno-nursing. It is a qualitative approach that takes the form of an inquiry in which the inquirer explores a central phenomenon by asking participants broad and general questions. Then detailed views of participants in words or images are collected (Denzin & Lincoln, 2011). During the developmental phase, phases of the interventional mapping framework (Bartholomew, Parcel & Kok, 1998) used to develop the programme to promote the uptake of organ donation among the Xhosa community.

The study used an ethno-nursing design, which is exploratory (Fetterman, 2010:9). The ethno-nursing researcher acts as a co-participant to discover how people know, experience, and practice care in their daily lives. It includes observation of participants, participation, and reflection with participants throughout the research process, allowing discovery of emic (people's) and etic (professional's) values, beliefs, care practices, and health practices (MacFarland, Mixer, Webhe-Alamah & Burk, 2012).

1.9.1.1. Qualitative Approach

Parahoo (2014:56) considers qualitative research as an appropriate way of exploring human experience to understand the human worldview. Exploration is undertaken to discover new lands, people, or customs and to learn from them. The study seeks to explore the uptake of organ donation among the Xhosa community. The values and norms created are shared from generation-to-generation families. Qualitative research is also the belief that reality is constructed individually and, therefore, the truth can never be known (Houser, 2013). However, it can be understood through various participant data collection methods.

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1.9.1.2. Ethno-nursing Research Design

Ethnography is a systematic process during which models of culture or subculture are observed, described and documented. Ethnography focuses more on cultural descriptions and seeks to understand people's views of a cultural system (Nikkonen & Janhonen, 1995). Additionally, ethno-nursing was developed to assist researchers in studying transcultural human care phenomena and discover the knowledge required by the nurses to provide care in an increasingly multicultural world (MacFarland et al., 2012). Leininger coined the phrase 'ethno-nursing research' and defined it as the study and analysis of local or indigenous people's viewpoints, beliefs, and practices (Parahoo, 2014: 244). In the study, ethno-nursing seeks to emphasise the pattern of the phenomena under study of interest to nursing, including care, health, culture and environmental context of the Xhosa community in view of barriers towards uptake of organ donation (Ray, Morries & McFarland, 2013).

1.10. PROGRAMME DEVELOPMENT

An IMF has been used effectively in the development of various programmes of public health importance (Fernandez, ten Hoor, van Lieshout, Rodriguez, Beidas, Parcel, Ruiter, Markham

& Kok, 2019). Interventions are plans or improvements associated with an underlying method to require future outcomes (Chen & Cohn, 2003), which may be explained through programmes and policies. Intervention mapping is a health promotion and health education programme-planning framework which helps build quality interventions that are systematically planned and based on theory and evidence (Bartholomew et al., 2011). It takes cognisance of the end-users (Xhosa community) and those involved in the implementation of the emergent programme. End-users refer to participants in the study who actively contributed, and team up with the researcher in the planning, development, and adoption of the programme. The IMF was introduced by Bartholomew, Parcel and Kok (1998) to assist programme planners with a structured process and theoretical applications in the development of evidenced-based programmes and allow them to make operative decisions at every step of development, implementation and evaluation of a programme (Bartholomew et al., 1998).

This IMF is grounded on three features, namely an environmental approach, active participant involvement, and the use of theories and evidence (Gandhi, 1998). The ecological system discovers which factors within the social and physical environment might influence identified health problems (Teater, 2014). The association between the environment and individuals is considered a change that could affect one's behaviour (Wong & Candolin, 2015). Therefore, stakeholder collaboration is essential for community-based solutions promoting health among group participants (Heritage & Dooris, 2009). Uniting the stakeholders, e.g., community members, traditional partners, community-based organisations, and faith-based leaders, is vital when attempting to implement a change affecting them. Using multiple theories to a problem helps researchers understand health and social issues (Glanz, Rimer & Viswanath, 2008). It enhances the success rate of implementing such a planned programme (Kok, Schaalma, Ruiter, Van Empelen & Brug, 2004). The programme development followed three phases, as illustrated in Table 1.1 below.

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Table 1.1: Research Methodology and Related Steps of the IMF

PHASES	STEPS
PHASE 1: Step 1	
Proximal programme objectives Objective 1: Qualitative situational analysis	Overview background of organ donation. Accessing community Conducting the situation analysis, Target population accessed, non-probability purposive sampling done, data collected analysed thematically
PHASE 2: Step 2&3	
Objective 2: Matrices of change objective and theory-based intervention development.	Stating emerged themes from the situational analysis Application of the elements of Dickoff et al. (1968) Stating performance objectives Selecting important determinants in theories Creating a matrix of change objectives Generating programme ideas with the planning group Identifying theoretical methods Choosing programme methods Selecting or designing practical applications
PHASE 3: Step 4	
Objective 3: Writing the programme	Themes, scope, sequence, and materials Prepare design document Drafting programme materials and protocols Re-looking programme materials Producing materials and protocols Specifying programme goals/objectives

Source: Bartholomew et al., 2011.

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1.10.1. Phase 1: Situational Analysis

During this phase, which is Step 1, the study followed an exploratory, descriptive approach in which individual and focus group ethno-nursing interviews were conducted with the Xhosa community, comprising traditional leaders, traditional healers, ministers of religion, and general community members.

1.10.1.1. Data Collection

Semi-structured individual and focus group ethno-nursing interviews were conducted with traditional leaders, traditional healers, ministers of religion, and general community members. The researcher explores and describes the socio-cultural barriers and religious orientation (to observe and interpret the nature of behaviour) of the Xhosa community in the Eastern Cape regarding organ donation. Their responses were used to develop a programme for promoting the uptake of organ donation.

1.10.1.2. Data Analysis

Leininger and McFarland (2006) in(Polit & Beck's (2012:565) data analysis guide was used to analyse data. The emerging themes were noted. The data analysis is described fully in Chapter 4. Considering the literature and other information from similar studies the research results were discussed. Furthermore, similarities and differences with other research studies were identified, and concepts were identified and analysed.

1.10.2. Phase 2: Matrices of change objective and theory-based intervention

This phase involved developing the matrices of change objectives (summary of analysed data – Step 2) from Phase 1, and theory-based intervention (method and practical application – Step 3) to the preliminary programme of the Intervention Mapping Framework to conceptualise the programme framework to promote the uptake of organ donation among the Xhosa community in the Eastern Cape Province.

1.10.3. Phase 3: Programme Development

A developed programme is described in Step 4. Step 5 entailed programme implementation, followed by Step 6, the programme evaluation. The study ended in Step 4, after the development of the programme.

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1.10.4. Description of the Programme

The programme's goal among the Xhosa community is to raise awareness of organ donation and encourage its members to commit, dedicate, and oblige them to reflect on their attitudes and feelings pertaining to organ donation. The overall theme/subject is the comprehension and overview of organ donation. The organisation/s involved in the programme is the DoH in the EC, whose role is to keep and approve the implementation of a programme in promoting the uptake of organ donation. Primary health care (PHC) will serve as the access point to the health delivery system because its facilities are in communities for proximity and utilisation. Intended beneficiary(s)/recipients for the programme include:

- All adults, both males and females (above 18 years of age) of the Xhosa ethnic group (traditional healers, traditional leaders, religious leaders, and general community members).
- The Xhosa community members across all socio-economic strata.

Phase 1, Step 1 of the adapted IMF was achieved through objective 1 (situational analysis) of the study, which is termed by Bartholomew, Parcel and Kok (1998:545) termed proximal programme objectives.

Phase 2, Steps 2 & 3, was achieved through objective 2.

- Step 2 involved matching the matrices of change objectives with the actual activities the Xhosa people expected to perform.
- Step 3, a crucial part of the process, is a theory-based intervention. This method, along with its practical application, is followed by the principles underpinning the programme. These principles provide direction for the different phases of the programme, from the developmental stage to evaluation.

While developing the programme's content, Knowles's (1968) principles of adult learning and other appropriate teaching methods in health education were applied.

1.10.5. Programme Review

The programme was sent to the panel of experts to review, comment, or make recommendations. The researcher included a review sheet for them to review the programme. The review sheet was adapted from the Checklist for Programme Report Content by Robertson and Wingate (2017). The programme was reviewed and adjusted, incorporating the expert panel's comments and recommendations. Chapter 6 describes a programme for promoting organ donation uptake.

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1.10.6. Implementation of the Programme

Programme development is a prerequisite for a Doctoral programme. Therefore, to implement it, complex resources (human and financial) were needed. Given the complex and evidence-based IMF, the processes involved in the development, and the time and inclusion of many participants from other districts to cover the entire province, the programme will be implemented and evaluated at a post-doctoral level.

1.11. ETHICAL CONSIDERATION

According to Parahoo (2014:111), there are ethical implications at every stage of a research process. The Department of Nursing Science Research Committee approved the research proposal. After that, ethical approval was granted by the Research Ethics Committee of the UFH. In addition, permission was granted by the Department of Health, Eastern Cape Province, to collect data. Semi-structured interviews were conducted without any coercion of participants. Anonymity and confidentiality ensured the right to privacy, fair treatment, and protection from harm. These ethical considerations were elaborated on in Chapter 2.

1.12. MEASURES TO ENSURE TRUSTWORTHINESS

Finally, to ensure the research's trustworthiness, appropriate criteria for qualitative research were discussed, and several methods, including member checks, peer reviews, crystallisation, and triangulation were suggested and later employed. Concerning research integrity, Lincoln and Guba (1985) suggest four criteria for ensuring trustworthiness in qualitative research: credibility, dependability, confirmability, and transferability. Guba and Lincoln (1994) also include authenticity, a construct in a constructivist paradigm. To ensure this study's rigour, the researcher adopted the five criteria proposed by Lincoln and Guba (1985;1994). Guba's model of trustworthiness was adhered to. This aspect is elaborated on in Chapter 2.

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1.13. DIVISION OF CHAPTERS

Chapter 1: Introduction to and Background of the study
Chapter 2: Research Design and Data Collection Methods
Chapter 3: Presentation and Discussion of Qualitative Findings
Chapter 4: Development Process (Conceptualisation and Intervention Mapping Framework)
Chapter 5: Programme Development
Chapter 6: Programme Review
Chapter 7: Summary, Limitations, Recommendations, and Conclusion

1.14. SUMMARY OF CHAPTER ONE

This chapter outlined and described the background, the rationale for the research, the aim of the study, objectives, and research questions. Philosophical assumptions and theories supporting the study were discussed. Steps in the IMF that guided the programme development

were described. The programme review method summarised that nursing is a practice discipline that caters to all racial groups and diverse cultures. Nursing care is established from the cultural context in which it is rendered. Therefore, nurses need to look at the worldview and environmental background of patients to render culturally sensitive care regarding organ donation, particularly cultural and social components that might negatively affect the uptake of organ donation. The comprehensive research design and method will be described in Chapter 2.



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CHAPTER 2: RESEARCH METHODOLOGY

2.1. INTRODUCTION

This chapter presents the research design and the data collection method relating to each adapted intervention mapping framework phase. The first section outlines the brief overview of Phase 1Step 1followed by the methodology. Phase 1 also outlined the description of the research strategy, including the research approach, research design, the research population, research setting, community entry, preliminary exploration, sampling method, and data collection process using semi-structured individual and focus group interviews conducted with Xhosa community members and data analysis, followed by reasoning strategies. The second section outlines Phase 2 Step 2 and entails the development of the matrices of change objective, and Step 3 describes theory-based intervention methods and practical application. The third section explains rigour, ethical considerations, and trustworthiness in detail. A summary of this study's research design and method is diagrammatically illustrated in Figure 2.1 and explained in subsequent subsections.

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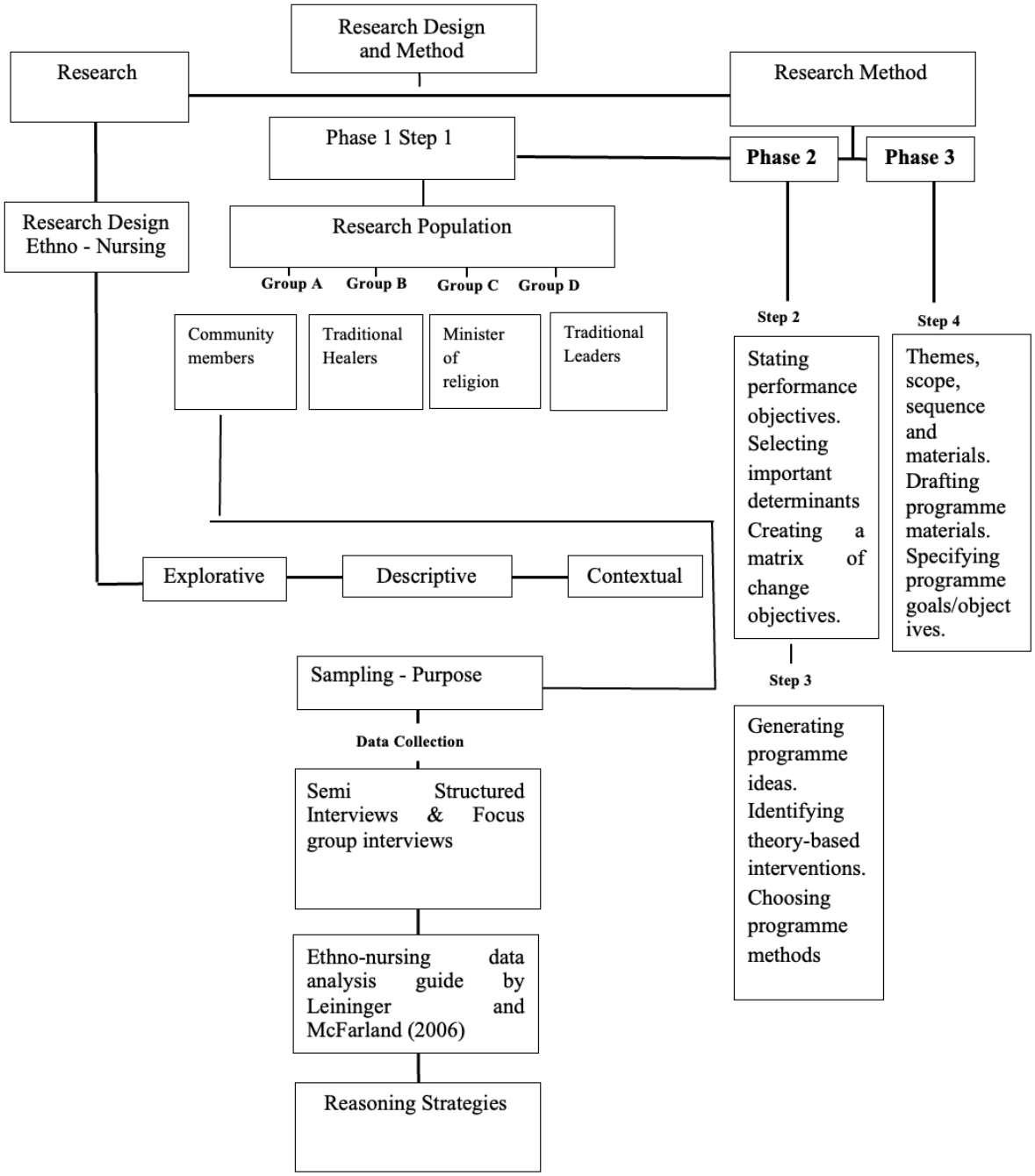


Figure 2.1: Summary of the Research Process

2.2. INTERVENTION MAPPING FRAMEWORK (IMF) PHASE 1

2.2.1. Phase 1, Step 1: Situational Analysis

Phase 1, Step 1 of the adapted IMF was achieved through objective 1 of the study, which is termed by (Bartholomew, Parcel & Kok, 1998:545) as proximal programme objectives. The situational analysis was an essential aspect of programme development that aimed to

understand the context, fill in possible gaps, and gather more information about this phenomenon (Wu & Picard, 2011). This was important since the anticipated outcome was a successful intervention addressing known challenges and specific requirements of the target group under study (Perez & Cannella:506). The exploration enabled the researcher to understand the current situation as well as the desired improvement thereof in terms of promoting the uptake of organ donation. This meant exploring the barriers towards the uptake of organ donation among the Xhosa community and, furthermore, how this specific population's cultural, personal, and religious orientation influences their uptake of organ donation. An IMF situational analysis was utilised to assess the feasibility of a programme. Community structures were evaluated to assess their capacity for allowing health professionals to enter villages to educate community members about organ donation. These specific Xhosa communities were readily accessible and eager to take part in the programme. During this phase, data were collected from the community members, traditional healers, religious ministers, and traditional leaders (Xhosa community), after which it was analysed.

Research objective: To explore and describe the barriers contributing to the low uptake of organ donation.

Research question: What are the barriers contributing to the low uptake of organ donation among the Xhosa community in particular?

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2.3. RESEARCH DESIGN AND METHOD

Phase 1 in the IMF consisted mainly of a situational analysis, in which a qualitative approach was used in combination with an ethno-nursing design to discover, describe and systematically analyse the care expressions, patterns and practices of people in their naturalistic environmental context (McFarland et al., 2012). An ethno-nursing design is, in short, a qualitative approach and takes the form of an exploratory, descriptive, and contextual inquiry.

2.3.1. Qualitative Approach

According to Streubert and Carpenter (2011:20), qualitative research is an enquiry process of understanding based on a distinct methodology that explores a specific social or human problem. During qualitative research, the researcher builds a complex, holistic picture, analyses words, reports detailed views of participants, and conducts the study in a natural setting. Therefore, this approach was used in conjunction with an ethno-nursing design. The researcher

explored and described the barriers contributing to the reduced uptake of organ donation within the Xhosa community.

2.3.1.1. Exploratory Research

Exploration by means of a qualitative approach is a vital and distinctive tool to better understand people (Parahoo, 2014:56). Exploratory research was used to establish facts, gather new data, and determine any relevant interesting patterns in the data (Mouton, 2009:103). An exploratory study adds to descriptive research in that it begins with a phenomenon of interest, which is then thoroughly investigated so that the fundamental nature of the phenomenon, including how it is manifested and the other factors to which it is related, can be explored (Polit & Beck 2008:20). In this study, the researcher was interested in exploring the underlying reasons or barriers for the low uptake of organ donation within the Xhosa community.

2.3.1.2. Descriptive Research

Descriptive research aims to provide a comprehensive summary of events. This approach is looking at answering the who, what, where and how (Ayton, Tsindos & Berkovic, 2023). The who in the study are the Xhosa community members, the what is the uptake of organ donation, the where is their natural setting, and the how was through semi-structured individual and focus group interviews. Descriptive study is an important and appropriate design for research questions that are focused on gaining insights about a poorly understood research area, rather than on a specific phenomenon (Sandelowski, 2010:79). Since qualitative descriptive study design seeks to describe rather than explain, unlike the phenomenological studies that seek to explain the phenomena (Ayton, Tsindos & Berkovic, 2023). In this study, the researcher described the barriers that contributed to a low uptake of organ donation.

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2.3.2. Research Design

Ethnography is a qualitative research approach used in anthropology and other social sciences to explore and describe the cultures and behaviour of people from their own natural setting (Parahoo, 2014: 245). Ethnography is used to glean a holistic view of a certain culture to understand nursing care behaviour, patient behaviour, and the processes of designated culture; it further describes, analyses, and interprets the ways of life of a particular culture or subculture. The most characteristic component of any ethnographic research is exploratory information-gathering (Fetterman, 2010: 8). It comprises fundamental characteristics such as immersive

observation, interviews, and participant observation to expand an understanding of a community's way of life, including their beliefs, values, and practices (Streubert & Carpenter, 2011:171; Parahoo, 2014: 245). Ethnography and ethno-nursing are interrelated but concentrate on different facets of cultural consideration in the context of healthcare. The research method developed by Leininger to underpin health practice is 'ethno-nursing' (Leininger, 2001). This attempts to combine concepts from ethnography and nursing, and 'focuses mainly on observing and documenting interactions with people of how these daily conditions, and patterns are influencing human care, health, and nursing care practices' (Leininger, 1985).

Ethno-nursing, on the other hand, is defined by Leinger (2006:70) as "a rigorous, systematic, and in-depth method for studying multiple cultures and care factors within familiar environments of people and to focus on the interrelationships of care and culture to arrive at the goal of culturally congruent care services". It is a specialised field within nursing that applies ethnographic methods to understand and address the cultural aspects of healthcare (MacFarland et al., 2012:262). Ethno-nursing focuses on how cultural beliefs and practices impact health, illness, and care. It involves studying the cultural context of patients to provide more culturally sensitive and effective nursing care. Ethno-nursing aims to integrate cultural understanding into nursing practices to improve patient outcomes and ensure that care is respectful and appropriate to the cultural needs of diverse populations (MacFarland et al., 2012:260). In summary, while ethnography provides a broad methodological framework for studying cultures, ethno-nursing applies these methods specifically to the field of nursing to enhance culturally competent care (Molloy, Walker, Lakeman & Skinner, 2015:18).

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Furthermore, an ethno-nursing design was used to explore barriers towards the uptake of organ donation in relation to socio-cultural and religious orientations that affect the health-related behaviour of individuals, groups, families the Xhosa community. This required that the researcher make use of the five principles of ethno-nursing, as follows: Firstly, since the first principle includes maintaining an open discovery throughout the study, the researcher listened carefully to what participants said, and developed a sincere innovation (McFarland, Mixer, Wehbe-Alamah & Burk, 2012:263). Next, by respecting the second principle, the researcher was sensitive to the emic view (local) and considered the effect of the etic view (professional) perspective (McFarland et al., 2012: 263). The third principle was adhered to by recording the shared information to preserve participants' ideas and meanings (McFarland et al., 2012: 263).

Fourth principle, a research assistant accompanied the researcher and lastly, research occurs in a natural setting (McFarland et al., 2012:263). The study utilised the above-mentioned design since it aimed at understanding and addressing cultural aspects of healthcare that contribute to the barriers towards the uptake of organ donation by the Xhosa community. The participant's responses contributed to the content of the programme and ensured its relevance and effectiveness. The Xhosa community is an ethnic group with cultural beliefs, customs, and religious beliefs, and have their own heritage.

Ethno-nursing, as a research design, is focused on understanding nursing care within the context of different cultural settings. While it offers valuable insights, there are several shortcomings associated with this approach:

2.3.2.1. Shortcomings of ethno-nursing research design

Cultural Bias: Researchers might inadvertently impose their own cultural perspectives and biases on the study, potentially leading to misinterpretation of data. This can skew findings and reduce the reliability of the results. Researchers engaged in reflexivity, critically reflecting on their own cultural biases and how these might influence the research process and outcomes (Molloy, Walker, Lakeman & Skinner, 2015:20). Collaborated with cultural experts or local practitioners who provided insights and help interpret findings from an authentic cultural perspective.

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Generalisability: Findings from ethno-nursing studies are often context-specific, meaning they may not be easily generalisable to other cultural or demographic settings. This can limit the applicability of the research outcomes to broader populations (Molloy, Walker, Lakeman & Skinner, 2015:20). The cultural context and boundaries of the study was clearly defined and assisted in understanding the scope of generalisability.

Complexity of Cultural Factors: Culture is multifaceted and dynamic, making it challenging to capture all relevant factors in a study. Ethno-nursing research may struggle to account for all the variables that influence nursing practices within a particular cultural group (Molloy, Walker, Lakeman & Skinner, 2015:21). Comprehensive cultural theory was used to systematically explore and describe cultural factors affecting nursing care. The researcher also made use of member checking, in which the respondents were asked to collaborate the findings.

Ethical Concerns: Conducting research in culturally sensitive environments requires careful consideration of ethical issues. Missteps can lead to cultural insensitivity or exploitation, potentially harming the community being studied (Parahoo, 2014:256). In the study, the researcher sought approval from an ethics committee of the university and permission from the Department of Health, including members knowledgeable about cultural research ethics (Traditional Leaders, Traditional Health practitioners, Ministers of Religion), to address potential ethical issues. Informed consent was signed by the participants. Comprehensive information about the study aims, and objectives were given in a cultural manner that respected local norms and practices and enabled participants to make an informed decision about participating in the study without coercion or influence. They were given the option to withdraw from the study at any point during its duration.

Resource Intensive: Ethno-nursing research often demands significant time and resources, including prolonged periods of participant observation and engagement. This can make the research process costly and logistically challenging. The researcher planned the budget and research schedule carefully to accommodate the time and resources required for ethnographic methods.

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Researcher's Influence: The presence of the researcher can sometimes affect the behaviour and responses of participants. This influence can alter the authenticity of the data collected and impact the validity of the research findings (Reeves, Peller, Goldman & Killo, 2013:e1370). The researcher defined and communicated the researcher's role to participants to minimise influence on their behaviour. Building relationships with the community enhanced trust and reduced the impact of the researcher's presence.

Data Interpretation: Analysing data from ethno-nursing research requires a deep understanding of cultural nuances. Researchers may struggle to interpret data accurately if they lack sufficient cultural competence or if the cultural context is complex. The researcher had the necessary cultural competence and understanding to accurately interpret data. This was also ensured by the use of member checking, in which the respondents were asked to collaborate on the findings.

Integration with Broader Evidence: Ethno-nursing research may focus intensely on specific cultural contexts, potentially making it difficult to integrate findings with broader evidence in the field of nursing. This can create challenges in synthesising knowledge and applying it universally (Molloy, Walker, Lakeman & Skinner, 2015:19). The study was limited to specific ethnic communities and the province. Finding was supported by the literature but cannot be generalised to other ethnic groups.

2.3.3. Research Setting

The setting of a study is defined as the site where the study is conducted. Three standard settings are – natural, partially controlled, and highly controlled, as stated by (Burns & Grove, 2009: 362). In this study, a natural setting was used, which is defined as an uncontrolled real-life situation or environment (Moule, Aveyard & Goodman, 2017:199). This native environment allowed the researcher to observe Xhosa people and their behaviour, real-world motivations, and constraints. This ethnographic approach aims to eliminate non-natural answers typical of controlled or laboratory conditions (Fetterman, 2010: 33). The research settings of this study were *inqila place* in the Great Place for traditional leaders and community members; hospital boardrooms and consulting rooms for traditional healers; and churches for the ministers of religion.

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The OR Tambo District Municipality lies in the eastern part of the Eastern Cape and borders the district municipalities of Alfred Nzo, Amathole, Chris Hani, and Ukhahlamba. The OR Tambo District is the poorest of these, with backlogs in infrastructure and socio-economic problems related to poverty and underdevelopment, such as bad roads (gravel), lack of electricity supply and network coverage resulting in inaccessibility of health facilities.

The Chris Hani District is situated in the north-east part of the province. It is made up of eight local municipalities, namely – Inxuba yethemba, Tsolwana, Inkwanca, Lukhanji, Intsika yethu, Engcobo, Sakhisizwe, and Emalahleni. It is the second-largest district, and most of its people speak isiXhosa, although Afrikaans speaking people predominate in the far west of it. The seat of Chris Hani district is Queenstown, while for OR Tambo district is Mthatha (Eastern Cape Municipalities, South African Government, 2020).

The profile of the selected districts is described in Table: 2.1

Table 2.1: Selected districts and sub-districts in the Eastern Cape Province

DISTRICT	SUB-DISTRICTS	POPULATION
OR TAMBO DISTRICT	KSD	442 318
	NYANDENI	**436 813**
	QAUKENI	659 431
	MHLONTLO	**221 827**
CHRIS HANI DISTRICT	INXUBA YETHEMBA	65 560
	INKWANCA	21 971
	LUKHANJI	**190 723**
	ENGCOBO	155 513
	SAKHISIZWE	63 582
	EMALAHLENI	**119 460**
	TSOLWANA	33 281

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2.3.3.1. Entry to the Site/Gaining/Access to the Setting

Formal permission is vital in any research and is required to protect both the researcher and the participants. The University of Fort Hare's Research Ethics Committee (UFHREC) (Appendix A) approved the proposal. The researcher sought permission to research selected districts from the Department of Health (DoH) in the Eastern Cape Province through the Eastern Cape Health Research Committee (Appendix B). Permission was granted by the coordinator of the traditional healers for both selected districts in the Eastern Cape (Appendix C). Permission to conduct research with the ministers of religion was sought from the Council of Churches in the OR Tambo region (Annexure D). Permission for traditional leaders and community members in the OR Tambo district was granted by the traditional council (Appendix E), and from the municipal manager for all categories of participants (namely, community members, traditional healers, ministers of religion, and traditional leaders) in the Chris Hani area (Appendix F).

2.3.4. Research Population

Population is defined as a specific category of distinct element/s that are the focus of the research (Burns an& Grove, 2009:343; Polit & Beck, 2012:306), . This study focused on the Xhosa community, divided into sub-groups, namely the Bhaca, Bomvana, Mfengu, Mpondo, Mpondomise, Xesibe, and Thembus. Each has its own distinct but related heritages and are found in selected districts of the Eastern Cape. The target population is the complete set of

individuals or elements who meet the sampling criteria (Burns & Grove, 2009:343). As mentioned, the target population included Xhosa traditional healers, traditional leaders, ministers of religion, and the general community members in the selected districts of the Eastern Cape.

The accessible population was comprised of the Xhosa community members in the OR Tambo and Chris Hani districts. Accessible is the part of the target population to which the researcher has reasonable access (Burns & Grove, 2009:344). The racial composition of the two districts is largely Black Africans, who constitute 93% of the entire population (Statistics South Africa, Census, 2011). The main language is isiXhosa (Pauw, 2018). The accessible population for the preliminary exploration of the study were Xhosa people in the Mnquma Local Municipality, Eastern Cape Province. Mnquma Local Municipality is comprised of the former Butterworth, Ngqamakhwe, and Centani Tribal Regional Council. This municipality has a total population of approximately 252 390 people, of which 99% were Xhosa-speaking; the remaining 1% of the population includes English, Afrikaans, Zulu, and Sesotho speaking people (Pauw, 2018).

2.3.4.1. Recruitment

Once permission was obtained from the above authorities, the researcher contacted the leaders of the four selected groups by emailing them a brief outline of the proposed research study, indicating its aims and objectives. Traditional leaders were accessed from the house of traditional leaders in the province and the districts, followed by an *Imbizo* (a gathering) called by the traditional leaders (the gatekeepers) for the Xhosa people to gather at the community centre. Positive responses were received within an average of two to four weeks from the traditional leaders accessing them and the community members in the OR Tambo district, while the responses from traditional healers were received within one to three months.

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The municipal manager of the Chris Hani district requested all the representatives of the selected groups to gather in the municipal boardroom, where the researcher presented the aim and the objectives of the study in person. Permission to enter the research field was granted (Annexure F) within a month after the presentation. The traditional leader organised other selected groups. The researcher then set up individual appointments, dates, and times suitable for the semi-structured individual and focus group interviews.

2.3.4.2. Preliminary Exploration (Pilot Interviews)

A preliminary exploration was conducted with five (5) participants and one focus group from one (1) category to explore interview questions and collect the data. The initial inquiry had one focus group of community members comprising two traditional healers, one minister of religion, and two traditional leaders. Subsequently, the preliminary exploration results were included in the main study. Below is the sample size of the preliminary exploration/pilot interview.

Table 2.2: The Sample Size for Preliminary Exploration/Pilot Study

Groups	Community members (A)			Traditional healers (B)			Ministers of religion (C)			Traditional leaders (D)		
Gender	M	F	Total	M	F	Total	M	F	Total	M	F	Total
Focus group 1	0	8	8									
Individual interviews				0	2	2	1	0	1	2	0	2

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The preliminary exploration was conducted within a specific cultural group, the Xhosa, located in the Mnquma municipal area of the Amathole district in the Eastern Cape. According to the 2011 Census, a substantial 78.85% of the population in this municipality relies on public health facilities. For this initial phase of research, the investigator selected a single municipality and focused on data collection from two districts, with one sub-district chosen from each.

A careful selection of study settings preceded the entry into the field. The researcher identified specific areas characterised by distinct geographical and conceptual boundaries, deemed most suitable for addressing the research questions. The main study was subsequently conducted in the Chris Hani and OR Tambo districts. Insights gathered during the preliminary exploration informed the selection of settings and participants.

This pilot study proved invaluable for enhancing the researcher's interview skills, utilizing culturally appropriate methods developed through initial participant interactions. This experience deepened the researcher's understanding of the local community, equipping her with the necessary skills to facilitate interviews in the main study and to gather rich, detailed data essential for the research objectives. Furthermore, the preliminary exploration facilitated the refinement and adjustment of research questions, aided in building rapport with participants, and improved engagement strategies.

2.3.5. Sampling

Sampling is the process of selecting a group of people to conduct a study and includes sample size (Burns & Grove, 2009:343). Becker, Bryman and Ferguson (2012: 262) argue that the purpose of qualitative sampling is for theoretical generalisation from sample to population. The number of participants in qualitative research is determined by data saturation. The study used a non-probability purposive sample to select its participants. The sampled research population comprised Xhosa community members from within four groups namely Community members (Group A), who were chosen because they are a diverse ethnic group in terms of various rites of passage traditions, in which the rites of passage might be a barrier to the uptake of organ donation (Pauw, 2018). Xhosa community members were purposely sampled at an *Imbizo* (a gathering called by a traditional leader) comprised of males and females, old and young. The traditional leader introduced the researcher to the Xhosa community members and then allowed the researcher to address them by stating the purpose of the visit. Many participants were initially unwilling to take part because they were fearful of the research topic; however, their cooperation was gained after explaining the aim and objectives of the study. Participants were then divided into groups according to age and gender, and all consented to participate in the study.

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Traditional healers *igqirha* (Group B) were selected because of their diversity in terms of relying mainly upon medicinal plants and herbs for the preparation of therapeutic substances to treat patients, many of whom have psychological undertones (WHO, 1978). The entry into the field followed the selection of the setting. In this study, male and female traditional healers who lived within the sub-district and were 18 years and older who were willing to participate and to provide consent were included. Two types of sampling techniques were used, namely purposive and snowballing (Moule, Aveyard & Goodman, 2017:174). Traditional healers were purposely sampled using a list of contact details provided by the provincial coordinator of traditional healers in the province; through networking, several other traditional healers were recruited to gather in one setting, which included municipal boardrooms or practice rooms of the traditional healer.

Ministers of religion (Group C) were selected because of their diverse training to support people in their pain, loss and anxiety, and triumphs, joys, and victories. For this study, selected

participants hailed from different denominations within the sub-district, were 18 years old and above, males and females, and were willing to participate and provide consent. Two sampling techniques were used, namely purposive and snowballing (Moule, Aveyard & Goodman, 2017:174). This group was purposively sampled by utilising a list of contact details provided by the district's chairperson of the Council of Churches, and, through networking, other ministers were recruited to meet in a setting which included municipal boardrooms or churches.

Traditional leaders – chiefs (Group D) were selected as their primary role is to regulate social behaviour within the community that they have control of, as the folk sector (Dlungwana, 2002:4). The folkway sector was chosen because it influenced African Black people's beliefs, culture, and behaviours, with an estimated 80% of this population consulting them before turning to Western medicine (George, 2002:493). For this study, only traditional leaders who resided within the sub-district were 18 years old and above; males and females who were willing to take part, and to provide consent, were included. As with the other groups, two sampling techniques were used, namely purposive and snowballing (Moule, Aveyard & Goodman, 2017:174). These traditional leaders were purposely sampled using a list of contact details provided by the secretary in the house of traditional leaders in the province; through networking, other traditional leaders were recruited to the community centre.

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2.3.5.1. Sampling Ethics

The rationale when choosing samples are justice, generosity, and trust, and these reflect respect for other persons (Burns & Grove, 2009:61). All genders participated in the study, from the age of 18 years and above, aged recognised, as they were the elders who will grant permission to organ donation for their relatives.

2.3.5.2. Sampling Size

Moule, Aveyard and Goodman's (2017:168) research shows that sample sizes in qualitative studies are generally small. Qualitative research typically depends on the depth of information required to obtain an insight into the phenomenon being explored; this depth is termed saturation. Researchers need not interview more participants once conversations with the participants begins to duplicate the earlier data (Holzemer, 2010:89). According to Guest, Bunce and Johnson (2006:61), it is suggested that saturation often occurs around 12 participants in a homogenous group, while Latham (2014) advises that the researcher go

beyond 12, but interview fewer than 15 homogenous participants–(a homogenous group is a group composed of parts or elements of the same kind or nature (Roller & Lavrakas, 2015:107).) Crouch and Makenzie (2006: 494) propose fewer than 20 participants; the above authors further mentioned that this number aids the researcher in building and maintaining a close relationship during the exchange of information with the participants. Data saturation and the number of participants determined the sample size in this study. One to two focus groups were formed in each category from the chosen sub-districts; a total of approximately six (6) to twelve (12) participants were purposively selected for these groups.

According to Gerrish and Lacey (2010:3620), a focus group should consist of five (5) to twelve (12) members. The group size must be large enough to ensure a diversity of perspectives but small enough to ensure that everybody has a chance to take part. Generally, it is advisable to invite more than the required number of group members to counter the inevitable problem of absenteeism. An average of six (6) to twelve (12) participants took part in each of the nine (9) focus groups. The following focus groups were formulated:

Three focus groups of community members (seven to ten participants in a focus group).
Three focus groups of traditional healers (six to seven participants in a focus group).
Two focus groups of ministers of religion from different denominations (six participants in a focus group). One focus group of traditional leaders (six participants in a focus group).

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Table 2.3: The Sample Size of the Study

Groups	Community members (A)			Traditional healers (B)			Ministers of religion (C)			Traditional leaders (D)		
Gender	M	F	Total	M	F	Total	M	F	Total	M	F	Total
Focus group 1	6	4	10									
Focus group 2	4	3	7									
Focus group 3										5	1	6
Focus group 4	4	4	8									
Focus group 5				3	3	6						
Focus group 6				3	3	6						
Focus group 7							5	1	6			
Focus group 8							5	1	6			
Focus group 9				1	6	7						

2.3.5.3. Exclusion and Inclusion Criteria

Criteria can be determined based on several considerations, including resource limitations, feasibility constraints, individuals' ability to participate, and design-determined restrictions (homogenous vs heterogeneous) (Polit & Beck, 2009). The following participants who met the following eligibility criteria were selected:

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Inclusion in the Sample

Registered traditional healers, traditional leaders, and religious ministers. Community members of 18 years and older. Both males and females.

Exclusion in the Sample

Sick people (diagnosed with severe illness and/or mentally incapable of being interviewed).

2.3.6. Data Collection Methods

Data collection is the process of choosing participants and collecting information; it starts by identifying the most appropriate site and gaining the necessary permission to access it (Burns & Grove, 2009: 441). Research methods generally involve the development of an interview schedule or an instrument, the forms of data collection and data analysis. Researchers propose an interpretation of their studies which will depend on whether they intend to specify the type of information to be collected in advance of the study or to allow it to emerge from the project's

participants (Creswell, 2009:16). In this study, the researcher allowed the information to emerge from the participants.

Semi-structured individual interviews and focus groups discussions were used to identify the barriers towards uptake of organ donation in the study's target population, the Xhosa community and regarding the determinants of their behaviour, specifically the low uptake of organ donation. Data collection within the target population – Xhosa community – and the implementers or stakeholders were also necessary for questions other than those regarding determinants i.e. less uptake of organ donation, such as questions about methods or changes that influence behaviour, and programme implementation. Ethno-nursing research design is a specialised approach that combines ethnographic methods with nursing research to explore and understand the cultural aspects of health and nursing practices. Here are the key features of ethno-nursing research design:

- Ethno-nursing research emphasises understanding health and nursing practices within specific cultural contexts. It explores how cultural beliefs, values, and practices influence health behaviours, experiences, and interactions with healthcare.
- Ethno-nursing research frequently uses in-depth interviews to capture personal narratives. However, researchers often immerse themselves in the community or setting they are studying to observe and understand health and nursing practices from an insider's perspective.
- An adequate period must be spent with participants in their natural environment to familiarise with the groups, gain their trust, build relationships, and immerse to sufficiently gain an in-depth understanding of what is happening (Parahoo, 2014:250). In this study, individual interviews and focus group discussions were conducted, along with observations of the participants' behaviour, their environment and setting, dress code and language.

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Parahoo (2014:250) states that it is difficult to specify what constitutes 'sufficient time' in a natural setting. However, what is of crucial importance is gaining trust and being accepted by the participants. At the same time, cultural immersion (depth and length of participation that ethnographers must have with the culture under study) – may take months or anything up to a year or more (Streubert & Carpenter, 2011:181) . Data collection in this study started in March

2017 and was completed in November 2017, approximately nine months. One to two interviews were conducted per day since the villages were far apart.

A focus group is a semi-structured group session moderated by a group leader, held in an informal setting to collect information on a chosen topic (Streubert & Carpenter, 2011:37). Essential features of a focus group include the following: flexibility, stimulation, cumulative, elaborative, and assistive, must be capable of producing rich data, and be inexpensive (Streubert & Carpenter, 2011:37). With the help of the traditional leaders, the community members were accessed and gathered at *inqileni place*. They were arranged in focus groups ranging from six (6)to ten (10) members of different age groups and genders. In contrast, the interview for the traditional healers took place in the municipal boardrooms as arranged by the coordinators of the selected districts. The chairperson of the Council of Churches from the selected communities organised the venue for the focus groups held in churches. The shortfall of the focus groups used in this study was group-thinking, which the stronger members of the group tended to dominate. However, the group leader was aware of this tendency and managed to overcome it during data collection.

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2.3.6.1. Data Collection for Focus Group Interviews

Interviewing is a primary mode of data collection in qualitative research and can be highly structured, semi-structured, or unstructured (Becker et al., 2012:286). An interview is the most critical data-gathering technique as it explains and places in context what the researcher observes and experiences. Focus group interviews of six (6) to ten (10) participants were conducted simultaneously to explore the barriers to organ donation uptake from the participants. This approach aided in obtaining the ideas of many participants within a short space of time and enabled rich discussions (Moule, Aveyard & Goodman, 2017:314). Each group discussion was pre-arranged to allow good attendance and solicit support.

Preparation of the field: A large room in a community centre *Nqila House*/municipal boardroom/church study room was secured and prepared for the focus group discussions. One traditional healer offered his practice room for the discussion. The chairs were arranged in a circular sitting formation to create an environment that facilitated discussion (Falout, 2014:282).

The researcher commenced each focus group discussion by introducing herself and the research assistant. The role of the research assistant was explained, the participants were welcomed the purpose of the session, and the expected length was clarified. Participants were informed that the sessions were recorded with their permission and were ensured of the confidentiality of the information they provided. The recording was necessary to enable the researcher to record the exact words of the interview, inclusive of questions so that she did not forget important answers and comments. Using a digital recorder also allowed the researcher to connect with the participants and pay attention to what they said. The participants were assured that their names would not be used when addressing them during the discussions; anonymity was ensured by assigning numbers to each participant and writing as 'Participant 1, 2 or 3'. Ethical considerations and voluntary participation were reiterated. The participants were allowed to ask questions about aspects they were unclear about before the sessions began, followed by the individual signing of the informed consent form (Appendix G).

Verbal interaction was conducted in the preferred language, Xhosa, through probing questions, treating language as a vital medium of communication. The researcher aimed to identify the barriers faced by the Xhosa community concerning organ donation uptake, exploring their opinions and comparing individual perceptions with those of others. This was accomplished through effective interview techniques, including casual conversations. Such comparisons helped the researcher identify common values that contribute to the community's hesitance regarding organ donation. All the participants were asked the following interview questions in Xhosa and responded in their Xhosa language:

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- What is your understanding of organ donation?
- What are your general views about organ donation?
- What are your religious beliefs regarding organ donation?
- What can be done to increase the uptake of organ donation?

A digital recorder was used, and field notes were taken to make a record with the assistance of the research assistant. The researcher was involved by interacting, attaching meaning, and conducting various research methods, such as observing their behaviours regarding the topic and environment. The data was gathered until the saturation stage was reached, meaning when no new information was obtained. Field notes were made during and after each interview while

the events were still fresh/evident in the researcher's mind. Field notes enhance the richness of the data collected by creating a detailed record of all occurrences during interviews. Note-taking is handled sensitively because taking notes in an interview can disturb the participants (Holloway & Wheeler, 2013:12). The discussion lasted approximately one hour. After each session, the researcher thanked the participants for their input, explained how the information they shared would be analysed, and contributed to the research, adding that copies of the research would be made available to their district municipalities, clinics, and hospitals.

2.3.6.2. Data Collection for Individual Interviews

Individual interviews were conducted only during preliminary exploration/pilot study. After identifying the participants, the researcher made an appointment to meet them.

Field preparation: A comfortable table room was used for the interview session in a community centre – *Nqila* – where the chief and community members gathered to hold meetings. The setting was relevant for the interview, with no distractions. It was winter, but the room was warm as the sun shone through the window. The seating arrangement increased face-to-face interaction, which facilitated observation and enhanced interaction (Moule, Aveyard & Goodman, 2017:309). The researcher explained the aim of the research and the interview process, signed consent forms, and the participants who could not write consented verbally and were allowed to put an 'X' on the space provided in the consent form (Annexure G). The researcher requested to record the data using a tape recorder, and the participants approved. Recording assisted in accuracy and catching up on all the information. The recorder was prepared before the recording, and extra batteries were available. Rapport was established between the researcher and the participant–researcher interaction that fostered trust and enabled communication (Prior, 2017:20). Semi-structured interviews with open-ended questions were utilised to collect data and provide thick data from participants in various settings (Parahoo, 2014:318). Each interview lasted thirty to forty-five minutes.

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An interview schedule was used to provide direction and uniformity of the interview. The interview schedule allowed the researcher the freedom to ask additional questions (Parahoo, 2014, p.318); therefore, designing an interview schedule was required. Questions were constructed for an effective semi-structured interview process, allowing for the good narration of participant's views. Questions were brief and precise, neutral, and open-ended, allowing the

researcher to access information that had not been expected (Adams, 2015). After each interview session, the researcher thanked the participants for their input, explained how the information they shared would be analysed, and contributed towards the research, adding that copies of the research would be made available to their district municipalities, clinics, and hospitals. Recorded interviews with audio tape, field notes, and observation notes were encrypted in software with a password.

2.3.6.3. Skills During Data Collection

The following skills were demonstrated during individual interviews, observation, and focus group discussions to encourage active participation without exposure to intimidation. Each interview session began with a short conversation, which created a warm and welcoming environment and put participants at ease (De Vos, Strydom, Fouche & Delport, 2011:371).

Active Listening

The skill was utilised throughout the interview sessions, which enabled the participants to willingly discuss their views on organ donation. Participants also felt that they were heard, which caused them to talk. Each participant was given attention while contributing to the discussion, and the research assistant minimised the distractions at all costs.

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Congruency

Refers to the interconnectedness between methods and questions, between the current study and the previous ones, between the theory and approach; it also refers to connections between study findings and contexts outside the study situation" (Polit & Beck, 2012:586). In this study, the interview schedule promoted uniformity in the phrasing of questions in a respectful manner. Sometimes, the follow-up question was not asked as it unfolded during the discussion, while the discussion provided the use of probing questions relevant to the discussion.

Observation

Leininger and McFarland (2006) in Polit and Beck (2012:545) "describe a participant observer's role as evolving through a four-phase sequence: 1) Primarily observation and active listening; 2) Primarily observation with limited participation; 3) Primarily participation with continued observation; 4) Primarily reflection and reconfirmation of findings with informants". In the study, the researcher adopted the initial phase of observing and listening to the

participants to obtain a broad view of the phenomena under study. Phase 4 was also adopted by the researcher which reflected on what emerged. Parahoo (2014:250) supports that holistic observation can take the nature of participant observation or non-participant observation in the natural environment, meaning that everything (what is seen, heard, read, or felt) is data.

Observation was used to capture the non-verbal cues such as body movements, body orientation, nuances of the voice, facial expressions, details of dress, choice and movement of objects during the interaction. Those cues communicated meanings to the phenomenon of interest, thereby adding a thick description to the data. The four categories of participants were observed to understand their characteristics, non-verbal communication, their interaction with others and their reaction to statements made by others. Field notes included the following observation from the four groups as cited by Spradley (1980) in Polit and Beck (2012:547), see below.

Language identification principle in which the speaker was identified by using quotation marks, parentheses, or brackets to reflect the same differences in the field. The verbatim principle was noted by recording what participants said to separate native and observer terms. The concrete principle was achieved by describing observation and avoiding generalisation or abbreviations; instead, the researcher included as much detail as possible. Observations were used to capture the behaviour, the dress code, the value system, the language, gender, and the artefacts among the four categories of participants in the study.

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Community Members (Group A)

Parahoo (2014:250) alluded to the fact that, for a study to be ethnographic, adequate time should be spent by the researcher with the participants to familiarise themselves with the participants. Arguably, it is difficult to specify what constitutes sufficient time to gain their trust. The researcher's observation was that the entry to the community via the traditional leader paved the way for the researcher to access the community members and that the use of participants' clan names built the relationship between her and the community members. Male and female participants were equally distributed in number. The researcher's observation was that the attachment/relationship and protection between the traditional leaders and community members is substantial. The traditional leaders in one sub-district refused to allow their community members to be interviewed without their presence. All women participants were wearing dresses and doeks, while their male counterparts all wore jackets. Male participants

removed their hats and caps during the interview; all the participants requested to speak isiXhosa, which was accepted. After the interview sessions, participants were served a cool drink and small bread – *rostile* – provided by their traditional leader. The researcher and the assistant were invited to the home of the traditional leader for a home-cooked meal.

Traditional Healers (Group B)

Initially, the researcher explained the research objectives, but they were still suspicious of the researcher's possible ulterior motive, especially with a topic related to human organs. The research assistant distributed the consent forms, which made some people feel uncomfortable by looking at the word "organ" in the documents. Some participants started making sounds, such as taking deep breaths. The traditional healer's focus groups comprised more female participants than males. The faces of some were covered with a white substance – *imbola* – that looked like calamine lotion, and some wore white towels either over their heads or around their waists; sometimes they wore animal fur around their wrists, especially the men. They wore their traditional clothing and requested to open the interview session with a prayer by singing their song type. They were continuously burping – *ukubhodla*. Another interview was conducted inside the traditional healer's private practice room; within the space, there was a makeshift miniature sacred place called *umsamo*. The room was decorated with dried plants and animal skins. Interviews and discussions were conducted in isiXhosa as their language of choice. The participants were provided with a snack after the session and were reimbursed for the cost of their transport, applying the TIE principle, as they came from different villages.

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Ministers of Religion (Group C)

The interview session was opened with a prayer by one of the ministers. The focus groups of ministers of religion responded differently to interviews in different district. Some interviews were conducted in a church and others in a hospital boardroom. The observations were as follows: the discussion in the hospital boardroom was quite vibrant, with laughter in between. The ministers spoke to each other, sometimes agreeing to disagree, many essential points that they highlighted were not previously anticipated by the study. Sometimes, they became angry about the concept of organ donation. The interview conducted in the church building was not as animated which meant the researcher had to probe more to obtain information. Quiet moments were noticed, as the participants were very emotional about the concept of organ donation. In a debriefing session with the research assistant, the conclusion was reached that the church setting contributed to the inactivity of the group. Male domination was also noted

among the focus groups of ministers of religion. At the end of the interview session, the researcher provided them with a light snack.

Traditional Leaders (Group D)

Circumcision/initiation season (rite of passage in Xhosa culture) in the Eastern Cape Province led the traditional leaders to back-to-back meetings with community members and health authorities, making accessing them difficult. Eventually, those who were available participated in the study. The following was observed among these groups of leaders, namely Ubuntu's principle, such as assigning somebody to wait for the researcher at the turn, gate, or street corner to the village for direction. If the researcher arrived in the early morning hours, breakfast was offered to her at the home of a traditional leader before the interviews commenced. Male domination was also noted, and although young chiefs were present, the majority were older, which led to the discussion that they were too old to donate their organs and, thus, recommended that the research be conducted on younger people. However, while the younger traditional leaders participated in the discussion, the older ones dominated the discussion, which the group leader managed to overcome. The following are reflective notes in participant observation studies that the researcher minimally writes:

- Observational notes – details what the researcher saw.
- Method notes – strategies that were employed or that might be employed in future observations.
- Personal notes – researcher's feelings during the research process.
- Theoretical notes – interpretive attempts to attach meaning to observations (Polit & Beck, 2012:549).

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Probing

Questions or statements were used to clarify the information provided by the participant (Burns & Grove, 2009: 405), and probing was employed when a participant did not understand a question or to clarify a statement. The purpose of probing was to elicit more information. The following probes were used:

- Is there anything else? Are there any other reasons? Could you please explain that? Could you please repeat what you have just said?
- The silent probe and the long pause indicated to the participants that they should continue listening while the researcher was speaking.

- Complimentary questions that are not directive and open-ended such as, what was your reaction when you heard about organ donation?
- Affirmative comments were also used, such as 'mh', 'okay', and other various probes used.

The greatest test of an interviewer is to use probes effectively during interviews, knowing when to probe, and which probes to use (Polit & Beck, 2012: 310).

Communication Techniques

Verbal communication was used throughout the study but kept as minimal as possible. Open-ended questions were asked to allow participants time to freely use their own words to describe organ donation uptake and making description words (De Vos et al., 2011: 371). Paraphrasing and repeating the participant's information allowed the researcher to use a few words to restate the participant's description of a view or understanding. Participants were constantly directed and redirected when they go astray from the topic. Simple language with minimal terminology used to enhance understanding and facilitate easy communication. A reflective summary used to summarise participant information and to clarify or confirm their understanding of the purpose of the group.

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Transcription

Transcription is "the process of making a verbatim written record of narratives from the interviews and focuses group discussions on preparation for data analysis" (Polit & Beck, 2012: 557). Data was prepared for analysis through a detailed transcription (Appendix H). Data transcription started immediately after the first interview and continued throughout all data collection approaches since it was an iterative process. Transcription was followed by data analysis; as such, areas not properly covered by such interviews were identified and corrected by returning to the participants. Verbatim transcription was carried out to ensure accuracy and reflection of participants' views/perceptions of barriers towards organ donation. It was crosschecked with the research assistant to avoid errors and bias during recording. An independent translator translated all the transcripts written in isiXhosa, which was later translated to English. See the Translation certificate attached (Appendix I).

2.3.7. Reasoning Strategies

Reasoning is the process of using existing knowledge to conclude, predict, or construct an explanation or outcome. Thus, reasoning strategies involve considering and selecting an efficient and effective method for solving a problem (Walton, 1990:401). Consequently, the following reasoning strategies were applied during data collection and analysis:

2.3.7.1. Inductive Reasoning

This is described as "making projections about different conditions, based on the existing knowledge" (Moule, Aveyard & Goodman, 2017: 155). The process was viewed as making probabilistic predictions (outcomes having varying degrees of certainty or uncertainty). The data analysis in Phase 1 allowed for codes and categories to emerge through inductive reasoning, which was applied to the context.

2.3.7.2. Reflexivity

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Although the researcher needs to remain impartial and stay focused on the research he/she becomes a member of the culture on some level. Through this type of participation, researchers came to realise that they may modify the culture and have the potential to lose their impartiality more than is typical in the usual conduct of research because of their prolonged involvement as a researcher and the participant in ethnography; thus, it is extremely difficult to maintain a completely detached view (Streubert & Carpenter, 2011: 174). Reflexivity is defined as being completely open about the decisions made in the research process (Engward & Davis, 2015). It is part of trustworthiness; an audit trail was established after the interviews (Moule, Aveyard & Goodman, 2017: 365), and member checking was carried out to determine the researcher's subjectivity. Methods of data collection, data analysis, and time spent with the data were described, which helped with reflexive thinking because it reflected how much the researcher knew about the data. Self-awareness and self-examination were practised because the researcher was aware of her role throughout the research process. She also submitted the research work periodically to the supervisor and co-supervisor for direction.

2.3.7.3. Bracketing

It is described as a strategy adopted by qualitative researchers to suspend their knowledge of a particular research topic (Moule, Aveyard & Goodman, 2017:366). The researcher minimised

bias by limiting reviewing literature comprehensively before commencing with data collection and analysis (Streubert & Carpenter, 2011:77). During preliminary data collection, measures were applied to identify researcher own biases and document how these might influence perceptions. The biases were discussed with colleagues, through self-reflection, peer debriefing, member checking, documentation and the researcher approached the study with cultural sensitivity and authenticity, which was essential for producing credible and applicable research findings.

2.3.7.4. Intuiting

This is a technique in qualitative research in which the researcher "focuses all awareness and energy on the participants" (Burns & Grove, 2009:529). The researcher gained insight and knowledge about how the participants understood the uptake of organ donation through that process.

2.3.7.5. Audit Trail

An audit trail refers to the steps followed in the research (Moule, Aveyard & Goodman, 2017:365). Such a trail helps to increase research rigour. Furthermore, it forces the researcher to be responsible for reporting the results and explaining how the results were obtained. By demonstrating the thinking and action process, researchers allow others to agree or disagree with each rational decision and to confirm, refute, or modify interpretations (Parahoo, 2014:238). The researcher kept the audio recording, the transcriptions, and field notes on the research to follow a trail of events.

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2.3.7.6. Triangulation

Triangulation in this study was applied to obtain multiple information from different sources and improve the probability that the interpretation and results were credible. According to Burns and Grove (2009) triangulation entails the combination of more than one theory, method, data source, investigators, data collection, and analysis methods when investigating a phenomenon. In this study, therefore, semi-structured interviews, observation, field and focus group discussion notes were used to serve as triangulation of data methods.

2.3.8. Data Analysis

The data analysis process allowed the researcher to obtain a greater understanding of the data and accurately interpret it (Creswell, 2003:190). According to Fetterman (2010:93), "the analysis in ethnography is as much of a test of the ethnographer as it is a test of the data". All recorded interviews were transcribed verbatim by the researcher within 48 hours of the interviews, and the ethnographic notes were read. The immediate transcription of the recorded data promoted capturing valuable information in text (transcribed interviews and field notes). Leininger and McFarland (2006) in Polit & Beck (2012:565) provided ethnographers with a four-phase ethno-nursing data analysis guide used in the study.

Table 2.4: Four Phase Ethno-Nursing Data Analysis

Ethno-Nursing Data Analysis Phases	Description
Phase 1	Raw data were analysed, including recorded interviews, observations, transcribed interviews, and field notes. Significant statements related to the domain of inquiry and research questions were extracted from it to formulate meaning for each statement and a code was assigned. According to Saldana (2013:3), a code is often a word or a short phrase that symbolically summarises and essence-captures a portion of text. The coded portion can be one word, a paragraph, or an entire page (2013:3).
Phase 2	Data were coded and classified according to the domain of inquiry (objectives). Coded data was developed into categories and domains labelled according to constructs of the culture care theory. Additional unique codes specific to the study were also added. Formulated meanings were grouped together and termed as categories (Saldana, 2013:9), which later integrated into descriptions, termed as themes or concepts.
Phase 3	Data were scrutinised to discover saturation of ideas and recurrent patterns of similar and or different meanings. Pinpointing participants' commonalities and differences regarding organ donation uptake was important for identifying their beliefs, values, and practices within their environmental context. Repeatedly comparing cultural similarities and differences led to results that would not have been discovered if only their diversities had been considered (McFarland, Mixer, Wehbe-Alamah & Burk, 2012:265). (McFarland, 2012).
Phase 4	Interpretation and synthesis of findings. The researcher elucidated and confirmed major themes, care actions, decisions, and new theoretical formulations with the participants ((McFarland, 2012).

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Follow-up interviews via face-to-face meetings and phone calls aided the researcher to clarify interpretations, meanings, and findings. An independent coder then analysed the information. The researcher and the independent coder discussed the results and reached a consensus regarding the findings (Appendix J). The themes and sub-themes are discussed in the next chapter. Phase 1 of programme development was achieved using a qualitative approach.

2.4. INTERVENTION MAPPING FRAMEWORK (IMF) PHASE 2

2.4.1. Phase 2 Step 2 and Step 3: Matrices of Change Objective, Theory-Based Intervention

Phase 2 involved conceptualisation. As described by Dickoff, James & Wiedebach (1968) and the (IMF), elements of practice theory were used to conceptualise the programme framework in promoting the uptake of organ donation among the Xhosa community in the Eastern Cape. The phase was meant to achieve Objective 2 of the IMF:

Research objective: To develop the matrices of change objective that will inform the programme to promote the uptake of organ donation among the Xhosa community.

Research question: What matrices of change objectives and theoretical-based interventions would be suitable to inform a programme development that promotes the uptake of organ donation among this community?

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2.4.2. Conceptualisation

Conceptualisation makes up Phase 2 of the programme development process. According to Burns and Grove (2009), this term refers to clarifying and analysing critical concepts in a study and integrating one's research into existing research and theory. The main themes and sub-themes were identified from the results obtained from the situational analysis in Phase 1. A schematic presentation of the elements of a practice theory described by Dickoff et al. (1968), within which the main concepts are categorised and arranged, elements are provided in Figure 2.2, below, and discussed in detail in Chapter 4 of this study.

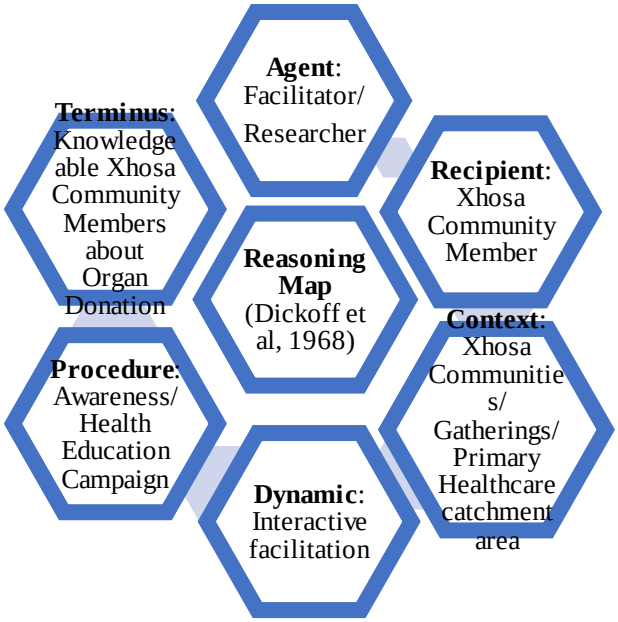


Figure 2.2: Reasoning Map (Dickoff et al., 1968)

The reasoning map (Figure 2.4) shows the integration and connection between the concepts. The 'agent' refers to the researcher with her scientific knowledge and skills who performs the activity. The 'recipient' is the Xhosa community (traditional healer, traditional leader, religious minister, and general community member) who needs to be empowered with comprehensive knowledge of organ donation. The 'framework' is the context (Xhosa communities/villages) in which the activity is performed. 'Terminus' is the endpoint of activity. The Xhosa community will be more knowledgeable about organ donation uptake. The 'procedure' is the "guiding process, technique, or protocol of the activity", which is the organ donation process in this study. The 'dynamics' refer to the energy source needed for the action: the relevant dimensions, realities, and theories (Dickoff et al., 1968). The framework is derived deductively from the idea.

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2.4.3. Methods of Adopted IMF – Phase 2

The programme framework was developed in collaboration with stakeholders (the Xhosa community that included all the categories) participated in study interviews, same actualised through active teamwork.

According to Bartholomew et al. (2011), beneficiary participation is essential to increase the acceptance and sustainability of a programme, in the development phases (Ceptureanu & Luchian, 2018:11). Therefore, Xhosa people were involved in all stages and the phases of the

programme development. Organisations and researchers advocate for stakeholders' involvement in research affecting them to utilise their inputs (Boaz, Hanney, Borst, O'Shea & Kok, 2018; Bartholomew et al., 2011; NICE, 2006).

2.4.4. Phase 2, Step 2: Matrices of Change Objective

The goal of the IMF, Step 2, was to generate a list of intervention methods that matched the proximal programme objectives (situational analysis) as stated in the matrices of Step 1, and to find practical ways of delivering those methods to the target population. From the situational analysis, Bartholomew et al.'s (1998:551) performance objectives are required to answer two categories of questions specifying health-promotion behaviour and environment, in which the first question is: what do the participants in this programme need to do to perform a health-related behaviour? – What do the Xhosa community in this programme need to do to improve the uptake of organ donation? Secondly, in terms of their environment: what will change in the environment because of this programme – what will vary among the Xhosa community regarding organ donation utilising this programme, and who will influence the change? – Who will make the change to the Xhosa community regarding uptake of organ donation. In response to these questions, the "effective performance objective breaks down the health-promoting behaviour and the desired environmental conditions into clear, concise statements that describe the criteria for achieving the desired change" (Bartholomew et al., 1998:551). Examples of intervention methods included:

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- community meetings, allowing persuasive communication (Bakir, Herring & Robinson, 2021).
- group meetings, allowing for problem-solving (Linabary, 2021).
- societal engagement (Bauer, Bogner & Fuchs, 2021)
- self-talk for cognitive behavioural restructuring (Legg & Stanborough, 2020)
- support groups for social/public support (Murphy & O'Hare, 2016)
- role-model stories for symbolic modelling (Al-Hoorie, 2021); and
- Role-playing for skill practice (Running & Bjorkly, 2019).

2.4.4.1. Preparation for Step 2

A meeting was held with the Xhosa community to familiarise them with the adapted IMF, and their roles, as stakeholders were specified during the development of Step 2 of the framework.

A conducive, safe environment was organised that allowed the community members to participate freely in the discussion without feeling embarrassed/intimidated or fearing persecution because of their feelings and ideas. The IMF agreed on equal power-sharing and secrecy. A place outside the community was arranged ensuring safety and encouraging participant confidence.

2.4.4.2. Group Meeting

A group meeting took place in an informal and friendly atmosphere. Participants were welcomed and allowed to introduce themselves. They were allowed to share their views and perceptions about organ donation to build personal relationships with the researcher and each other. The methods or ideas included in the development of the programme were provided by all the invited stakeholders. The folkway sector (emic) was presented by two traditional leaders, three ministers of religion, four traditional healers and two general community members who participated in the interviews and focus group discussions. Two medical doctors, one organ transplant coordinator, a social worker, and one critical care trained professional nurse who were purposely selected presented the professional sector (etic). The situational analysis resulted in the emergence of themes and sub-themes from the semi-structured interviews, observations, and focus group discussions presented to the groups by the researcher. Information gathered from the participants was supported with literature.

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Phase 1 was discussed with the stakeholders, and an agreement was reached about holding a workshop.

- Stakeholders in a meeting acknowledged that the Xhosa community members lack knowledge/information and understanding of organ donation.
- Adequate information about organ donation is essential to promote the uptake of organ donation.
- The Xhosa community members should be assisted in understanding the information and in making their own decisions regarding organ donation during collaboration with healthcare professionals, and
- Healthcare professionals should be sympathetic and empathetic when dealing with the issue of organ donation as it is a sensitive and uncomfortable topic. Group members highlighted a change to promote organ donation.

This collaborative work allowed participants to take ownership of the programme (Tanner, 2017) and initiated a learning need for both the researcher and stakeholders. The content of the discussion focused on:

- Bringing together the matrices of change objectives, based on the goals and objectives for the programme, as identified in Step 1 (Bartholomew et al., 2011).
- Participants acknowledged the outcomes for behaviour change and environmental change of the Xhosa community.
- Stating performance objectives (Bartholomew et al., 2011); and
- Discussing how the theoretical determinants in behavioural theories (theoretical assumptions in Chapter 1) were significant (Botes, 1995).

These tasks were completed to enable the development of real matrices. The matrix of change is the primary tool or foundation of the intervention mapping (Bartholomew et al., 2011). It entails planning for the programme, specifying areas in which changes will occur due to the programme (Bartholomew et al.., 2011). A set of changes addressed by the programme, both individual and environmental, was documented to improve community health outcomes and the quality and lifespan of its members (Community-Based Prevention, 2012.

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Programme Outcomes from Themes (Phase 1) – First Task

Programme effects are specific behaviours the Xhosa community should achieve through the intervention programme. Positive effects of the programme on the Xhosa community were anticipated and actualised through participation in the programme. A thorough situational analysis and literature support were performed during the first phase. They offered insight into the reasons behind the lower rates of organ donation within the Xhosa community, highlighting how environmental barriers impede their self-regulation and commitment to the practice.

The situational analysis conducted confirmed that the Xhosa community lacked knowledge/understanding of organ donation uptake or had little information regarding organ donation. The participants displayed both negative attitudes to the uptake of organ donation. They highlighted several barriers and further mentioned the challenge of not reaching out to rural areas by the health professionals to give information on organ donation. Therefore, a health education environment should support intrinsic motivation and instil confidence and

positive attitudes to organ donation (Kong, 2022). Organisational environmental factors, such as teaching methods, may contribute directly or indirectly to low uptake (Karami, Pakmehr & Aghili, 2012:3270; Shukla, 2018). Therefore, the planning group recommended a community facility approach to health education during the situational analysis to facilitate health education and improved outcomes of the Xhosa community. According to the National Institute for Health and Care Excellence (NICE 2006), interventions implemented in a real community setting, such as the mode and source of delivery, improves intervention effectiveness.

Performance Objectives – Second Task

The second task included sub-dividing behavioural and environmental outcomes into performance objectives. Performance objectives were matched with activities the Xhosa community expected to perform. The planning group utilised their professional knowledge, experiences, and creativity to develop performance outcomes.

Selection of Important Determinants in Theories – Third Task

The third task includes the development of determinants of behaviour, which were actualised using constructs from the theories of behaviour change (Chapter 1). Determinants are factors that are associated with self-regulation within individuals (cognitive factors/core system of thoughts) that they can easily control or those factors within the environment (social and structural factors) that can be changed (Bartholomew et al., 2011; Leininger, 1988). An IMF is a theory-based intervention and involves identifying the task of developing an educational programme. It was convenient for the group to know that interventions to change behaviour regularly may be effective if grounded in appropriate theory, which relates to the determinants of behaviour (Davis, Campbell, Hildon, Hobbs & Michie, 2015:338; Sutton, 2004:96). Theory simplifies the understanding of those factors that work best because theory-based interventions use contributing trails (Abraham & Michie, 2008; Hardeman, Sutton, Griffin, Johnston, White, Wareham and Kinmonth, 2005:676).

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The educational programme was intended to affect behaviour change. Therefore, theory-guided behavioural constructs to enhance changes in this community were derived from the following theories: the behaviour change self-determination theory, social cognitive theory, information motivation and behavioural skills model, the health-promotion theory (Chapter 1), and Leininger's theory of environmental determinants. Determinants of behaviour, such as self-

efficacy, proficiency, autonomy, attitude, outcome expectations, and knowledge, were selected.

Matrix of Change Objective – Fourth Task

This task involved matrices for each performance objective. Performance objectives and determinants of behaviour were used in forming tables for the matrices. The matrix of change objectives represented the trail of essential changes expected to occur in the conduct of the community, reflecting pathways and actions taken by healthcare professionals (Bartholomew et al., 2011). The matrix specifies what the Xhosa community needs to learn, and the changes expected in their environment (Leininger's theory in Chapter 1). This task was the primary tool for intervention mapping (Bartholomew et al., 2011) since it entailed the detailed planning of the proposed programme. The themes from the data analysis of the situational analysis (Phase 1) provided a clear statement of the barriers towards uptake of organ donation, which indicated the communal behaviour and attitude to be changed and strengthened a positive attitude. The environmental factors linked to the needed change (observational notes).

2.4.5. Phase 2, Step 3: Selecting Theory-Based Methods and Practical Strategies

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The planning group mirrored the theoretical assumptions that guided the study. It was acknowledged that certain assumptions were applied as they indicated changes in the determinants of behaviour of the relevant community were also needed towards self-regulation and environmental factors (Bartholomew et al., 2011), such as educators in the healthcare environment. Theoretical assumptions formed the underlying basis of the programme. A theoretical method is a general practice for inducing changes in the determinants of behaviour and environmental conditions (Bartholomew et al., 2011). Xhosa people in the community (of all categories) were required to implement specific behavioural changes to enable a quality of life through organ donation; therefore, using theoretical methods to influence behaviour change may help in commencing and supporting healthy behaviour. A practical strategy is the 'first-hand' use of suitable theoretical approaches for programme activities. Research has shown that interventions targeting fundamental determinants of behaviour are more effective when planned by using appropriate theories. Consequently, the programme development group identified applicable theoretical methods for changing behaviour determinants to ensure effectiveness in changing behaviour (van Achterberg, Huisman-de Waal, Ketelaar, Oostendorp, Jacob & Wollersheim, 2011; Sales, Smith, Curran & Kochevar, 2006:s43).

The fourth task led to the creation of programme ideas with the planning group by:

- Identifying theoretical methods for teaching.
- Choosing programme methods for teaching.
- Selecting or designing practical applications that addressed change objectives.

Programme Ideas Generation – First Task

Programme ideas were generated with the planning group, and the promotional education was completed in Step 2 by the planning group. The programme's structure was deliberated based on the themes from the needs analysis. The literature support enabled the planning group to understand the programme better and paved the way for more discussions about what should be included based on the group's practical experiences and creativity. The programme's purpose was to change the behaviour of the Xhosa community towards organ donation.

Theoretical methods identified – Second Task

Theoretical methods were identified for influencing changes in the determinants of behaviour (Bartholomew et al., 2011). The performance objectives and related activities were chosen to utilise the behaviour's determinants. The group then drew up a list of change objectives by matching the list of methods of change and their applications, after which they discussed, deliberated on, and outlined the most relevant ways to address the selected behaviour determinants.

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Programme methods – Third Task

The most applicable methods and approaches used in teaching and health-promotion were identified. During health educational programmes, communicating information, processes, and skills to community members needs a careful selection to understand the message and integration. Such methods or approaches always depend on the goal achievement and the topic under discussion. Brainstorming was used to identify the techniques or processes which would be used. The techniques included individualised teaching, demonstrations, literature materials, or pamphlets, elaboration, participation, active listening, tailoring, modelling, overview lectures, role-play, feedback, and discussions. The environmental methods chosen were discussions, demonstrations, and seminars.

Practical Applications – Fourth Task

To ensure that the practical applications addressed the change objectives, reasonable selection or designing practical applications were selected carefully. This step entailed applying the theoretical methods discussed in the previous task, matched with the goals to differentiate theoretical methods from practical applications. Brainstorming highlighted various approaches, such as individualised teaching, demonstration, literature materials, elaboration, lectures, role-playing, feedback, and group discussions.

2.5. INTERVENTION MAPPING FRAMEWORK (IMF) PHASE 3

2.5.1. Phase 3, Step 4: The Development of a Programme Promoting Uptake of Organ Donation

This phase involved the steps of (IMF) in developing a health education programme in promoting organ donation among the Xhosa community in the Eastern Cape Province. The phase meant to achieve objective 3 of the study:

Research Objective: To develop a programme to promote the uptake of organ donation among the Xhosa community.

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Research Question: What nature of a programme would aid the promotion of uptake of organ donation?

2.5.2. Methods of Phase 3

This phase was aimed at creating an inspired and structured educational programme relevant to the needs and culture of the Xhosa community. A structured educational programme was created based on the steps completed in the previous sections and the themes that emerged from the situational analysis (Bartholomew et al., 2011). The level of education, cultural practices, and ethnic background of Xhosa community members are considered, and the dimensions of the health institutions and available resources measured for the programme implementation. At this stage, the professional sector (etic) was involved, and an iterative movement back and forth was applied to determine any shortcomings to the programme. The following programme goals were achieved collaboratively with the members of the planning group:

- Creation of themes, scope, sequence, and a list of materials for the programme.

- Preparation of materials used for teaching methods and practical applications.
- Reviewing available program materials and selected materials that matched the change objectives, methods, and practical applications.
- Drafting material and protocol for the programme.
- Re-examining programme materials and protocol.
- Producing materials and protocol.

The activities outlined in this step necessitated the application of scientific methodologies. A comprehensive discussion regarding the matrix of change objectives established in Step 2 took place, with all professionals actively participating and creatively drawing on their knowledge and experiences. The program was designed to be culturally relevant, incorporating materials that resonate with the norms and values of the Xhosa people.

2.5.3. Creation of the Programme Plans and Structure

The Theme, Scope, Sequence, and a List of Materials – First Task

The requirements for the programme were based on the tasks performed in the previous steps. The programme development was built on the assumption that optimal health is essential for both organ donor and the recipient, regardless of their gender, educational status, socio-economic status, ethnic, or cultural background.

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Preparation and Designing the Document – Second Task

The planning group developed the programme by applying the behavioural objectives, performance objectives, matrices (previous steps), and situational analysis themes. The methods used are derived from Step 2. The content to be included in the programme was extended to incorporate detailed views that participants would easily recall (Chapter 4). The teaching tools were intended to excite different senses in the individuals, such as visual, auditory, tactile, and necessary for learning (Lowenstein, Foord-May & Romano, 2009). These teaching tools may affect the individual psychologically, and that impact is an essential factor for behaviour change (Nasaba, Esmaeilib & Saremc, 2015:26). The tools were aimed at:

- Providing various content materials to enable the educator to tap into the learner's learning style,
- Abstract or complex clarification, and

- Simplifying complicated explanations by making them easy to understand.

Draft Programme Materials and Protocols – Third Task

The widely used materials included handouts, brochures, booklets, pamphlets, logbooks, notebooks, and goal-setting action plan books. The proposed material will be re-read to identify those most culturally subtle and personalised to the needs and characteristics of the population. The situational analysis confirmed no teaching in public health institutions on organ donation (Chapter Four). Existing materials from health organisations, such as WHO and Organ Donation Foundation, and compatible with the planned programme could be reviewed for teaching. Appropriate material will be made available, such as guidelines on organ donation, policies, and readable materials; however, due to low literacy levels, certain materials could be adapted to equip the relevant population (Williams, Muir & Rosdahl, 2016:10).

To improve the outcome of the materials for the participants and to improve understanding, it should be tailored to the needs of the participants (Powell, Beidas, Lewis, Aarons, McMillan, Proctor, Khinduka & Mandell, 2017:177; Jensen, King, Carciopplo & Davis, 2012:1460; Kreuter, Oswald, Bull & Clark, 2000: 305). McCray (2005:152), has indicated that many health-related topics are written at levels higher than the participant's reading ability, and the language at the 6th-grade level that the participants do not understand, which may affect their understanding and retention. Therefore, the materials could be adapted with due consideration for the low educational status of participants.

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Produce Materials and Protocols – Fourth Task

The Organ Donor Foundation in South Africa that produced materials related to organ donation was contacted for pictorial posters, radio messages, and video clips. Health information on the internet could also be evaluated to ensure its reliability and quality by tracing the source – peer-reviewed quality source, author, and date of every source and address to assess the site's credibility. The National Institute of Health (2007) advised users, through Medline Plus's Guide to Healthy Web surfing, to evaluate written health information from all sources before usage. A few materials will be developed for use with the participants to provide content-specific details tailored to their needs. Healthcare professionals will be assigned to perform the tasks. The target audience, especially their literacy levels, frequently used words, and objectives to be achieved with the material developed and the programme's content layout were considered.

Re-Examining the Programme Materials – Fifth Task

The adapted and developed materials will be reviewed by a group of Xhosa individuals to ensure that the messages conveyed in the designed leaflets and posters reflect the needs of the participants (Patterson, 2022: 77). All materials, including posters, written content, and audio messages, will be evaluated for audience reactions (Sinyai, MacArthur & Rocotagliata, 2018:847). The goal is to understand the audience's perception of these materials and messages. This review process will involve sharing the materials with two groups of Xhosa people, who will have the opportunity to provide additional information and share new ideas related to the program. Feedback from gatekeepers will also be integrated. An organ transplant coordinator, medical doctor, and social worker will be consulted to review the components of the program. The educational program was developed based on the tasks outlined in Steps 2, 3, and 4.

2.6. PROGRAMME REVIEW

Reviewers were selected based on their competence, a transparent process, and their possessing several types of expertise. Each reviewer has sound knowledge of the phenomenon being studied. The reviewer has a broad understanding of the economic and social development issues and challenges within the Xhosa community. Reviewers were familiar with the Xhosa community's culture, tradition, and characteristics. Consequently, they were equipped to understand and respect the local customs, beliefs, and practices throughout the reviewing process.

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The goal of this review was to ensure that the programme met the appropriate standards of quality and integrity. Three (3) external review panel members were appointed based on the criteria explained in the composition of the evaluation team. A letter requesting their participation in the review panel was emailed to them with the consent form attached. Upon their signing the consent form, a draft programme and the checklist were emailed to them. Reviewers responded after two (2) to 12 weeks after the initial request. Their responses are attached as appendices, and their recommendations considered.

2.7. MEASURES TO ENSURE RIGOUR

Credibility is ensured by using the framework of trustworthiness of data and interpretation (Lincoln & Guba, 1985:290). Leininger acknowledged the work of Lincoln and Guba (1985:290) and further added three qualitative criteria to evaluate ethno-nursing research: meaning-in-context, recurrent patterning, and saturation (McFairland, Mixer & Webhe-Alamah, 2012:267 in Leininger, 1991b:200b).

2.7.1. Trustworthiness

Trustworthiness in a qualitative study refers to the truth value of its results (Lincoln & Guba, 1985:290). Reliability in qualitative research aims to support the argument that the study findings are "worth paying attention to" because they meet the following criteria, namely: credibility, dependability, confirmability, transferability, and authenticity for the qualitative approach. Lincoln and Guba (1985:290) suggest four measures for ensuring qualitative research's trustworthiness. Guba and Lincoln (1994:114) also include authenticity, a construct in the constructivist paradigm. To ensure this study's rigour, the researcher adopted the five criteria proposed by Lincoln and Guba (1985; 1994).

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2.7.2. Credibility

Refers to evaluating whether the research findings represent the interpretation of the data drawn from the participant's original data (Lincoln & Guba, 1985:290). Therefore, credibility is equivalent to the internal validity of the positivist, which refers to confidence in the truth and interpretations or the belief in the findings (Polit & Beck, 2012:585). The researcher achieved this criterion by applying the following measures:

- Ensuring that the research methodology integrated adequate operational steps, such as using the purposive sampling method and data derived from semi-structured interviews, observation, and focus group discussions.
- Ensuring that **prolonged engagement** with the participants and context was achieved through visits to the Xhosa villages to become familiar with the culture. At the same time, rapport was established before the research started. Between 30 minutes to 2 hours were spent with the participants during data collection. The researcher was immersed in the data by engaging in repeated readings.

The **literature review** was conducted to confirm the results of the data analysis. The literature also provided the results of other studies (Moule, Aveyard & Goodman, 2017:81).

The researcher's experience and qualification are considered as the researcher was the principal instrument of data collection and analysis (Polit & Beck, 2012:583) and there was a need for explicit information about the role of the researcher during the research process.

Research scrutiny was performed through discussions with colleagues and peers. The feedback was used to refine the methods, and to improve the research's general outlook, and make use of member checking, in which the respondents were asked to collaborate on findings and peer examination with colleagues who have experience in qualitative research (Lincoln & Guba, 1985:313).

2.7.3. Transferability

Transferability refers to the extent to which the findings can be transferred to other settings or groups, which depends on the degree of similarity between the actual situations to which it is transferred (Moule & Goodman, 2009:395). Transferability is linked to generalisability and external validity in quantitative studies and related to the extent of applying the results of a survey to another situation (Struebert-Speziale & Carpenter, 2007:49). A detailed description of the process, participants, contexts, and results provided allow the reader to gain insight and make a given transfer. The researcher brought enough information, which included the culture, context, and elements of the participants and offered a suggestion about transferability, which the reader used to determine whether the results provided a thick description of the new setting.

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2.7.4. Dependability

Dependability refers to using an inquiry audit in which the reviewers examine both the process and the product of the research for consistency (Lincoln & Guba, 1985:317). Dependability matches with reliability in a quantitative study. The criterion focused on the integrity of the investigation and the stability of the data over time and conditions. According to Lincoln and Guba (1985: 317), credibility cannot be obtained in the absence of dependability; therefore, dependability was achieved through the utilisation of multi-methods of data collection. The researcher in this study achieved this through data collection, peer debriefing, and an audit trail since the input of the planning group was valuable from the planning stage to the programme

development. Additionally, the supervisor's information was used. Triangulation of results of the different techniques were considered before the programme development. Additionally, a wide range of participants took part in the study during the data collection. Among participants were traditional leaders, traditional healers, ministers of religion, and the general community members from different Xhosa villages and different districts of the province. Therefore, triangulation of data sources was conceivable, and an image of participants' behaviour was constructed because of the contributions made (De Vos, Strydom, Fouche & Delport, 2011:420). Participants were given autonomy to voluntarily participate in the study and to discontinue at any data collection stage without fear of penalty.

2.7.5. Confirmability

Confirmability refers to the degree to which the neutrality of the research interpretations is demonstrated through a 'confirmability audit' provided through an audit trail of raw data, analysis notes, reconstruction and synthesis products, process notes, personal notes, preliminary development information (Lincoln & Guba, 1985:320). It is also based on proving that the data represents participants' views and that the transcript was created (Polit & Beck, 2012). In this study, data collection is guided by the interview guide with open-ended questions. The supervisor scrutinised the interview guide and an experienced colleague scrutinised the interview guide before data collection. The experienced independent coder analysed data to ensure the accuracy of the data interpretation. The participants' voices were heard through accurate data transcription and supported data results. Member checking after preliminary exploration and data collection, member checking were ensured by taking the transcript back to some of the participants to check whether the transcribed words represented their thoughts and experiences accurately (Polit & Beck, 2012:591). Reflexivity was done intermittently to evaluate the researcher's role as the study unfolded, actions recorded, and thoughts used to understand self-involvement, influences, and biases.

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2.7.6. Authenticity

Refers to the ability to "show different realities in the research process, from the data collection to the interpretation of results", this is the extent to which the readers can follow the trend in the phenomenon of interest by feeling and grasping the mood of the study (Polit & Beck, 2012:585). A detailed description of the research process is provided.

2.7.7. Meaning-in-Context

Focuses on the significance of interpretation by the researcher, understanding of the participants' actions, events, communication, and other activities in their environmental context (McFairland, Mixer & Webhe-Alamah, 2012:267 in Leininger, 1991b:200b). Meaning-in-context was achieved by reporting the observed participants' behaviours, actions, and communication within their environment without alteration by permission of the gatekeepers.

2.7.8. Recurrent Patterning

Refers to experiences, human events, and lifeways that patterned tendencies over time. In Phase 3 of the data analysis, data was scrutinised to examine the universal and diverse meanings of cultures, the commonalities shared by the groups, and their different views, beliefs, and practices (McFairland, Mixer & Webhe-Alamah, 2012: 267 in Leininger, 1991b: 200b).

2.7.9. Saturation

Refers to the notion that data is collected until redundancy occurs, participants share similar content, and the researcher notes the recurrence of the same information. During data collection, the researcher listened carefully to participants to determine the repetition of ideas as the research continued (McFairland, Mixer & Webhe-Alamah, 2012:267 in Leininger, 1991b:200b).

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2.8. ETHICAL CONSIDERATIONS

An Ethical Certificate Number REC-270710-028-RA LEVEL 01 for the study was received from the University Research Ethics Committee (Annexure A). Permission to research in the selected districts was obtained from the Department of Health of the Eastern Cape Province through the Eastern Cape Health Research Committee (Annexure B).

The study was based on the Belmont Report (1979), which articulates three main principles, and Chennells and Schroeder (2017) San Code, which embraces four pillars. The main principles of the Belmont Report are beneficence, respect for human dignity, and justice. The four pillars of the San Code are respect, honesty, justice, fairness, and care.

2.8.1. The Principle of Beneficence

This principle is based on "do no harm". No harm was anticipated, but some form of discomfort was noted as organ donation is associated with death, which is a sensitive subject of discussion. Participants were supported psychologically through debriefing sessions after their interviews and the focus group discussions (Brink, 2010:40). The discomfort was noted in the facial expressions and the tone of voice of some of the participants. The researcher's contact details were made available for any clarification of issues. Exploitation was avoided since the data was collected after the appointments were made and agreed upon. The study had minimal risks in comparison to its perceived benefits. According to the Chennells and Schroeder (2017), (San Code), emphasis is on keeping promises by giving back something to the research communities. These gifts are not of monetary value but rather knowledge and skills. Adequate information about the study was given to assist the community in understanding the purpose and benefits of the research. The participants were informed that they might be contacted again to clarify information (member checking). The participants were provided with a snack after the session and were reimbursed for the cost of their transport, by applying fairness in terms of consideration for the participants' time, inconvenience and effort – the TIE principle.

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2.8.2. Principle of Respect for Human Dignity

Chennells and Schroeder (2017) San Code, emphasise that the researchers should "knock on the door and wait for the 'come in', not the window". The community should be approached through their respective community leaders. Permission to access the community was sought through traditional leaders. Rapport was established before the interviews and focus group discussions and was maintained throughout the research period. Participants voluntarily took part and could terminate any time during the interview or meeting without penalty. Their self-esteem was maintained throughout the interviews or discussions by treating them equally allowing each participant to talk freely without intimidation. Their views and opinions were listened to and respected. The San Code by Chennells and Schroeder (2017) stresses that the researchers must respect population groups' culture, avoid taking photographs and publishing them without consent, and should respect their norms and values. The researcher took no pictures during data collection, and the researcher dressed appropriately to show respect to the Xhosa culture and removed her shoes at the traditional healers' bidding.

2.8.3. Principle of Justice

The proper selection of the participant ensures the right to fair treatment to participate in the study as guided by the eligibility criteria (Brink, 2010: 40). Criterion followed without discrimination. The participants who refused to take part and walked out were not victimised. Knowledge was shared honestly, and the themes that emerged from the research were presented to the stakeholders of the planning group in the development of the educational programme. In addition, two principles were applied:

1. ***Right to privacy:*** the collected information was kept confidential ("under lock and key") in a safe place; only the supervisor and the co-coder had access to it (Brink, 2010: 33). Data not linked to any participants.

   Anonymity was guaranteed, audiotapes were numbered, and transcripts were kept separately from the audiotape recordings, and kept in a secure place (Babbie, 2008:69).

2. ***Informed consent:*** all information about the aim and purpose of the study, as well as the research process was communicated to participants. Potential benefits were disclosed to the participants. They were briefed in isiXhosa as their preferred language and informed about the use of audiotape and its rationale, and their permission was granted. They were further assured that their identities would not be disclosed while the recorder was used. Participants were informed about the field notes being taken during data collection. Participants were allowed to ask questions with the researcher providing clarity; written and oral consent was obtained from participants.

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2.9. SUMMARY OF CHAPTER TWO

The intervention mapping framework (IMF) by Bartholomew et al. (2011) guided the methodological process, thus providing the study's structure. Data was collected in phases and steps in which each phase and step inform each other. The research setting was established, and the target population was selected and accessed. A purposive sample was used to sample participants. All eligible participants were included. The Phase 1, Step1 situational analysis of the IMF was conducted through semi-structured interviews and group discussions in isiXhosa, which generated data obtained from the participants. Transcription of data was done and translated to English and back translation for accuracy. The data analysis was carried out using Leininger and McFarland (2006) in Polit & Beck (2012:565), which provided ethnographers

with a four-phase, ethno-nursing data analysis guide, which was used with a descriptive analysis approach to generate themes and categories. Phase 2 was a collaboration involving the researcher and the stakeholders in the development of an educational programme promoting the uptake of organ donation and was done by using data from Phase 1 and relevant literature. The results of the situational analysis are presented in chapter four and discussed alongside the literature. The educational programme is written in Chapter Four.

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CHAPTER 3: PRESENTATION AND DISCUSSION OF THE QUALITATIVE FINDINGS

3.1. INTRODUCTION

In Chapter One, the aim of the study was discussed together with the research design and method in Chapter Two. Chapter Three presents an analysis of the data collected from focus group discussions and individual interviews using a semi-structured interview schedule with community members, traditional healers, ministers of religion, and traditional leaders. This data included the themes, sub-themes, and categories that emerged during the situational analysis of the IMF. The results of reflective and field notes made by the researcher soon after completion of the interviews were added to the data. The results discussed in conjunction with literature control, allowed for the verification of the findings.

3.2. OPERATIONALISING FIELDWORK

Upon arrival at the research setting, the interviewer (the researcher) commenced each session by informing the participants again of the aim and objectives of the study and the part that they may possibly play in it and requested their consent for participation. Participants were assured that their participation was voluntary and that they should not feel obligated to take part. The interviewer also informed them that the sessions would be recorded with a digital recorder. Anonymity was ensured by not using their real names; instead, they were addressed as 'mother/father/sister/brother/Reverend/Chief/Sir'. All participants were prepared to share barriers towards the uptake organ donation and were unabashed in elaborating on what they perceived were related issues that contribute to the low uptake of organ donation.

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All participants were asked the same questions in the interview guide, after which the interviewer probed further as each interview progressed to encourage the participants to expand on their initial answers. Interviewing methods were used for probing and prompting to add depth to the initial response, particularly clarification probing, which ensured that specific words or phrases were explained as fully as possible. All participants were asked the following questions:

- What is your understanding of organ donation?
- What are your general views of organ donation?
- What are your religious beliefs regarding organ donation?

- What needs to be done to improve the uptake of organ donation?

Although this section has been described in detail in Chapter Two, the data analysis was briefly summed up as a reminder since it was the focus of this chapter. All the transcripts were read to obtain an understanding of the whole. The data gathered during the focus group discussions and individual semi-structured interviews were analysed using Leininger and McFarland's (2006) in Polit and Beck (2012:565), a four-phase ethno-nursing data analysis guide provided for ethnographers.

This data analysis guide assisted in identifying themes in the data, which allowed for the structured organisation of data to take place (Creswell, 2009:192). An independent coder assisted in the identification of themes. The researcher had several discussions with the independent coder, and a consensus was reached concerning the themes. Every theme and sub-theme are substantiated by appropriate quotations from the raw data and compared with relevant literature and research. Data analysis was performed to explore and describe the barriers contributing to the low uptake of organ donation among the Xhosa community.

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3.3. RESULTS AND DISCUSSION

Obtained results from the semi-structured focus group discussions and individual interviews with community members, traditional healers, ministers of religion, and traditional leaders constituted Phase 1, Step 1 of the situational analysis and presented in this chapter. Four themes with sub-themes were identified. Broadly, the themes related to participants' lack of knowledge and understanding of organ donation, negative attitudes to organ donation, barriers/impediments towards the uptake organ donation, and finally, their suggestions in promoting the uptake of organ donation emerged. The following section discusses these themes and sub-themes. Some of the responses from all the groups were similar, while there were responses that were different from each group. However, those responses were indicated in the discussion. Below are identified themes and sub-themes of the community members, traditional healers, ministers of religion, and traditional leaders.

Table 3.1 represents a comprehensive summary of the identified themes and sub-themes. However, to simplify the discussion, diagrammatic illustrations of the relevant themes and sub-themes are presented at the beginning of the discussion of each theme.

Table 3.1: Themes and Sub-Themes Emerged from Community Members, Traditional Healers, Minister of Religion and Traditional Leaders Regarding Uptake of Organ Donation

NO	THEMES	SUB-THEMES
1	Lack of knowledge/information and understanding of organ donation	*1.1 The invisibility of organ donation/ Public awareness not reaching rural communities* 1.1.1 No discussions of organ donation 1.1.2 Casting doubt on whether organ donation works 1.1.3 Inability to pass unknown information regarding organ donation 1.1.4 Lack of understanding of brain death *1.2 Decision-making process/ Collective decision-making* 1.2.1 Family as potential organ donors 1.3 *Lack of clarity regarding ethical concerns*: 1.3.1 Organ donation is a lengthy, and complicated process 1.3.2 Clarity regarding structures involved in organ donation and ethical questions around it
2	Negative views towards organ donation	*2.1 Fear of organ donation* 2.1.1 Fear of death 2.1.2 Fear of pain and anxiety 2.1.3 Fear of crime 2.1.4 Fear of rejection by the ancestors. 2.1.5 Fear of social stigma 2.1.6 Fear of character transfer *2.2 Health Matters* 2.2.1 Uncertainty about own health status 2.2.2 Organ donation delays death *2.3 Societal concerns* 2.3.1 Organ donation perceived as a Western idea 2.3.2 Organ donation perceived as a family topic 2.3.3 Fiction/unrealistic 2.3.4 No interruptions of God's creation 2.3.5 Socialisation to the African norms
3	Impediments to the uptake of organ donation	3.1 *Cultural factors* 3.1.1 Traditional medicine preferred to medical treatment 3.1.2 Loss of relational ties if donated outside the family 3.1.3 Preservation of the family lineage 3.2 *Religious factors* 3.2.1 Taboo subject in the church 3.2.2 Prayer outweighs medical intervention 3.3 *Economic factors* 3.3.1 Value attachment is a form of a reward
4	Suggestions in promoting organ donation	*4.1 Strategies to encourage the uptake of organ donation* 4.1.1 Early education and discussion of organ donation within the family and community at large 4.1.2 Involvement of the Departments of Health and Education

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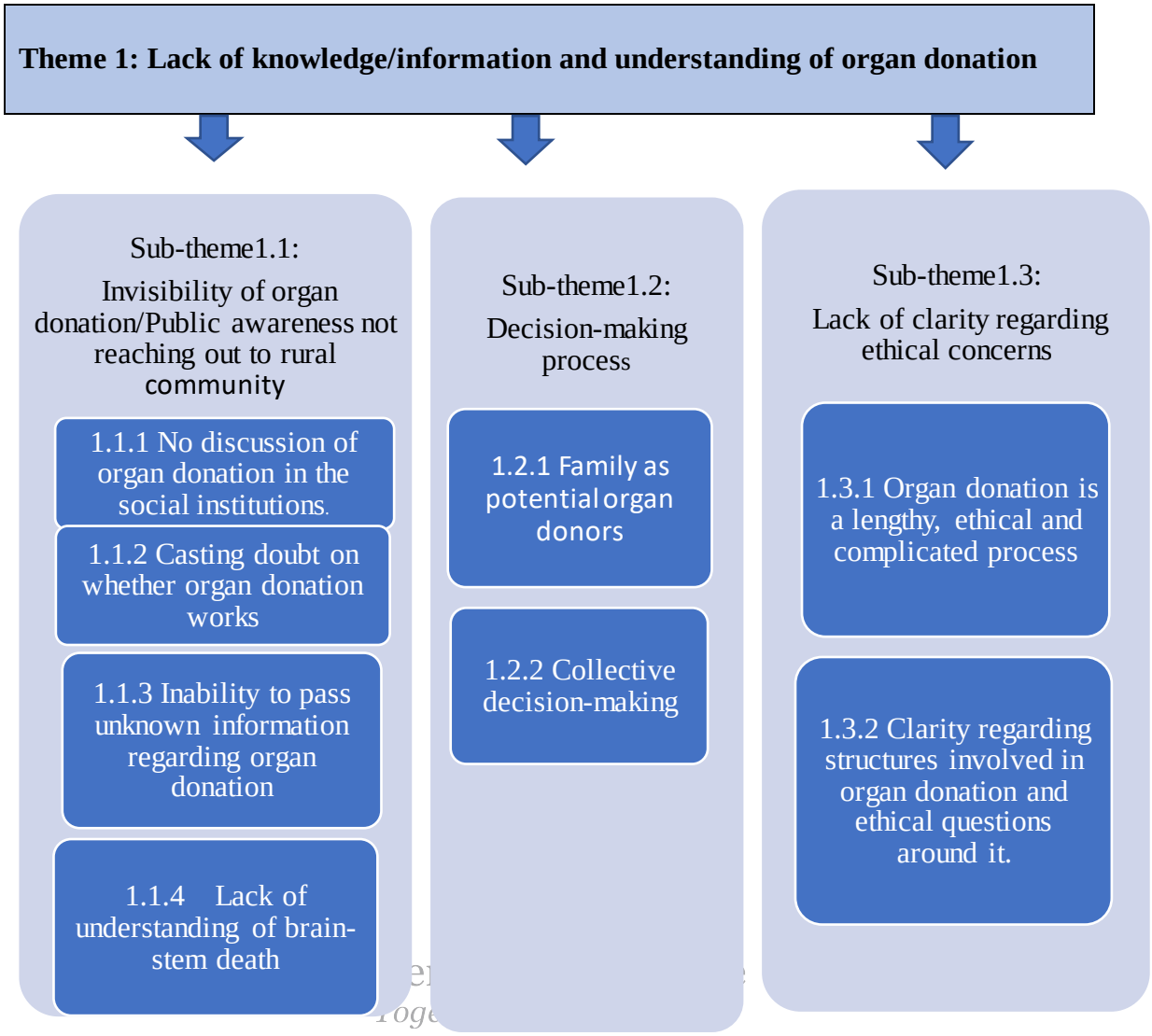


Figure 3.1: Theme 1: Lack of Knowledge and Understanding of Organ Donation

3.4. THEME 1: LACK OF KNOWLEDGE AND UNDERSTANDING OF ORGAN DONATION

The study's results indicate that the Xhosa community, including community members, traditional healers, ministers of religion, and traditional leaders, lack the knowledge and understanding of organ donation. Within their lack of knowledge regarding organ donation, three sub-themes emerged:

1.1. All participants (community members, traditional healers, ministers of religion, and traditional leaders) cited invisibility of organ donation by highlighting the following:

No discussions of organ donation; Casting doubts on whether organ donation

works; Inability to pass unknown information on organ donation and showed lack of understanding of brain death.

1.2. All participants (community members, traditional healers, ministers of religion, and traditional leaders) lack family decision-making concerning the family as potential organ donors.

1.3. All participants (community members, traditional healers, ministers of religion, and traditional leaders) lack clarity regarding ethical issues since organ donation is a lengthy, ethical, and complicated process; clarity regarding structures involved in organ donation and ethical issues around it; and lack of altruism.

Overall, in theme one, the participant's explanation showed a general lack of knowledge and understanding of organ donation, including the invisibility of organ donation, lack of understanding of brain death, the decision-making process regarding participation in organ donation and lack of clarity regarding ethical issues. The participants' views differed as some had never heard about organ donation before. In contrast, others claim they had heard of it from the media (radio and TV) and family but have never encountered a person who either donated or received an organ. They further maintained that no one had ever come to rural areas to educate them about organ donation. Traditional healers specifically expressed that they were uncomfortable to even speak about it, while the ministers of religion stated that they were not clear in terms of its importance.

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Furthermore, the ministers of religion implied that organ donation is not a simple thing but is something the Xhosa community can practice if educated. Traditional leaders, on the other hand, mentioned that their people were not educated on organ donation; therefore, they saw no reason to donate organs. The following shared views indicate a lack of knowledge and understanding of organ donation by the participants:

> *"Never heard about it, not in my family, but I used to hear about people from far away, maybe even those that are surrounding us are saying, but not in my home family or else in our home generation said that there is someone with that condition. I hear from people around, maybe neighbours these things. I also watch it on TV, not that it is in the house."* **(Individual interview 1, page 26).**

"Yes, let me begin, I can say briefly we know, or we hear about it but maybe, we are not clear on how important and who must do it, but in a nutshell, we are not having a problem of helping especially if the person is dying or needs the organ, that is my understanding. Though maybe, there is no information given on workshops training that has been done to our people, it is not something that cannot be done by our people especially Xhosa people". **(Focus group 8, page 30).**

"But in reality, people who are Xhosas are just being accused in this thing, not that they don't want to do this thing. They were never taught about this thing, they don't know about this thing, and they don't know what it is for, if they can be taught and know that this blood will also help them, they will not refuse..." ***(Individual interview 2, page 44).***

"It is the first time I hear something related to organ donation, I never heard of it. Never heard about the one who is scared, even the one who is going to donate ***(an organ)" (Focus group 9, page 22).***

"This is scary and unusual; it makes me uncomfortable to take an organ from a person and give it to another person." ***(Focus group 5, page 17).***

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"I did not hear about organs, but I heard about blood donation…." ***(Focus group 1, page 1).***

"Knowledge is facts, information, descriptions, and skills acquired through experience or education, the theoretical or practical understanding of a subject" (Hassam, Lant & Cameron, 2020). Bolisani and Bratianu (2018:2) believe that "knowledge is a result of the reasoning process and that our sensory experience plays a role", the authors further explained that knowledge is based on rational reasoning, eliminating views or opinions that arise from the senses. The participants' opinions did not indicate their familiarity, awareness, or understanding of organ donation uptakes, such as facts about or descriptions of the phenomenon. The responses indicate that some Xhosa families and their respective social institutions (religion, education, and family) do not engage in discussions related to organ donation uptake; hence, participants had mostly heard about it through social media.

Educational programmes have been found useful internationally to increase knowledge related to organ and tissue donation (Yilmaz, 2011:370; Mc Glade & Pierscioneck, 2013:np; Cantarovich, 2014:838; Radunz, Benko, Stern, Saner, Paul & Kaiser, 2015:np; Siebelink, Verhagen, Roodbol, Albers & Van de Wiel, 2017). According to Yilmaz (2011:370), the education intervention approach indicated an increased consent rate and corrected misinformation about organ donation. According to McGlade and Pierscioneck (2013), an educational program enhances student nurses' knowledge about organs that can be donated after death, the procedures for registering as an organ donor, the legal aspects of organ donation, and the concept of brain-stem death. The study observed that this education positively changed students' attitudes toward their willingness to donate organs.

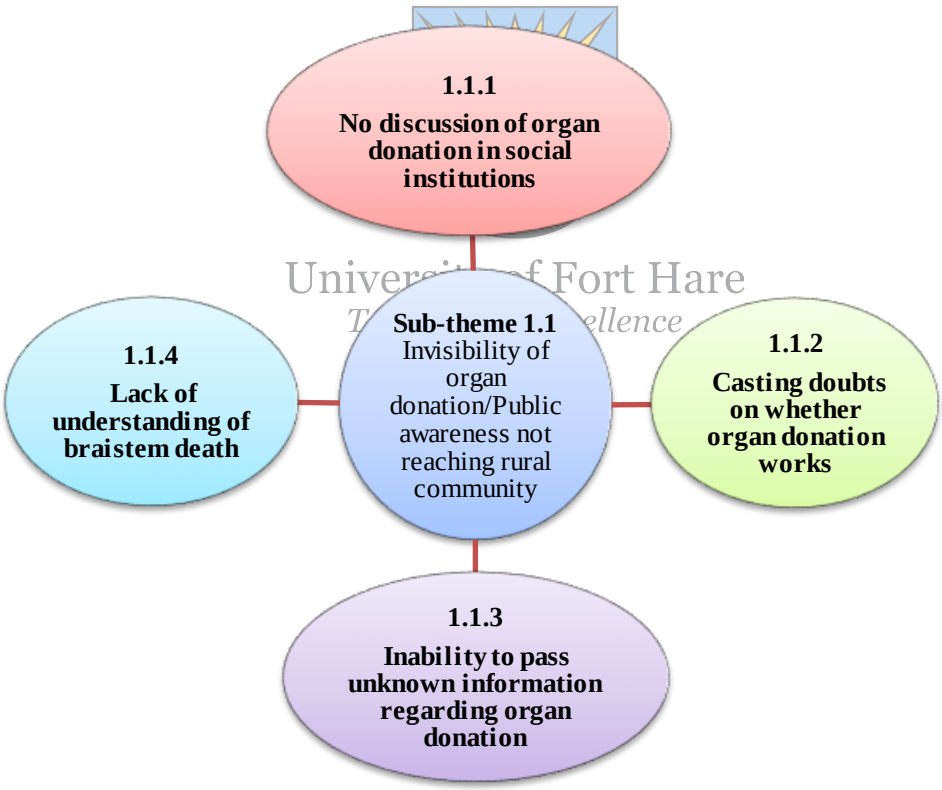
Cantarovich (2014:838) suggests that a school teaching programme should be taken as an academic discipline, integrating knowledge and skill in an educational context, considering interaction during learning modified to different society's peculiarities and conduct. Cantarovich (2014:838), in their study, proved that youngsters as young as 10 years old understood information on organ donation. According to Siebelink, Verhagen, Roodbol, Albers, and Van de Wiel (2017:np), their examination of the effects of a newly developed lesson on organ donation among primary school pupils and the teacher support yielded positive results towards organ and tissue donation lesson, which led to the promotion of family discussions at home. Therefore, educational programmes in schools support family discussions. In their intervention study, Radunz, Benko, Stern, Saner, Paul and Kaiser (2015) delivered a lecture to medical students on organ donation, which significantly improved their knowledge of and attitude to organ donation. Unawareness and prejudgment identified by Cantarovich (2018:49) remained general causes of society's unresponsiveness to the social need of organ donation with deference to the deceased donor. The explanation for this behaviour is traced to the notion that people are only partly aware of how recognised and frequent the transplantation of organs and tissues is today. People only recognise the need for organ and tissue donation when they are diagnosed with organ failure. Society is unaware that the body offers a unique source of life after death. People are unaware of organ donation and transplantation (Bardell, Hunter, Kent & Jain, 2003; Liu et al., 2015; Makara-Studzińska et al. 2013 in Cantarovich, 2018:50).

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Theme 1: Summary

Society needs to be educated about organ donation and informed that when a person is declared brain-dead, there is an opportunity for a brain-dead person to contribute significantly to humankind by agreeing to organ donation while still living.

From Theme 1: As indicated previously, three sub-themes emerged and were encapsulated in participants' lack of knowledge and understanding regarding organ donation. **Sub-theme 1.1** deals with the **invisibility of organ donation**, which consists of *no discussions of organ donation in social institutions*, *casting doubts on whether organ donation works*, *inability to pass unknown information regarding organ donation* and a *lack of understanding of brain death.* Each related component within the sub-theme will be discussed in the following subsections. A graphical presentation of Sub-theme 1.1 with its related details is presented in Figure 3.2 below.



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Figure 3.2: Sub-theme 1.1 – Invisibility of Organ Donation

3.4.1. Sub-Theme 1.1: Invisibility of Organ Donation, Public awareness not reaching out rural communities.

Participants came out strongly that, as much they heard about organ donation, they never saw a person who neither donated nor received an organ and survived that ordeal. They expressed how they wish to see, touch, and communicate with an organ donor and recipient recently undergoing such procedures. General community members showed interest in how removing an organ and transplanting to another person is performed, wondering where to go if one wishes to donate. All participants agreed that the health care providers provided them with knowledge of current health problems, including HIV/AIDS, but never mentioned organ donation. Traditional leaders suggested organ donation should be publicised the same way as HIV/AIDS awareness. They also indicated no public awareness regarding organ and tissue donation in rural areas. Following are verbatim statements from the participants:

> *"I have never heard or seen a person who has done that …What if I die while they are removing the organ? What happens after I have donated? It should be done to another person recently and see that he is alive".* **(Focus group 1, page 12).**

> *"Not much knowledge about organ donation, because it is something that I always hear about and never see it happening; so, you know that what you hear is not the same as what you see."* **(Individual interview 1, page 27).**

> *"The thing is I don't know how the kidney is taken out from me, what are they (medical team) going to do to take out this kidney and be taken to that person, what my body is going to feel? On the other hand, is there anything that will be funny? Where to go when we want to donate an organ? Is it the kidney only discussed? What about other organs? …"* **(Focus group 1, page 13)**

> *"I think it has become a tradition for the medical fraternity not to open these medical discourses to the novices like us. I think this step is very important; even medical advances are not open to discussions for ordinary citizens. These discussions are flying historically above the heads of those people***." (Focus group 8, page 40)**

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The Arab community living in Australia view organ donation as being out of sight, out of mind and irrelevant, as they are not aware that it is happening (Ralph et al., 2016). Ralph et al. (2016) further explain that other participants lacked the enthusiasm to register for organ donation since they did not know how to register and claim that registration is not easily accessible.

"Healthcare policy in South Africa, which is rightly focused on primary healthcare interventions as a cost-effective strategy to improve the health of the population, should not neglect transplantation" (Thomson, 2017:36). Community members only know about this when a known member of the community or the family need an organ donation; hence, the invisibility of organ donation. Furthermore, Thomson (2017:36) states that the culture is dynamic and changes over time. Therefore, all healthcare professionals need to engage with communities in South Africa to make organ donation a norm, which could be applicable in the Eastern Cape Province to make organ donation visible. A community-based study comparing rural and urban populations on knowledge and attitudes towards organ donation identified that participants received information mainly from television (Alghanim, 2010:27). More than 90% of participants from rural and urban areas reported little contribution of health care providers in providing knowledge about organ donation and transplantation (Alghanim, 2010:27). According to Jernigan et al. (2013:738), participants' mistrust of the local health care system influences the health messaging of organ donation promotions. It became evident that the participant had to witness something or a person who donated or received an organ to believe. The following subsections will further describe the invisibility of organ donation as mentioned by the participants.

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Sub-theme: Conclusion

This confirms that the participants have very limited or no knowledge on organ donations.

3.4.1.1. No Discussion of Organ Donation in the Social Institutions

If organ donation is not discussed in the places where Xhosa people meet, it will remain invisible to them. Participants in the study had heard about organ donation mainly through social media or from other people informally, not in families or at church, school, and clinics. Some had never heard of it at all. Only one participant in one focus group had heard about organ donation from family. Even then, it was not a discussion, but there was a need in the family for organ donation. Ministers of religion found information regarding organ donation

from books or, at times, driven by verses in the Bible. They also mentioned that they came across it when their loved ones became sick and needed organ donation. Participants shared their experiences in this regard:

> *"Our understanding as ministers of religion truly speaking is that this is general. We cannot say this informs it, and we got it from the books we read or may be driven by the Bible verses that speak about love."* **(Focus group 8, page 30).**

> *"I want to come to a question of the church; now, in the church, I have never spoken about organ donation, I was just speaking about praying, (all the group laughing) may be other pastors have done that organ donation," ….. "This thing of organ donation is not an issue that we talk about in our gatherings…nobody ever talks about this"* **(Focus group 8, page 32).**

> *"I think one of the greatest challenges that we have, especially as the Xhosa nation; I think we need to agree that some of these things, we were never exposed to them. Nobody ever talks about this, because this is something that we grow up, and perceived as an issue that has to do with White people, you know, it has never been an issue to us as 'abantu abamnyama' (Black people) (I) organ donation, you see!... You only understand the need for blood donation if you or somebody very close to you gets involved in an accident… that's when you realise the importance, now I would like to use the same analogy when it comes to organ donation…"* **(Focus group 8, page 33)**

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Introducing a discussion about organ and tissue donation may be challenging for some people. Raising the issue of death may be uncomfortable or even considered taboo, especially where the younger generation is involved.

According to Murray, Miller, Dayoub, Wakefield and Homewood (2013:12), positive attitudes to and discussion of organ donation may increase registration and make university students eager to donate and suggest that families be allowed to express ideas to one another in conversation or debate, that alone encourages organ donation discussion even if there is no consent required at that particular moment. According to Lee Barr, Conners and Cowart (2017:37), nurses in paediatric units are not permitted to initiate a discussion or education with families about organ donation. Their standard policy refers to an organ procurement

organisation (OPO), and only the OPO coordinator can approach the family on the possibility of organ donation. This policy aims to prevent litigation on hospital staff from the conflicts of interest; the policy also aims to avoid raising false hope of organ donation if the client is not eligible (Lee Barr et al., 2017:37). However, the nurses only engage in a discussion after the initial approach by the OPO coordinator.

"Organ shortage is a social, psychological, ethical, moral, and political problem, causing unjustifiable damage to public health. In contrast, the solution to organ shortage fundamentally depends on the current social behaviour towards organ donation. This alternative could be achieved if the strategies to modify frequent people's attitude towards organ donation are evaluated and revised" (Cantarovich, 2018). Thomson (2017:36) claims no mandated requirement for discussing a potential donor with a transplant team in SA. There is no system to audit the standard of end-of-life care discussions to ensure that all families are allowed to support organ donation. It has been noted that organ donation is not discussed at the family level among Xhosa community people in the rural Eastern Cape Province. Discussions are initiated when the family members are affected.

Sub-theme: Summary

Participants across the board confirmed no discussions and public awareness about organ donation among families, schools and even in church.

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3.4.1.2. Casting Doubts on Whether Organ Donation Works

Apart from traditional leaders, other participants were uncertain about organ donation as a treatment option for organ failure. General community members indicated their fears regarding the procedure of organ transplantation by a medical team disbelieving that a human being can survive after kidney donation. Traditional healers prefer traditional medicine to the transplantation of human organs. Ministers of religion need more clarification but singled out how one kidney can function properly, and some strongly believed that prayer and faith are a solution to organ donation and transplantation. Participants expressed their uncertainty by making the following verbal expressions:

> *"If a mistake happens while still trying to take out the kidney, what am I going to do; What if I die while they are taking it out..."* **(Focus group 1, page 13).**

"People think that if I donate with my kidney, I shall die while the receiver lives on. So, people think that you cannot survive with one kidney." **(Focus group 4, page 10)**

"As traditional healers, we believe in the use of herbs to cure a sick person more than organ donation" **(Focus group 5, page 17).**

"To me, this thing organ donation needs more clarification, especially for the layman; I am grappling with the question saying when the person is declared dead? Moreover, when is alive? How does the doctor say that this person has to die? Those are the things that I am grappling with, you see. And then again, the concept of death is a concept we do not necessarily share the same meaning; we must feel about death, but the concepts itself are not necessarily the same, so now there are challenges we are faced with, in other words, now we need more clarification about this…two kidneys and maybe you donate one, a person now fears that if it is one it will not be able to function properly…" **(Focus group 8, page 32).**

"…. I have seen the woman who donated a kidney for her daughter. The woman is still alive, but her daughter has passed away. I do not have any deductions from that, but I say what I have seen, but I do not have direct experience with organ donation and transplantation. In that case, there were members in the church who were diagnosed with kidney failure, and then we prayed for and was a lot of prayers. They showed us the results of some time that the doctors do not see this thing that was seen. You see now I am speaking from the perspective of saying there are instances where you prayed when the medical evidence was saying you need a transplant, and then now we pray and then again after some time, the very same one who comes to see me, in this instance she said, "I am healed" **(Focus group 8, page 32).**

"There is an opinion that says if your kidney is taken out, you will never continue to bear children if your kidney is donated to another person. You see now that thing is fearful because another person is still young, is growing and I never heard that what is taken out is taken from an old man, it is taken out from those who are still growing, it is said that is a what is wanted." **(Focus group 3, page 46).**

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The most common misconceptions and doubts concerning organ donation and transplantation among medical and non-medical students include beliefs in illegal organ trade, doubts about brain death and its role in describing the death of a human being, and a distrust of the medical staff's education and impartiality (Nowak, Pfitzner, Koźlik, Kozynacka, Durajski & Przybyłowski, 2015:873). Along with doubts and misconceptions, Girlanda (2016:457) identified the following common myths about organ donation, namely: being declared dead before the actual death is known to be an organ donor, receiving better medical care if choosing to be an organ donor, fear the organs might be sold if registered for organ donation, the belief that a person can be too old for organ donation, yet there is no cut-off age for donating organs. Successful transplants can be achieved with donors in their eighties.

Sub-theme: Summary

Many fears emanate primarily from a lack of knowledge, leading to doubts about whether organ donation saves lives. The operation may be successful, but other diseases may befall the recipient or donor.

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3.4.1.3. Inability to Pass Unknown Information Regarding Organ Donation

Despite their crucial role in the community, ministers of religion express a significant lack of understanding regarding organ donation processes. During interview sessions, they consistently articulate the need for clear and comprehensive information on this subject. It was noted that discussions about organ donation are virtually non-existent within their churches, primarily due to the ambiguity surrounding the topic. One minister mentioned that while they address health issues like hypertension and diabetes through other church members, organ donation remains an untouched subject. Similarly, traditional leaders, who serve as vital community gatekeepers, possess the authority to mobilise individuals for community gatherings – imbizo, yet they refrain from discussing organ donation due to their own limited knowledge. While traditional healers have participated in workshops addressing various health concerns, including diabetes, hypertension, tuberculosis (TB), and HIV, there has been no professional development focused on organ donation.

The following are their verbatim statements:

> *"The right time to me is when people are meeting like we have meetings, you can talk to them in those meetings where us as leaders we will be able to talk to them in a public*

place so that they can be able to know the importance of organ donation. I want to say when we go to meet people, and doctors should be present so that they can explain this medically. Yes, I mean those people who studied to be doctors, who can explain its advantages and disadvantages, who will be able to answer when questions are asked." **(Focus group 3, page 48).**

We are more enlightened than our people because we are the ministers of religion, but there is no place where we found this information as ministers. Hence, we are not confident to pass it. We try to use all the expertise that we have in our church in various fields. We have doctors, engineers, and other educated people. Now, whenever there are huge gatherings, we try to identify problem areas, and I happen to be on the medical board of the church as well. We even have a clinic in the church that serves the church community during our main gatherings in Easter and December youth festivals. You know, during that time, which is when we have an opportunity of getting to precisely know the predominant ailments within the church community are and how we can..." **(Focus group 8, page 30)**

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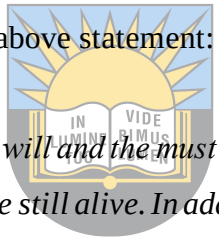
Alghanim (2010:25) mentions that in a community-based study done in Saudi Arabia on knowledge and attitude towards organ donation, which compared rural and urban populations, it was reported that television was the predominant source of information about organ donation. Over 90% of the participants indicated that the health care providers rarely offer them information on organ donation and transplantation (Alghanim, 2010:25). Information from social media is not enough to educate people on organ donation and transplantation. Nhlapo (2004) mentioned that Pooe, as head of the Kidney Unit at the Baragwanath Hospital, said, "I know and respect the peoples' cultures; we need to drive the point home that too many Black people are waiting for organs, but Black families are not donating because of a lack of information. We are trying to reach the townships because we have realised that a lot of awareness still needs to be created about organ donation". The above statement shows that the information regarding organ donation is reaching big cities only and leaving out townships and rural areas.

Sub-theme: Summary

The leadership strata in the community are prepared to create a platform for the medical fraternity to address the community about organ donation.

3.4.1.4. Lack of Understanding of Brain Death

Responses from community members and traditional healers reveal a significant lack of understanding regarding the concept of brain death. Some participants expressed the opinion that it would be preferable for individuals declared brain-dead to have established a will that permits their relatives to consent to organ donation. Additionally, there were sentiments among some that a person declared brain-dead should instead be afforded a proper burial. There was a palpable concern among community members and traditional healers regarding the removal of organs without their prior knowledge, indicating a pervasive mistrust. This mistrust is further exacerbated by beliefs that brain death may be intentionally declared as a means to facilitate organ procurement for transplantation. Conversely, religious leaders attributed this gap in understanding to the medical community's failure to engage in informative discussions with societal groups about organ donation, particularly regarding the implications of brain death. This lack of dialogue underscores a critical need for improved communication and education surrounding organ donation practices and the medical definitions related to brain death.
The following responses confirm the above statement:



"...maybe we need, things like will and the must state in his will. It should be something that a person talked about while still alive. In addition, maybe inform the family **(Focus group 1, page 4).**

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"Let me say I am stupid what you say because if a person is dead…. there is nothing else that the family can do with him except to take him to the graveyard, so now what is it that can still be taken from him?" ***Saying that in anger.***

"While the person is dying, it is not nice to all at home, especially the parent. I can be despondent when I discover that something is being taken from him. I would want him to be buried the way he was so that he does not help somebody else when he is dead." ***(Emotionally shaking head)."***

"Mother, this thing is like this, if I allow that my child's part is taken when he is dead, that will always stick on my heart that maybe there is a way of killing people deliberately to get some organs." **(Focus group 4, page 10).**

"...will never donate with my child's organ or my brother's so that it can help another person while he is dead. I am sad because in my mind what will ring is that they will cause head injuries to people to get organs." **(Focus group 4, page 11).**

"We also do not want people to be harvested. We want people to live as complete beings." **(Focus group 5, page 21).**

"I think it has become a tradition for the medical fraternity not to open these medical discourses to the novices like us. I think this step is crucial. Even the medical advances are not open for discussions with the ordinary citizens." **(Focus group 8, page 39)**

In a retrospective study, Ghorbani, Khoddami-Vishteh, Ghobadi, Shafaghi, Rostami, Louyeh and Najafizadeh (2011:406) investigated families of potential organ donors who had refused organ donation. This article concurs with Yousefi et al.'s (2014:328) findings from their study which explored the experiences of families concerning organ donation of a family member with brain death. Both studies found that all the families had hope for their loved one's recovery. However, the leading cause of refusal to donate was the denial of brain damage as actual death (Ghorbani et al., 2011:406). Rebuffing of brain-stem death measures, selling of organs to unknown organ end, religious belief, uncertainty about brain-death finding, unstable family attitude, unknown donor wishes, and fear of objection by other family members were all factors preventing organ donation.

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Yousefi et al.'s (2014: 328) study reported shock, unknown organ donation process, conflict of opinions, and disturbing associations; families expressed well-being desires, everlasting life, what the deceased would want, guarantee, and eternal honour. Brain-stem death is a crucial step to organ donation, as only legally certified dead people can become deceased organ donors (Etheredge, 2019). This definition of brain death in South Africa is legally accepted but tends to be challenging to understand, especially in terms of mechanically ventilated patients, who look well-perfused (pink in colour and warm on touch). It is hard for people to believe that such a patient has been declared dead (Etheredge, 2019).

Sub-theme: Summary

Participants doubt the authenticity of brain death certification and thus, do not accept death because ventilated brain-dead patients have chest movements that indicate breathing.

Sub-theme 1.2 deals with the **decision-making process** in which the first *point of entry to organ donation is the family*; the family must make the decision collectively to promote the organ donation process. Each related component within the sub-theme is discussed in the following subsections. A presentation of Sub-theme 1.2 with its related details is presented in Figure 3.3 below.

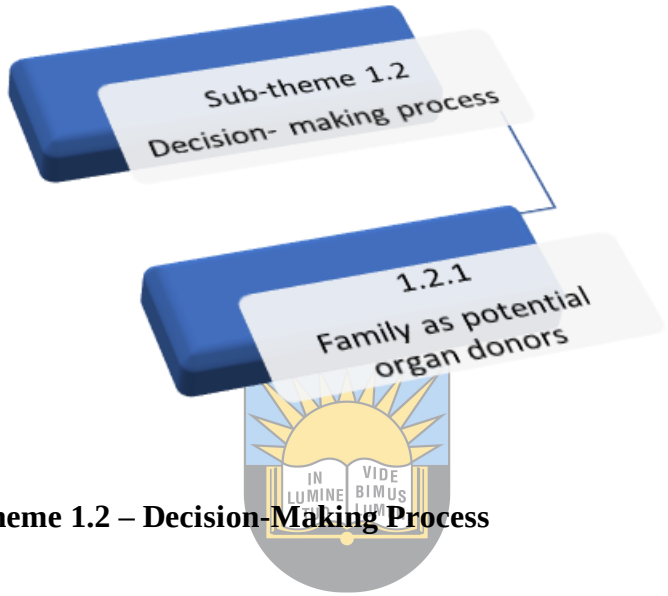


Figure 3.3: Sub-Theme 1.2 – Decision-Making Process

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3.4.2. Sub-Theme 1.2: Decision-Making Process/Collective decision-making

"Decision-making is one of the basic cognitive processes of human behaviour by which a preferred option or a course of action is chosen among a set of alternatives based on specific criteria" (Wang & Ruhe, 2007:73). Included in the decision-making process, participants noted that for organ donation to take place in the families, all members are involved as potential organ donors. The decision of whether to donate relies on the family. The family associated organ donation with death. Organ donation, whether by living or after brain death donors, poses a unique ethical dilemma since it may risk a healthy person's life, while donation after brain-death is regarded as stripping someone of their organs. Some participants felt that the deceased relative should have given them direction on what to do in case of brain death. Therefore, relatives of unregistered donors are likely to make unstable decisions. Participants narrated the stories about organ donation in the verbatim statements below:

> *"I remember the first meeting that was held in the family, Dr A called the whole family, and then everybody was part of the family, starting from my father's siblings, ourselves,*

*(**aborarhati, abodadobawo**) and all that (extended family members). Then he addressed the whole family on the issue of my father has got end-stage renal failure, he needs an organ, a kidney to live with..."* **(Focus group 8, page 31).**

"...When doctors realised that they would not save her life, they called her uncle and requested to harvest her parts as per wish. She further said she should consult the family before agreeing to that. The meeting never sat because family members did not show up. The harvesting did not occur because the father never came back while consultation of the broader family may yield positive results after an adequate explanation." **(Focus group 7, page 41).**

The family and relatives of brain-dead potential donors are in a dilemma regarding what decision to make. In some instances, non-donor families would safeguard their deceased's body, especially if they do not know the wish of the deceased, while donors' families tend to respect the dead's last will. However, non-donor families justified their decision with external influences, such as having too little time and information to make such a decision and needing support during decision-making (Groot, van Hoek, Hoedemaekers, Hoitsma, Smeets, Vernooij-Dassen & van Leeuwen, 2015).

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Morgan and Cannon (2003), as cited in Robinson and Ariola (2015:177), identified the types of knowledge that are more persuasive and less influential than others in the donation decision-making process. The more compelling include the knowledge of the transplant allocation system and knowing a waitlist candidate or recipient, while the less effective include a knowledge of statistics, the registration process, medical suitability, and a donor/donor family. However, information alone cannot fix the problem, mass media and campaigns are helpful in the USA. Healthcare professionals need to be skilled in approaching the families as they drive the family for organ donation (Miller & Breakwell, :2018). Therefore, they should provide clear, straightforward, and accessible information on both the causes and the diagnosis of neurological death. Families need support in decision-making and the time to think about it and ask questions. Further, Miller and Breakwell (2018) suggest that discussions with families should allow them to establish whether the deceased had previously expressed a wish to donate and be allowed time to accept the death and its context. These key findings are also applicable to the Xhosa community members.

Sub-theme: Summary

Making important decisions relating to organ donations during a crisis is difficult in African households; considerable time is required to make such critical decisions. Therefore, each member of the family should have a will.

3.4.2.1. Family as Potential Organ Donors

Community members and the ministers of religion were aware that family members were potential organ donors. The first point of contact when a family member requires an organ is the immediate family, extended family, and society. There are ethnic groups with rare tissue typing in which the need for organs can be found from the same ethnic group. Matching organs for donation may be found in such groups. Participants recognised that blood donation is sometimes only needed from family members, unlike organ donation.

The following are the verbalisations of several participants:

> *"When you talk about your relative, I think blood should match, in terms of the DNA, the donor blood should match mine, being that we are from the blood of one parent… They were always calling, asking if anyone is there who could help from home because the hospital could not help him… concerning blood, you can help a person even if that person is not related to you, who is in need, even if not a family member."* **(Focus group 1, page 1).**

> *"……so, as a result, my younger sister, then, there were a couple of people that we're able to raise or volunteer, and then my younger sister…and she had compatibility, so it was my younger who was able to donate. He was diagnosed with kidney failure, and then now the recommendation of doctors was that, is there a next of kin who can assist and then the family appeal to the brother."* **(Focus group 8, page 32).**

Although the Consent/Authorisation Best Practice Development Group (2013) have developed impressive improvement pathways in promoting organ donation, this group is still grappling with one critical hurdle, namely stubborn resistance to change the proportion of families who give their authorisation for organ donation. A family refusal represents the biggest step down in losing potential organ donors in the donation pathway. A collaborative, compassionate, and

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supportive milieu is recommended by (Shemie, Robertson, Beitel, Chandler, Ferre, Evans, Haun & Torrance, 2017:17) to achieve an effective discussion with families of potential organ donors since this will assist in the realisation of the wishes of the potential donor. Shaw and Gardiner (2018) further suggest that emphasis should be placed on the potential benefits when approaching the family of potential donors. This can be achieved by providing information about the recipient to families when considering whether to allow organ donation and full details on the consequences of their decision to donate.

Sub-theme: Summary

Families are aware that the organ donation approach mostly starts with blood relatives, followed by extended family and friends. Lastly is the society.

Sub-theme 1.3 deals with the **lack of clarity regarding the ethical issue.** Participants took the organ donation process lightly, not realising that organ donation is lengthy, ethical, and complicated. Participants highlighted the need to know where to go if one wishes to donate; therefore, structures involved in organ donation and issues around it need clarification, and the lack of altruism established. Each related component within the sub-theme is discussed in the following subsections. A presentation of Sub-theme 1.3 with its related details is presented in Figure 3.4 below.

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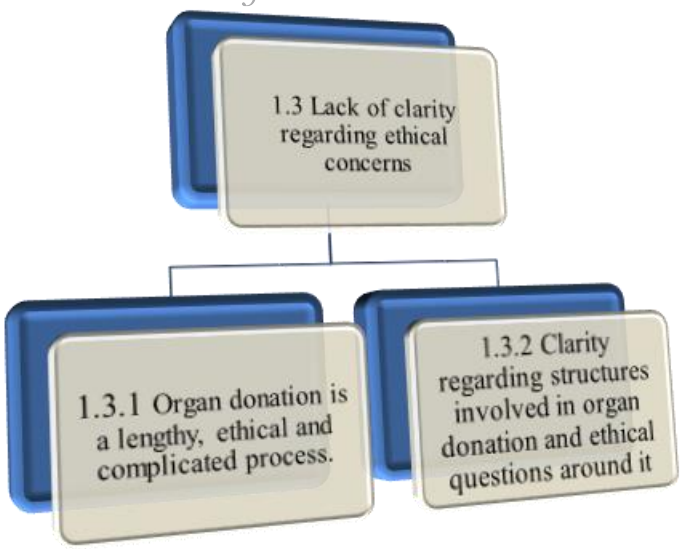


Figure 3.4: Sub-Theme 1.3 – Lack of Clarity Regarding Ethical Concerns

3.4.3. Sub-Theme 1.3: Lack of Clarity Regarding Ethical Concerns

While participants had heard about organ donation in its various forms, the information/subject and the process were still unclear to them. Participants desired to understand the moral principles and ethics of organ donation uptake. Clarity regarding organ donation uptake will assist these Xhosa community members to choose whether to donate in a specific situation and the rationale for such choices. Participants further stated that the matter of organ donation is not simple. The following statements were made regarding clarity:

> *"Don't have much knowledge about organ donation. It is something that I always hear about and have never seen it happening, so you know what you hear is not the same as what you see. To me, this thing organ donation needs more clarification, especially for the non-professional. I am grappling with the question saying when the person died? Moreover, when is alive? How does the doctor say that this person will die? I am grappling to understand those concepts, you see. And then again, the concept of death is a concept, and we do not necessarily share the same concept of death, we must feel about death but the concepts itself are not necessarily the same, so now there are challenges we are faced with, in other words now we need more clarification about this. I do not think it is a simple thing of taking organ replacing with other; some things lead to that; what are those? And then again, what are the measures that are taken for the one who has donated?"* **(Focus group 8, page 32)**

> *"...To add sister, that we are unable to learn or not having people to teach us about this thing and give us broad information that this thing happens and encourage us to do it. We don't have broad information about this thing, which is why we doubt now to do other things."* ***(Focus group 4, page 8)***

> *"We consider a human being in its totality. You do not remove a heart and think you have not interfered with the person. You have wronged that person; those bones will be complaining about their heart that was taken and donated to another person."* ***(Focus group 5, page 9)***

> "*We hear about when they talk about it, in such that I have this question that says, "Is it a must that this organ must be received from the family, or it can be received from anyone?"* ***(Focus group 9, page 21)***

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"This concept of organ donation, first I would like to understand the ethics underlining it and the philosophy driving it and then now, it says now if you are saving person's life, but how is this concept life defined? When you are saying, you are saving a person's life, what you mean by that? And then, those are things concerning this organ donation." ***(Focus group 8, page 29)***

An "ethical concern is a problem or situation that requires a person or organisation to choose between alternatives that must be evaluated as right (ethical) or wrong (unethical)"; it requires a lot of thinking and planning to figure out a solution (Business Dictionary, 2019). There are two specific ethical principles that govern live donation. Firstly, the principle of autonomy concerning the decision to donate an organ must be based on informed consent and the safety of the transplantation (Concejero & Chen, 2009:1660). As the participants mentioned above, there is no clarity regarding the uptake of organ donation. The donor is not forced to donate. Once the decision to donate is made, the risk to the donor must balance out the benefit to the recipient. Secondly, the whole process of organ donation needs one to act meticulously within the boundaries of what is ethically, morally, and legally acceptable in society (Concejero & Chen, 2009:1660). Bakari, Jimeta, Abubakar, Alhassan and Nwankwo (2012:58) indicate that organ or tissue donation is considered a treatment option in cases of organ failure that touches on the important rights of people; hence, there is a need for more clarity. Worldwide, researchers and government bodies have approved that informed consent for organ or tissue donation is necessary and should be obtained without coercion before any transplantation is undertaken.

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Sub-theme: Summary

Participants believe that organ removal from a human makes them incomplete. They prefer organ donation to occur only within family circles, ensuring donor consent is obtained without coercion.

3.4.3.1. Organ Donation as a Lengthy, Ethical, and Complicated Process

The following category emerged when the participants were willing to donate but did not fully understand the process. Participants expressed concern that blood donation and transfusion do not require consent from family members. In contrast, organ donation involves notifying relatives and addressing their concerns about the approach to the potential donor within the family. The following are statements made by the participants:

"Another challenge is that we do not understand the intricacies of organ donation." (**Focus group 6, page 15)**

"*...I am thinking now, how we get to another level, the approach to donating an organ, the concept of the donor's safety. Practically, I am not against it, but I am thinking of this now, how do we approach him? And then, now, lastly, the other thing, there is a belief that needs to be addressed; this donor organ, donor business is associated with the business of saying that you know. The reason I am raising this thing, I think some of us or myself need a detailed explanation of this thing of organ donation. Hence, I am raising the issue, to save from death, what is death? I am raising that from the medical point of view now because this thing of organ donation is practised in medically, medically what is death?"* **(Focus group 8, page 34)**

"I don't think it is a simple thing of taking organ to replace with other; there are things that lead to that, what are those? And then again, what are the measures that are taken for the one who has donated?" **(Focus group 8, page 32)**

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The waiting list is too long for people who are waiting for organs. A previous study investigating the complex reasons for organ shortage in South Africa identified religious and cultural beliefs as influencers of decisions about the remains of loved ones, of which many people need their relative's body to be buried in full and intact. Another major reason that delays organ donation and transplantation mentioned by the participants, especially religious ministers, is death, particularly brain death. According to Beyar (2011), death is a critical step in deceased donor transplantations and often the most problematic and emotional stage. Sometimes, the family do not agree with the medical team's diagnosis of brain death, which results in them distrusting the medical community and delaying the organ donation process.

Delays often occur in families since they are not all engaged in discussions related to organ donation. In their mapping of the processes and patterns of family organ donation discussions, Pitts, Raup-Krieger, Kundrat and Nussbaum (2009:424) offer the following insight into the process of organ donation:

- the time to initiate the topic of organ donation
- the topic shifting allowing flexibility on the issue

- the establishment of consensus

Cooperation, collaboration, and challenge are conversational styles and strategies that can be used. Organ donation is related to the evaluation stages, such as brain-death diagnosis, maintenance, and documentation, with much care for the non-donor (Freire et al., 2015).

Sub-theme: Summary

Organ donation is quite a lengthy process. Awareness campaigns should include all processes involved in organ donation.

3.4.3.2. Clarity Regarding Structures Involved in Organ Donation and Ethical Concerns

Participants repeatedly mentioned that they did not know where to go for donation or how the organs were removed from one human being and transplanted to another. Participants also demonstrated knowledge of the blood donation process, although some still needed clarity on the difference between blood and organ donation. Some participants did not know which organs were suitable for donation; they also confused donation with skin grafting. The following are verbatim statements that demonstrate their limited understanding of organ donation structures:

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> *"To add to my big brother, when a person loses his leg, he gets fitted with an artificial leg. Nobody is asked to donate a leg. Nobody in her family offered to donate with a leg. We do not make organ donations. All we do is to enquire from the hospital as to what we can do to help our sick relatives to be well."* **(Focus group 5, page 18)**

> *"We never heard on our side that a person's relatives are called to donate blood for him. But in hospital, you will find blood; they check it first if it is suitable for you, and you don't know where it comes from."* **(Focus group 1, page 2)**

> *"There may be something about blood donation. There are special places where blood is drawn and kept. A person can go to those places if he wants to donate*." **(Focus group 4, page 7)**

> *"Where to go when we want to donate an organ. The thing is, I don't know where to start to take out the kidney, how is it going to be taken out from me? What are they*

going to do to take out this kidney and be taken to that person? What my body is going to feel or is there anything that is going to be funny or…?" **(Focus group 1, page 13 Pilot (Preliminary exploration))**

According to Glazier (2018), the primary law that governs organ donation in the United States is termed the Uniform Anatomical Gift Act (UAGA); this law describes informed consent as unsuitable for regulating organ donation. The UAGA, in Glazier (2018), preferred gift law, which is the legally binding and voluntary transfer of something from a donor to a recipient and does not involve payment. It furthermore (2018) states that informed consent is the concept of permission granted by a patient for a particular treatment after weighing its risks against its benefits, including the available alternatives. UAGA in Glazier (2018) also argue that there are no risks or benefits to the donor in deceased donation since the donation occurs after death. However, organ donation in South Africa is self-sacrificing, whether it is a living or dead donation, and does not involve any financial reimbursement (Slabbert, Mnyangani & Goolam, 2011:261). The Organ Donor Foundation of South Africa's preliminary studies [Accessed November 2019] discovered that little or no knowledge or understanding surrounded by misinformation influences an individual response to the concept of organ donation.

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Additionally, traditional cultural beliefs play a significant role in the low uptake of organ donation. Participants of this study interpreted the artificial replacement of limbs as being the same as organ transplantation, which indicates their limited knowledge. To become a donor in South Africa, individuals must register themselves on a donor registry and inform their family members, healthcare providers, lawyers, religious leaders, and loved ones of their wish. The structure, process, and outcome of organ donation were the deficiencies in material, human resources, and lack of adequate protocols (Freire et al., 2015).

Sub-theme: Summary

Structures or stages involved in organ donation should be clearly stated with ethical dilemmas existing along these stages.

3.5. THEME 2: NEGATIVE VIEWS OF ORGAN DONATION EXPRESSED BY ALL PARTICIPANTS

Theme 2 with related sub-themes is presented in Figure 3.5 diagrammatically as follows (below):

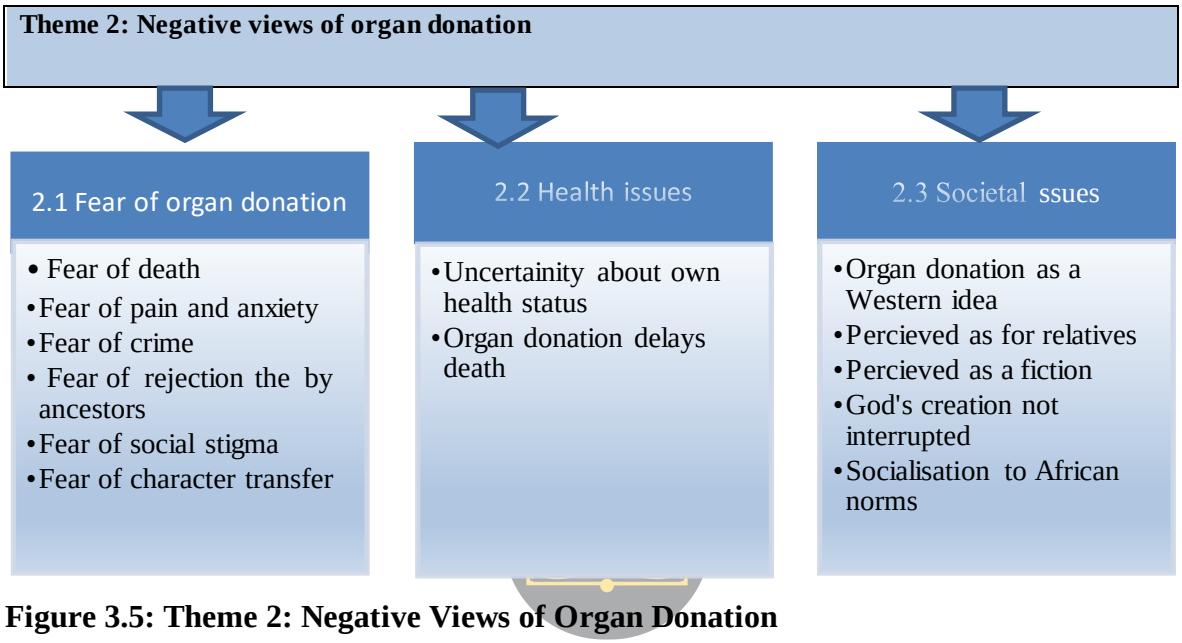


Figure 3.5: Theme 2: Negative Views of Organ Donation

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Various negative views verbalised by all the participants, included in these views, three sub-themes emerged: All the participants (community members, traditional healers, ministers of religion, and traditional leaders) expressed fear of organ donation in general. Among the fears, the fear of death, fear of pain and anxiety, fear of crime, and the fear of being rejected by the ancestors were indicated as paramount.

All the participants (community members, traditional healers, ministers of religion, and traditional leaders) were concerned about the ill health of the donor and the recipient, worried that they were not eligible for donation because of ill health and were uncertain about their health. They had a general feeling that organ donation is delaying death. All the participants (community members, traditional healers, ministers of religion, and traditional leaders) mentioned general societal issues that may hinder them from donating organs. Among those societal issues, participants regard organ donation as a Western idea, perceived organ donation as for relatives, perceived it as fiction in social media and that God's creation should not be interrupted.

Some participants demonstrated a lack of knowledge and understanding regarding organ donation, which led to the expression of negative views on the topic. Ministers of religion were not fearful of death; rather, their concerns centered on issues of ill health. In contrast, traditional healers felt uncomfortable discussing organ donation and expressed worries about the quality of life for both the donor and the recipient. Community members and traditional healers appeared uncertain about their commitment to organ donation. The primary fears voiced by community members and traditional healers included medical conditions that could prevent them from donating, concerns about their dignity, the potential for body mutilation, and the fear of losing their ancestral connections. Fears towards organ donation were verbalised below by several participants:

"I can't donate because what if I die while they are taking it out and giving it to another person". **(Focus group 1, page 3)**

"...it is something that will make me die because I am not complete now; my parts are removed while still alive, and ancestors won't allow that." **(Focus group 4, page 9)**

"If a mistake happens while still trying the kidney, what am I going to do? Because doctors make mistakes that" **(Focus group 1, page 12 (Preliminary exploration))**

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".... However, I also have that fear of donating with my kidney and end up dying. This is what causes fear". ***(Focus group 6, page 15)***

"We need to protect the dignity of people because we know that God created a complete person. If you are going to interfere with a body structure, you are reducing that person's dignity by bringing another part. We know that a person who is not well is given herbs. Organ donation will change the person and lower his dignity" **(Focus group 5, page 18)**

"We traditional healers do not donate with our organs because some people have infections, some have diabetes, some have HIV and AIDS. We cannot donate because the blood has to be tested first, and their organs are checked. I, for one, cannot donate." **(Focus group 5, page 20)**

"Vultures… Somebody will say now; you are stripping my son alive, these" **(Focus group 8, page 38)**

Literature also reveals negative views, which contribute to less uptake of organ donation. Furthermore, other factors hindering organ donation include religious beliefs, the complexity of the donor process, lack of discussion of organ donation in social circles, fear of body mutilation and organ trade (Gorbani et al., 2011:405; Darlington et al., 2019). Regarding the above-mentioned negative influences on organ donation, Cantarovich (2018:50) emphasises that the fear of death and respect for body integrity are not essentially linked to ignorance or misinformation but a significant barrier towards deciding to donate. Participants expressed their concerns in the following verbatim statement:

"…If people are prepared before that there is this incident like you said, then they can hear it when it is spoken, will say, this is something we know but because, this thing of ignorance is the one which makes people reluctant. They do not know the value, and it is only known by that one and that one. They do not know the value of important this thing…" **(Focus group 8, page 40)**

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Fear of death significantly inhibits the acceptance of organ donation and transplantation. Research indicates that negative attitudes towards organ donation are linked to higher levels of fear of death (Yan, Qiu & Huang, 2018; Rios et al., 2018). However, the concept of the "dying of the self" is less closely associated with fears of death, whether about one's own mortality or that of others (Cantarovich, 2018, p.50). Concerns about body integrity, fear of body mutilation, and worries about losing mobility or any part of the body structure are central issues that contribute to negative attitudes towards organ donation. These concerns can create ethical and moral reservations regarding the treatment of the body at the time of death. Additionally, the desire to preserve the body's image plays a significant role in family decisions about organ donation (Kalayoglu et al., 1988, cited in Cantarovich, 2018, p.50).

Theme 2: Summary

All participants expressed fear of participating in organ donation mentioning different reasons such as being fearful of doctors committing mistakes during operation or rendering the donor an incomplete being.

From Theme 2: All participants (community members, traditional healers, ministers of religion, and traditional leaders) expressed a general fear pertaining to organ donation. A presentation of Sub-theme 2.1 with its related details is presented in Figure 3.6

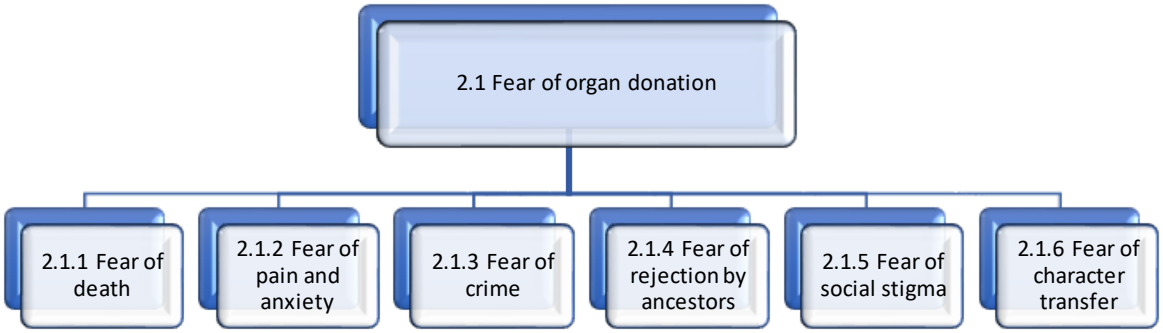


Figure 3.6: Sub-Theme 2.1: Fear of Organ Donation

3.5.1. Sub-Theme 2.1: Fear of Organ Donation

Fear as a negative emotion caused by a real or perceived threat may change behaviour. Behavioural change results in a negative attitude that is not deliberate but circumstantial to negative influences. In the case of organ donation, participants expressed a general fear of organ donation. The fear of death, pain and anxiety, fear of body mutilation, and rejection by the ancestors are among the concerns. Given the urgency, a negative attitude towards organ donation needs to change and be considered a civic responsibility. Fear of organ donation leads physically fit people to donate organs and aggressively choose not to donate. Potential organ donors are discouraged by several myths surrounding organ donation. Such as not being cared for to save an organ, as health care practitioners are eager to get organs for transplantation, the possibility of being falsely declared dead and the increasing age or ill-health condition. Participants expressed their fears as follows:

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> *"We are aware that it helps, but when it has to be done you personally, it is not easy."*
> **(Focus group 6, page 16)**

"We fear to be crooked, do not trust what the doctor said that this person will survive, cause head injuries to get organs…may be a way of killing people deliberately to get organs… make me die early" **(Focus group 4, page 7)**

Results of 27 articles that were systematically reviewed by (Newton, 2011) showed altruistic motivation as the most identified motivator for becoming organ donors. This motivation can be influenced by creating a sense of commonality with the broader community. Giving information to the participants that donated organs will create an outlet for the waiting list for the organ. Maintenance of body integrity without harm to progression into eternal life and immoral ways of obtaining organs by medical professionals were identified as the most common barriers to organ donation (Newton, 2011).

Sub-theme: Summary

Data collected from the study reveals that participants expressed fear of organ donation, imagining that the quality of life of the donor might be compromised.

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3.5.1.1. Fear of Death

Embedded in the fear of organ donation is the fear of death, which is a relatively complicated phobia. Most of the participants expressed fear of dying. Some people fear that if donated, their health will deteriorate till death, while others are afraid to die because of removing the kidney. Some believe that the path to salvation is straightforward and narrow and fear that any deviations or mistakes (being or without a body part incomplete) may cause them to be eternally condemned. The following were verbatim statements:

"People think that if I donate with my kidney, I shall die while the receiver lives on. So people think that you cannot survive with one kidney." **(Focus group 6, page 17)**

"…But I also have that fear of donating with my kidney and end up dying. This is what causes fear." **(Focus group 6, page 15)**

Willingness to donate is affected by psychological factors such as a core system of thought, sentiment, and emotional connections, while cultural factors include death, taboo, meaning and respect (Yan, Qiu & Huang, 2018:604). Maximum organ value, positive mentality, pleasure,

traditional thinking, and sometimes certainty are cultural and psychological factors contributing to the willingness to donate (Yan et al., 2018:604). Conversely, conducting death education is essential, cultural guidance, strengthening social support, and respecting the opinions of the families that encourage donation (Yan et al., 2018:604). Understanding the brain-stem death concept is still a problem among the population of Hovane, Cuba. It could be the same among the Xhosa community (Rios et al., 2018:3240), while the transplantation community are concerned that the ordinary human fear of 'mistaken death' will discourage people from registering as organ donors (Pullen, 2019:2146).

Sub-theme: Summary

Participants fear that donating with an organ will compromise the donor's longevity and body strength while the receiver lives on.

3.5.1.2. Fear of Pain and Anxiety

All the participants except the ministers of religion seemingly do not fear death itself. Instead, they were afraid of the circumstances that often surround the act of dying. They were fearful of crippling pain, debilitating illness, or even the associated loss of dignity. Having some death anxiety is an entirely normal part of the human condition. However, for some people, thinking about their death or the process of dying can cause intense anxiety and fear. Talking about organ donation triggered fears in the participants. Fear of pain and anxiety expressed by the participants refers to the donors and the recipients. Consenting to organ donation in the brain-stem death of a relative, participants expressed emotional pain and anxiety with a feeling of deserting a loved one. The following confirms the above statement:

> "*…if you have pains with this and you will say if that one was still here, I would be healthy."* **(Focus group 4, page 9)**

> *I think both; even the donor becomes weak, even the one received takes time to be all right. "There are two kidneys, and maybe you donate one; a person now fears that if it is one, it will not be able to function."* **(Focus group 3, page 48)**

> *"The recipient will be a weak human being; he will not be strong as he was before; he will be constantly sick."* **(Focus group 6, page 19)**

"I don't want to donate my child's organs: that will stick to my heart, after donating the organ I will feel pain" **(Focus group 4, page 11)**

Anxiety is one of the most noticeable hindrances in organ donation that cannot be fully disregarded. However, allowing people who donated before with the prospective donors the chance to make informed decisions may increase the number of people willing to consider organ donation (Bozkurt, Uyar & Demir, 2019:1140). Living organ donation has a significant health impact on the donor due to removing an organ, as in surgery and during recovery. There are long-term health consequences (Ferguson, Murray & O'Carroll, 2019:1081). Bozkurt, Uyar and Demir (2019:1140) confirmed the health-related anxiety-adding concern of having an unattractive surgical scar and being unable to do physical activities.

Sub-theme: Summary

Participants believed that donating an organ like a kidney weakens both parties; the donor and the recipient will be a source of anxiety.

3.5.1.3. Fear of Crime

All the participants verbalised that they had feared donating organs. They heard from the social media reports on human trafficking in persons for organ removal. Participants expressed their uncertainty by making the following expressions:

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"... In hospitals, they take from our sons and daughters' healthy organs to sell, somebody will say now; you are stripping my son alive…. " **(Focus group 8, page 40)**

"These days' people are being killed and found without parts, and there is, maybe, not sure if this is true or not;" **(Focus group 8, page 40)**

"... Has said that people have been mutilated to sell their parts, which is another area that we cannot ignore." **(Focus group 8, page 40)**

"That leads to people thinking that they can make money by selling body parts to be rich." **(Focus group 5, page 17)**

"…but these days are always scared because there are these people who go about asking for organs, and we don't know what they do with them". **(Focus group 9, page 25)**

"We believe that thou shall not kill. While discussing this subject, I am reminded of the stealing of body parts, people are killed for body parts. Due to a lack of donors, people or groups of people can become desperate, or even doctors from private hospitals can kill people and harvest their parts to save their relatives. I, therefore, suggest that organ donation can promote violence" **(Focus group 7, page 42)**

Public perception regarding less uptake of organ donation among the South African population includes suspicion of the biomedical system in SA (Etheredge, 2019). "Sometimes there are perceptions that doctors in hospitals cannot be trusted, or that some aspects of practice are unethical" (Etheredge, 2019). Selling and purchasing human organs for transplantation is a widespread crime (Efrat, 2016), which leads people to be afraid to participate in organ donation. The disproportion between the need for organs and the supply of organs for transplantation has led to transplant-related crimes, including human trafficking for the removal of organs and trafficking in human organs. The crucial role of health professionals in preventing transplant-related crime is the consistency in evaluating prospective donors and their intended recipients, checking the legitimacy of the relationship between the donor and the recipient, ensure that donation is altruistic (Gil, López-Fraga, Muller & Gill, 2017:1300).

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Sub-theme: Summary

The general fear among the participants in giving consent to remove an organ in case of brain death was that giving such permission may lead to human organ trafficking.

3.5.1.4. Fear of Rejection by Ancestors

Fear of rejection by ancestors was identified as a socio-cultural barrier to consent for an organ donation among Xhosa general community members and the traditional healers. Traditional healers came out strongly that they had a fear of losing their ancestral link. Talking about organ donation made them uncomfortable. On the other hand, ministers of religion verbalise that only the spirit that transcends to heaven, not in a bodily form, the body is buried before decomposition. Participants shared their beliefs in this regard:

"It is not right to donate your organ; it will not be correct to go to your ancestors with incomplete organs." **(Focus group 6, page 15)**

"He cannot be an ancestor having received a heart from a donor." **(Focus group 5, page 18)**

"Ancestors never allow organ donation…deceased person should be taken straight to the grave" **(Focus group 4, page 10)**

The fear of rejection is identified as powerful and often has a far-reaching impact on people's lives (Fritscher, 2019). Most people experience nerves when placing themselves in situations that lead to rejection. Fear of rejection tends to affect people's ability to succeed in many personal and professional situations. An elderly community member and a traditional healer confirmed that removing a deceased person's organs is against the Black culture with the belief that the deceased's spirit continues to wander and is not accepted by the ancestors (Zikali, 2018). However, ODF will conduct a volunteer programme that encourages the public to train and educate communities about organ donation. Eastern Cape's Congress of Traditional Leaders of South Africa encourages organisations like ODF to work closely with traditional leaders to access the communities. Bengu and Uys (2004) recommended applying culture repatterning and restructuring, as stated by Leininger, 1978 in George 2002, such as sensitive educational campaigns to dispel fears and correct misconceptions.

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Sub-theme: Summary

Generally, there is a belief among Africans that there is a link between the living and the dead. This link is maintained through the ancestors; hence, participants believe that going to ancestors with a missing organ may result in rejection, which may disqualify one from being an ancestor.

3.5.1.5. Fear of Social Stigma

A fear of social stigma by the Xhosa community members and the traditional healers was identified among the fears. Participants fear society's judgement of whether they are donating an organ or receiving the organ. Below are verbatim statements:

"Even community members will constantly be teasing you, reminding you that you have a missing organ and you just scared and think that let me stop because if something happened to me, they were saying it is that kidney even if you were going to die" **(Focus group 6, page 17)**

"*…you will donate to that family then this thing will be talked about right, agree with each other after donation and there will be no more relationship between you and they will not talk to you, and don't care about you". "I gave my kidney after some time, becomes sick, then people will then say it is that so-and-so's kidney, and look as if I am the one who caused the person sick."* **(Focus group 1, page 14)**

"To us Black people, if you have a missing organ and fall sick, it will be said the reason you are sick is because of that missing organ" **(Focus group 6, page 16)**

"The reason I say that I think of another person that I should give him. His family comes and say, "why do you care about donating your kidney "and you just get scared and think that let me stop because if something happens to me, they are going to say it is that kidney even if you were going to die." **(Focus group 9, page 25)**

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It is legal to trade kidneys for donation in Iran. Trading is regulated by law and subsidised by the national government. The Iranian model offers several kidneys for transplantation instead of the American model, which relies on altruistic donation (Nayebpour & Koizumi, 2018:55). Coercion, dissatisfaction, and social stigma investigated by Fry-Revere et al. (2018) ethnographically showed no evidence of coercion irrespective of legalised trading. However, 68% of the paid living donors felt pressure to donate due to extreme poverty or other family pressures, while 74% complained about the donation process and its results.

Furthermore, 84% of donors indicated fear of social stigma because of their kidney donation. Segev (2017) ended the stigma of HIV infection in organ donation after obtaining permission from the United Network for Organ Sharing in the US. Stigma ended by performing the first HIV-positive to HIV-positive organ transplant at The Johns Hopkins Hospital with success in which other countries followed, including South Africa. However, among the Chinese population, publicising knowledge of organ donation, promotion of family discussions, training of health professionals and students, of establishing an incentive system, and

implementing regulatory oversight may combat unfavourable public opinion (Shumin, Woo & Lei, 2014:28).

Sub-theme: Summary

Everything is done above board with Xhosa people, and there is no confidentiality. When one donates an organ, who is making the donation and who the recipient is should be known. That is where the question of stigmatisation comes in.

3.5.1.6. Fear of Character Transfer

Participants were concerned that their personalities would change if they received an organ. Participants were explicitly worried about the negative behaviour that if a donor was a thief/drinking a lot, the recipient might be a thief or an alcoholic. They wanted to know if there is a possibility that an organ recipient inherits the memories, talents, and qualities of a donor. Following are the verbatim statements:

> *Sometimes my sister may be a thief; when she donates with her arm to a person living a good life, it may spoil the receiver. We attach importance to inheritance; you cannot take my brain and put it in another person because people think differently.* **(Focus group 5, page 18)**

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> *In fact, yesterday I was listening on the radio, but I do not know if it was a joke that an athlete donated a heart to a woman in Brazil. Now this woman feels, you know, more energetic, and she likes to run (**all participants laugh**), and she knows who donated the heart to her. You understand those, you know those people of the broadcasting breakfast show, they like to make people laugh, and you will not know if it is true or whatever. If people are listening to that sometimes, they may think, ok if I get a donor who is like this, and then it means I will behave like that, things like those…"* **(Focus group 8, page 39)**

> *"This thing of two parts in a human being will lead to confusion. In our dreams, a person appears as a duplicate contrary to when a person retains his parts. That is why we discourage organ donation"* **(Focus group 5, page 19)**

The literature related to character transfer is scanty, instead of in the process of organ donation and transplantation, the recipient is in a heightened emotional state, which makes the recipient cling to the information as a way of connecting with the donor, thus making the recipient decipher the qualities of the donor (Lego, 2015). Adolescent participants who received a heart transplant identified emotional and psychological apprehensions regarding accepting donated hearts as their own. Adolescent participants also contemplated the potential attainment of personal qualities or characteristics of the donor, wondered comprehensively about the donor, and wished for donor information. Still, people are not worried about the transfer of personality and qualities of the donors (Anthony, Nicholas, Regehr & West, 2019:98).

Sub-theme: Summary

Participants raised concerns about character transfer because of organ donation, assuming that donor characteristics will be automatically transferred to the recipient.

Sub-Theme 2.2 deals with the general health. A presentation of Sub-theme 2.2 with its related details is presented in Figure 3.7

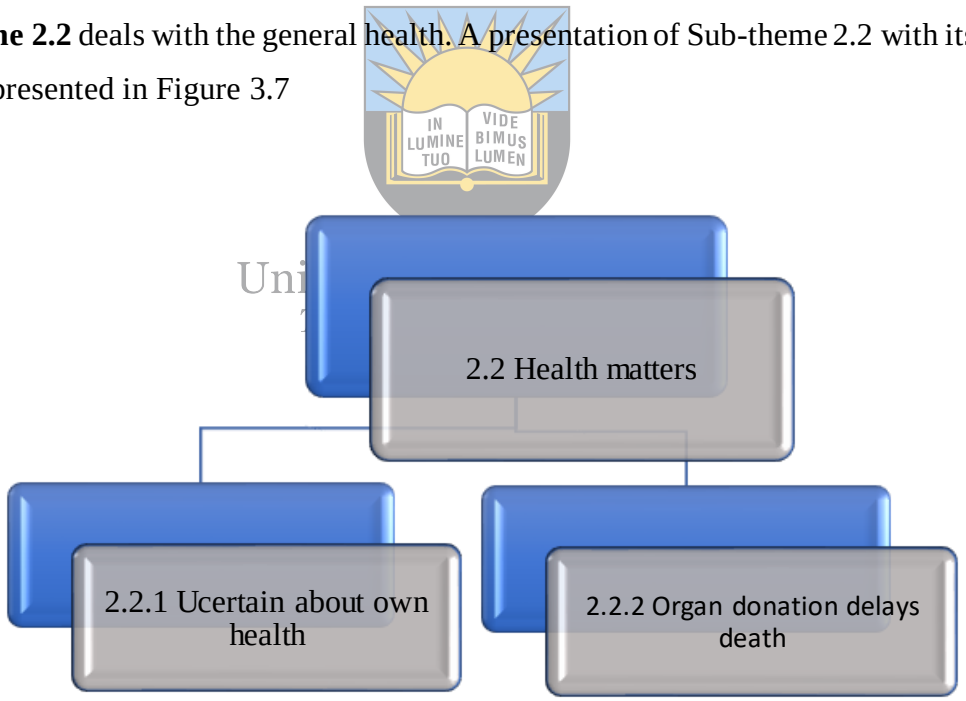


Figure 3.7: Sub-Theme 2.2 – Health Matters

3.5.2. Sub-Theme 2.2: Health Matters

All the participants were concerned about the health of the donor and the recipient, which may deteriorate after organ donation and after the transplantation. Participants were unsure of their health status and for others to donate their organs that might infect the recipient. Participants

were also concerned about the about donation age, which recommended energetic young adults donate organs. These health matters also included the poor health status of the cadaver. They felt that people waiting for organs should be allowed to die peacefully as organ transplantation will often render them weak and in need of health care. Below are verbatim statements:

> *"When I think, this kidney is required from those who are still growing; it is because they still have energy, those who are still growing, the old ones no longer have the energy they are not going up as the father that you are talking to he is slowing down in energy".* **(Focus group 3, page 49)**

> *"Sometimes you will find out that if you did an operation and the collapsed kidney is removed…. I think both even the donor becomes weak, even the one received takes time to be alright"* **(Focus group3, page 48)**

> *"What if the life span of the person who needs a donor is supposed to come to an end? it is good to make people live longer at the same time not reducing the life of others"* **(Focus group7, page 43)**

> *"My next question is whether it will not infect the receiver assuming that the donor is HIV-positive while I am HIV-negative"* **(Focus group7, page 42)**

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In SA, any individual under the age of 70 years, in good health and clear of any predefined chronic diseases that might cause further health complications for the recipients, is eligible for organ donation. Organ Donation in South Africa, Western Cape Government (2019). Council for Medical Schemes (CMS) (2012), the recipient is assessed to form a diagnosis of end-stage organ failure without any absolute or relative contraindication to the proposed procedure and psychological readiness for transplantation. Living donation candidates were evaluated to determine the desire to donate and informed of the risks related to the process and all information required to give informed consent. The donor's health assessed by the physician, excluding infections, predicts the risks associated with the procedure and transplant ability of the donated organ. Blood tests are performed from the deceased donation to exclude diseases and determine the compatibility (CMS, 2012).

Sub-theme: Summary

The participants expressed a concern that the donor's health status might be a risk towards organ donation.

3.5.2.1. Uncertainty about Own Health Status

Participants were concerned about their health and considered organ donation. They were aware that, before donation, one must be healthy. They verbalised that in the era of the HIV pandemic, it is not safe to donate if HIV-positive. Also, the recipient might be infected if they received an organ from the infected donor. As much as they were unsure about their health status, they were also afraid to undergo medical tests. Participants shared their experiences in this regard:

> "*...there are these diseases that you will find out that sometimes we hide the disease that we have, to donate organs, it should be known that you are healthy those tests be done, we Black people we don't want to know our health status we dodge that thing. We have a fear being tested...,"* **(Focus group 4, page 7)**
>
> *"We are sick with diabetes and other sicknesses, so our blood might be tainted"* **(Focus group 6, page 16)**

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Little literature was found in support of participants who wish to donate but are uncertain of their health status. Underlying fears for health included the challenges in processing information about the complications donors suffer from, which conflicted with the determination to donate (Hanson, Ralph, Manera, Gill, Kanellis, Wong, Crag, Chapman & Tong, 2017:1854). Unsettling uncertainty, in which donors are troubled by the slight possibility of harm, fearing donor outcomes, preoperative demonstrated by other participants (Hanson et al., 2017:1854). Tumin et al. (2015:2247) added medically unfit and scared of surgery to become a living organ donor. Martin, Stone and Scott (2010) identified sources of uncertainty across the transplantation trajectory. Uncertainties identified before transplantation were insufficient information about the diagnosis, complex decisions about transplantation, unknown organ availability, unclear expectations about medical procedures, doubt in the meaning of life, and questioning others. Post-transplantation, participants were uncertain about the complex medication regimen, unpredictable future health, possible stigmatisation reactions,

and complex interaction with the deceased donor family. Bratton, Chavin and Baliga (2011:247) further added that minority groups suffer from disparities in deceased and living donation. African Americans' barriers to living donation include unwillingness to donate, comorbid medical conditions, trust or fear of the medical community, loss to follow-up, poor coping mechanisms, fear of surgery, and lack of awareness about living donor kidney transplantation.

Sub-theme: Summary

Potential organ donors are troubled by the slight possibility of harm, fearing donor outcomes.

3.5.2.2. Organ Donation Delays Death

Participants believed that receiving the organ would prolong one's life instead of allowing those in need of organs to die peacefully. Irrespective of getting an organ, participants were also concerned that the recipient would be weak and need care. Participants interpreted organ donation negatively as the patient with organ failure falling sick, suffering, making frequent hospital visits, needing constant care, and might requiring dialysis in case of kidney failure. Read below:

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> *"…Let him die if he must die. That would mean he was meant to die, and the hour has arrived" Every person has a date that God determines on when he is going to die…. let him go in peace"* **(Focus group 5, page 21)**

> *"What if the life span of the person who needs a donor organ is supposed to come to an end; it is good to make people live longer at the same time not reducing the life of others*" **(Focus group 7, page 43)**

> *"The sickness will get worse if I donate, such as HIV and diabetes. I know that a heart gets removed from one person and transplanted to another, and it works; that is, death delayed. It is not advisable to delay a person's departure while he lives as a disabled person and we do not have time to look after disabled people*" **(Focus group 5, page 19)**

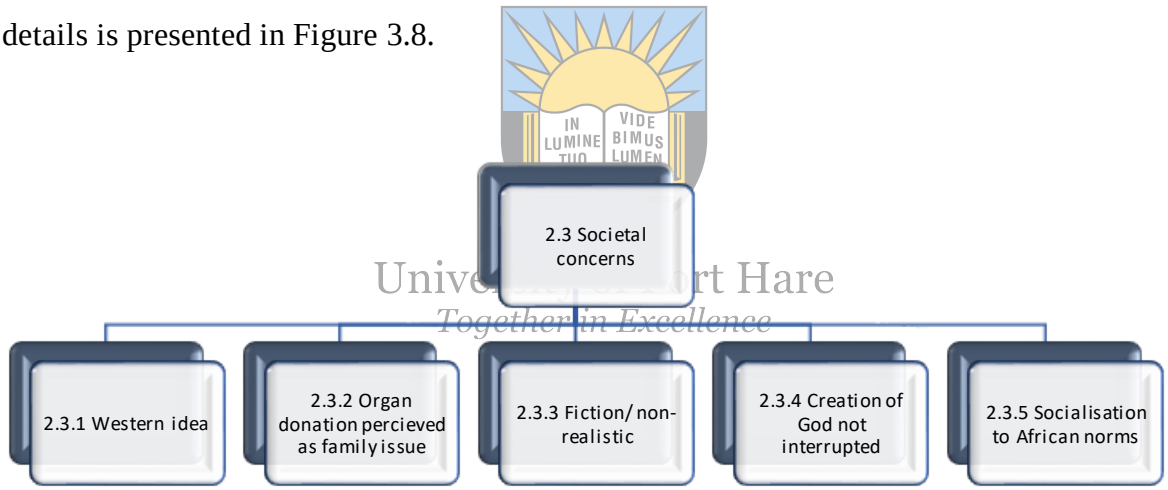
One of the main benefits of organ donation is an increased life span. Some patients waiting for organ donation are kept alive through artificial means like dialysis, ventilators, or ventricular

devices. Without a transplant, patients would die; with the transplant, recipients can live for many more years (Moritsugu, 2013:244). Improved quality of life even for the recipient who is not at risk of death. Organ donation allows an individual to live without long-term, costly treatment. Kidney transplants are much cheaper than dialysis to keep the individual alive. Walker and Sque (2016:75) acknowledged that organ and tissue donation has the potential to balance hope and misery at the end of life when the wishes of the dying patient, deceased donor, and bereaved families are fulfilled.

Sub-theme: Summary

Despite the massive call from the South African Government for everybody to undergo HIV tests given the HIV/AIDS pandemic, many Blacks are not responding positively to that call because of fear.

Sub-Theme 2.3 deals with societal concerns. A presentation of Sub-theme 2.3 with its related details is presented in Figure 3.8.



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Figure 3.8: Sub-Theme 2.3 Societal Concerns

3.5.3. Sub-Theme 2.3: Societal Concerns

A *social issue* is a *problem* that influences many individuals within a society. Among societal issues, participants view organ donation as a Western idea, exclusive for the relatives (meaning one should donate for the family member), fiction, and interference with God's creation. The following views were expressed during focus group discussions:

> *"The issue of organ donation among Xhosa people is a serious societal issue that affects everyone. We need to pay attention to getting the Xhosa nation on board by*

*educating people as early as possible, not only in the schools but wherever the people are gathered. This issue must be brought to the table." (**Focus group 8, page 41.***

*"The reason I mention this is that I took it to myself this as part of building the nation because this might be medical, but it has concerns of society. That is why I am saying there is beauty in it. Then people also by doing it, as people becoming enlightened what this thing is, some of these things are challenges that we are facing, possible may be the results of great resistance based on perceptions and ignorance." **(Focus group 8, page 41)***

According to Etheredge (2019), in SA, religious and cultural beliefs are identified as barriers to the uptake of organ donation, and they influence the decisions people make about the remains of their loved ones. Most families prefer that a relative's body remains whole and intact, similar to burying a person within a stipulated period. Societal issues contribute mainly to the gross shortage of organs and pervade the social stuff from population and legislation down to the practice of healthcare workers in hospitals. Cotrau et al. (2019:13) agree with Etheredge (2019) in South Africa that issues affecting the multi-ethnic societies in Rome include the lack of awareness regarding organ procurement, brain death, and misconceptions that need to be rectified.

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Sub-theme: Summary

Organ donation should be seen as a medical problem, and it must be understood as a societal challenge.

3.5.3.1. Organ Donation is a Western Idea

Participants claimed that organ donation is a Western idea, and it is a new phenomenon to them. Their ancestors never talked about it while they were still alive; hence, the participants perceive organ donation and transplantation as something that White people practised. They further view it as a form of oppression towards Black people. Participants responded as follows:

*"...we view this as something affecting Whites" **(Focus group 6, page 16)***

"I want to say for example us as amaXhosa we are people who don't understand easily, we see these things on TV because Whites donate these things and they know that people should help each other, we have this fear now because our customs are not the same" ***(Focus group 9, page 25)***

"To my understanding, the then time is not stupid when White people came, they oppress us that is why we are scared now. These educated people sold us out to these Whites." ***(Focus group, 9 page 27)***

"*We see these things on TV and assume that it's a White man's problems* ***(Focus group 6, page 17)***

"As we are being informed that White people practice organ donation. If this is a way for them to develop themselves, it is bad to do development." ***(Focus group page 5, page 18)***

"*…truly speaking (enyanisweni) it was not ours us as Black people. I think White people have (abelungu bebene) the way segregation, and you know there was no thinking of organ donation because it is expensive to do that and it was not affordable for the Black people..."* ***Focus group 8, page 36.***

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"...because this something that we grow up to perceive as an issue that has to do with White people, you know, it has never been an issue to us as abantu abamnyama (Black people) organ donation, you see! Trying to adverse the reason why this thing of organ donation is not an issue that we talk about in our gatherings." ***Focus group 8, page 35.***

Kidney donation and transplantation started in SA Johannesburg in 1966, followed by the first heart transplant in 1967 done in Cape Town. These operations occurred in big cities, and few Black people knew about it (Etheredge & Fabian, 2016). It is worth noting that after 20 years of democracy in SA, there still exist challenges of inequities in all aspects of life. The uptake of organ donation is not an exception, which could be attributed to the geographical inaccessibility of health services and information, especially in low-resource regions, including the Eastern Cape Province. Demonstrations of political will improve the situation through

national education campaigns and the implementation of mandated organ referral in public hospitals nationwide (Etheredge & Fabian, 2016). The low number of organ donations concerns thousands waiting for transplants. Koretzky (2017:427) concluded, "The period from January 1968, when Dr Chris Barnard transplanted Clive's heart into the body of Mr Blaiberg to the Turkey transplant in May of the same year provides a fascinating window into social and political implications of medical procedure. The temporal context for these interracial transplants, in a year of turbulent racial politics and social movements, set the stage for intense discussion of race, politics and identity in the Black press". Organ donation, started by the White population during the apartheid era in South Africa, led the participants to perceive it as a White initiative to oppress Black people.

Compared with the White population in America, African Americans showed a willingness to donate their organs to relatives. However, they had lower rates of signing a donor card and lower scores on the 'Trust in the Healthcare System' scale. Furthermore, they believe that doctors will not try to save a life if the person is known to be an organ donor. It was perceived that famous or rich people were more likely to get a transplant. There was greater mistrust in the equity of the donation system and more favourable about providing benefits to donor families than White respondents (Siminoff, Burant & Ibrahim, 2006:998). African Americans, Black Africans, and Black Caribbean populations in the United Kingdom and Xhosa community participated in the study regards organ donation as a 'White issue', which is the barrier to organ donation (Morgan, Kenten, Deedat & Donate Programme Team, 2013:379).

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Sub-theme: Summary

There is a perception among participants that organ donation is a Western idea. A need to bring this matter up for discussion on all relevant structures was identified to make people more enlightened.

3.5.3.2. Organ Donation Perceived as a Family Topic

Participants perceived organ donation as something practised by blood relatives. To them, no one should donate outside the family because only family members can assist in time of need. The following refers:

> *"It is a sibling that is needed...."* **(Focus group 1, page 4)**

"It is good to donate something, but I think that you can donate to someone who is your family." **(Focus group 4, page 8)**

"...And again, added by what I did that she is my family he/she can help me when I have a problem in my body, maybe when I have blood shortage though you just see blood infused not knowing where it comes from, she can be able to help me for what I short of or visible kidney...." **(Focus group 4, page 9)**

"I volunteer. I am coming to the fact that the family will say, why do you care about that person. That is why I say rather a person can get a kidney from his family" **(Focus group 9, page 25)**

Family members, such as a parent, child, brother, or sister, can be living related donors, and a donation can also be obtained from someone passionately associated with the recipient, such as a good friend, spouse or an in-law (living unrelated donor). A genetic link between the donor and the recipient is no longer obligatory to certify a successful transplant. However, transplants performed between family members with the same genetic makeup have a low risk of rejection (National Kidney Foundation, 2019). According to Irving et al. (2012:2529), the participants' families often decide on organ donation and that influence could have either a positive or, more often, negative impact on an individual's decision. Some participants felt obliged to ask family members. In contrast, some thought that a decision from family members regarding organ donation would ensure that loved ones are not burdened later with a difficult choice and interfere with the grieving process for families.

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Sub-theme: Summary

Participants were receptive for organ donation to be practised within family circles; in this way, the recipient can reciprocate by assisting when the donor requires assistance.

3.5.3.3. Fiction/Non-Realistic

Almost all the participants heard about organ donation from social media, such as television and the radio. They were unsure if the information from the social media was accurate and viewed it as fiction. Participants narrated the stories about the organ donation in the verbatim statements below:

"Sometimes we watch these things on TV we don't know about them even if it is a true story or just a story" **(Focus group 3, page 48)**

"He sees it as Nongqawuse, we are told something that will never happen, and he sees it on television, and he sees it as a waste of his time" **(Focus group 1, page 2)**

"In fact, yesterday I was listening on the radio, but I do not know if it is a joke that in Brazil, an athlete donated a heart to a lady. Now, this lady feels, you know, more energetic, and she likes to run (all participants laugh), and she knows who donated the heart to her. You understand those, you know those people of the breakfast show, they like to make people laugh, and you will not know if it is true or whatever" **(Focus group 8, page 39)**

Josephine and Balamuruga (2013) identified television (TV) as the principal respondent's source of information about organ donation. Morgan, Harrison, Long and Afifi (2005:677) also agreed that family members receive important information about organ donation through the media, which sometimes portrays a negative picture. The press actively referenced premature declaration of death, character transfer, the US Black market for organs, corruption in the medical fraternity and improper allocation of organs. The public believes these myths to be valid from the media. Therefore, these myths should be counteracted effectively in promoting organ donation through the media. Less uptake of organ donation is influenced by a hostile and often sensationalist portrayal of organ donation in the press and the reports of unethical research in the continent (Etheredge, 2019).

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Sub-theme: Summary

Hearing about organ donation for the first time and from social media platforms results in them not being sure whether this is a myth or a fact.

3.5.3.4. No Interruption of God's Creation

Participants were not sure if one kidney would function well on their own. They believed that for a person to survive both kidneys should be working simultaneously. It was not a mistake for God to create two kidneys. Therefore, there should be no interference with God's creation. The following are their statements:

"When you have one kidney, we think that it can shorten your life because the other kidney was helping this one it is not clear if it will have power that is equal to two kidneys, and then I will not have a long life; it will be short because of the missing kidney. There are such thoughts when donating with a kidney. In addition, another thing that we think a lot about God created two. There is a reason for creating the two of them. We are afraid of having one kidney." **(Focus group 3, page 48)**

"*We consider a human being in its totality. You do not remove a heart and think that you have not interfered with the person. You have wronged that person; those bones will be complaining about their heart that was taken and donated to another person."* **(Focus group 5, page 20)**

Most people understand organ donation as the decisive form of disfiguring the human body; this concern often stems from the Bible (1Corinthians 6:19), in which Christians are expected to keep their bodies pure with no intervening, according to the Will of God. Contradictorily, the most compelling argument for organ donation is to demonstrate love and compassion towards others; such an act is demonstrable in the Bible (Old Testament), where God commanded to love Him and one's neighbours (Leviticus 19:18 and Matthew 5:43). Therefore, donating an organ demonstrates a selfless sacrifice for one another (Dopelt, Siton, Harrison & Davidovitch, 2022).

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To overcome some of the myths associated with organ donation, transplant teams, donation coordinators, intensivists, and nephrologists need to work collaboratively, considering religious concerns. Olivier, Woywodt, Ahmed and Saif (2010:442) concluded that giving information about organ donation is not enough to overcome the apprehensions of prospective donors as they use religious fears to obscure their reluctance to donate. Some respondents felt donating an organ was 'playing God' while others believed no one should mediate if a person were 'meant' to die (Irving et al., 2012:2528). After death, maintaining body wholeness was the most common religious objection to organ donation. Others also believed that they did not 'own' their body, but rather it belonged to their God, and therefore, they could not donate (Irving et al., 2012:2528).

Sub-theme: Summary

Donating organs, such as a kidney, defeats God's purpose of creating each person with two kidneys. Yet others debunked this view through citing scriptural references to prove that organ donation is a show of love.

3.5.3.5. Socialisation to African Norms

The community of Xhosa people believe in learning to behave in a way acceptable to the society in which one belongs. Participants mentioned that organ donation is not an African thing. Their ancestors have never talked to them about it. Therefore, they are expected to adapt to the norms of a culture or society. During primary socialisation, they learn everything from their elders. Organ donation uptake is not something that is mentioned. Below are several participants' verbatim statements:

> *"We African people we say for us to trust something should come from one of the Chiefs that you named or come to us and tell us someone like this and this is coming to us, and now we start to believe."* **(Focus group 4 page 9)**

> *"We have a belief that we grew up under what says, "you must never do such a thing" …. Other because we are Africans, So, those things are built within us…. So, ancestors as Africans, I will respond to what I know ancestors that is our forefathers it is something that they were not going to appreciate because it was never mentioned. Most of us Africans believe in ancestors even if we don't believe in them now, we once believe them."* **(Individual interview (P), page 29)**

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Research by Maniam and Zolkepli (2010) indicates that the supportive influence from the agents of socialisation affected, to a certain degree, the behavioural formation of becoming an organ donor in their exploration on how sustainable health can be encouraged through the role of socialisation among the Malaysian youth in the context of decision-making process towards becoming an organ donor. However, A later study by Knox, Parkinson and Ahani (2020) reveals that the impediments to organ discussion among Australian youth were consideration (the absence of initial thought) and opportunity (a time or set of circumstances that make it possible to discuss organ donation). According to the trans-theoretical model by Prochaska and Di Climente (2005), the availability of opportunity might upkeep the mechanism of change utilising the steps of readiness, which further leads to the change of behaviour. Certain ethical

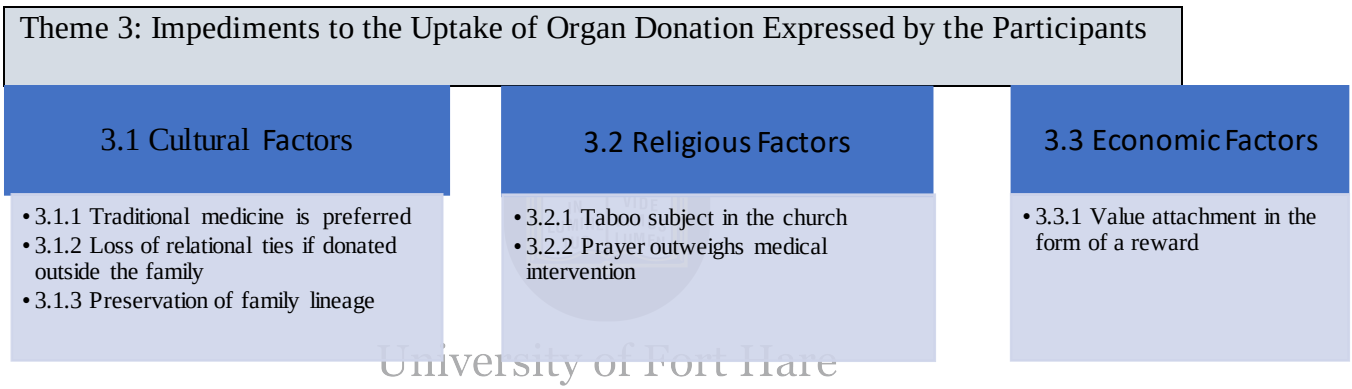
ideals, principles, doctrines, myths, or symbols of a social movement can predict an individual's likelihood of becoming an organ donor (Chan, 2019:258).

Sub-theme: Summary

Participants asserted that organ donation is not an African concept. African ancestors never practised this ritual; therefore, it is taboo, and the chiefs view it as a foreign practice.

3.6. THEME 3: IMPEDIMENTS TO UPTAKE OF ORGAN DONATION EXPRESSED BY ALL PARTICIPANTS

Theme 3 with related sub-themes diagrammatically presented in Figure 3.9 as follows:



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Figure 3.9: Theme 3: Impediments towards the Uptake of Organ Donation

In theme 3, participants discussed cultural, religious, economic, and personal barriers to organ donation. Among these is the consultation of traditional healers who confer with ancestors by talking to bones, singing clan names, administering traditional medicine, and performing rituals. On the contrary, ministers of religion conduct prayer, and traditional leaders strengthen moral values. Participants also complained of the activities happening in big cities and nearby townships. In contrast to such activities rural areas are neglected in educational empowerment, infrastructure, and public awareness campaigns. Below are several verbatim statements reflecting this sentiment:

> *"… There is no one who can reach out to us like the way you now reached out to us…It means there are few chances Mother can come here to the rural areas. And here in the rural areas, you are in the dark."* **(Focus group 1, page 2)**

"We are people who attach importance to inheritance. It is possible to find no similarities in families. This makes us reluctant to donate in case there is no resemblance." **(Focus group 5, page 18)**

"The reason why we dislike organ donation is that we want to maintain the difference that exists. We are guided by our dreams when we heal. This thing of two parts in a human being will confuse our dreams because a person will appear as a duplicate in a dream, contrary to when a person retains his parts. That is why we discourage organ donation." **(Focus group 5, page 19)**

"I have never spoken to about organ donation, I was just speaking about praying, ***(all the group laughing).*** *May be other pastors have made that organ donation, but I don't have direct experience and in that there were members who were diagnosed with kidney failure, and then we pray for that."* **(Focus group 8, page 33)**

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Barriers to organ donation are a global problem. In their systematic review study Alsadat, Abdolmagid, Narges and Mozhgan (2018) identified cultural barriers in families that were not familiar with the culture or concept of brain death. Such educational barriers included inadequate education and insufficient knowledge of the issue at hand, especially brain death and the decision to donate. Religious barriers included maintaining respect for the dictates, prohibition of fragmentation of the myth in Islam, and people believing in forms of physical resurrection. Emotional barriers were identified as being the source of family dissatisfaction with the treatment of brain-dead patients, early termination of medical treatment, and separation from the patient (Alsadat, Abdolmagid, Narges & Mozhgan, 2018:179). Da Silva and Frontera (2015: 116) indicated that there are several reasons for the worldwide barrier relating to donation, including a lack of standardisation of brain death and organ donation criteria, variable clinical definitions, and legal definition of brain death, inconsistence legal upholding of brain-death criteria, racial, ethnic, and religious perspective on organ donation. In addition, physician discomfort and community misunderstanding of the process of organ donation constitute a barrier to the loss of potential donors (Da Silva & Frontera, 2015: 116).

Theme: Summary

Traditional healers asserted that their ancestors must guide them in a dream; if not, anyone receiving a donated organ may lose his/her identity. Hence, they do not support it.

Sub- Theme 3.1 present cultural factors. A presentation of Sub-theme 3.1 with its related details is presented in Figure 3.10 below.

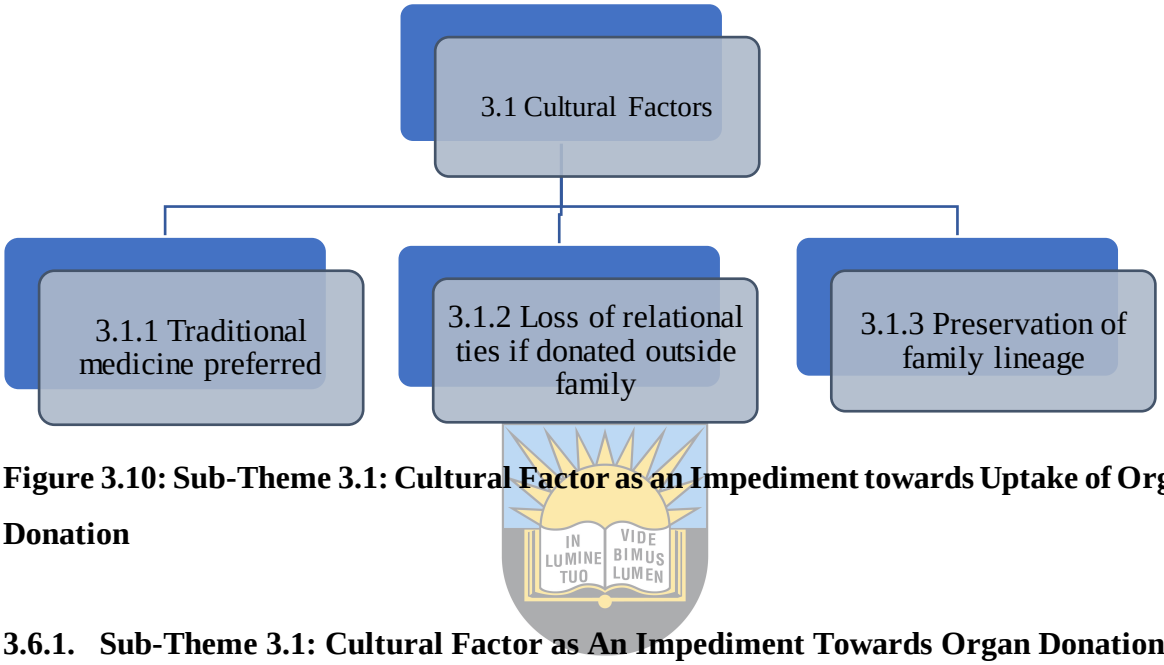


Figure 3.10: Sub-Theme 3.1: Cultural Factor as an Impediment towards Uptake of Organ Donation

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3.6.1. Sub-Theme 3.1: Cultural Factor as An Impediment Towards Organ Donation

Cultural factors emerged as a sub-theme among the barriers to organ donation under theme 4. Within this, participants still preferred traditional medicine to medical intervention for organ donation. However, they indicated that they would donate their organs to family members to keep the relational, familial ties. Participants believe that a male child should carry the family lineage; therefore, if complications such as death arise in donation, the family name will end. Below are several verbatim statements reflecting this sentiment:

> *"I say old people are the ones who believe in something that has to do with ancestors; they said that I must arrive complete."* **(Focus group 1, page 1)**

> *"Traditional healers believe that you cannot make organ donation; we use our herbs to cure a sick person." We get our guidance from our ancestors and rely on our herbs. That is the reason we cannot use other person's parts. We respect a person's parts."* ***(Focus group 5, page 18)***

> *"If you are still alive and your organ is taken for the second time, maybe the ancestors will never allow that we don't know that is as belief. We never heard that there is someone who was never accepted because there is a missing organ."* **(Focus group 4, page 10)**

Attitudes towards any decision, including whether to donate, are influenced by culture (Hawryluck & Knickle, 2019). Unspoken assumptions regarding the meaning of health, illness, and death may affect communication regarding organ donation. Knowledge of cultures with the care desires using the culture care theory has become crucial in nursing to know and assist diverse cultural groups (Leininger, 1978; 1991 in George, 2014:430). This theory has guided nurses in meaningful and stimulating ways in understanding diverse cultures in nursing practices and research (Leininger, 1991). Possessing knowledge and accommodation of cultures enable health professionals to understand how Xhosa people view health, and perceive the cause and nature of illness, as well as how they perceive the nature and the meaning of death. Lastly, to understand how Xhosa people perceive organ donation, healthcare professionals need to honour any death-related rituals or observances that Xhosa people wish to honour or to perform (Hawryluck & Knickle, 2019).

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Xhosa people are bound by culturally based care factors, recognised by Leininger as influences on human care expressions, beliefs, and practices related to health, illness, and well-being, or facing death and disabilities (George, 2014:430). One of the barriers to organ donation among this community is their cultural belief system. Research by Bhengu and Uys (2004:25) points out that there is a greater connection between the Zulu-speaking people and their ancestors; if they participated in organ donation, they believe they would lose their ancestral link since the ancestors do not accept them if they are not buried in full. As such, this could also be true for Xhosa people. While there is a strong cultural belief that a donor's spirit is transferred to its recipient, others may seek approval of the ancestors before donation, and the ancestral approval is sought by performing the traditional rituals (Irving et al., 2012:2528 in Molzahn et al., 2004). An elderly community member and a traditional healer in Eastern Cape, South Africa, is quoted verbatim by Zikali (2018) as saying, "as a traditional healer, I have a strong belief in the existence of ancestors, and I directly communicate with them. If I die and have missing organs, I will not be accepted by my ancestors; the body of the deceased must be treated with respect."

Sub-theme: Summary

Cultural beliefs dictate that ancestors expect people to arrive complete when they die. If not, they will be rejected. It is further believed that the donor's spirit is transferred to the recipient during organ donation.

3.6.1.1. Traditional Medicine Preferred to Medical Treatment

Although traditional healers agree to participate in organ donation, they still prefer to use traditional medicine than organ donation as a treatment option for organ failure. The following two verbatim statement below are reflecting this sentiment:

> *"The reason why we dislike organ donation is that we want to maintain the differences that exist; we are guided by our dreams when we heal."* **(Focus group 5 page 19)**

> *"I am satisfied with this incense. I won't say tablets are wrong because if you overdose medication, it kills."* **(Focus group 9, page 27)**

A Xhosa person prefers cultural rituals; this then limits their use of high technology tools and instruments as in hospital admission (George, 2002:492). However, in studies conducted in the USA and UK, participants expressed a lack of confidence in medical teams that retrieve the organs for transplant as well as limited understanding of brain-stem death in general (Shillings et al., 2006:839; Morgan et al., 2006:233).

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Sub-theme: Summary

Traditional healers prefer the use of conventional medicine to organ donation because they are guided by their dreams when they heal.

3.6.1.2. Loss of Relational Ties if Donated Outside the Family

Participants preferred to donate organs to their families, as they were within reach for support. Participants perceived that families share the same blood group and tissue typing. Therefore, a relative with organ failure should not wait that long as the matching organ can be found within the family. This avowal is confirmed by the verbatim statements below:

"The thing is that you can't take my organ and put it in another person because we belong to different blood types." **(Focus group 5, page 18)**

"It is good to donate something, but I think that you can donate to someone who is your family. Another thing now, Sister, the truth is you see two kidneys, and how do you give it to a person who is not related to you and if your other kidney fails because you will be left with one and that person will not help you in anything. And it is better if you donate to the relative you know. But do you think your relative from home will help you?" **(Focus group 4, page 8)**

"...but it took a long time for people, especially Black people Xhosas, to accept the thing of blood donation because people believed in that, if I take away my blood, it means my ancestral link is somehow lost to another family, and it is a problem for me. I cannot donate blood, but with perseverance, people were constantly bombarded with organ donation, I mean blood donation, blood donation until people got to a point where they saw the need. Now I would like to use the same analogy when it comes to organ donation." **(Focus group 8, page 35)**

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The primacy of family emerged as a theme that reflected participants' beliefs who participated in the study of Asian Americans 'attitudes and behaviours towards deceased organ donation, they indicated more inclination to donate to family only (Siminoff et al., 2019:77). In their systematic review on factors that influence the decision to be an organ donor, Irving et al. (2012) revealed that willingness to donate to a family member or friends is more desirable than to an unknown person even if they would not consent to a deceased nor living donation.

Sub-theme: Summary

Donating to a family that one has no relationship with may result in the loss of an ancestral lineage.

3.6.1.3. Preservation of Family Lineage

Participants view the male child of the family (patrilineage) as the person who is supposed to look after the family and carry on their name; therefore, they are prohibited to donate organs

since they fear he might not survive his donation, leading to the end of the family's ancestry. This is the verbatim response from the participant:

> *"Look, I would like to donate my kidney for my dad* ***mh… from other group members****. Then it was my dad who said to me; I am the only son in the family, and my boy, you are still very young, the whole family lineage or whatever depends on you. I cannot allow you to take that risk because you may donate and the other kidney get a disease that may affect you, that means it will be the end of my lineage."* **(Focus group 8, page 33)**

Lineage, succession group counted through only one parent, either the father (patrilineage) or mother (matrilineage). All lineage members trace their common ancestry to a single person (Lineage Sociology, 2008). The literature is not specific about family lineage as a barrier to organ donation. Instead, family members' disagreements were health-related (Kuyong et al., 2018). In Jabri et al.'s (2016) study, a lack of awareness and the fear of the unknown was the most important barriers among the Saudi population. Molina et al. (2018) identified the leading causes of a family refusing to donate is their little understanding of brain-death and the unknown wishes of their deceased. They further state that continuing with the protocoled process for approaching the families of potential organ donors, education of society as a key to overcoming myths, fears, and perceptions related to the refusal to donate are ways of overcoming these barriers.

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Sub-theme: Summary

The male child, particularly the firstborn, is regarded as the heir of a family. Therefore, he is barred from donating an organ, as it may put his life in danger.

Sub-Theme 3.2 presents religious factors towards organ donation. A presentation of Sub-theme 3.2 with its related details is presented in Figure 3.11

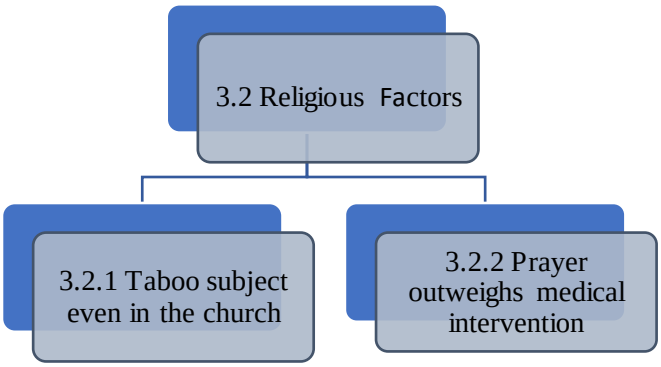


Figure 3.11: Sub-Theme 3.2: Religious Factors as an Impediment towards Uptake of Organ Donation

3.6.2. Sub-Theme 3.2: Religious Factors as an Impediment to Organ Donation

Religious factors also emerged as a sub-theme. Within this element, some participating ministers indicated that they have never talked about organ donation at church, while some prefer prayer over medical intervention. Ministers of religion in other focus groups saw organ donation as a good thing but never talked about it in church. Below is a statement from one participant:

> *"…. the perception of churches based really on biblical teachings …that is really what we are preaching to people, and there is real evidence to that fact that says people, after being prayed for, are getting healed and even medically when they are coming back…if you go to God, you are going to be healed. But now this thing depends on the level of faith in a person; there are those people who do not have that level of faith."* ***(Focus group 8, page 34)***

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Most religions view organ donation as an act of neighbourly sacrificial love and charity; therefore, all members are encouraged to support organ donation. Other denominations left the decision to donate up to everyone. Only the Shinto religion discourages injury to a dead body in case of deceased donation, while Gypsies opposed organ donation as they believe in the afterlife (National Kidney Foundation, 2020; Olivier et al., 2011:441).

Randhwa and Neuberger (2016) noted that the role of faith plays an important part in the decision to donate organs; therefore, there is a need for the engagement of faith leaders regarding organ donation, diagnosis, and definition of death. The uncertainties regarding

religion differed between groups, which reflects several significant aspects of ethnic identity and understanding. Religious concerns often play a more significant role than concerns about clinicians and transplant teams (Olivier et al., 2011:442). These are further compounded by the fact that patients seldom verbalise their religious concerns since the issue of transplantation is new to them anyway and because they meet with transplant teams that they do not know. On the other hand, health professionals may wish to avoid this sensitive issue altogether or may lack knowledge of religious matters about transplantation; some may be entirely unaware of it.

Sub-theme: Summary

Some religious leaders do not conduct awareness education on organ donation; on the contrary, they drive people to believe that everything can be cured through prayers.

3.6.2.1. Organ Donation as a Taboo Subject, Even Within the Church

The participating religious ministers tend to focus on preaching and praying for physical ills, while the church's mission is to save souls from sin and social ills. Refusing to donate one's organs is a societal issue but is not taken seriously. Although some ministers present health talks in their respective churches, organ donation was not a subject they discussed. Others utilised their congregations' skills to address health-related topics. Still, they only mentioned kidney donation and how the church viewed the subject. Below are three verbatim statements from the participants:

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> *"I want to come to a question of the church; now, in the church, I have never spoken about organ donation, I was just speaking about praying,* ***(all the group laughing)*** *may be other pastors have made that organ donation."* **(Focus group 8, page 33)**

> *"Faith is very important, very crucial to us as Christians, but even with faith, you know the way we discuss this thing as church community."* **(Focus group 8, page 35)**

> *"...you see, unless no one can be, (how can I put it now) relate otherwise, so we have been going along around Bible revivals in South Africa. I never had other pastors talking about organ donation. I am talking about healing."* **(Focus group 8, page 34)**

"There is a necessity of debating something that whom we might have been taken them lightly. This one of the areas that we take them as taboo." **(Focus group, 8 page 40)**

In Australia, studies on attitudes and beliefs pertaining to deceased organ donation in an Arab-speaking community reveal that participants receive mixed messages. Their religious leaders never raised the topic of organ donation; some believed that donating an organ is a reward associated with going to heaven (Ralph et al., 2016:5). Generally, when people are confronted with deciding about organ and tissue donation after a loved one's death, their religion and beliefs suddenly become very important to them. As the decision is made, their religious stance, which was not clearly stated or discussed before, is often raised. The clergy are encouraged to know their religious group's doctrine or position regarding this type of donation and to further discuss it with their congregants (Theological Perspective on Organ and Tissue Donation, 2020). A more favourable attitude was found among the religious respondents, who know their religious stance on organ and tissue donation, than those who did not know their religious view (Rios et al., 2017:1024).

Sub-theme: Summary

Pastors are supposed to look holistically to their members; however, they only look at the spiritual aspect.

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3.6.2.2. Prayer Outweighs Medical Intervention

Not all ministers know their denominations' stance, position, law, or policy regarding organ and tissue donation. Their views were not the same regarding the encouragement of the congregants to donate organs. Some ministers embrace organ donation and understand it as a sacrificial love to one another. Prayer can delay the process of organ donation as some of the ministers expressed a desire to pray first and agree to organ donation and transplantation as a last resort. Following are verbatim statements from some of the ministers of religion:

"...There was something presented in the report that needed to be replaced, and they should get it from someone's eye. This lady now was taken to a specialist with this illness in Cape Town, and then again, when she went there, we were praying for her, praying for her, praying for her. Then now, when she came back and said, no man, the doctors had not seen any more what was seen in the eye. You see now, I am speaking

from the perspective of saying, there are instances where you pray, and the medical evidence was saying you need a transfer, and then now, we pray and then again after some time, the very same one who comes to see me, in this instance she said "I am healed", we are talking about organ donation, we are talking about faith." **(Focus group 8, page 36)**

"We see now, there are two things now, we believe that God ***Heals****, the Doctor C****ures,*** *we encourage the members to go to the doctors but the final person to heal is God."* **(Focus group 8, page 36)**

Personal prayer in patients dealing with a chronic illness, patients mostly pray for relief from physical and mental suffering (Jors et al., 2015). Furthermore, prayer can be a resource that allows patients to positively transform the experience of their illness, which implies reverse organ failure and, therefore, no transplantation of an organ. However, undertaking prayer or other religious rituals by the chaplains can assist patients in getting treatment. Also, prayer through chaplains provides pastoral care that supports family decisions both during and after the withdrawal of the life support in deceased donation (Timmins, Caldeiras, Murphy & Pujol, 2018).

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Sub-theme: Summary

Religious leaders operate on comparison bases, asserting that prayer works better than medical intervention; they do not appreciate that medical intervention is God's intervention through medicine.

Sub-Theme 3.3 presents economic factors. A presentation of Sub-theme 3.3 with its related details is presented in Figure 3.12

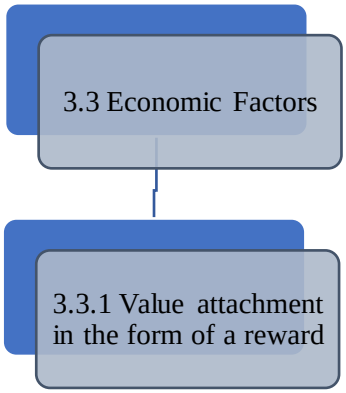


Figure 3.12: Sub-Theme 3.3: Economic Factors as an Impediment Uptake of Organ Donation

3.6.3. Sub-Theme 3.3: Economic Factor as an Impediment towards Organ Donation

They suggested that people might agree to donate if a monetary value could be attached to organ donation. Participants, especially community members and traditional healers, were concerned about the support to the society; they proposed some compensation in exchange for donating organs. Following are verbatim statements:

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Herewith, a few statements from the participants:

> *"I may donate to a person of higher standing in society while I am at the lower ranks, and I will be tempted to tell him that he is alive because I donated my kidney without him having paid a thing. Therefore, the person ends up being a victim because now I want to be paid for donating my kidney."* **(Focus group 6, page 17)**

> "*I was going to ask one thing some people love money, and a person will say give me money to get what you want. Is that acceptable?"* **(Focus group 2 page 6)**

> ***"****Another thing that I am thinking about is that maybe the government can give compensation so that when one donates are told, you will get something for what you have donated."* **(Focus group 3, page 50)**

Medical, surgical, legal, ethical, and religious issues are important in all organ transplant procedures. The financial economics of organ transplantation affect the government, healthcare insurance companies, and uninsured individuals; hence, the distribution of financial burden is not the same among countries (Altinors & Haberal, 2018:109). Organ transplantation offers

patients a longer, better quality of life and is remarkably less expensive than dialysis. Financial incentives can increase organ supply, such as kidneys, but buying and selling of organs is illegal in some countries (Garwood-Gowers, 2019). The National Organ Transplant Act (NOTA) and the Uniform Anatomical Gift Act (UAGA) do not permit the buying and selling of human organs. Legally acceptable compensation includes only a settlement for living donors' expenses justifying the financial loss resulting from the donation process rather than encouragement to donate organs (Parada-Contzen & Vasquez-Lavian, 2019:7; Harbell & Mathur, 2019:185).

In their conceptual argument favouring a financial incentive, Shaikh and Bruce (2016:109) argue that financial compensation would promote the uptake of organ donation, thereby increasing the number of donors. Secondly, organ donors do not receive any benefit while the recipients receive organs. Thirdly, the support of society is important as half of the population participated in a poll by United Network for Organ Sharing Ad Hoc Donations Committee, favoured compensation for organ donors. Same Shaikh and Bruce (2016:109) argue that financial incentives could offer a real or apparent element of bullying for those who may feel this is their only option to obtain an income, which, in turn, could create disparities between, such as buying and selling of human organs for survival. Current donors may refuse to donate as they may feel undermined on their altruistic compensation.

Sub-theme: Summary

Generally, compensation was expected when donating an organ for another person. Probably the government may consider making a form of payment to donors.

3.7. THEME 4: SUGGESTIONS TO PROMOTE THE UPTAKE OF ORGAN DONATION, AS EXPRESSED BY ALL PARTICIPANTS

Theme 4 with related sub-themes is diagrammatically presented in Figure 3.13 as follows:

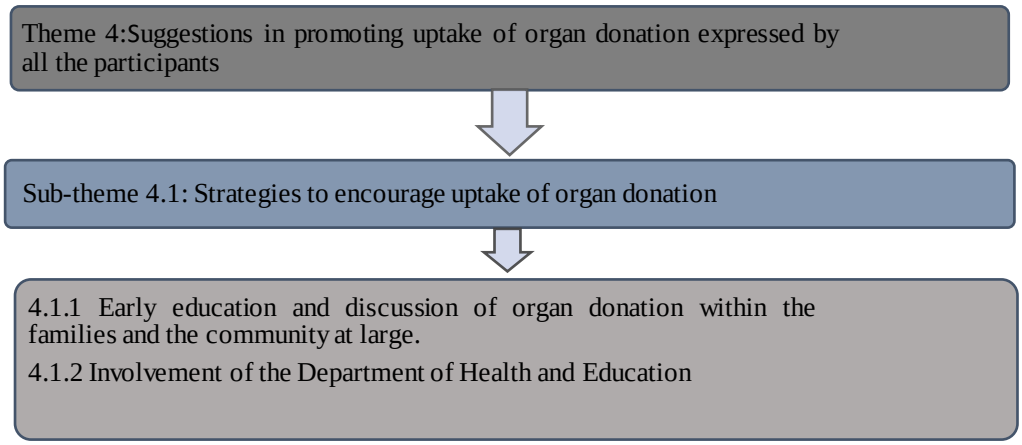


Figure 3.13: Theme 4: Suggestions in Promoting the Uptake of Organ Donation

Overall, participants made suggestions to promote the uptake of organ donation among Xhosa people. Traditional leaders as gatekeepers in the rural Xhosa community, showed a willingness to allow community entry to health practitioners for education and public awareness purposes regarding organ donation on the condition that permission is sought. Community members verbalised their need to be educated on organ donation via backing from traditional leaders. Ministers of religion showed a willingness to mobilise their congregants to publicise organ donation. Traditional health practitioners showed a willingness to promote the uptake of organ donation in collaboration with the Department of Health practitioners. Participants encourage that information on organ donation be communicated via workshops, awareness campaigns, meetings, social media, pamphlets, support groups, and social networks in simple and understandable language. Settings in which the education would take place include the *Great Place (Inqila/Imbizo)*, schools, churches, clinics, hospital catchment areas, political rallies, family homes, and anywhere where people gather. Below are the verbatim statements:

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> *"Workshops can be conducted during the week, not during weekends. At schools or community churches….at the great place because that is where meetings are held."* **(Focus group 1, page 4; Focus group 4, page 12; Focus group 1, Pilot page 14; Focus group 6, page 17; Individual Interview, page 30)**

> *"…even if we are in places like the church, we can have an opportunity to be checked and be told that it is important to donate an organ or to donate blood... and even in meetings."* **(Focus group 2, page 6)**

"…two ways is to call people called by me (the chief) as the head of the place, when I talk to community things include this. The second one is to set a date for us ….and you to organise (organ donation team), now adding to what is going to be preached…" (**Focus group 2, page 6)**

"There must be pamphlets, flyers, broadcast, or advertise on TV and radio, things like awareness must be done, and it should be something practical to people so that they can see it because sometimes you can read a pamphlet, and sometimes you can understand but when someone is in front of you, talking face-to-face is better. I am Xhosa, but I quickly understand in English than when I read in isiXhosa, so the pamphlet that I get is always not what I want. IsiXhosa sometimes has difficult words." **(Focus group I Pilot page 14; Focus group 9 page 26)**

"We can also include media for people who are on Facebook or social networks. Another thing is door to door, door to door helps a lot." **(Focus group 1 Pilot page 14)**

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"AmaXhosa are people who like to be respected, and they are the people who respect chiefs and kings. Approach amaXhosa through chiefs and King, as protectors of the nation. To help so that amaXhosa can know about this thing, we can go to the King, speak at a meeting, tell the kings about the importance of organ donation. When the chief and kings agree, that is when they will inform the nation." (**Individual interview, page 30)**

Maximum impact in educating large audiences can be achieved through campaigns based on a theoretical framework guided by the objectives and the key messages, which are behavioural-focused (Randolph & Viswanath, 2004:436), suggesting assessment of the effect on an individual's intention to act. Conversely, Symvoulakis et al. (2018:1166) suggest reconsidering and converting from a one-size fit all campaign to a community-based targeted message that is culturally and linguistically sensitive is highly recommended for raising awareness and truly embracing organ procurement reform (Etheredge et al., 2014:137).

In terms of South Africa, Dimo (2018) established that a lack of awareness or education, religious, and cultural backgrounds, and myths inhibit the majority of Black South Africans from registering and donating their organs. Furthermore, the author recommended developing a social work model to increase public awareness of organ donation in Black communities and evaluate the legislation regulating organ donation and transplantation in South Africa (Dimo, 2018). Marcondes et al. (2019:1262) suggested that health institutions should invest in continuous and permanent education for all health employees and financial investment for greater dissemination on the subject to support organ donation uptake.

Theme 4: Summary

Various suggestions for promoting organ donation through media adverts were suggested.

3.7.1. Sub-Theme 4.1: Strategies to Encourage Uptake of Organ Donation

In rural public hospitals and clinics, waiting times in the catchment area are utilised for health talks, except for organ donation from the health practitioners and therefore, suggested organ donation be included. Participants highlighted that information distributed in meetings at a Great Place *(inqila)* and church gatherings would reach out to many more community members. Gathering the community members for educational empowerment will allow them to ask questions. Participants in all categories verbalise that hearing information motivates them to share it. Another group of traditional healers strongly agreed that Xhosa people are willing to participate in organ donation but need to communicate with their ancestors in their own way. Participants believe that having the information will change their behaviour; changed behaviour will influence others to participate in organ donation. Ministers of religion, traditional healers, and traditional leaders need educational empowerment as the influencers of behaviour among Xhosa people regarding the uptake of organ donation. On the other hand, political involvement is essential to revising legislation related to organ donation. Participants debated the strategies as follows:

> *"...at churches and at meeting places whereby a group of people are gathering, and at our courts, we have a right to preach such thing as we correct each other in our community when we meet."* ***(Focus group 2, page 6)***

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"After attending a workshop, one become motivated and keen to share knowledge and motivate others." (**Focus group 6, page 17)**

"...communicate with ancestors by burning incense and say ", presenting the person who is sick; what must I do. You must mention your problem of organ donation to the ancestors and wait for their answer. ...it will come through a dream and ancestors will tell you what you should do." (**Focus group 9, page 25)**

*"This thing is like that it has some respect you must first go and ask from the ancestor even if you are going to donate your organ if the family is not donating. You ask and be permitted by them if you do so you are closing that question that asks why you are not complete.***" (Focus group 9, page 25)**

"Old people are ancestors, and they can agree." (**Focus group 9, page 26)**

". We must be informed of organ donation. Once we have the information, we will be able to share and empower others. Yes, we know that we were created to be rigid (resistant to change), but when information is in our minds, we will be able to help each other." **(Focus group 9, page 27)**

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"Especially pastors, we should not leave them out because they are part of teaching people." (**Individual Interview, page 30)**

". Choosing religious leaders as target group was a right thing ...because people believe in religious leaders." (**Focus group 8, page 36)**

"Traditional healers as well to be a target, and the politicians because now the politicians have a lot to say in education so that now we do not get a situation where there is a haul in rallies about this." (**Focus group 8, page 39)**

"Identify as early as possible groups who are resistant to this rather than facing resistance when you are implementing the campaign. Then when you identify groups, devise a strategy now of dealing with them, so now when you approach the Department

of Education about this proposal, to be part of the curriculum." (***Focus group 8, page 39)***

A comprehensive strategy facilitates the future of behaviour change and health promotion using a behaviour-change approach and a policy framework that creates a supportive environment and empowerment of people to gain more control over making healthy lifestyle decisions (Laverack, 2017). Provision of information regarding organ donation should include what is involved and how information has assisted others using television advertisements, commercials, and seminars at work or school to overcome their distrust of the medical community (Robinson & Arriola, 2015:178). The key to improving organ donation is the provision of targeted health education, behaviour change communication and the application of legal interventions (Jagadeesh et al., 2018). Culture and the role of traditional healers are fundamental to understanding African people's reluctance to donate their organs.

Bogopa (2010) as cited in Muwanga (2018), further noted that "this sense of communal utilitarianism may be seen as a positive platform for organ donation, for what could be said to be more in line with the concept of Ubuntu than giving one's organs to save another. It can further be said that Ubuntu is in tandem with the ethical principle of beneficence, to act for the benefit of others". Traditional healers in the study mentioned the maintenance of difference between traditional medicine and Western medication; this implies that African societies comprehend illness differently from the West. These views may impede organ donation (Bogopa, 2010 cited in Muwanga (2018). Therefore, understanding the traditional view of healing in this instance is fundamental. Traditional healers abide by strong ethical principles and have confidence that alleviating suffering and saving lives in all forms is their duty. In that sense, Western medicine has a similar goal, namely, to relieve suffering and preserve life. However, there are contradictory beliefs among the healers themselves, since not all favour surgery, let alone organ donation (Muwanga (2018).

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Sub-theme: Summary

As part of a strategy to promote organ donation, participants agreed empowerment with information sharing in community settings and media platforms is essential.

3.7.1.1. Early Education and Discussion of Organ Donation within the Families

Participants would like to participate in organ donation. Still, they only become aware of the concept only when a close friend or a relative suffers organ failure and/or is declared brain-dead. Knowing about organ donation at an early stage would make it easier to discuss in families. All the participants in all the categories (namely, community members, traditional healers, ministers of religion, and traditional leaders) agree that deceased donors should record their decision to donate in a will and inform their families while still alive. A will can assist families in determining their wishes and facilitate the organ donation process. If the information on organ donation is shared with schoolchildren from an early age they can initiate a discussion with their parents. For a long time, organ donation has been regarded as taboo and, thus, has remained a neglected topic within families. Community members, ministers of religion, and traditional leaders suggested early information on organ donation before the need for organ donation ascended. Participants mentioned that requesting organ donation while grieving and sad about losing a loved one resists agreeing on it unless prepared early in life. Below are verbatim statements. In promotion of organ donation, participants expressed the following:

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> ***"****I think that, when we are workshopped, and informed, maybe we need, things like will and he (the deceased) must state in his will the wish to donate an organ. It should be something that a person talked about while still alive, and maybe inform the family."* **(Focus group 1, page 4)**

> *"Even at schools maybe at least children encourage parents about the 'talk'."* **(Focus group 1, Pilot page 15)**

> *"The way we discussed soapies at home, that should be the way we discuss organ donation. The way we engage, we talk about it, I think that will be the only way one would encourage."* **(Focus group 8, page 40)**

> *"… It should start from the family before it goes to these debates/ platforms and also ends up in the books of learners at school."* **(Focus group 8, page 40)**

> *"I think education must be ongoing, till people understand what we mean when we talk about resurrection, there must be continuous education"* **(Focus group 7, page 44)**

"I think this matter can be taught at school as part of the Life Skills programme. It may be difficult to change the mind-sets of the elderly; hence starting from the young age may yield the desired results." **(Focus group 7, page 45)**

"Teaching us while still at home, hear them while still in the community so that we can help each other." **(Focus group 9, page 26)**

"I encourage that thing that says (always visit) coming to us, preaching organ donation so that we can understand it because it is not easy to understand for us Black people, we did not know these things." **(Focus group 9, page 27)**

"This thing must be discussed when things are still rosy. When things still ok and the whole family is fine." **(Focus group 8, page 40)**

"I would soon say as soon the child understands, as early as grade 1. They must understand the importance of donation, organ donation, blood donation or whatever, but the earlier we do that, the better. So, if we are saying that we are closing the gap between the White and the Black people, then let our children be exposed to these things." **(Focus group 8, page 40)**

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A study by Siebelink, Verhagen and Van der Wiel (2017) indicated noteworthy support in primary schools for a lesson on organ donation, which further facilitated family discussions. Similarly, a study by Byrne et al. (2019) agreed that early education presentation meaningfully increased awareness of the issues related to planned organ donor registration, independent (self-determination) of age and deficit. Waterman and Rodrigue (2009:7) recommend educating patients, donors, and the public as early as possible, by utilising multiple communication channels such as the media and the internet. In addition, dialogue in churches, and other community settings, discussion at the family dinner table, and conversations in healthcare settings other than transplant centres are crucial, before life-threatening organ failure. This way, individuals can ask questions, learn about all their options, and, hopefully, develop positive organ donation approaches. The healing process of a patient in traditional African societies involves not only the healing of the individual who is sick but also their family and, as such, their social environment must be taken into consideration (Botha, 2004 as cited in Muwanga 2018:42). Additionally, Bogopa (2010), as cited in Muwanga (2018), highlighted

that the Xhosa-speaking people consider that emotional or bodily dysfunction needs collaboration active treatment and the support of the family members.

Sub-theme: Summary

Intention to participate in organ donation must be written in a will, with the family being informed at an early stage while the potential donor is still alive.

3.7.1.2. Involvement of the Departments of Health and Education

Participants expressed willingness to donate organs, but only if given information or education on the subject. Community entry via community leaders is the key to accessing people for educational purposes. The following was expressed by participants:

> *"We must be given information in the community; it should be given to us by the Department of Health."* **(Focus group 2, page 6)**

> *"The kings can talk to people because people depend on Kings. The way we are ruled as amaXhosa is through the king. We are ruled as people without talking about Xhosas through government only. The government now is practising rule that has always been there of chiefs and kings and improving we included Government… specialists should be sent, who are able to communicate with chiefs and kings to mobilise people so that people can know."* **(Individual interview page 30)**

> *"For example, at schools there are these subjects called LO I hear children talk about that LO is life orientation and it talks about health, everything that happens on health so I can say during this LO they have an LO class and LO activities, so they need to be taught about this organ donation."* **(Individual interview, page 30)**

> *"The Department of Education together with the Department of Health need to stress this matter even if we are people, who are different we are one. This thing really needs that we are empowered, know the important things that can help us and help the health of the nation."* **(Individual Interview page 31; Focus group 8, page 40)**

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> *"Identify as early as possible groups who are resistant to this rather than facing resistance when you are implementing the campaign. Then when you identify groups, then devise a strategy now of dealing with them, so now when you approach the Department of education about this proposal, to be part of the curriculum."* (**Focus group 8, page 39)**

Behavioural change requires better planning of policy interventions (especially the laws regulating organ and tissue donation) and the coordination of agencies (Organ Donor Foundation, 2020) involved in changing behaviour and empowerment activities at the community level. Government departments, specifically DoH and DoE are needed to assist in the development of policies at national level (Laverack, 2017). According to Siebelink, Verhagen and Van der Wiel (2017), educational programmes should upkeep the notion of developing a curriculum on organ donation that commences in the highest grades of primary schools and carries on to middle/junior high school. The curriculum would add to health literacy and afford children and their families correct educational material, enabling them to make good decisions about organ donation. Waterman and Rodrigue (2009:9) support educational awareness of organ donation and transplantation on most issues. These include impartial and medical correct educational programmes, reaching out information suitable for low levels of health literacy, understandable languages, culturally sensitive education, and media to address familial differences in living organ donation without compromising the age and race. Another concerning issue is motivating education that utilises approaches promoting the uptake of organ donation. Interventions that show promise in decreasing racial disparities should be implemented at multiple sites, and educators should be well trained for such programmes.

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Sub-theme: Summary

The involvement of the Department of Health in mobilising communities is critical. Total behavioural change is necessary for the successful implementation of organ donation.

3.8. SUMMARY OF FINDINGS ON THEMES AND SUB-THEMES ABOUT ORGAN DONATION

An elementary method to improve the credibility of the data was used to provide information using three methods of data collection such as individual semi-structured interviews, partial

observation, and focus group discussion from the participants during the data collection. During the data analysis, themes and sub-themes emerged from the data. The summary from the themes is tabulated in Table 3.2. The emerging themes aided the development of a programme.



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Table: 3.2. Summary from the Themes and Sub-Themes

	Theme 1	**Sub-theme 1.1**	**Sub-theme 1.1.1**	**Sub-theme 1.1.2**	**Sub-theme 1.1.3**	**Sub-theme 1.1.4**
1. Lack of knowledge and understanding of organ donation.	Society needs to be educated about organ donation and informed that when a person is declared brain-dead, there is an opportunity for a brain-dead person to contribute significantly to humankind by agreeing to organ donation while still living.	This confirms that the participants have very limited or no knowledge on organ donations.	Participants across the board confirmed no discussions and public awareness about organ donation among families, schools and even in church.	Many fears emanate primarily from a lack of knowledge leading to doubts if organ donation really saves lives. The operation may be successful, but other diseases may befall the recipient or donor.	The leadership strata in the community are prepared to create a platform for medical fraternity to address the community about organ donation.	Participants doubt the authenticity of brain death certification, and thus, do not accept death because ventilated brain-dead patients have chest movements that indicate breathing.
		Sub-theme 1.2	Sub-theme 1.2.1			
		Making important decisions relating to organ donations during a time of crisis is difficult in African households; considerable time is required to make such critical decisions. Therefore, each member of the family should have a will.	Families are aware that the organ donation approach mostly starts with blood relatives, followed by extended family and friends. Lastly is the society.			
		Sub-theme 1.3	Sub-theme 1.3.1	Sub-theme 1.3.2		
		Participants believe that removing an organ from a human being renders the person incomplete, wishing organ donation to be confined to family circles and that the donor consent without coercion.	Organ donation is quite a lengthy process, awareness campaigns should include all processes involved in organ donation.	Structures or stages involved organ donation should be clearly stated with ethical dilemmas exist along these stages.		
	Theme 2	**Sub-theme 2.1**	**Sub-theme 2.1.1**	**Sub-theme 2.1.2**	**Sub-theme 2.1.3**	**Sub-theme 2.1.4**
2. Negative views of organ donation	All participants expressed fear for participating in organ donation mentioning different reasons such as being fearful of doctors committing mistakes during operation or	Data collected from the study reveals that participants expressed fear of organ donation, imagining that the quality of life of the donor might be compromised.	Participants fear that donating with an organ will compromise the donor's longevity and body strength while the receiver lives on.	Participants believed that donating an organ like a kidney weakens both parties; the donor and the recipient will be a source of anxiety.	The general fear among the participants in giving consent to remove an organ in case of brain-death was, giving such permission may lead to human organ trafficking.	Generally, there is a belief among Africans that there is a link between the living and the dead. This link is maintained through the ancestors; hence participants believe that going to ancestors with a missing organ may result in rejection,

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	rendering the donor an incomplete being.					and this may disqualify one from being an ancestor.
		Sub-theme 2.2	Sub-theme 2.2.1	Sub-theme 2.2.2		
		The participants expressed a concern that the donor's health status might be a risk towards organ donation.	Potential organ donors are troubled by the slight possibility of harm, fearing donor outcomes.	Despite the massive call from the South African Government for everybody to undergo HIV tests given the HIV/AIDS pandemic, many Blacks are not responding positively to that call because of fear.		
		Sub-theme 2.3	Sub-theme 2.3.1	Sub-theme 2.3.2	Sub-theme 2.3.3	Sub-theme 2.3.4
		Organ donation should not only be seen as a medical problem; it must be understood to be a societal challenge.	There is a perception among participants that organ donation is a Western idea. A need to bring this matter up for discussion on all relevant structures was identified to make people more enlightened.	Participants were receptive of organ donation being practised within family circles; in this way, the recipient can reciprocate by assisting if/when the donor requires assistance.	Hearing about organ donation for the first time, and from social media platforms, results in them not being sure whether this is a myth or a fact.	Donating organ such as kidney, defeats God's purpose of creating each person with two kidneys. Yet others debunked this view thought citing scriptural references to prove that organ donation is a show of love.
	Theme 3	**Sub-theme 3.1**	**Sub-theme 3.1.1**	**Sub-theme 3.1.2**	**Sub-theme 3.1.3**	
3. Impediments to the uptake of organ donation	Traditional healers asserted that their ancestors must guide them in a dream; if not, anyone receiving a donated organ may lose his/her identity. Hence, they do not support it.	Cultural beliefs dictate that ancestors expect people to arrive complete when they die. If not, they will be rejected, and the spirit of the donor is transferred to the recipient during organ donation.	Traditional healers prefer the use of conventional medicine to organ donation because they are guided by their dreams when they heal.	Donating to a family that one has no relationship with may result in the loss of an ancestral lineage.	The male child, particularly the firstborn, in the family is regarded as the heir. He is, therefore, barred from donating an organ since it will put his life in danger.	
		Sub-theme 3.2	Sub-theme 3.2.1	Sub-theme 3.2.2	Sub-theme 3.3	

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		Religious leaders do not conduct awareness education on organ donation; on the contrary, they encourage people to believe that everything can be cured through prayers.	In church, the pastors should be looking after their members holistically; however, all they do is address spiritual aspects.	Some church leaders operate on a comparison basis, asserting that prayer works better than medical intervention. They do not understand that medical intervention is God's intervention through medicine.	Perhaps there should be an incentive offered to potential donors.	
	Theme 4	**Sub-theme 4.1**	**Sub-theme 4.1.1**	**Sub-theme 4.1.2**		
4. Suggestions to promote the uptake of organ donation	Various suggestions for promoting organ donation through media adverts were given.	As part of a strategy to promote organ donation, participants agreed empowerment with information sharing in community settings and media platforms is essential.	Intention to participate in organ donation must be written in a will, with the family being informed at an early stage while the potential donor is still alive.	Participation by the DoH in the mobilisation of communities is critical. Total behavioural change is necessary for the successful implementation of organ donation.		

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Table 3.3: Triangulated Findings and Change Objectives Included in the Programme

Themes/Sub-Themes	Conclusions	Components of the Programme
OBJECTIVE 1: INCREASE KNOWLEDGE AND UNDERSTANDING OF ORGAN AND TISSUE DONATION		
Increase knowledge of organ and tissue donation	Xhosa people need knowledge and an understanding of organ donation, including brain death, and, especially, the ethics around it.	An overview of organ and tissue donation – the definition, ethics, legislation, organ donation registration, and the background.
	Reduction of psychological discomfort that may occur to the donor before, during, and after donation.	
	Potential organ donors need to move from the little understanding of organ donation to make proper decisions when faced with organ failure in the family or society.	
	Motivational interviewing should be an underlying method of teaching about organ donation	
Awareness of ethics surrounding organ donation	Self-awareness of the ethical principles and human rights involved in organ and tissue donation is fundamental	
	Xhosa people can become **self-determined** when their need for competence, connection, and autonomy are fulfilled	
Awareness of the legislation governing organ and tissue donation, including prevention of organ trade	Xhosa people need to engage in family discussions regarding organ donation with the assistance of health care practitioners to decide to donate organs	
	Collaboration with the DoH is essential to understanding organ donation law. Measures should be put in place to overcome fears of organ donation-related crime. Legislation governing organ donation process.	
	A commitment to confirm their wishes in the form of a written or recorded verbal will	
Structures involved in organ donation	Xhosa people need to know the steps to follow when deciding to donate as well as the process of organ donation in detail.	
OBJECTIVE 2: CREATE A FAVOURABLE ATTITUDE TO THE UPTAKE OF ORGAN AND TISSUE DONATION		
Health concerns of both donor and recipient. Fear of death and a fear of stigmatisation Awareness needed on the fear of character transfer, pain, and anxiety,	Awareness of the possibility of harm during surgery as a living organ donor. Inform Xhosa people that surgical procedures are performed only when the benefits outweigh the risks.	Overview of the process of organ retrieval, operation of organ donation. Alleviation of participants' fears.
	Public awareness campaign to address all levels of society, ensuring a buy-in by society to curb the related social stigma. Xhosa community members should believe in themselves and stand up against social stigmatisation.	
Xhosa people often distrust the medical community and are fearful of organ donation procedures.	Modelled behaviour from previous candidates of organ and tissue donation is essential to gain this community's trust.	
	A positive attitude to organ and tissue donation should be inculcated through the **application of social cognitive theory**.	
Discussion of organ donation in families at home	Awareness of the origin of organ donation in South Africa was explained, as well as successes it has obtained.	

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	The behavioural change model is applicable to providing Xhosa people with information aimed at changing their beliefs, attitudes, and behaviours.	
OBJECTIVE 3: REGULAR HEALTH CHECK-UPS TO PROMOTE A HEALTHY LIFESTYLE		
Fear of general health screening needed to become a donor.	Xhosa people need to understand they must be cleared of any predefined chronic diseases that might cause further health complications towards organ donation	The overall maintenance of healthy living has a life-long effect. Good health allows to do many things, including organ donation.
	Awareness will emphasise the assessment of a living donation candidate to determine their desire to donate and inform them of any risks related to the procedures.	
	Self-directing towards a healthy lifestyle that includes regular screening on communicable and non-communicable diseases to participate in organ donation.	
OBJECTIVE 4: ADDRESS SOCIETAL, CULTURAL, AND RELIGIOUS BELIEFS ABOUT ORGAN DONATION		
Fear of the loss of identity, dignity, and family lineage if donating an organ.	Traditional leaders as custodians of African culture and tradition should play a leading role in motivating Xhosa people to participate in organ donation, including dismissing the myth that by donating an organ, individuals will lose their identity and dignity.	Overview of the awareness on societal, cultural and religious barriers towards the uptake of organ donation.
Rejection by ancestors	Awareness campaigns and health education should take note of the strong cultural belief Xhosa people have of traditional practices and ancestors.	
	Traditional health practitioners have direct access to ancestors; therefore, they should communicate with the ancestors on behalf of families to promote uptake of organ donation.	
Belief in prayer to cure organ failure. Awareness of changing the mind-set that organ donation is a Western idea	The custom of religious faith in organ donation is essential as a source of strength and a coping mechanism (Saad & de Medeiros, 2012). However, prayer must not be the means to an end (i.e., it must assist the believers to participate in organ donation).	
	Cultural congruent care facilitates the application of action-decision modes, such as accommodation, negotiation, and culture preservation, all of which need collaboration between the health practitioner and the client (Xhosa community member). Use of **motivational interviewing** aiming at changing behaviour.	
OBJECTIVE 5: STRENGTHEN THE PROMOTION OF ORGAN DONATION UPTAKE THROUGH VISIBLE INTERVENTIONS		
Organ donation should not be viewed as the preserve of the elite.	Use of effective teaching methods by health professionals to different groups of Xhosa people in all district municipalities in promoting the uptake of organ donation.	Communication, collaboration with healthcare professionals especially the organ transplant coordinator and Xhosa community in promoting the uptake of organ donation
Availability and accessibility of information related to organ donation.	All hospitals and community health centres should have information relating to organ donation on display to promote public interest in organ donation.	
	Ongoing information-sharing in Xhosa community gatherings, including church, information-sharing among peers, community members, and families.	
	Social support offered to Xhosa families with relatives who need organs for survival, and those facing having to donate organs of their deceased.	
Possibility of using media to promote the uptake of organ donation.	Social media has opened unending possibilities for the promotion of ideas and concepts; this channel of communication, which is sometimes free, should be explored by Xhosa community members.	
Possibility of including organ donation in school curriculums.	Homes of the Xhosa people should be assisted in promoting the uptake of organ donation by targeting young ones and the youth through formal education.	

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Relevant information and educational materials.	Use of latest technology and methods to guide Xhosa people regarding the uptake of organ donation.	
Structure of a programme in promoting organ donation.	Public awareness should allow time for active participation, question time, and demonstration.	
	Provision of an environment conducive to adequate education and the promotion of comfort.	

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3.9. SUMMARY OF CHAPTER THREE

The results of the study revealed that Xhosa people (all categories participated in the study) had little knowledge regarding organ and tissue donation. Their inadequate knowledge was reflected in subjects such as the ethics surrounding organ donation, the law governing organ donation, the structures involved in organ donation, and the process and procedure. They also displayed no understanding of brain death.

The results also revealed negative views which contributed towards barriers to promoting the uptake of organ donation. Among the opposing views were the fear of organ donation in general, death, pain and anxiety, crime, rejection by ancestors, social stigma, and personality changes. There was a general uncertainty about their health statuses in terms of donating, as well as negative societal issues, including the view that organ donation is a Western idea or is perceived as being only for relatives and fiction in social media.

All participants enumerated various challenges, including cultural beliefs, such as the potential loss of an ancestral link if organs are donated outside their families, whether an incomplete body structure may lead to unacceptance by the ancestors and other religious factors. Participants expressed that public awareness of organ donation does not reach rural areas. Traditional leaders look forward to public awareness and campaigns to promote the uptake of organ donation. Next, Chapter Four will discuss the development of a programme using the results of the situational analysis (Phase 1) guided by the steps from the IMF (Bartholomew et al., 1998).

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CHAPTER 4: DEVELOPMENT PROCESSES (CONCEPTUALISATION AND INTERVENTION MAPPING FRAMEWORK)

4.1. INTRODUCTION

The framework is derived deductively from the practice theory. For this study, the elements of Dickoff et al. (1968), together with the Intervention Mapping Framework (IMF) introduced by Bartholomew, Parcel and Kok (1998), was chosen to guide the development of the programme. This chapter describes Phase 2, consisting of steps two and three, and Phase 3, which includes Step 4 of the above-mentioned IMF. Phase 2 Step 2 describes the conceptual framework, using both the elements of Dickoff et al. (1968), and methods used in preparing matrices of change objectives for the Xhosa community, with various tables in the chapter. In Step 3, the concepts of the theories that guided the study were used as determinants of behaviour (Bartholomew et al., 1998). Step 4 defines the programme objectives, thereby setting the stage for the programme (Bartholomew et al., 1998). Figure 5.1 illustrates the steps followed in programme development in Phases 2 and 3.

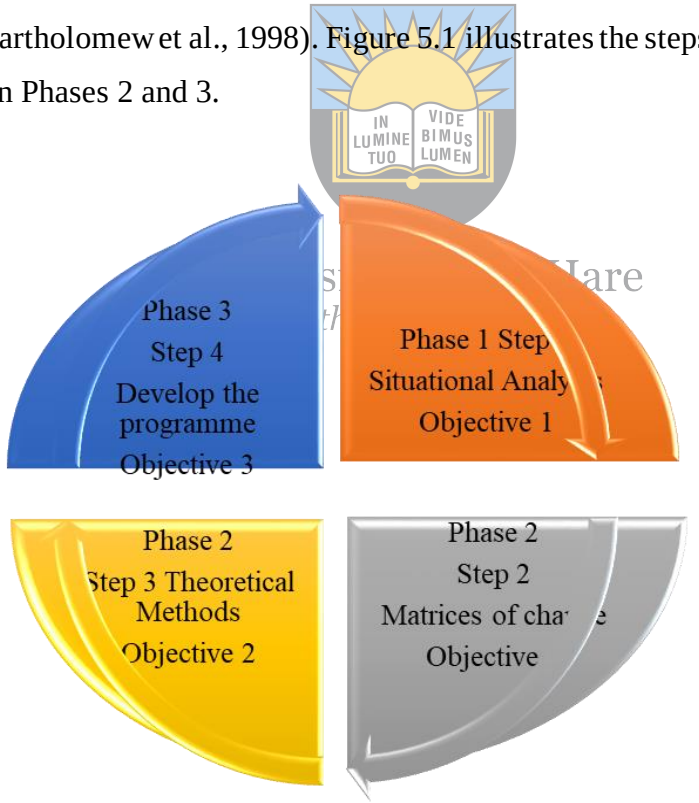


Figure 4.1: Phases 1 (Step 1), Phase 2 (Step 2 & 3), and Phase 3 (Step 4) of the Intervention Mapping Framework (IMF).

4.2. PHASE 2: STEPS 2 AND 3: MATRICES OF CHANGE OBJECTIVE AND THEORETICAL BASED INTERVENTIONS

Conceptualisation makes up Phase 2 of the programme development process and the steps of the Intervention Mapping Framework (IMF) in developing a promotion programme for the uptake of organ donation among the Xhosa community in the Eastern Cape Province. According to Burns and Grove (2009), 'conceptualisation' refers to clarifying and analysing critical concepts in a study and integrating one's research into existing research and theory (the process of forming a general idea). The conceptualisation was derived from information acquired from the situational analysis (Chapter Three) and the contribution specified by the planning group and the stakeholders in steps 2 and 3 of the IMF, described in this chapter. Elements of practice theory, as described by Dickoff, James and Wiedenbach (1968), were discussed, as well as the relevant methods of IMF, as indicated in the reasoning map in Chapter Two.

Research objective: To develop matrices of change objectives and theory-based interventions that informs the programme to promote an uptake of organ donation among this community.

Research question: What matrices of change objectives and theoretical-based interventions would be suitable to inform a programme to promote the uptake of organ donation among this community?

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4.2.1. The Elements of Practice Theory

The conceptualisation of the programme was based on the practice-orientated theory of Dickoff et al. (1968), which explained the concepts and analysed the prescribed activities aimed at realising the programme goals, namely: agent, recipient, context, dynamics, procedures, and terminus. These elements were defined as follows:

4.3. AGENT

The term 'agent' in this study refers to the researcher, health professionals, and the planning group who facilitated the programme development to promote the uptake of organ donation among the Xhosa community. The agents were the main people responsible for planning, coordinating, and developing a programme (Dickoff et al, 1968). Figure 4.2 indicated the agents' characteristics and capabilities, which were to empower potential and promote roles

and responsibilities, while facilitating the implementation of the programme in promoting the uptake of organ donation among the Xhosa community. The characteristics and capabilities are described in more detail below:

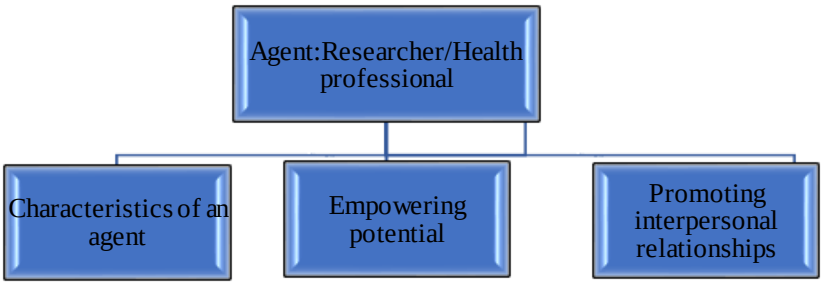


Figure 4.2: The Agent

4.3.1. Characteristics and Roles of the Agent

The agent's responsibilities included the following: to design, plan, implement, monitor, and evaluate a health-promotion/education programme. Agents are hardworking people, committed and passionate about health-promotion, assertive, inventive, approachable, honest, trustworthy, self-motivated, attentive, knowledgeable about the phenomena under study and proficient to handle situations (culturally congruent in dealing with a cultural group).

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4.3.2. Empowering Potential

The agents empower others with the view of enhancing knowledge, skills, and ability to enable recipients to address the barriers that impede Xhosa people from engaging in an uptake of organ donation. To sustain the programme, recipients need to be empowered to become near experts in knowledge transfer of organ donation to families and the community at large.

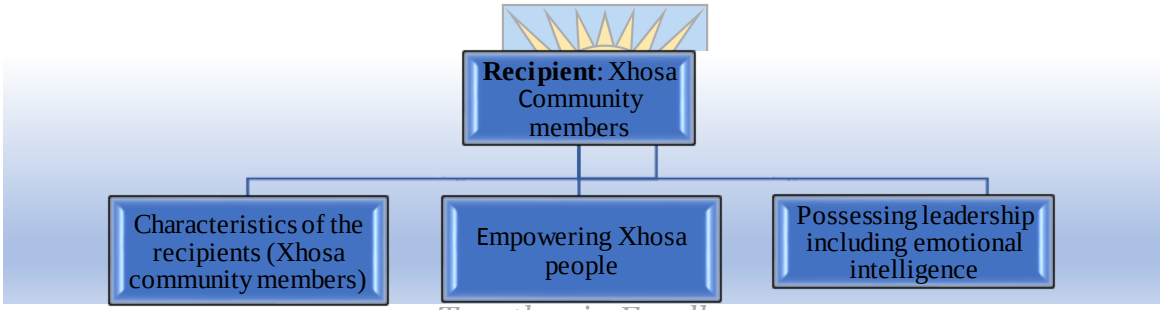
4.3.3. Promotion of Interpersonal Relations

One of the roles of the agents is to ensure that interpersonal relationship becomes a tool for a successful implementation of the programme by creating a conducive environment that facilitates good communication. The programme requires continuous engagement and information exchange among different stakeholders, both internal and external. Programme development was described as requiring connection between a resource system (developers) and an intermediate user system (implementers). All these categories, developers, and

implementers form part of agents as described by both Dickoff et al. (1968) and Bartholomew et al. (1998).

4.4. RECIPIENTS

The term recipients refers to Xhosa community members, the educational programme was designed to meet their needs. Figure 4.3 illustrates the recipient as the beneficiary of the educational programme. Health professionals and Xhosa community members were expected to participate in the educational programme. Participation assists in improving their knowledge, skills, and abilities with the view of enabling them to disseminate updated information regarding organ donation as they demonstrated limited knowledge and understanding of organ donation.



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Figure 4.3: The Recipient

4.4.1. Characteristics of the Recipients

The programme was designed to equip recipients with relevant updated information that encourages a change of attitude towards uptake of organ donation. Specific qualities or characteristics that could be acquired include active participation, active listening, reflective feedback, thinking positively, avoiding critiquing self or others, patience, problem-solving through the empowerment process and empowering others (traditional leaders, traditional healers, and the religious ministers). Community members in the study were a diverse ethnic group in terms of various rites of passage that they perform, which might be a barrier to the uptake of organ donation. Traditional healers are a diverse group in terms of relying upon medicinal plants and herbs to treat people suffering from various illnesses rather than organ donation. Religious ministers are also members of the community but are diverse in terms of training to support people in their pain, loss, triumphs, joy, and victories by using prayer rather

than organ donation as a treatment option for end-stage organ failure. Traditional leaders are the gatekeepers of the Xhosa community. Their primary role is to regulate social behaviour. This folkway sector influences African-Black people's beliefs, culture, and behaviours.

4.4.2. Empowering the Recipients (Xhosa People)

Collaboration between community health practitioners and health committee members assisted in reaching out to the general community members. That allowed continuous community engagement, in the process, empowerment might occur through health education. The creation of a favourable environment and promotion of a positive culture focused on behavioural change. The recipient's views informed the educational programme during data collection within the different Xhosa communities. The programme was designed to promote ownership, effective interpersonal relationships, and motivational strategies to improve the uptake of organ donation. Attending sessions during programme implementation would enhance knowledge, skills, and abilities to enable recipients to perform several activities, such as supporting families who need organ donation to survive, assisting community members to stand up against stigmatisation, and identifying community members in need of care.

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4.4.3. Possessing Leadership Including Emotional Intelligence

Graham, Arthur and Mensah (2014:407) state that a successful programme requires the determination and commitment of leaders with good leadership skills and abilities to advance a theory of change and self-determination that can be translated into practice. The leadership (traditional leaders, religious ministers, and traditional healers) had to motivate and influence Xhosa people to change, develop the courage to facilitate programme implementation.

The intervention mapping framework (IMF) (Bartholomew et al., 1998) was intended to make the steps in planning interventions explicit enough to elucidate the process, and to facilitate collaborative planning by individuals of varying backgrounds. The philosophy of health education or health-promotion was built on the principle of self-determination of individuals, groups, and communities. According to Dickoff et al. (1968), individuals and communities were to be the recipients of the programme. The recipients should receive the knowledge, act on the knowledge, while beneficiaries participate in the programme development; end-user systems are programme participants who are either recipients or beneficiaries according to (Bartholomew et al., 1998).

4.5. CONTEXT

The context represented communities/villages where Xhosa people live. Primary healthcare facilities connect directly with the communities through clinic committees, which form part of the context. Xhosa communities have distinct cultural heritages and rituals under the rule of traditional leaders and traditional healers who are custodians of African culture. Figure 4.4 below illustrates the context of the legal framework by creating an empowering environment with resources and support and policies and procedures that include monitoring and evaluation of the programme. The local government is responsible for providing services to PHC via different clinics and community health care facilities within the local government. Community healthcare services play a significant role in healthcare as they link the PHC services to the people at a grassroots level. Health committees are formed at a community level and they are functional by complementing the services of PHC through active participation in health issues (Health Care in South Africa, 2012). It was important to understand the context of Xhosa community members concerning the accessibility of services and the legal framework regulating organ donation in South Africa. The link between the legal framework and health context policies and procedures needs to be established to support Xhosa communities to improve their organ donation uptake.

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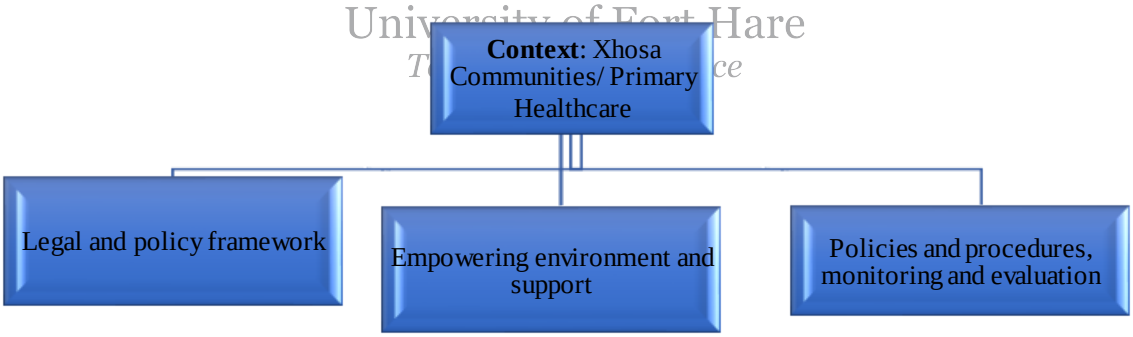


Figure 4.4: The Context

Eastern Cape Province in South Africa was the specific context relating to the Xhosa community rural villages where the research study was conducted. Contextual research refers to a research study conducted in a specific environmental context to understand events within a natural context in which they occur (Babbie & Mouton, 2009:272). All ethno-nursing research occurs in the field (Streubert & Carpenter, 2011:172). The researcher accessed the location of the culture of interest. The critical feature in ethnographic studies is the natural context of the research is conducted. Adequate time was spent in the natural environment with

the participants, becoming acquainted with the groups, gaining their trust, and building relationships (Parahoo, 2014:250).

4.5.1. The Eastern Cape Province Health Context in South Africa

South Africa is comprised of nine provinces and functions on three levels of governments, namely national, provincial, and local. The National Health Department is responsible for providing legislation in the form of acts, policies, strategies, guidelines, and programmes regarding healthcare services. Health care in South Africa varies from the most basic PHC offered by the state, to highly specialised, high technology health services available in both the public and private sectors. The public sector is under-resourced and struggles to deliver services to about 80% of the country's population (Van Rensberg & Ataguba, 2012). The local government is responsible for providing PHC services via different clinics and community health care facilities within it. Community health care services play an essential role in health care as it links the services to people at grassroots level as health committees are formed at a community level. At the primary health care level, general health services, such as preventive, promotion, curative, and rehabilitation services, are provided by the local government (World Health Organization, Primary Health Care, 2019). PHC serves as an entry point to the health delivery system as these facilities are in communities for the sake of proximity and utilisation. The health care delivery system is generally poor (Ataguba & McIntyre, 2012), preventive measures such as educating the community are absent with poor utilisation of facilities.

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Population groups in South Africa include Whites, Natives (Black), Indians, and Coloureds. The Black population is divided into major groups, namely the Nguni people, who consisted of Zulu, Xhosa, Ndebele, Swazi, and Sotho. Sotho people consist of Northern Sotho (Bapedi), Southern Sotho (Basotho) and Tswana, Shangaan-Tsonga, and Venda (South African History Online, 2019 (SAHO). The largest ethnic group in South Africa is the Zulu, and many of them live in the Kwa-Zulu Natal (KZN) and Gauteng provinces. The second largest is the Xhosa, located primarily in the Eastern and Western Cape provinces (SAHO, 2019). These South African ethnic groups are also found beyond South Africa's boundaries in neighbouring countries (SAHO, 2019). This study was conducted among the Xhosa community in Eastern Cape. The literature shows that organ donation has been explored among the Xhosa community living in the major cities of the Western Cape (Cape Town), Gauteng (Johannesburg and

Pretoria), and the Eastern Cape Province (Port Elizabeth) (Etheredge, Turner & Kahn, 2014:135).



Figure 4.5: Map of South Africa with its Provinces (Researchgate.net)

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4.5.2. The Specific Context of the Study

The Eastern Cape Province is in the south-eastern part of South Africa (Eastern Cape Municipalities, 2020). It is the second-largest province with eight district municipalities, situated mainly between the Western Cape (WC) and KwaZulu-Natal (KZN) provinces. Its population is the third largest of all the nine provinces, with most of its inhabitants speaking isiXhosa. The central (Chris Hani) and eastern (OR Tambo) districts of the province form the traditional home of the Xhosa people (Provincial Profile Data, Eastern Cape province, Census, 2011). This study was conducted in OR Tambo and Chris Hani districts, two of the eight districts of the Eastern Cape, which are mainly rural. They were purposively selected for the study because they include a racial composition of predominantly Black Africans and constitute 93% and 99% of the entire population (Statistics South Africa, Census, 2011). The primary language in these areas is isiXhosa.



Figure 4.6: Map of the Eastern Cape Province with Municipal Districts (Municipalities.co.za)

4.5.3. Legal and Policy Framework

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The Human Tissue Act, no 65 of 1983 (SA, 1983) stipulates in Section 2 that "anyone competent to make a will (16 years or older) may donate an organ by signing a document attested to by two competent witnesses (14 years or older), or by indicating the wish through a clause in a will, or orally before two competent witnesses". In SA, living donations are recognised only if the donors are related to the patient or the patient's spouse. If a friend or an altruistic donor (living donation to a stranger) wants to donate an organ, an application must be lodged with the DoH. The Department will examine the application thoroughly, to determine that it is not for financial gain, as Section 28 specifically prohibits any payment for donated human organs. Sections 61 and 62 of the National Health Act 2003 (SA, 2003) generally have the same requirements for an organ donation in the case of a deceased donor as the Human Tissue Act, 65 of 1983. The only difference of any note is that the new Act in Section 1 acknowledges 'brain death' as death.

4.5.4. Empowering Environment and Support

Lessons on organ donations will include informing the participants about the rights of organ donors up to the principle of confidentiality. Organ donation sites would be made public with a register for the potential donors, preferably in each district in a province. Some participants might be agreeable to disclosing their names for the community to understand that organ donation is not a mystery. Detailed procedure on how organ donation is undertaken will be explained given the fact that most of the beneficiaries (rural people) are not exposed to organ donation discussions. Clear noticeboards in hospitals placed in areas that will be visible to beneficiaries and referral systems on how to go about donating organs will be written and communicated. Effective communication between health care professionals and beneficiaries will be established.

4.5.5. Policies and Procedures, Monitoring, and Evaluation

Human, financial, and material resources should be available for implementing the programme. Reading material should be provided for the beneficiaries. Information dissemination on social media regarding organ donation will assist the beneficiaries. Health care professionals will facilitate the interpretation and understanding of policies and guidelines on organ donation. Lastly, research and information management should be facilitated.

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4.6. DYNAMIC: INTERACTIVE FACILITATION

The term ‘dynamics’ refers to the forces involved in bringing about change. The dynamics were derived from the situational analysis. The competencies of the agent and the dissemination of scientific knowledge should be designed in such a way that Xhosa community members ideally engage in organ donation uptake. Figure 4.7 illustrates how people behave, react, and affect each other as forces that stimulate change and are constantly changing and developing (Hornby, 2006). To interact means to influence each other while permitting a two-way flow of information between the healthcare professional and Xhosa community members. Association for Talent Development define facilitation as “the act of engaging participants in creating, discovering, and applying learning insights”.

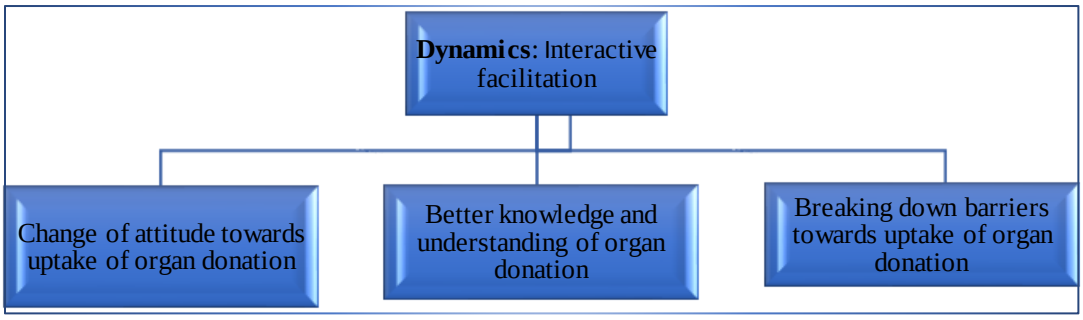


Figure 4.7: Dynamics

4.6.1. Change of Attitude towards the Uptake of Organ Donation

Motivational interviewing (MI) as the goal-orientated method of communication is applied by the agent "with particular intention to the language of change, strengthen personal motivation for and commitment to a target behaviour change by eliciting and exploring an individual's own argument for change" (Miller & Rollnick, 2013:29). According to Kraybill and Morrison (2007), MI contributes to the preparation of people for change and is useful in influencing the intrinsic motivation of the Xhosa community members while building their self-reliance to change, and an empathic person-centred counselling approach. The changing of a behaviour or an attitude lies with an individual. The onus is not on the healthcare professional. The latter (planning groups) are only expected to initiate a need for change.

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4.6.2. Knowledge and Understanding of Organ Donation

The Oxford English Dictionary (2021) refers to knowledge as "the information, understanding and skills that one gained through education or experience of something or event in life". The first theme that emerged from the study was the lack of information and understanding of organ donation by the Xhosa community members. This led to the development of the programme to promote the uptake of organ donation among this group. The educational programme planned to have an emotional impact on behaviour (Villaseñor, 2017); therefore, theory-guided behavioural constructs to enhance changes in the Xhosa community were derived from theories of behaviour change self-determination theory, social cognitive theory and information motivation and behavioural skills model, health-promotion theory (Chapter One) and Leininger's theory for environmental determinants. Determinants of behaviour such as self-efficacy, skills, autonomy, attitude, outcome expectations, and knowledge were selected.

4.6.3. Breaking down Barriers to Organ Donation

To overcome the barriers to organ donation, Xhosa community members should possess the ability to make their own decisions without being controlled by anyone else. In the case of an individual adult, (Xhosa person) should be capable of making rational and informed decisions on own behalf regarding participation in organ donation and endorse that decision by making it known through a signed written or verbal will. Autonomy as a construct of the self-determination theory that is psychological in nature needs to enhance a behaviour change (Cherry, 2019). This theory suggests that people can become self-determined when the need for competence, connection, and autonomy was fulfilled (Cherry, 2019).

The intervention mapping steps provide a framework for asking 'why' or 'how' questions about the determinants of behaviour and environmental conditions, subgroups of the target population, behaviour, and environmental change methods (Bartholomew et al., 1998). Brainstorming techniques assisted the agent in determining provisional answers to the planning questions, which were refined using multiple approaches to literature control and information gathered from the target population.

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4.7. PROCEDURE

Figure 4.8 illustrated the components of the procedure (programme) as follows: firstly, the learning content in the context of promoting the uptake of organ donation; secondly, the paradigm of learning methods; and, thirdly, various approaches to facilitate the programme, guidelines for implementation of the programme.

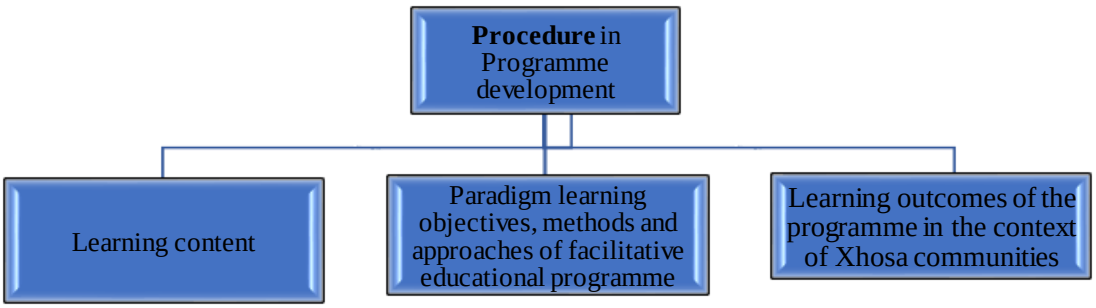


Figure 4.8: Procedure

The programme was designed to achieve the following performance and behavioural objectives, which are discussed extensively in this chapter:

- An overview of organ and tissue donation
    - Explain the importance of organ and tissue donation.
    - Explore the personal determinants influencing individuals' decisions to donate organs.
    - Describe the organ retrieval process and alleviate fears:
- Steps for the organ donation and retrieval process.
    - Address common fears and misconceptions related to organ donation from a personal perspective.
    - Promote healthy living and its lifelong benefits:
- Significance of maintaining good health for overall well-being.
    - Emphasise the role of healthy living in enabling individuals to participate in organ donation.
    - Raise awareness of societal, cultural, and religious barriers:
- Discussion and description of the impact societal, cultural, and religious beliefs decisions around organ donation.
    - Encourage understanding and respectful dialogue to overcome these barriers.
- Foster ongoing communication, collaboration and information-sharing between individuals and healthcare professionals regarding organ donation.

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4.8. TERMINUS

Terminus includes implementing the programme and the results, leading to overcoming the barriers contributing towards promoting the uptake of organ donation among Xhosa people and their relationship with healthcare professionals. Figure 4.9 illustrates the result that the programme must have.

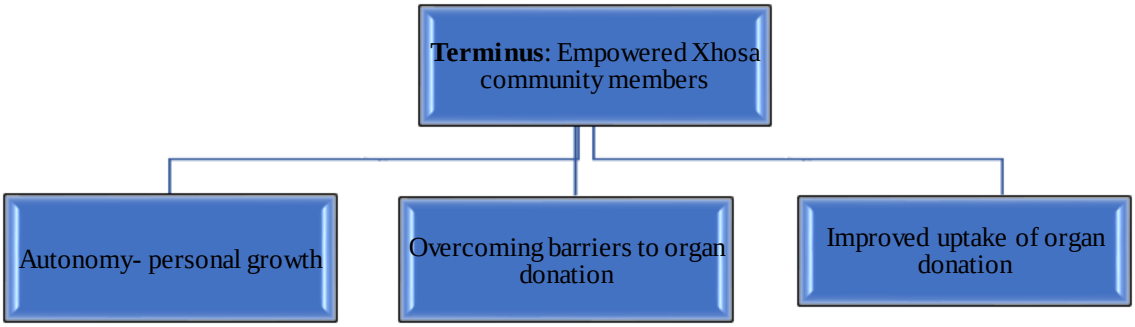


Figure 4.9: Terminus

4.8.1. Autonomy – Personal Growth

Autonomy, self-determination, and psychological well-being are important conditions for personal growth and are linked to positive functioning and high quality of life. The programme should assist Xhosa people in making moral decisions and acting on them regarding the uptake of organ donation. Health professionals need to help the beneficiaries become self-directed with greater control over their healthcare decisions in all healthcare and community settings. The goal of the programme is its implementation within Xhosa communities in the Eastern Cape Province, South Africa. The terminus of the programme was discussed in this chapter.

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4.9. PREPARING MATRICES OF CHANGE OBJECTIVE (STEP 2)

Stakeholder involvement in the development of programmes is a vital part of the IMF (Ceptureanu & Luchian, 2018:11). Xhosa community members, traditional healers, ministers of religion, traditional leaders, and health professionals represented stakeholders as they worked with the researcher in the planning and the development of the programme. The researcher and the stakeholders formed a planning group committee of all the stakeholders, a casual workshop was held, a friendly atmosphere was created, and the participants were individually welcomed. The roles and responsibilities of each person and time assurance were highlighted; the valuable performance of each member of the group was acknowledged. The planning group was allowed to introduce themselves and to share their experiences regarding organ donation. Healthcare professionals were then allowed time to describe their core concerns in terms of the uptake of organ donation and what change they expected the workshops would provide for the Xhosa community.

The basic tool for the matrix of change in intervention mapping entails planning for the programme, specifying areas of change that should occur because of the programme, and identifying what could be done to make a change because of the programme (Bartholomew et al., 2011). The changes needed to be addressed by the programme at both individual and environmental levels were recognised to improve health outcomes and quality of life (and prolong lifespans) among the Xhosa community.

4.9.1. First Task – A Set of Changes to be addressed by the Programme

The overall desired outcome of the programme is to improve the uptake of organ donation among the Xhosa community. The behavioural outcomes focused on activities aimed at attaining the above-mentioned outcome. By the end of the programme, the Xhosa community would be expected to (objectives):

- Demonstrate improved knowledge and understanding of organ and tissue donation.
- Have changed their attitude to the uptake of organ and tissue donation (by means of the alleviation of their fears and the dismissal of myths).
- Maintain regular health check-ups promoting a healthy lifestyle for future organ donation.
- Accept societal, cultural, and religious beliefs around organ donation (and stand up against social, cultural, and religious barriers to organ donation).
- Embrace the promotion of organ donation uptake through visible interventions.

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The healthcare professionals in the planning group will assist in the implementation of the programme and use the programme as a manual. Organisational environmental factors, such as educational teaching methods (approaches) (Shukla, 2018; Karami, Pakmehr & Aghili, 2012:3270), may contribute (either directly or indirectly) to the low uptake of organ donation therefore, a community facility approach to health education requires an adjustment to the new programme to facilitate effective promotion of the uptake of organ donation. The organisational environmental objectives to address the environmental outcomes for the planning group were that by the end of the programme, they will be able to:

- Use a reasonably collaborative team approach in health education.

- Implement interventions in a real-life community setting through community meetings for persuasive communication, group meetings for problem-solving, self-talk for cognitive behavioural restructuring, support groups for social support, and role-modelling stories for symbolic modelling.

- Implement community-focused health-promotion/group methods (group discussion, role-play brainstorming, workshop/seminar, demonstration, mini-lecture, problem-solving, panel discussion and field trip/ mini-tour; and

- Use motivational interviewing.

4.9.1.1. A Collaborative Team Approach

This is a process of partaking during which people work together to attain anticipated results. Collaboration aims to achieve collective ideas, realise positive results for the listeners they work for and building a reliant structure to address issues and opportunities (Green & Johnson, 2015). The collaborative team to promote uptake of organ donation should involve medical practitioners, professional nurses, organ transplant coordinators, psychologists, social workers, organ procurement team, relevant professionals, and community representatives (Kapelus, Karim, Pimento, Ferrara & Ross, 2009) as cited in (Tzenalis & Sotiriadou, 2007). They should work together to achieve a common goal as professionals focusing on community uncertainties regarding organ donation and functions as a multi-disciplinary group.

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Collaboration teams emphasise teamwork, innovative thinking, and equal participation to achieve objectives, define and communicate team goals, recognise individual strengths, promote a community-working environment, and foster honesty and open communication to improve results in health education (Reeves, Xyrichis & Zwarenstein, 2018:3). Healthcare professionals (planning groups) were engaged during each of the various stages of the programme's development. In the collaboration process, interpersonal relationships were developed exposing the planning group members to team building. The programme was developed in sectional form, stipulating content and approaches that will be utilised. Resilient headship that supports the values and principles of public health is a critical element of programme development; therefore, healthcare professionals lead the team as the coordinators, followed by the leaders of community organisations.

4.9.1.2. Motivational Interviewing

"Motivational interviewing (MI) is a collaborative, goal-orientated method of communication with a particular attention to the language of change, is intended to strengthen personal motivation for and commitment to a target behaviour change by eliciting and exploring an individual's own argument for change" (Miller & Rollnick, 2013:29). Motivational interviewing and the trans-theoretical model of behavioural change, MI, and MITTM are the latest alterations of the humanistic approach to psychotherapy and counselling. According to Kraybill and Morrison (2007), MI contributes to the preparation of people for change, it influences intrinsic motivation while building self-reliance to change; it is an empathic person-centred counselling approach. Changing of behaviour or an attitude lies with an individual, not on the healthcare professional. Healthcare professionals (planning groups) are expected to initiate a need for change.

The motivation includes discussion between a healthcare professional as a facilitator and a client (Xhosa community members). The discussion aims to address uncertainty about the change regarding uptake of organ donation, which will enable the client (Xhosa community members) to assure himself or herself (innate) to change depending on their main beliefs and concerns, which may be different to the conventional health education where a client is influenced to change the behaviour.

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Open-ended questions, affirmation, reflective listening, and summary reflections are the simplest methods and skills that are often used during a successful motivational interviewing approach (Miller & Rollnick, 2013). The essence of this emphasises the company between healthcare professionals and their clients, thus stimulating clients' internal motives. When a healthcare professional asks open questions, they invite the client to tell their story in their own words without leading them in a special direction and, therefore, must be willing to listen to the client's responses. Healthcare professionals, who are also counsellors, collaborate and engage their clients in conversations that will help the clients to motivate themselves as they advance their understanding and put forward the rationale for their concerns and debates for change. The counsellor makes affirmative statements and gestures, recognising the client's strengths and behaviours that lead to positive change, whether small or big. These affirmations assist clients in building confidence in their own ability to change. As a primary skill, reflective

listening in outreach is the trail for winning clients over in relationships, building mutual trust, and promoting change (Miller & Rollnick, 2013).

Special applications of reflecting listening are the summary made by the healthcare professional throughout the conversation. After the client has spoken about organ donation, has recounted a personal experience, or when their encounter is about to end, a summary is made to ensure clear communication between the speaker and the listener. A summary provides a stepping stone to change ((Miller & Rollnick, 2013). Motivational interviewing is focused and goal-orientated, helping to resolve clients' uncertainty by increasing the focus on the inconsistencies between their current behaviours and their desired goals without arousing resistance to change (Braastad, 2017:1). Behaviour change requires determination and ongoing publicity in terms of organ donation information but, most of all, lasting behaviour change relies on goal setting. A goal is a broad statement about the short-, medium-, and long-term expectations of what should improve because of the programme (desired result). Outcome objectives assist in monitoring the progress towards achieving the programme goals. The outcome and each of its determinants should specify the following:

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- Who will the programme specifically affect?
- What will change because of the programme?
- How much change will occur after the implementation of the programme?
- By when the change will be seen or observed, (what indicators will determine the change)?

Outcome objectives should be SMART, meaning Specific (single key result), Measurable (behaviour that can be measured), Achievable (realistic in terms of available resources), relevant (makes a difference) and Time-specific (can be accomplished within the set timeframe). Since the set goals will be used as a yardstick to measure the level of achievement, they will be written down and kept for future reference to determine the change of behaviour. The setting of goals is a major task for healthcare professionals during the programme. The principles of motivational interviewing will be addressed in the programme. The literature review showed that most empirical support for motivational interviewing has been found in the field of addiction and substance abuse. Nowadays, motivational interviewing has been applied across a broad range of settings: (e.g., health, corrections, human services, education), populations (e.g., age, ethnicity, religion, sexuality and gender identities), languages, treatment

format (e.g., individual, group, telemedicine), and concerns (e.g., health, fitness, nutrition, risky sex, treatment adherence, medication adherence, substance use, mental health, illegal behaviours, gambling, and parenting) (Miller & Moyers, 2017:764). MI associates well with other evidence-based approaches in formal research studies and is well-matched with the values of many other disciplines and evidence-based approaches (Miller & Moyers, 2017:764).

4.9.2. Second Task – Sub-Dividing the Behavioural and Environmental Outcomes into Performance Objectives

The second task was sub-dividing the behavioural outcomes and the environmental outcomes into performance objectives (Bartholomew et al., 2011). This involved matching the objectives with the programme and the actual activities participants were expected to perform. Performance objectives are the participants' detailed and expected behaviours, in this case, the behaviours of the Xhosa people (Table 4.1).

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Table 4.1: Behavioural Objectives Matched with Performance Objectives to Improve Uptake of Organ Donation Among the Xhosa Community.

Behavioural objectives	Performance objectives
Overview of organ and tissue donation – personal determinants.	• Define organ and tissue donation • State the legislation that regulates organ donation • Discuss ethics surrounding organ donation • Identify which organs and tissues can be donated and why • Identify the types of organ donation • Describe the meaning of brain death • Identify structures involved in organ donation (first point of entry when deciding to donate) • Consider registration for organ and tissue donation • State the benefits of organ and tissue donation • Describe the background of organ donation
Overview of the process of organ retrieval, operation of organ donation. Alleviation of fears – personal determinant.	• State risks and benefits of the operation on organ donation • State the elements of the consent form • Make informed decision to donate organs • Talk about organ donation with peers • Learn from people who have donated before • Access information on organ donation, read pamphlets provided • Interact with healthcare professionals to get updated information
Overall maintenance of healthy living has a life-long effect. Good health practice for future organ donation.	• Perform routine health check-ups at least once a year • Improve nutrition by following a proper, healthy diet • Improve physical fitness • Practice good hygiene • Maintain a healthy and safe environment • Describe the need for social support • Describe problem-solving skills
Overview of awareness of societal, cultural, and religious barriers to the uptake of organ donation.	• Overcome barriers towards the low uptake of organ donation. • Equip and empower traditional leaders, traditional health practitioners, and religious leaders. • Engage traditional leaders to address societal and tradition regarding organ donation. • Engage traditional health practitioners since they can communicate directly with the ancestors. • Accept religious teachings about organ donation.
Information-sharing through continuous collaboration and communication with healthcare professionals.	• State goals for organ donation awareness campaigns • Participate actively during counselling (MI) • Ask questions during educational campaigns and workshops • Ensure mutual respect and power-sharing • Accept teaching as a client-centred approach • Allow motivation for behaviour change

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4.9.3. Third Task – Selecting Important Determinants of Behaviour

The third task includes the personal and environmental determinants of behaviour created by utilising the theories stated in Chapter One. Determinants are the factors that are associated with self-regulation within the individual (cognitive/core system of thoughts) that they can easily control, as well as environmental factors (social and structural) that can be modified (Bartholomew et al, 2011; Leininger, 1988) as action-decision modes. IMF is theory-based, objectifying the task of developing an educational programme; therefore, it was convenient for the group to know that interventions to change health-related behaviour may typically be effective if grounded in appropriate theory, the theories that directly talked to the determinants of behaviour (Davis, Campbell, Hildon, Hobbs & Michie, 2015:338; Sutton, 2004:96). Theory simplifies the understanding of factors that work best because theory-based interventions make use of contributing trails (Abraham & Michie, 2008; Hardeman, Sutton, Griffin, Johnston, White, Wareham & Kinmonth, 2005:676).

The educational programme was planned to have an emotional impact on behaviour; therefore, theory-guided behavioural constructs to enhance changes in the Xhosa community were derived from theories of behaviour change self-determination theory, social cognitive theory, and information motivation and behavioural skills model, health-promotion theory (Chapter One) and Leininger's theory for environmental determinants. Determinants of behaviour such as self-efficacy, skills, autonomy, attitude, outcome expectations, and knowledge were selected.

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4.9.3.1. Self-Efficacy

Refers to an individual's belief in their capacity to execute the behaviours necessary to produce specific performance attainment (Bandura, 1977). It mirrors self-assurance in the ability to exert control over one's own inspiration, behaviour, and social environment (Bandura, 1977). A personal judgement of how well one can execute courses of action is required to deal with the prospective situation/s (Bandura, 1977). Self-efficacy theories regulate how people feel, think, motivate themselves, and behave. Such theories produce these varied special effects through four major processes that comprise cognitive, motivational, affective, and selection processes (Bandura, 1994). People with a high guarantee in their abilities quickly recuperate their sense of efficacy, irrespective of whether their hard work is in the face of failure. They

associate failure with insufficient determination or deficient knowledge and skills that are acquired.

The effects of self-efficacy theories on **cognitive processes** means that most courses of action are initially organised in thought by predicting events and developing ways to control those events. **Motivational processes** include self-regulation of motivation in which individuals motivate themselves before the exercise of forethought (Sung-il, 2013). **Affective processes** mean exercising control over stressors that yield less anxiety and facilitate control of disturbing thought (Bandura, 1994). **Selective processes** enable people to create a beneficial environment in which to exercise control over those things they encounter daily. As people are partly the product of their environment, they can shape the course of their own lives by influencing the type of activities and environment they choose. This can be achieved by avoiding activities and situations they believe exceed their coping abilities (Bandura, 1994). Self-efficacy is an imperative construct to overcome barriers to the uptake of organ donation.

4.9.3.2. Autonomy

Autonomy is defined as independence in one's thoughts or actions, the ability to make one's own decisions without being controlled by anyone else (Dictionary Autonomy, 2020). In the case of individual adult (Xhosa person) should be capable of making rational and informed decisions on his/her own behalf regarding participation in organ donation and endorse that decision by making it known through signed written or verbal will. Autonomy is a construct of the self-determination theory that is a psychological need to enhance a behaviour change (Cherry, 2019). Theory suggests that people can become self-determined when their needs for competence, connection and autonomy are fulfilled (Cherry, 2019).

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4.9.3.3. Attitude

Attitude refers to "feelings, beliefs and behaviour dispositions directed towards people, groups, ideas or objects" (Bohner & Dickel, 2011:395). It influences the behaviour of the individuals and determines how they behave in a particular situation. Attitude is composed of cognitive components, which are based on information or knowledge, such as the belief that donating an organ is painful. It also includes affective or emotional components, which are based on feelings, like the fear of death or anxiety about donating an organ, along with behavioural components that reflect how attitude influences one's actions or behaviours. An attitude is

essentially like a statement that is either negative or positive, depending on the dislikes and likes of the matter in question (Banaji & Heiphetz, 2010:353). In the study, the Xhosa community expressed both negative and positive views regarding the uptake of organ donation; therefore, the programme seeks to promote the uptake of organ donation among this demographic by creating favourable attitudes and strengthening the positive attitudes that already existed.

4.9.3.4. Behaviour Cognition

This is the "act of knowing, acquiring information about something, which is referred to as behaviour capacity" (Bandura, 1998). To perform a specific behaviour, knowledge of such behaviours is required to achieve the desired results. Programmes to change behaviour often include information to improve people's knowledge about individual and environmental problems or their solutions in the hope that it will motivate them to make necessary changes (Spehr & Curnow, 2011). Programmes are intended to improve knowledge of a particular issue, to change attitudes in their intrinsic value, and to lead to a change in behaviour. The study was intended to promote the uptake of organ donation through knowledge about organ donation to change the attitudes of Xhosa people depending on their intrinsic value, which might lead to a change in the behaviour. This illustrates that for a mission to be executed effectively, learning or the impartation of knowledge are prerequisites.

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4.9.3.5. Outcome Expectations

These are personal beliefs in the effect of an action to achieve a particular outcome (Lippke, 2017). Outcome expectations are subjective estimates that are often seen as being important in deciding to change behaviour and can regulate behaviour when used together with efficacy (Bandura, 1997 as cited in Lippke, 2017). It is a construct derived from the social cognitive theory (Sutton, 2001). It is not enough to be aware of the existence of a health threat, people also need to know how to act on such a threat (regulate their behaviour) by being cognisant of the potential links between their actions and the subsequent outcomes. These outcome expectations are prominent principles in the motivation to change according to Bandura (1997), as cited in Schwarzer (2015). An organ donor may find more good reasons to donate an organ than good reasons to influence others to donate, such as 'if I donate an organ then I will save a life.' Similarly, positive outcome expectancies, like 'if I donate the organs of my deceased

relative, I will save more lives,' are important in the motivation phase, when a person must carefully weigh the pros and cons of specific behavioural outcomes.

This disparity does not lead directly to action but can help to form an intention to act. The pros and cons represent positive and negative outcomes expectancies that are classic in rational decision-making. However, such possibilities between actions and outcomes need not be worded and evaluated; instead, they can be diffused mental representations loaded with emotions. Outcome expectancies are prospective, whereas outcome experiences are retrospective (Schwarzer, 2015). Organ donation is a treatment option that can save or transform the life of another person. This relies on donors and their families agreeing to donate the organs and tissues to deceased relatives. It requires taking responsibility for one's health (donor and the recipient) and continuous care to ensure the positive outcome of the donation and transplantation process. Acceptable information is delivered over lectures, group discussions, MI, goal setting, and role modelling and will be utilised to achieve a positive outcome in the programme development.

4.9.3.6. Knowledge

This is facts, information, descriptions, and skills which are acquired through experience or education, the theoretical or practical understanding of a subject" (Oxford English Dictionary, 2019). Bolisani and Bratianu (2018:2) believe that "knowledge is a result of the reasoning process and that our sensory experience plays a role"; and further explained that knowledge is based on rational reasoning removing views or opinions that arise from the senses. The participant's views in the study showed neither familiarity, awareness, nor understanding of organ donation uptake, such as facts or descriptions about the phenomenon being studied. The development of a programme in the study is aimed at changing behaviour that will include information to improve people's knowledge about the environmental factors or the solution that will motivate them to make a change (Spehr & Curnow, 2011).

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4.9.4. Fourth task – Creating Matrices for each Performance Objective

Performance objectives and determinants of behaviour were used in the form of tables for the matrices. A matrix of change objective presented the tracing of important changes expected to occur in the behaviour of clients, reflected as marks for immediate changes in behaviour and the potential to influence behaviour, and actions taken by healthcare professionals

(Bartholomew et al. 2011). The matrix specifies what the clients need to learn, and the environmental changes expected to occur. Tables 5.2 and 5.6 were constructed for each stage of intervention planned for the performance objectives of the clients (Xhosa community).



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Table 4.2: Matrix: Overview of Organ Donation – Personal Determinant

	Performance objective	Knowledge	Self-efficacy	Attitude/belief	Outcome expectation
i	Define organ and tissue donation	Ability to differentiate between organ donation, blood donation, and prostheses.	Express confidence in describing organ donation with family and peers.	Willingness to participate in the promotion and informing family members about organ donation.	Engage easily in a discussion about organ donation.
ii	State the legislation that regulates organ donation	Demonstrate understanding and recall of the legislation that regulates organ donation.	Efficiently describes the content that regulates organ donation.	Effectively apply/ utilise information regarding the legislation that regulates organ donation.	Share correct information regarding the legislation that regulates organ donation among family and peers.
iii	Discuss ethics surrounding organ donation	Understand the need to sign a consent decision to donate.	Express confidence in sharing with family and friends the wish with to donate.	Willingness to donate is expressed by signing a living will and sharing it with family and friends.	Family members know his/her wishes regarding organ donation – resulting in the smooth process.
iv	Identify the organs and tissues that can be donated	List the organs and tissues that can be donated.	Correctly identify on a chart or torso the organs that can be donated.	Exhibition of enthusiasm in imparting knowledge and organs that can be donated.	Family and friends know organs and tissues that can be donated.
v	Identify the types of organ donation	Distinguish between live and deceased donation.	Efficiently describes the two main types of organs and tissue donation.	Correctly teach family members about teaching about the two main types of organ donation.	Family members.
vi	Describe the meaning of brain-stem death	Distinguish between death and brain death.	Efficiently correctly describes death and brain-stem death.	Correctly teach family members about death and brain-stem death to dispel myths around organ donation.	Family members know the difference between death and brain-stem death thus know when to let go.
vii	Identify structures involved in organ donation (first point of entry when decided to donate)	List structures involved in organ donation and explained how to access them for registration.	Direct interested family members and friends on how and where to register for organ donation.	Render support and information to family members and	Family members and friends know the structures involved in organ donation and how to access them for registration.
viii	Consider registration for organ and tissue donation	Locate and contact structures involved in organ donation.	Formally register with the Organ Donation Foundation as an organ donor.	Willingness to wear and display organ donation bracelet in public or keep donor card in the wallet and attach donor sticker on ID book or card.	Write a living will stating the desire to donate organs and let it be known by family members.
ix	State the benefits of organ and tissue donation	List the benefits of organ and tissue donation.	Proclaim to family and peers the benefits of organ and tissue donation to all stakeholders involved.	Invite an organ recipient to relate the benefits of organ and tissue donation.	Family members and friends share information on the benefits of organ donation with other members of the community.

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Table 4.3: Addressing Fears Regarding Organ Donation- Personal Determinant

	Performance objective	Knowledge	Self-efficacy	Attitude/belief	Outcome expectation
i	State risks and benefits of donor operation during organ donation.	Identify risks and benefits associated with donor operation during organ donation	Express confidence in describing the risks and benefits of donor operation during organ donation.	Enthusiastically informing family members and friends about the risks and benefits of the donor operation.	Being knowledgeable about risks and benefits, one will be calm and able to cooperate during the donor operation
ii	State the elements of informed consent.	Relate the elements of the informed consent in the preferred language before signing the consent form	Express confidence in describing the elements of informed consent regarding organ donation.	Actively participate in a discussion about the elements of informed consent organ donation.	Willingly decides to donate organs
iii	Talk about organ donation with peers.	Reinforce knowledge by talking freely about organ donation to family and friends	Express confidence by debating about organ donation with family and friends.	Affirmatively support organ donation in a debate with family and friends.	Accept and promote uptake of organ donation
iv	Learn from people who have donated organs before.	Inquire knowledge about the experiences of donating an organ from people who donated before	Visibility of donors and their experiences show the feasibility of organ donation.	Display eagerness to learn from people who donated before.	The visibility and success of organ donation encourages one to engage in organ donation
v	Access information on organ donation, read pamphlets provided.	Ability to seek, retrieve, and impart information effectively related to organ donation	Show induced habit to information seeking process regarding organ donation.	Guiding family and friends to quality information and high performance of searching behaviour.	Significantly change political and social perspective regarding organ donation by making fact-driven decisions
vi	Interact with healthcare professionals to get updated information.	Increased collaboration, brainstorming and more ideas developed around the uptake of organ donation	Expressed confidence in making informed decisions regarding organ donation.	Life-long learning process achieved through interaction with healthcare professionals.	Family and friends are more likely to open and disclose information

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Table 4.4: Overall Maintenance of Healthy Living as a Life-Long Effect – Personal Determinant

	Performance objective	Knowledge	Self-efficacy	Attitude/belief	Outcome expectation
i	Perform routine health check-ups at least once a year	Ability to know own health early that may hinder organ donation.	Expressed increased use of routine health check-up.	Planning and encouraging family and friends to perform health checks	Health check increases chances for treatment and cure before organ donation
ii	Improve nutrition by taking a proper diet	Identify healthy diet and state cost and choice to keep him/her healthy.	Demonstrate confidence in identifying options for an effective healthy diet.	Feeling positive about nutritional management	Describing expectation that family members will use the right diet
iii	Improve physical fitness	Describe different physical activities that one can choose to practice.	Demonstrate and identify appropriate exercises.	Feel positive about increased physical activity	Physical activity will stabilise the health of individuals
iv	Practice proper hygiene	Increasing quality of life and improving emotional well-being.	Express confidence in keeping him/her hygienically.	Positive attitude towards proper hygiene expressed	Encouraging friends and family on good hygiene measures
v	Maintain a healthy and safe environment	Ability to know that a healthy and safe environment promotes health.	Capacity to execute behaviour that is necessary to maintain a healthy and safe environment.	Motivated to live a healthier and more sustainable lifestyle in today's environment	Design and implement plans to create a healthy and a safe environment
vi	Describe the social support needed	Describe the advantages of social support regarding organ donation.	Express confidence in the use of social support concerning organ donation.	Positive attitude towards the use of social support regarding organ donation	Assure that social support assist individuals to cope with the organ donation process
vii	Describe problem-solving skills	Ability to describe the problem-solving skills.	Express confidence in problem-solving.	Positively discuss the problems encountered with organ donation.	Application of problem-solving skills assists individuals who wish to donate

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Table 4.5: Addressing Social, Cultural, and Religious Beliefs, Motivation for a Behavioural Change – Environmental Determinants

	Performance objective	Knowledge	Self-efficacy	Attitude/belief	Outcome expectation
i	Overcome barriers towards less uptake of organ donation	Identify barriers and ways to overcome them	Get confidence in your ability to overcome the barriers		
ii	Equip and empower traditional leaders, traditional health practitioners, and religious leaders	New ways of thinking/ new skills obtained/ spurring to investigate further on their own	Reflect confidence in the ability to control one's motivation, behaviour, and social environment	Increased knowledge and improves attitude towards the uptake of organ donation	Application of what is learnt/ effective sharing of knowledge, practices, and technologies in support of organ donation.
iii	Engage traditional leaders to address the societal and tradition regarding organ donation	Important agents in mobilising rural communities since they command respect for people	Confidence in harmonising community customs and traditions with the ethos of the constitution	Facilitation and mediation within the communities regarding uptake of organ donation	The decision to donate organs is made by people with traditional leaders facilitating the process.
iv	Engage traditional health practitioners to address ancestral issues regarding organ donation	Ability to describe the role of traditional healing and cultural approach towards medicine	Confidently express the safety and quality of traditional health services regarding uptake of organ donation	Ancestors guide and protect the living, and have the power to intervene in people's lives	Xhosa community understand the functioning of the cultural setting, the role of traditional healers and supports the potential for integration of both traditional and Western medicine.
v	Accept religious teachings about organ donation	Determine the different interpretations concerning different religions concerning organ donation	Confidence in clarifying exactly the religious stance regarding organ donation	Positively influence and individual's decision-making on the organ donation matter	Understanding that religious background is important to comprehend the fears of donor families about organ donation.

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Table 4.6: Information-Sharing Through Continuous Collaboration and Communication with Healthcare Professionals- Environmental Determinant

	Performance objective	**Knowledge**	**Self-efficacy**	**Attitude/belief**	**Outcome expectation**
i	State goals for awareness campaigns regarding organ donation	Well stated goals of the awareness campaigns regarding organ donation.	Confidently shares goals of the awareness campaigns on organ donation with other stakeholders.	Eagerly and actively participate in sharing the goals of the awareness campaigns for organ donation	Xhosa community members attend awareness campaigns and demonstrate comprehension of organ donation.
ii	Participate actively during counselling (MI)	Recognise the need for individual counselling concerning fear of organ donation as expressed by each client.	Efficiently demonstrates the skills in counselling of Xhosa community members.	Encourages and fosters a positive attitude towards the uptake of organ donation during counselling	Individuals who underwent counselling display calmness and less anxiety as their myths dispelled.
iii	Ask questions during educational campaigns and workshops	Asks relevant questions during educational campaigns and the workshops.	Efficiently demonstrates skills of asking questions during educational campaigns and workshops.	Display positive attitude when asking questions during educational campaigns and the workshops	A positive attitude yields positive comments from the audience (Xhosa community members).
iv	Ensure respect and power-sharing	Describe respect and power-sharing.	Display self-confidence in communicating respect and sharing with others.	Exemplary commands respect and power-sharing	Xhosa community members display respect and the ability to share power among each other.
v	Accept teaching as client-centred approach towards change	Ability to listen and to give special attention to change statements of clients regarding organ donation.	Problem recognition and concern intention to change the behaviour.	Displays optimism when conducting teaching sessions regarding behavioural change	Points and comments made by clients show concern about the problem at hand and intention to change behaviour.
vii	Accept motivation for behaviour change	Describe the intrinsic motivation and effect of change of behaviour.	Express confidence in motivating Xhosa people for a behaviour change.	Avail themselves to motivate others	Xhosa community members are instrumental in motivating others towards behavioural change.

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4.10. SELECTING THEORY-BASED METHODS AND PRACTICAL STRATEGIES (STEP 3)

Four tasks were performed by the planning group to realise this step in the Methodology (Chapter Two). The programme was formulated based on the completion of the tasks performed in Step 2.

4.10.1. First Task – Programme Ideas Generated

After the topics in the sections of the programme had been drawn up, the planning group reflected on the content of the programme. The healthcare professionals in the planning group facilitated this by constructing valuable and imaginative knowledge addition especially in their fields of speciality. Behavioural objectives and performance objectives were used to develop the content of the programme.

4.10.2. Second Task-Identifying Theoretical Methods

Theories of behavioural change, and the culture care diversity and universality theory were discussed in Chapter One and compared to the supporting literature. The planning group identified theoretical methods that would enhance the facilitation of the content and enable active participation in the Xhosa community. Behaviour changes method or behaviour change technique, a theory-based method for changing one or several psychological determinants of behaviour such as a person's attitude or self-efficacy, were considered. An intervention based on theory is likely to be effective (Dombrowski et al., 2012; Taylor, Conner & Lawton, 2012).

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For a behaviour change method to be effective it must aim at a determinant that foresees a behaviour, it must be able to change that determinant and provide an explanation using a practical application in a way that preserves the parameters for effectiveness and relevant with the target population, culture, and the context (Kok, Gottlieb, Peters, Mullen, Parcel & Ruite, 2015). A taxonomy of behaviour changes techniques conceptualised by Abraham and Michie (2008) used as a template in classifying constructs from the theories of motivation, and behavioural skills model, social cognitive theory, and theory of culture care diversity and universality. The constructs of the motivational interviewing theory framework were used for the behavioural determinants of the health care professionals; these were motivation, individual counselling, and goal setting.

Table 4.7: Change Objective Matched with Theoretical Methods

Change objectives	Theoretical methods	Definition
Description of organ and tissue donation	Provide information behaviour health link IMB Provide information on consequences IMB, SCogT	General information about organ donation. Information about the benefits and costs of an action or inaction focusing on what will happen if the person does or does not donate organs (Dalal, 2015: 44).
Overview on the process of organ retrieval, operation of organ donation. Alleviation of fears – personal determinant	Model or demonstrate the behaviour SCogT, SD Prompt identification as a role-model SCogT, SD	Show a video of organ donation process. Indicating how a person who previously donated an organ may be an example to others and influence their behaviour (EI-Menyar et al., 2020:122).
Overall maintenance of a healthy living as a life-long effect. Good health allows folks to do many things including organ donation.	Provide information about the health behaviour link to consequences (Short & Mollborn, 2015). SCogT, IMB, SD.	General information about maintenance of healthy behaviour
Overview awareness on societal, cultural, and religious barriers towards uptake of organ donation.	Prompt barrier identification. Provide information SCogT, IMB. Provide information about others approval SCogT, Culture care diversity and universality	Identification of barriers towards less uptake of organ donation, and how to overcome such barriers. Information about what others think about organ donation and whether others will approve or disapprove any proposed behaviour change
Information-sharing through continuous collaboration and communication with healthcare professionals	Provide general encouragement, information, persuasive communication, peer education SCogT, SD Motivational interviewing Demonstrate behaviour	Praising or rewarding the person for effort or performance without being contingent on specified behaviours (Law, Siu & Shek, 2012). Prompting the person to provide self-motivating statement and evaluation of a behaviour to minimise resistance.

Note: IMB – Information-motivation-behaviour skills model

SCogT – Social Cognitive Theory; HPT – Health-Promotion Theory; SD-Self Determination

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4.10.3. Third task – Approaches and Methods Used in Teaching and Learning

Approaches together with methods were selected according to the goals and the nature of the topic, and to communicate information that allows for the understanding of the message and integration thereof. Approaches will be used in each section of the programme at different times to enhance active participation and information-sharing with others. Various methods and approaches such as written instructions (literature materials or pamphlets), overview lectures, role-play, and group discussions together with environmental methods chosen were

discussions, demonstrations, seminars, and awareness campaigns. These methods illustrated in Figure 4.10



Figure 4.10: Teaching Methods

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4.10.3.1. An Overview Lecture

This is an oral presentation intended to present adequate information or teach people about a particular subject (organ donation) and is often augmented by pictures (to illustrate verbally communicated information) and teaching aids. Critical information (regarding organ donation), its history, and background (of organ donation) is conveyed best through this lecture method. Audiences (in this case, the Xhosa community) receiving lectures learn better through listening, while a facilitator (instructor) attempts to impart adequate and complete knowledge of the subject (organ donation). The lecture is a didactic instructional method, taking the form of one-way communication from the active facilitator to the more or less passive audience (Ekeler, 1994:89). Differences in learning abilities and respect for cultural beliefs and values will be accommodated by the facilitator. New knowledge is gleaned from previous knowledge.

4.10.3.2. Written Instructions

Instructions are written on how to perform a task, and are also called instructive writing (Nordquist, 2019). Effective instructions commonly include visual elements, such as pictures, diagrams, and flowcharts, that clarify the text. It should be written in language that is easily

understood by many clients and the target population. Instructions should be clear, simple, and written in language that is easy to read at 4th to 6th-grade levels (Brewer, 2019:11).

4.10.3.3. Discussion Method

Discussion stimulates the flow of information and allows members of the group to participate. It is a constructive process involving the listening, thinking, as well as speaking abilities of the clients (Akshaya, 2017; Wilkinson, 2009), can be used as one of the teaching methods about organ donation especially in the family circles. This method allows for the creation of rapport with students, encouraging their critical thinking and the clear articulation of ideas (Mckeachie & Svinicki, 2006 as cited by Abdulbaki, Suhaimi, Alsaqqaf & Jawad, 2018:126).

4.10.3.4. Demonstration or Actions

This is when the instructor (health professional) performs an action or job to show clients what to do and how to do it and, through an explanation, highlights why and when it is done. The demonstration method of teaching lets individuals increase their understanding of complex skills and principles while following along and paying attention to the learning process. The acquired knowledge becomes permanent because this method requires the application of different human senses (Tersoo, 2017). This method is based on demonstrating skills, principles, and theory via a performance, movie, slide, presentation, or live play. Demonstration sessions promote thinking skills and enable learners to think more creatively (Basheer, Hugerat, Kortan & Hofstein, 2017:566). To facilitate learning, the study's instructor (healthcare professional) used video slides to show the organ donation process.

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4.10.3.5. Role-Playing

"Is a learning approach that allows students to immediately apply content as they are put in the role of a decision-maker who must decide on policy, resource allocation, or some other outcome" (Macdonald, 2004). Role-playing is the best way to develop several skills, including those of initiative, communication, problem-solving, self-awareness, and teamwork (Blatner, 2009). The main purpose of this type of training is to typically get learners to look at the material they are learning more positively, whereby the instructor influences them to alter their mental maps of the world instead of just being satisfied with new information (Blatner, 2009). In this programme, the role-playing educational method assisted Xhosa community members in applying immediate organ donation content in a relevant, real-world context. This teaching

method facilitates the Xhosa community members to tackle decision-making by playing a character that might guide them away from their standard self-imposed control. Xhosa community members will be able to engage in higher-order thinking and learn organ donation content more deeply.

4.10.3.6. Real-Life Stories

Storytelling can be used as a means of sharing experiences and interpreting those experiences. Ethics, values, cultural norms, and differences can be taught through telling stories. To be effective, it should take place in a social environment that provides authentic social cues about how knowledge is applied (Cajete, Eder & Holyan, 2010). Stories teach people about life, about individuals and others. It is a unique way to cultivate understanding, respect, and appreciation for other cultures. It can also promote a positive attitude to people of different backgrounds, racial groups and religions. Through stories, universal world truths are revealed, in that they show how different people may share the same life experiences and how human nature and a sense of connectedness can rise above culture (Green, 2004).

According to Van den Berg and Dichaba's (2013) study on real-life experiences during teaching and learning, the narratives revealed by student teachers who had vastly different experiences showed that despite these differences, they could make fundamental mind-shifts to embrace more inclusive worldviews. In the context of this study, real-life stories are used to encourage clients to identify with people affected by organ and tissue donation; in turn, this enabled clients to consider organ and tissue donation within actual scenarios. Real-life stories of organ and tissue donation assist learners/clients to understand the feelings of someone who is waiting for a transplant and the feelings of someone who has received a transplant. It equally allows clients to identify the benefits of receiving a transplant. These stories allow the learners/clients an opportunity to explain and comprehend the need for the uptake of organ donation and equip them to describe dilemmas involved in organ and tissue donation. The communication skills of listening and firmness by listening to different viewpoints will be developed. This will allow people to express their thoughts and emotions about organ and tissue donation. This type of storytelling allows clients to direct questions at real people and, therefore, touches those who have been affected by organ and tissue donation. This approach provides information that is discussed with peers and considers different perspectives and experiences of organ and tissue donation.

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4.10.3.7. A seminar

This teaching method is a discussion, providing general guidance for a group working on an advanced study or research project. It is organised in the form of a workshop meant to exchange information on techniques and approaches being explored by members of a study or research group and further assists in the development of new imaginative solutions to research problems by providing motivation and report and stimulating active participation and permit adaptive instruction (Devi, 2017:165).

4.10.3.8. An Awareness Campaign

This is typically defined as a constant effort to educate individuals and enhance public awareness about an issue or course. The aim of public awareness is to reach out to the public regularly and to deliver the message in the most acceptable way to make a difference in accomplishing the desired behavioural change (Symvoulakis, Markaki & Rachiotis, 2018). Deliver the message to the audience and organisations and measure the number of people who attended (Luthor, 2019). It is a marketing strategy to build public recognition of a problem through media, messaging, and an organised set of communication tactics. Targets many people over a specific period to generate specific outcomes and achieve predetermined goals.

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4.10.4. Fourth Task – Methods and Practical Applications

Designed practical applications were matched with the change objectives to address the objectives. This step entailed the application of theoretical methods and teaching approaches linked to the determinants of behaviour to ensure accuracy (Table 4.8).

Table 4.8: Theoretical Methods and Teaching Approaches Matched with Behaviours

Determinants and Change Objectives	Methods	Applications
Knowledge of organ and tissue donation.	Information regarding organ and tissue donation. • Overview lecture • Discussions • Posters, pictures • Reading material • Real-life storytelling • Role-play	Health care professionals give a lecture on organ and tissue donation. • Information feedback by allowing time for questions • Divide clients into groups for discussion (legislation, types of organ donation, and brain-stem death) • Real-life stories (ethics and dilemmas) • Picture educational material (showing organs to be donated/ visual picture of seven major organs) • Written instructions (reading material on organ donation) • Role-play (elements of consent and decision-making)
Process of organ retrieval, operation of organ donation. Alleviation of fears – personal determinant.	Information on the process of organ and tissue donation. • Video slides show • Real-life storytelling • Demonstration	Health care professionals inform clients on the process of organ donation. • Showing the process through recorded video • Storytelling on the process of organ and tissue donation • Demonstrate using a flow chart a sequence of events on the process of organ donation
Knowledge of healthy living has a life-long effect. Good health allows to do many things including organ donation.	Information on maintenance of health for ability to donate. • Discussions • Skill Demonstration • Counselling applying Motivational interviewing. • Written instructions.	Healthcare professionals give information on the maintenance of a healthy lifestyle in readiness for organ and tissue donation. • Clients actively participate in group and as individuals. • Demonstration of hygiene practices, good nutrition, physical activity, and stress management techniques. • Distribute and interpret literature materials. • Information motivates clients to take actions. • Learn where and how to obtain health information and advice on organ and tissue donation.
Knowledge on overcoming societal, cultural, and religious barriers towards the uptake of organ donation.	Empowerment and equipment of traditional leaders, traditional health practitioners, and religious ministers through information-sharing.	Health care professional facilitates the empowerment of traditional community leaders through knowledge transfer. • Divide Xhosa people into groups for discussion (legislation, types of organ donation, and brain-stem death) • Real-life stories (ethics and dilemmas) • Reflect on personal attitudes, feelings, and thoughts on organ and tissue donation

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	• Active participation in healthcare and group discussions • Information workshops • Seminar • Goal setting for awareness campaigns • Real-life storytelling	• Allow discussion on different standpoints and views about organ and tissue donation in mixed groups • Exposure of Xhosa people to seminars (to learn new imaginative solutions to problems regarding organ and tissue donation) • Information feedback through questions and answers • Monitoring of behaviour using goal-setting chart after an awareness campaign
Outcome expectations of change in behaviour of Xhosa community regarding of uptake of organ donation.	Information provision. • Feedback lectures • Pictorial presentation • Role-play • Group discussion • Seminars • Awareness campaigns	Xhosa community leaders, religious leaders, traditional health practitioners and Xhosa community members demonstrate knowledge and understanding through: • Role-play (elements of consent and decision-making). • Lectures on organ and tissue donation using literature materials with illustrations. • Understanding of written instructions (reading material on organ and tissue donation). • Picture educational materials on body systems (showing organs to be donated/ visual picture of seven major organs). • Facilitates group discussion on organ and tissue donation. • Active listening assertiveness and communication during the seminar asking questions on new imaginative solutions to health problems regarding organ and tissue donation. • Feedback on the Xhosa community's ability to successfully learn and synthesise new information on organ and tissue donation.

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4.11. PHASE 3, STEP 4: PROGRAMME COMPONENTS AND MATERIALS

Phase 3 involved step 4 of the adapted IMF that guided the programme development in promoting the uptake of organ donation among Xhosa community in the Eastern Cape Province. The phase was meant to achieve objective three of the study:

Research objective: To develop a programme in promoting the uptake of organ donation among the Xhosa community**.**

Research question: What nature of a programme would aid in the promotion of the uptake of organ donation?

This step was meant to develop a programme that should be suitable to the desires of the Xhosa community and sensitive to their culture in the rural OR Tambo and Chris Hani districts of the Eastern Cape. From the findings obtained out of the situational analysis in Phase 1, the planning group agreed on the components of the programme and resources that support the programme. Xhosa community members remained considered at every point regarding their level of learning, socio-economic rank, cultural beliefs, and ethnic background. The planning group also thought of the dimensions of health facilities and available resources thereof before the programme was incorporated into the actual context. To adequately produce the materials for the programme and outline the scope of the study, six tasks were performed. The programme was intended to conform to Xhosa community members, the planning group, and the relevant health professionals. The extent, process, mode of approach, and tools needed for the programme were designed (Chapter Six). The approaches used were derived from Step 2 (Table 4.8). The content was extended to comprise a more detailed point of view that participants could easily remember (Chapter Four).

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4.11.1. Reviewed Available and Developed Programme Materials

Programme materials were teaching instruments that were intended to excite the individual senses, such as visualisation, hearing, tangible that are essential for understanding. The teaching tools included the handouts, brochures, booklets, pamphlets, and notebooks. These tools will be searched from the internet, and some will be created to facilitate teaching and learning. Some of the illustrative material will be designed to engage learning on all sections in organised and custom-made to suit the population and their literacy level. Educational

materials will be requested from the Organ Donor Foundation in South Africa. The adapted and developed material will be re-looked by asking a few Xhosa people to guarantee that the programme notes in the developed booklets, posters, and communications were thoughtful of the desires of the participants. All samples of materials, such as written materials and audial communications, will be examined to assess audience reaction. Feedback received from the Xhosa people after exposure to the content of the programme will be reported to them. Results will include the simple teaching language choice, and the pictographic materials used in the booklets should be ethnically sensitive. The educational material produced will be cantered on the tasks performed in Steps 2, 3, and 4. The materials will be based on the objectives of the programme, and the stakeholders' suggested changes and adjustments will be affected.

4.12. SUMMARY OF CHAPTER FOUR

Chapter Four presented the process suggested by the planning group in producing the programme components and materials, considering the Xhosa community, which was the programme's beneficiary, and the context in which it should be used. The programme's objectives were considered, the material will be re-checked with a few Xhosa people, and adjustments and modifications will be implemented as necessary. A structured educational programme was developed using the steps of the IMF. A training workshop will be organised about using an MI framework, communication skills, and an educational manual for healthcare professionals – a detailed description of the programme to promote the uptake of organ donation will be presented next in Chapter Five.

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CHAPTER 5: PROGRAMME DEVELOPMENT

5.1. INTRODUCTION

The developed programme presented was formed from the views of the Xhosa community members and the planning group. The content in all the sections of the developed programme focused on the uptake of organ donation. The sections discuss the goals of the programme, the principles underpinning it and the benefits of the programme.

5.2. GOAL OF THE PROGRAMME

The goal of this programme among the Xhosa community is to raise awareness of organ and tissue donation and to encourage them to commit themselves to reflecting on their personal attitudes, feelings, and thoughts about organ and tissue donation. Understanding the attitude and knowledge of Xhosa people that affect their willingness to commit as organ donors is crucial to developing an effective programme in the selected districts of the Eastern Cape Province, South Africa. Attitude correlates strongly with commitment to organ donation (Tam, Suen & Chan, 2012:1199). The overall theme/subject is comprehension and an overview of organ and tissue donation.

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The objectives of the programme are that by the end of the programme implementation, Xhosa people will:

- Understand organ and tissue donation better than they currently do.
- Make their attitude favourable towards organ donation (Their inherent fears and myths will be diminished).
- Adhere to healthy lifestyle undertaking regular health check-up.
- Continuously engage society on all beliefs (be they cultural or religious) that may have a negative impact towards organ donation.
- Consciously encourage communities to accept organ and tissue donation.

Healthcare professionals in the planning group should be able to:

- Work as teams, emphasising on co-ordinated health education.

- Organise community forums where they are not in existence to have regular communication for trouble shooting all queries that arise while mobilising for organ donation.
- Organise groups within communities into forums to be used for health promotion (group discussion, role-play brainstorming, workshop/ seminar, demonstration, mini-lecture, problem-solving, panel discussion and field trip/ mini-tour), and
- Constantly and consistently encourage communities to view organ donation as a way of living.

5.3. ROLE-PLAYERS IN THE PROGRAMME

The healthcare professionals responsible for organising the programme include nurses, doctors, organ transplant coordinators, social workers, psychologists are the healthcare professionals. As new developments arise, healthcare professionals may consult experts in offering education on organ and tissue donation. The participants in the programme will be Xhosa people, which include the following four categories, namely traditional healers, traditional leaders, ministers of religion, and the general community members. The difference between the roles of health care professionals and clients (Xhosa people) are clearly defined, however, the demarcation of their roles does not affect their collaboration. Clients (Xhosa people) will have exposure to multiple healthcare professionals to get information. The available, prepared teaching manual will openly elucidate the role of clients (Xhosa people) as adult learners and healthcare professionals.

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The sharing of knowledge and experiences among participants benefits teamwork, thereby assisting each other's growth and goal achievement. Teamwork between clients (Xhosa people) and healthcare professionals will continue to achieve the desired knowledge. Discussion among the groups, role-playing, and engaging in activities will further facilitate teamwork. Clients (Xhosa people) will be exposed to other disciplines, and specialists in these disciplines will be involved in some educational activities to expose them to information that could motivate positive change.

Xhosa community members who meet the following eligibility criteria can participate in the programme:

- All adults, males, and females (above the age of 18 years) belong to Xhosa ethnic group (traditional healers, traditional leaders, religious leaders, and general community members).
- Xhosa community members across the socio-economic position.
- Attendance is encouraged even if one attended before, as continuous learning is imperative to understand organ and tissue donation.
- Family members of Xhosa people who are currently diagnosed with any type of organ failure, on haemodialysis in case of kidney failure and on a waiting list for an organ.
- Informing of Xhosa community about the programme at a diagnosis of organ failure, diabetes mellitus, hypertension, and renal failure by the healthcare professional with an emphasis to stimulate their zeal and interest to obtain more knowledge about the complications of their chronic diseases.
- Xhosa community members who donated an organ or a tissue before and who is a recipient of an organ.

5.4. UNDERLYING ASSUMPTIONS OF THE PROGRAMME

For this programme, it is expected that:

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- Xhosa community members lacking knowledge and understanding of organ and tissue donation will be introduced to organ donation knowledge through different teaching methods and approaches that will facilitate learning and change in behaviour
- Xhosa community members to facilitate a behavioural change, the healthcare professional will to exhaust the possibilities of the Xhosa community member's intrinsic factors through the engagement of Xhosa people to participate in demonstrations, discussions, role-playing, and giving homework to discuss organ and tissue donation at home to encourage thoughtfulness and self-confidence.
- Xhosa community members who discuss organ and tissue donation may understand it better and develop confidence in decision-making to behaviour change.
- Motivational interviewing will create comprehension of organ and tissue donation; Healthcare professionals will inspire Xhosa community members to put forward their consciousness and self-regulatory process to affect their results.
- Healthcare professionals delivering the programme will give appropriate and passable information to Xhosa community members in enabling change of attitude and allow

real-life storytelling by Xhosa people who experienced organ donation and transplantation.

- Attitudinal change communication will modify Xhosa community members' tradition, cultural, and religious beliefs, attitudes perceptions, the core system of thought and behaviour through tailored messages and a supportive environment.
- Comprehension into a health problem would be gained through dialogue and persuasion between healthcare professionals, traditional healers, and traditional leaders since community as the society's responsibility views the health of the individual.

5.5. THE ROLE OF MOTIVATIONAL INTERVIEWING

Motivational interviewing and the trans-theoretical model of behavioural change, MI, and MITTM are some of the latest developments of the humanistic approach to psychotherapy and counselling. According to Kraybill and Morrison (2007), motivational interviewing contributes to the preparation of people for change, since it influences intrinsic motivation while building self-reliance to change; it is an empathic person-centred counselling approach. The responsibility of changing of a behaviour or an attitude lies within an individual, not healthcare professionals. Healthcare professionals (planning groups) are expected to initiate a need for change.

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The motivation comprises a discussion between a healthcare professional (as a facilitator) and a client (Xhosa community members). This aims to address any uncertainty about the change required in terms of the uptake of organ donation, which will enable the client (Xhosa community members) to assure himself or herself (innate) to change depending on their main beliefs and concerns that are different to the conventional health education where a client is influenced and persuaded to change the behaviour.

The essence of motivational interviewing is to emphasise the connection between healthcare professionals and their clients, thus stimulating clients' internal motives. Below are the processes to be followed during an MI session.

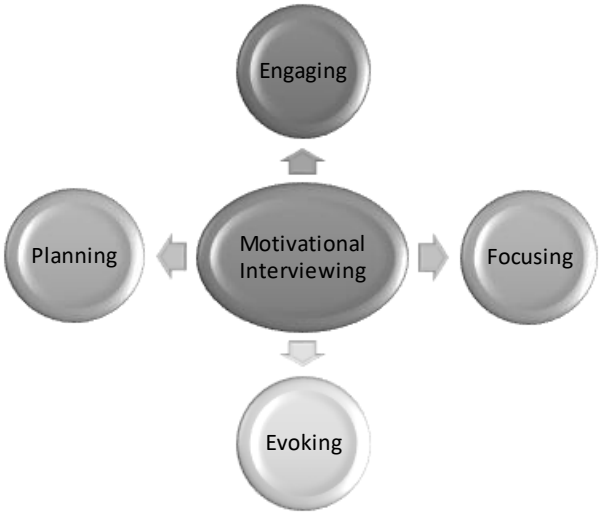


Figure 5.1: The Four Processes of Motivational Interviewing

5.5.1. Processes of Motivational Interviewing

Motivational interviewing consists of four key client-centred processes that assist individuals to outline their goals and move forward (Dore, 2017). These work together to direct the clients towards motivation for change. The client-centred processes of MI involve engaging, focusing, evoking, and planning.

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Engaging: is commonly known in EPIC as the "Hi" process. This initial component of MI is the creation of a firm therapeutic relationship between the counsellor and the client. For an effective relationship to develop, qualities like empathy, acceptance, a focus on client strength, and mutual respect are essential for such agreement. The client should be comfortable talking with the counsellor. Mutual respect is made possible in part by the creation of quality collaboration so that authority does not thwart the client approach. The counsellor works to understand the clients' perspective without any outside agenda or judgement. Encouraging a tone of equal partnership in a counselling relationship requires that the counsellor be willing not to only acknowledge, but to recognise the client strength, the knowledge base of the client, insight, and values throughout the process of doing the work" (Dore, 2017). A lot of reflective listening is used, as previously mentioned in the OARS acronym.

Focusing: is commonly known in EPIC as the "What?" process**.** The focusing process on MI comprises finding a clear direction of a conversation while some therapeutic situations will come with some obvious focal points or goals (Miller & Rollnick, 2012). Some clients already have material to work on, while others may lack insight and direction to take for the next step.

Focusing is about assisting the client to define what is truly significant to him or her and utilise such information to set the tone of the work. The counsellor establishes what goals for change does the client have and should of course support them, but the focus of MI is on encouraging the person to do the work of finding his or her own area of being trapped, uncertainty or struggle and setting goals accordingly (Dore, 2017).

Evoking: is commonly known in EPIC as the "Why?" process. Its purpose is to evoke a person's own internal motivation for change to reinforce and build that overall motivation. Being recognisable when clients say something that indicates willingness or readiness to move towards change is an important part of evoking process. Clients may perhaps make statements that state their desire to change and may be apprehensive about the consequences if they do not change or may indicate that the change is critical to their ability to move forward. Special attention is given to change statements, which are statements made by the client that point towards a willingness to change. Open-ended questions are useful tools for evoking this sort of talk and better understand the client's relationship with and attitude to change. Asking them to share examples or elaborate on their responses to the open-ended questions about change is another good way to gather information. Once the individual is engaging in change talk, be sure to reflect and summarise, as mentioned in the OARS acronym above (Dore, 2017).

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Planning: this is commonly known in EPIC as the "How?" process. An important thing about this is that the plan is optional coming from the clients, and is based on their unique values, wisdom, and self-knowledge. (Planning encompasses both developing a commitment to change and formulating a specific plan of action" (Division of Criminal Justice, 2020). Each of the four processes is geared towards nurturing and building the clients' motivation to change, and any other attempts on behalf of the counsellor to "take the reins" during the planning process may undermine or reverse the client's sense of empowerment (Dore, 2017).

5.5.2. Counselling Skills in Motivational Interviewing

For effective counselling in MI, healthcare professionals should have empathy, develop transformation, avoid argumentation, roll with resistance, and ability to support efficacy. Healthcare professionals expressed **empathy** by listening reflectively, avoiding judgemental comments while accepting uncertainties voiced by the client, having the wisdom to see the world through the client's eyes. Healthcare professionals should comprehend clients' experiences that

can enable change. **Developing discrepancy** assists clients to notice differentiation between present behaviour and the desired change. When clients see what they are doing will lead to a future goal are more motivated to change. To **avoid argumentation**, healthcare professionals should gradually diffuse clients' defensiveness; also, resistance to change demonstrated by clients warrant healthcare professionals to change the strategy. **Rolling with resistance** requires healthcare professionals to reframe the client's core system of thought by encouraging the clients to consider new perspectives and should value their clients as being their own change agents. Healthcare professionals should **support self-efficacy** by providing hope, thereby increasing the clients' self-confidence in their own ability to change the behaviours of others. To appraise other areas in which clients were successful (Rosengren, 2009).

5.5.3. Motivational Interviewing Core Skills

For a successful motivational interviewing approach, open questions, affirmation, reflective listening, and summary reflections (OARS) are the simple methods and core skills used often (Miller & Rollnick, 2013). When a healthcare professional asks **open-ended questions**, they invite the client to tell their story in their own words without leading them in a direction and must be willing to listen to the clients' response. The healthcare professional, who is also a counsellor, collaborates with and engages clients in a conversation that will facilitate the latter to motivate themselves as they advance understanding and put forward the rationale for their concern and debates for change. Open-ended questions open the door for exploration, gathers broad descriptive information, and are useful to avoid the question-answer trap, or putting the client in a passive role (Miller & Rollnick, 2013). They often start with words and phrases such as: "How"; "Tell me about"; "What"; and usually go from general to specific.

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The counsellor makes **affirmative statements** and gestures, recognising the client's strength and behaviours that lead in the direction of positive change, no matter how small or big. Such affirmations assist in building the client's confident in their ability to change. Affirmation further supports promotes self-efficacy and prevents discouragement. It includes a positive comment on an attribute such as: "You are determined to get your health back"; or "I appreciate your efforts despite the discomfort you are in". Affirmation must be sincere (Miller & Rollnick, 2013).

5.5.4. Reflective Listening

As a primary skill in outreach is the trail for winning clients in relationships, building mutual trust and promoting motivation to change (Miller & Rollnick, 2013). Reflective listening involves listening and understanding the meaning of what the client says. It strengthens the empathetic relationship and encourages further exploration of the problem and feelings of the client. Levels of reflection simply include reflection, complex reflection, and double-sided reflection. In simple reflection, the counsellor (healthcare professional) stays close to the client, repeat what the client says, or rephrases the statement made by the client. In complex reflection, the counsellor paraphrasing major restatement infers meaning or continues the paragraph. Lastly, the reflection attempts to reflect both sides of the uncertainties the clients' experiences (Miller & Rollnick, 2013).

Special applications of reflecting listening are the summary made by the healthcare professional, summaries can be made throughout the conversation or periodically summary of what has occurred in the counselling session. After the client has spoken about organ donation, has recounted a personal experience, or when their encounter is about to end, then a summary is made to ensure clear communication between the speaker and the listener. A summary provides a stepping-stone towards change (Miller & Rollnick, 2013). A strategic summary includes the selection of information that should be included, what can be minimised, or information that can be left out. Additional information that can be incorporated into summaries includes past conversations, assessment results and collateral reports (Miller & Rollnick, 2013).

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5.6. CONTEXT AND DURATION OF THE PROGRAMME

Context according Nouraldeen (2015:13) is the section of the real world in which some events or discourse takes place and in terms of which such an event can be fully understood. The context in the programme will be offered are the rural community clinic catchment areas and rural community centres of the selected rural sub-district in the Eastern Cape Province. It is regarded as a compulsory programme for all the Xhosa community members. However, Xhosa community members should be encouraged to attend since a single education programme will not effectively motivate the clients to change their behaviour and decide to be organ donors. Duration of the programme as the average amount of time between the initial and the implementation of the programme (Ballesteros-Perez et al., 2020:1). Some institutions have

formal policies that define hour credit and its application to courses and a programme. The credit hours are viewed frequently as a proxy for how much content students understand, and the amount of time student learning has taken place, and credit hours used to define the length of the programme of study (Lake Michigan College, 2018). Therefore, the duration of the programme will adopt a moderate length programme – 5 days or 1 week (5-20 CPD) depending on the number of learning hours and the learning objectives.

Learning Hours:

Each learning objective is allocated 8 hours per day, and will include lectures, practical activities, assessments and any independent study.

Hours Per Credit:

a common standard is adopted:

- 1 CPD credit = 10 learning hours.

Calculation of Total Credits:

Total number of credits of the CPD programme = 80 hours

Total learning hours per day = 8 hours

Total number of learning hours /Total number of hours per credit

80 hours /10 = 8 CPD credits

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5.7. PRINCIPLES UNDERPINNING THE PROGRAMME

Programme development in promoting the uptake of organ donation among the Xhosa community is expected to change behaviours, therefore principles of teaching and learning will be applied during implementation. Principles of teaching and learning will give direction to the programme development from the developmental stage to evaluation. Principles of adult learning by Knowles (1968) and other appropriate methods of teaching in health education will also be applied during the development of the programme content. Principles of adult learning and teaching, and application to the programme were explained in Table 5.1.

Table 5.1: Knowles Andragogy Theory Application to the Programme

Knowles andragogy theory	Applications to the programme
Mature age adults want to learn what is constructive to them since they have a more secure self-concept than children do.	The teaching approach should be designed to stimulate their learning activities and should be easily understood. Since adults are self-directed, their contribution to the content and the process of learning is acknowledged. The content of the programme will be designed to ensure stimulation, delivered on time, appropriate, and relevant to the client's needs.
Adults have a range of experiences to base on as they learn, unlike children who are in the process of acquiring new learning experiences.	Recognition of individual's experiences with organ donation in the families should be considered in teaching and their contribution will be acknowledged to strengthen knowledge power and self-determination. The presenters of the programme will acknowledge clients (Xhosa community members) who donated before that, their diverse experiences, knowledge, and interests that could be further improved through individual counselling and own goal setting.
Adults mostly have come to a point in which they value education and are ready to focus on learning.	The content of the programme is directed towards achieving their current and the yet to come needs. Content of the programme should focus on issues related to the improvement of their quality of life, as adults are looking for practical ways. The clients (Xhosa community members) will be fully engaged in their programme, actively participate in each step of learning. Approaches through self-determination should be encouraged.
Adults are looking for practical problem-centred approaches to learning.	The programme will impart knowledge and problem-solving skills, decision-making, and persuasive communication skills, which will enable clients (Xhosa community members) to make informed decisions to donate organs, thus improving their quality of life as they engaged in healthy behaviour.
Adults are driven by internal motivation.	Health care professionals will use a motivational interviewing framework in eliciting intrinsic motivation in clients (Xhosa community members) such as praises and rewards. Reasons for their learning in each step or each applied method will be given at every stage of the programme. Interesting written instructions as in reading material and pictorial designs that will appeal to their senses and relevant will be used.

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5.7.1. Active Learning

Active learning is generally an instructional approach that involves actively engaging students with course material through different teaching approaches and methods such as discussions, problem-solving, case studies, and role-play in the learning process. Teaching approaches applied will facilitate client's (Xhosa community members') contributions, such as a group discussion, role-play, demonstration, and allowing clients to evaluate the programme after each session.

Active learning methodologies are more learner-centred than inactive approaches such as lectures, but if utilised, the instructor (healthcare professional) guidance is still fundamental in the active learning environment. Active learning assists in stimulating higher-order intellectual

skills such as application of knowledge, analysis, and synthesis of information, which occupies learners in deep rather than superficial learning and transfers knowledge better.

One of the assumptions of Knowles's (1980) andragogy theory of learning is that adults seek practical reasons to learn, therefore, interaction with healthcare professionals will expose their inquisitiveness. Learning activities that the clients will participate in such as group discussions; role-plays etc., during the programme will stimulate action, as learning is personal in nature. Background knowledge will be considered as a foundation to learning. Engaging in group discussions, questions and answers, and other approaches will upturn adult's engagement learning.

Goals that were set by the clients (Xhosa community members) at the beginning of the programme must be realised. Relevant knowledge and skill acquired should mark behaviour change.

5.7.2. Principles of Health Education

Health education is a fundamental component of any programme to improve the health of a community and has a key role in promoting health (Hubley, 1984; 1054). The important decision that forms the foundation of any planning are judgements over what the desired change should be, setting of the health education, who should carry it out and how it should be done (Hubley, 1984:1054). These principles of health education were used in developing the methods and approaches in communicating information to Xhosa community members.

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Interest: health teaching should be related to the interest of people; therefore, health programmes should be based on the 'felt need' so that it becomes the people's programme. This health education programme was developed based on the information from the situational analysis (Phase 1 Step 1 of the IMF that led to the need of the programme. It was also established to fit within the existing lifestyle and culture of the community without conflicting with local beliefs. Health education tailored to meet clients' (Xhosa community) needs and interests (Yang et al., 2019:5). To enable modified interventions, health educators should be well-informed about the needs of the target group.

Participation: a high degree of participation tends to build a sense of involvement, personal acceptance, and decision-making, thus providing a maximum response. Health programmes are unlikely to succeed if community participation is not a fundamental measure. The health education programme was designed to adopt an educational approach to activities that involve clients in promoting the uptake of organ donation.

Motivation: in every person, there is a fundamental desire to learn. This desire is driven internally by motivation. Primary motivation is forcing that drive people to initiate action while secondary motivation is created by external forces in the form of rewards or appraisal. The main aim of motivation is to change the attitude. Motivation is contagious in nature; one motivated person may spread motivation throughout the group (Miller & Rollnick, 2013). Individual differences related to learning abilities were considered. Individual counselling will be conducted to enable discovery, and a collaborative care plan tailored to the clients' identified needs and preferences. Motivational interviewing was applied (Rosengren, 2009).

Comprehension: Always communicate in the language people understand. Teaching should be within the mental capacity of the learners in terms of the level of understanding, education, and literacy of learners to whom the teaching is directed (Davin, 2020:6). Reading materials will be written in 4th-6th-grade language and communicated in a language easy to comprehend (Brewer, 2019:11). Interpreters will be invited during implementation in cases where language might be a barrier.

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Reinforcement: repetition of a message at intervals is required. If the message is repeated in different ways, people are more likely to remember (Haleem et al., 2016). During the implementation of the health educational programme, reinforcement of information will be facilitated by communicating information more than once and the health education programme will be repeated periodically.

Known to unknown: recognition of previous knowledge is an essential element of health education. Health communicators should be utilising the existing knowledge of clients to hang on to the new knowledge. Adult learning should focus on adding to what clients have already learnt in the past (Palis & Quiroz, 2014:119). Health education should move from the concrete to the abstract, from simple to the complex and from the easy to the difficult.

A diverse perspective approach is needed for behaviour change: all healthcare workers have a role to play in health education since a community of joint knowledge allows for effective joint teaching, therefore, a multi-disciplinary approach has been shown to create an understanding of human behaviour (Cohen, Talia, Crabtree & Young, 2005:s17). The programme includes the use of healthcare professionals from other disciplines to impart knowledge, skills, beliefs /values and motivates clients to attempt behaviour change through goal setting. Community leaders as agents of change in the community will be utilised in health education work. Their attributes include understanding the needs and demands of the community, assisting in community entry, provision of proper guidance taking initiative, receptive to the views and suggestions of people. Community leaders could control and compromise various sectors in the community.

Credibility: is the point to which the message to be communicated is alleged as trustworthy by the receiver. Good health education must be consistent and compatible with scientific knowledge and with the local culture, educational system, and social goals.

5.8. BENEFITS OF THE EDUCATIONAL PROGRAMME

The following are the expected benefits of the programme:

5.8.1. Benefits to Xhosa Community Member (Individual)

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- Xhosa community members will be empowered with knowledge and skills on a general overview of organ and tissue donation.
- Knowledge will enable Xhosa community members to support each other when the need for organ donation arises.
- Address myths and misconceptions regarding organ and tissue donation.
- Motivation to register for organ donation.

5.8.2. Benefits to Family

- Xhosa families will engage in free discussions regarding organ and tissue donation.
- Family members will share their wishes to donate organs.
- Decision-making on donating organs of a family member in case of brain death.
- Family members will contribute to caring for their loved ones (on a waiting list for organ donation and family member who has donated an organ).

- Strengthen healthy lifestyle on prospective donors.

5.8.3. Benefits to Healthcare Facilities

- Readily available prospective organ donors.
- Visibility of organ transplant centres to community members and availability of organ transplant coordinators.
- Establishment of a database for prospective organ donors.
- Provision of guidance to health care professionals on how to approach relatives of brain-dead patients in considering organ donation.
- Understanding the behaviour and tradition of Xhosa people regarding organ and tissue donation.
- The programme could enhance collaborative teamwork in promoting the uptake of organ donation.

5.8.4. Benefits to Xhosa Communities

- Mobilisation of community through community leaders to stand up against social stigmatisation regarding organ and tissue donation.
- Promote collaboration among various stakeholders (traditional leaders, traditional healers, and religious leaders) in promoting the uptake of organ donation as agents of change.
- Programme can create awareness in the community of the availability of support to prospective organ and tissue donors.

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5.9. SUMMARY OF CHAPTER FIVE

Chapter Five encompasses the elements of the programme. Comprehension and overview of organ donation present the central theme in the programme's goals. Both Xhosa community members and the healthcare professionals described the desired objective of the programme. The role-players in the programme were described, and the underlying expected assumptions of the programme were highlighted. Change requires the application of MI to facilitate behaviour change; therefore, the process of motivational interviewing is discussed under engagement, in which the healthcare professional builds a trusting relationship with Xhosa community members, focusing on what needs to be changed. The evoking process explains the need to change the behaviour; lastly, the healthcare professional plan to develop a commitment to change the behaviour. Throughout the processes of MI, counselling skills were applied, such as empathy, developing a discrepancy, avoiding argumentation, rolling with resistance to change, and supporting self-efficacy through appraisal of a good attitude. Context and duration of the programme explained. Knowles's theory of adult education applied as the principle underpinning the health education programme. Principles of health education were discussed.

Xhosa community members, individuals' families, healthcare facilities, and the Xhosa community will benefit from implementing the programme. The programme review will be described in Chapter Six.



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CHAPTER 6: PROGRAMME REVIEW

6.1. INTRODUCTION

In the previous five chapters, the researcher provided an overview of the research study. The research design and methods were comprehensively discussed. Presentation and discussion of qualitative findings were further described. Chapters three and four concluded Phase 1 of the research study. Chapters five and six covers Phases 2 and 3 of the programme development. Chapter six presents the description of the programme. This chapter discusses the programme review on two aspects. Firstly, the steps followed in the review of the programme, and, secondly, the comments and the recommendations from the expert panel reviewers.

The process of programme development was described in Chapter Two and Chapter Five. The completion of Phase 1, comprising data analysis of semi-structured individual and focus groups discussions, led to Phase 2, Step 1 conceptual Framework by Dickoff et al. (1968) and then Step 2 included steps in programme development by Bartholomew et al. (1998). These steps guided the development of the programme. Phase 3 Steps 3 and 4 provide a description of the programme, see Chapter Six. For the programme to be implemented, it requires a review.

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6.2. SELECTING PROGRAMME REVIEWERS

Reviewers were selected based on competence and through a transparent process, they possessed different types of expertise. Reviewers have no interest in the programme being evaluated, and their work was conducted impartially without potential adverse effects. A well-qualified evaluation team conducted a review of this programme. Each review team member is experienced in the study and has sound knowledge of the subject to be evaluated. The team possess broad knowledge and understanding of the economic and social development issues and the challenges within the Xhosa community. The evaluation team was familiar with the Xhosa community's culture, tradition, and characteristics. Throughout the evaluation, they were equipped to understand and respect the local customs, beliefs, and practices. Three expert panel members were selected for the programme and contacted to confirm availability for reviewing the programme. The number of evaluators depends on the review size (United Nations Evaluation Group, 2016:25). Typically, a programme can have anywhere from three to ten reviewers depending on the complexity of the programme and the area of specialities. Each participant panel member received a participation information letter (See Appendix K).

The last paragraph of the letter requests consent to participate. Permission was obtained from each member confirming voluntary participation in the study. In cases where personal sessions were not possible, email or telephonic communication was used. The draft programme is given to the selected panel reviewers via email.

6.3. PROGRAMME REVIEW PROCEDURE

For the expert reviewers to assess the draft programme, the researcher used a review sheet from the Checklist for Programme Evaluation Report Content developed by Robertson and Wingate (2017). For this research study, this review was adapted. The panel members were requested to complete the review sheet (See Appendix K) and to make comments and/or recommendations.

6.3.1. Aspects in the Review Sheet (checklist)

The facets of the review sheet included citation information, description of the context, and a score rating of 1 to 7 and four domains. The score from 1-3 strongly disagree with the programme content, and 5-7 strongly agree with the programme content. A checklist used for programme review provided an insight into the programme development.

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6.4. COMMENTS FROM THE EXPERT PANEL REVIEWERS

The rating score, comments, and or recommendations from the three reviewers are presented according to the domains used in the review checklist. The scores as rated by the reviewers were calculated for each domain. Table 6.1 shows the calculated rating scores from the three reviewers.

Table 6.1: Programme Review Rating Scores

Domain 1: Programme description	**Reviewer 1**	**Reviewer 2**	**Reviewer 3**
1. The overall goal(s) and objective(s) of the programme are specifically described	7	7	5
2. Organisation(s) involved in the programme and its role(s) is clearly described.	6	7	6
3. Intended beneficiary(s) for the programme designed to serve is clearly stated.	7	7	6
4. Programme design is clearly described	7	6	6
5. Context in which the programme operates is clearly described	7	4	5
6. The programme' stage of maturity is identified	7	4	6
TOTAL = 110/126 (87%)	**41/42**	**35/42**	**34/42**
Domain 2: Evaluation background			
1. Purpose and intended use of evaluation are clearly stated.	7	5	6
2. Stakeholder engagement is clearly explained	6	6	6
3. Responsiveness to culture and context is considered.	7	6	5
4. Evaluation team composition and selection clearly described.	7	6	6
TOTAL = 73/84 (87%)	**27/28**	**23/28**	**23/28**
Domain 3: Evaluation method			
1. Methods employed for programme review are clearly described	7	4	6
2. The strength and limitations of the programme are clearly described.	7	4	6
TOTAL = 34/42 (81%)	**14/14**	**8/14**	**12/14**
Domain 4: Recommendations			
1. Development process explained clearly	7	4	6
TOTAL= 17/21 (81%)	**7/7**	**4/7**	**6/7**
The overall quality of the programme [17/21 (81%)]	**7/7**	**5/7**	**5/7**

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The higher the score rating that was attained per domain, the greater the agreement related to the domain assessed, thus validating the content of the programme. Generally, all the reviewers recommended the programme with modifications.

6.4.1. Comments for Modifications

The reviewers made the following general comments: Only comments related to the programme were counted.

6.4.1.1. Reviewer One

- Talk to theory of change, including Health Human Rights

Researcher's note: The educational programme was planned to have an emotional impact on behaviour; therefore, theory-guided behavioural constructs to enhance changes in the Xhosa community were derived from theories of behaviour change self-determination theory, social cognitive theory, and information motivation and behavioural skills model, Health-promotion theories, and Leininger's theory for environmental determinants. All these theories are embedded under the theory of change.

- Description of the role played by the Department of Social Development, as they are the social support.

Researcher's note: The nurses, doctors, organ transplant coordinators, social workers and psychologists are the healthcare professionals who formed part of the planning committee and will be offering the programme. As the need arises and the emergence of new developments, healthcare professionals may consult other healthcare professionals in providing education on organ and tissue donation.

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6.4.1.2. Reviewer Two

- How would the researcher motivate the targeted beneficiaries to firstly attend the programme and secondly to maintain their attendance for the entire duration of the programme?
- Suggested beneficiaries to take part in a programme instead of providing information in motivating beneficiaries.
- The programme should be tailored for all

Researcher's note: Traditional leaders as custodians of African culture and tradition and stakeholders in the programme should play a leading role in motivating Xhosa people to participate in organ donation, same as encouraging attendance for the entire duration of the sessions.

6.4.1.3. Reviewer Three

- To clarify the Xhosa community, clearly define or explain this from the onset to indicate that the researcher is examining cultural and spiritual beliefs (citing sources) among isiXhosa speaking communities.
- Describe the meaning of ethnic group (to engage anthropological literature on this to define this clearly).

Researcher's note: Xhosa people are members of native communities inhabiting the Eastern Cape Province, South Africa, and their primary language is isiXhosa. A community is a social group determined by geographic boundaries, and the Xhosa community is the central subgroup with their own distinct but related heritages (Pauw, 2018).

6.5. PROGRAMME SUMMARY

This section provides a summary of the programme promoting uptake of organ donation among the Xhosa community people. A copy of the final programme is available (see Appendix L).

6.5.1. Programme Title

Programme in promoting the uptake of organ donation among the Xhosa community in the rural districts of the Eastern Cape Province, South Africa.

6.5.2. Scope and the Purpose

The goals of the programme, underlying assumptions, organisations involved in the programme and their roles, beneficiaries of the programme and programme design are discussed in detail in Chapter Five of this study and under the programme description in domain one.

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6.5.3. Review Background

The purpose and intense review, stakeholder engagement, responsiveness to culture, review team composition, and selection are discussed in detail in the programme under domain two.

6.5.4. Review Method

Domain three of the programme contains the methods employed for programme review and the programme's limitations.

6.5.5. Editorial Independence

The responses from the Xhosa community members (traditional leaders, traditional health practitioners and religious ministers) and suggestions brainstormed by the planning group of health professionals and the community members formed the basis of the development of this

programme. The study's supervisor and co-supervisor were instrumental in the programme's conception and design. However, funding was received from the institution (SETA). This programme is editorially independent of the funding body. No conflict of interest applies to the development of this programme and no changes were made as the reviewers recommended it.

6.6. SUMMARY OF CHAPTER SIX

The draft programme was submitted to an expert review panel. Upon the completion of the review process, suggestions applicable to the programme were reflected, and the final programme will be prepared. This chapter describes the programme summary; the final comprehensive programme will be included as an annexure. The next chapter concludes the study and presents the limitations, and recommendations related to the study.

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CHAPTER 7: SUMMARY, LIMITATIONS, RECOMMENDATIONS, AND CONCLUSION

7.1. INTRODUCTION

This chapter is a summary of the research study conducted and the development of a programme aiming at promoting the uptake of organ donation among the Xhosa community in the Eastern Cape Province, South Africa. The key findings, the limitations of the study and recommendations for further research are incorporated in this chapter.

7.2. KEY FINDINGS OF THE RESEARCH

The status of organ donation in the selected districts of the Eastern Cape Province in South Africa needs effective intervention to promote uptake of organ and tissue donation. Approximately 5 000 South African adults and children are awaiting a life-saving organ or cornea transplant but only 0.2% of the population are registered organ donors (Organ Donor Foundation, 2019). Situational analysis reveals that most Xhosa community members lack knowledge and understanding of organ and tissue donation. Xhosa community members know and understand organ donation as an invisible phenomenon to them, foreign to their culture, and perceive it as something brought by the White community. They claim not to have seen an individual who donated or received an organ. In their public community clinic catchment areas, they are provided education on current chronic conditions such as diabetes mellitus and hypertension but never on organ and tissue donation.

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i. Xhosa community members viewed organ and tissue donation as a service of humanity (Ubuntu), showed a willingness to donate but highlighted fears or concerns regarding their health status amid communicable and non-communicable diseases. They demonstrated fear of ill-health and death of the prospective donor and the recipient of an organ.

ii Misconceptions and myths still exist among Xhosa community members such as character transfer, incomplete body structure, organ trade, and rejection by the ancestors in the afterlife.

iii. Few religious ministers demonstrate an understanding of organ and tissue donation; many still do not know their religious stance regarding the uptake of organ and tissue donation. Therefore, engagement with ministers of religion is essential.

iv. Traditional leaders, as the custodians of African culture and tradition for the Xhosa community, offered to play a leading role in promoting the uptake of organ donation by opening their gates to health care professionals who come to their communities and educate Xhosa people. Traditional healers accept that organ donation is possible through communication with the ancestors (ancestor worship). The practice of religious faith in organ donation is indispensable, as a source of strength and a coping mechanism. Therefore, prayer should be directed towards promoting the uptake of organ donation among religious followers.

v. A nurse-led structured health education programme to promote the uptake of organ donation was developed based on the situational analyses of Xhosa community members through a collaborative process with the planning group and relevant healthcare professionals. This was facilitated actively by applying all stakeholders' experience, knowledge and creativity utilising IMF. which is underpinned by behavioural change theories. Various teaching methods will be used to communicate the information to Xhosa community members.

7.3. LIMITATIONS

The study was restricted to Xhosa communities in selected districts of the Eastern Cape Province. Therefore, it may not be generalised to other districts and ethnic groups in the province. This qualitative approach and the ethno-nursing design may not be transferable to ethnic communities; instead, it was conducted to create a rich contextual comprehensive barrier that contributes to the low uptake of organ donation among the Xhosa community in their own context. Upon consideration of the complex and evidence-based IMF and the processes involved in the study, the extent of this research requires more human and financial resources as well as time to include participants in other districts to cover the entire province; therefore, a future study would be the implementation of the programme and subsequent evaluation thereof.

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7.4. RECOMMENDATIONS

7.4.1. Department of Health

Based on the evidence of this study, the Eastern Cape DoH should approve the implementation of the developed educational programme to promote the uptake of organ donation and enable

the Xhosa community to have adequate knowledge and understanding of organ and tissue donation. The South African Government's healthcare system, which is focused on primary healthcare reengineering, should regard organ donation as a fundamental need to be considered by integrating organ donation programmes into existing programmes. Organ donation programmes should be included in the calendar year programmes or year plans by the Department of Health of campaigns over the year. Organ donation could be associated with NCDs like Hypertension and Diabetes Mellitus with their complications like organ failure which may end up in transplant.

7.4.2. Department of Education

Based on the evidence of this study, the Department of Education should include organ donation content in the school curriculum. Literature indicates that school teaching programmes should be taken as an academic discipline, integrating knowledge and skill in an educational context, considering interaction during learning modified to different society's peculiarities and conduct.

7.4.3. Healthcare Institutions

Adoption and implementation of health educational programmes in promoting organ donation in healthcare institutions is recommended. The researcher is of the view that this programme will also improve the knowledge of healthcare professionals regarding the understanding of African culture and tradition in relation to organ donation. Working collaboratively with influential figures of culture and tradition such as the community leaders, traditional healers, and religious leaders will promote the uptake of organ donation.

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7.4.4. Nursing Practice

The recommendations in the programme can be incorporated into the health facility policies and in-service education programmes presented in hospitals for nurses. Intensive and emergency care nurses can play a major role in organ donation processes. Approaching Xhosa families for consent for donation after adequately being counselled about the clinical situation in case of brain death is a skill; therefore, the nurses need to be trained on MI of Xhosa families. The availability of organ transplant coordinators in the intensive care unit, preferably of the same culture, is recommended as they are trained personnel to approach Xhosa families or

ICUs sharing one transplant coordinator or even hospitals in a region to avoid financially engaged recommendations.

7.4.5. Nursing Education

The aim of education, including nursing education, is to influence change in human behaviour in a specific direction in a particular healthcare context. Education, in general, is critical in improving the quality of care that nurses provide to community members. Nursing educators have a responsibility to uphold the standards of professional practice. Nursing students should be trained in cultural congruent care since, in their profession, they will often meet individual clients with unique needs that require holistic nursing care.

7.4.6. Nursing Research

To understand the underlying dynamics influencing organ donation in various contexts and settings, this study must be replicated on a larger scale in a different context that does not apply to the Xhosa ethnic group in the province. Further research of this nature and programme is recommended for primary, high school, and university students, as the literature shows that research will contribute to solving the problem of low organ donation uptake. The study's pilot implementation is also recommended.

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7.4.7. Community Organisation

The solution to the organ shortage fundamentally depends on changing social behaviour towards organ donation. Based on the evidence of this study, training and empowerment of key community leaders in society on organ and tissue donation may assist in changing the negative attitude towards organ donation. Therefore, educational empowerment of community organisation leaders is recommended, as they are custodians of the culture and tradition of the Xhosa people. This collaboration should be comprised of community nurses and community clinic committee members since they are close to the community.

7.4.8. Xhosa Communities

7.4.8.1. Culture Care Preservation and Maintenance

Xhosa community members should be allowed to communicate with their ancestors in their own way/language regarding organ donation by performing the ritual practices. This could be

achieved by involving traditional healers in the process. All family members should be involved when the family is approached for consent for donation. A threat to one family member in Xhosa tradition concerns the whole family and the community.

7.4.8.2. Culture Accommodation and Negotiation

Sensitive cultural education about organ donation is essential to Xhosa community members. A pastoral minister should be invited to explain and alleviate the fear and anxiety by explaining life and the afterlife to overcome their religious beliefs.

7.4.8.3. Culture Care Repatterning and Restructuring

Restructuring the healthcare system by appointing traditional leaders, traditional healers, and religious ministers to lead awareness campaigns about organ donation, as they are trusted figures in Xhosa communities and genuinely care for their people.

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7.5. CONCLUSION

The study aimed to provide insight into the barriers to organ donation uptake among Xhosa community members in selected rural districts of the Eastern Cape Province. The study's findings served as a foundation for developing an educational programme to promote organ donation within this community. The results indicate that Xhosa communities – comprising traditional leaders, traditional healers, ministers of religion, and general community members—exhibit limited knowledge and understanding of organ donation, hold negative perceptions of it, and offered suggestions to enhance its uptake. The study's purpose was to create a programme to promote organ donation uptake, utilising the IMF (Bartholomew et al., 2011). Phase 1 of the programme involved a qualitative situational analysis that included a background overview of organ donation uptake through literature review, application of ethno-nursing design, gaining entry to the Xhosa community, data collection, and subsequent data analysis along with discussions. Phase 2 focused on developing the programme framework using matrices of change objectives, theory-based intervention methods, and practical applications. A structured health education programme was drafted in Phase 3. The researcher described the limitations and recommendations of the programme.

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Appendix A - Ethical Clearance Certificate

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ETHICAL CLEARANCE CERTIFICATE
REC-270710-028-RA Level 01

Certificate Reference Number:	SEE051SDON01
Project title:	**Development of an intervention programme to promote /facilitate uptake of organ donation among Xhosa Community in the Eastern Cape Province**
Nature of Project:	PhD
Principal Researcher:	Tobeka Dondashe-Mtise
Supervisor:	Prof E Seekoe
Co-supervisor:	Prof D Goon Dr LR Mlisa

On behalf of the University of Fort Hare's Research Ethics Committee (UREC) I hereby give ethical approval in respect of the undertakings contained in the above-mentioned project and research instrument(s). Should any other instruments be used, these require separate authorization. The Researcher may therefore commence with the research as from the date of this certificate, using the reference number indicated above.

Please note that the UREC must be informed immediately of

- Any material change in the conditions or undertakings mentioned in the document

The Principal Researcher must report to the UREC in the prescribed format, where applicable, annually, and at the end of the project, in respect of ethical compliance.

Special conditions: Research that includes children as per the official regulations of the act must take the following into account:

Note: The UREC is aware of the provisions of s71 of the National Health Act 61 of 2003 and that matters pertaining to obtaining the Minister's consent are under discussion and remain unresolved. Nonetheless, as was decided at a meeting between the National Health Research Ethics Committee and stakeholders on 6 June 2013, university ethics committees may continue to grant ethical clearance for research involving children without the Minister's consent, provided that the prescripts of the previous rules have been met. This certificate is granted in terms of this agreement.

The UREC retains the right to

- Withdraw or amend this Ethical Clearance Certificate if
  - Any unethical principal or practices are revealed or suspected
  - Relevant information has been withheld or misrepresented
  - Regulatory changes of whatsoever nature so require
  - The conditions contained in the Certificate have not been adhered to

- Request access to any information or data at any time during the course or after completion of the project.

- In addition to the need to comply with the highest level of ethical conduct principle investigators must report back annually as an evaluation and monitoring mechanism on the progress being made by the research. Such a report must be sent to the Dean of Research's office

The Ethics Committee wished you well in your research.

Yours sincerely

Professor Gideon de Wet
Dean of Research

13 March 2015

Appendix B - Eastern Cape Department of Health Provincial Permission

Eastern Cape Department of Health

Enquiries: Zonwabele Merile
Tel No: 040 608 0830
Date: 28th July 2015
e-mail address: zonwabele.merile@echealth.gov.za
Fax No: 043 642 1409

Dear Ms T Mtise

Re: Development of an intervention programme to facilitate uptake of organ dona (EC_2015RP15_596)

The Department of Health would like to inform you that your application for conducting a research on the abovementioned topic has been approved based on the following conditions:

1. During your study, you will follow the submitted protocol with ethical approval and can only deviate from it after having a written approval from the Department of Health in writing.
2. You are advised to ensure, observe and respect the rights and culture of your research participants and maintain confidentiality of their identities and shall remove or not collect any information which can be used to link the participants.
3. The Department of Health expects you to provide a progress on your study every 3 months (from date you received this letter) in writing.
4. At the end of your study, you will be expected to send a full written report with your findings and implementable recommendations to the Epidemiological Research & Surveillance Management. You may be invited to the department to come and present your research findings with your implementable recommendations.
5. Your results on the Eastern Cape will not be presented anywhere unless you have shared them with the Department of Health as indicated above.

Your compliance in this regard will be highly appreciated.

SECRETARIAT: EASTERN CAPE HEALTH RESEARCH COMMITTEE

Ikamva elilqoqambileyo!

Appendix C - Eastern Cape Department of Health Traditional Health Practitioners



Province of the
EASTERN CAPE
HEALTH

• Room 12 • Block F • Bhisho Business Village • Bisho• Eastern Cape Private Bag X0038 • Bhisho • 5605 •
REPUBLIC OF SOUTH AFRICA +-Tel.: +27 (0)40 608 1948 • Fax: +27 (0)40 635 0515• 0766628191

Date: 06 March 2017

Dear Ms. Mtise

RE: DEVELOPMENT OF AN INTERVENTION PROGRAMME TO FACILITATE UPTAKE OF ORGAN DONA (EC_2015RP15_596)

This is to inform you that the permission to conduct a study on the above named matter has been granted, as this was communicated and got approval from Epidemiology and Research Section in the Department of Health. The interviews with Traditional Health Practitioners in the selected districts have been arranged.

Kindly comply with the conditions stipulated in the approval letter from Research Unit.



.....

Ms .N. NTANJANA **Date**.....06/03/2017

ASSISTANT DIRECTOR: TRADITIONAL HEALTH SERVICES

Appendix D - OR Tambo District Council of Churches Permission

THE METHODIST CHURCH OF SOUTHERN AFRICA

MTHATHA CIRCUIT -1306

No.3 Frere Road Mthatha 5099

Telefax: 047 531 0921 email: mcsamthatha1306@gmail.com

Submitting ourselves to the will of the one who transforms us for the better!

SACC Transkei Region

Address

Phone/Fax No.

12 September 2017

Tobeka Mtise Dondashe

c/o University of Fort Hare

Faculty of Health Sciences

P.O. Box 1054

EAST LONDON

5200

Dear Sir/Madam

SUBJECT: REQUEST FOR PERMISSION TO CONDUCT RESEARCH

Your request dated 28 August 2017 received by our office on 6 September 2017 bears reference.

Kindly be advised that your request to conduct the study titled: Development of a Programme in Promoting Uptake of Organ Donation among Xhosa Community People in Eastern Cape Province has been approved.

You may contact our office for any further assistance that you may require during your interaction with ministers.

Good luck with your study.

N.A. SEJA

Yours sincerely

REV. N. SEJA

Appendix E - OR Tambo District Traditional Council Permission

NJIVENI LOCATION
P.O.BOX 223
LIBODE
5160

16 May 2017

Tobeka Dondashe – Mtise
c/o University of Fort Hare
Faculty of Health Sciences
P.O Box 1054
East London
5200

Dear Sir/ Madam

Re: REQUEST FOR PERMISSION TO CONDUCT RESEARCH

I refer to the above-mentioned subject and your request dated 13 March 2017, received on 20 March 2017.

Please be advised that your request to conduct a research titled: Development of a Programme in Promoting Uptake of Organ Donation among Xhosa Community /People in the Eastern Cape Province has been approved.

You may contact office of the Chief for any assistance that you may require. We wish you the best of luck in your endeavor.
Yours Sincerely
.....
Name and Surname
Designation

INKOSI YAKWA NDANYA A/A
S. MKONO - (073) 481 1625
Email: smkono1401@gmail.com
SIGN:.....DATE 16/05/2017
GIBISELA TRADITIONAL COUNCIL

Appendix F - Chris Hani District Permission

CHRIS HANI
DISTRICT MUNICIPALITY
SUSTAINING GROWTH
THROUGH OUR PEOPLE

Municipal Managers Office

TEL: 045- 808 4621
FAX: 045 –838 3346
Email: rhall@chrishanidm.gov.za

PRIVATE BAG X 7121
QUEENSTOWN, 5320

Enq: R. Hall

26 October 2017

Tobeka Dondashe Mtise
c/o University of Fort Hare
Faculty of Health Sciences
P.O. Box 1054
East London
520

Dear Sir/Madam,

Re: REQUEST FOR PERMISSION TO CONDUCT RESEARCH

I refer to the abovementioned subject and your request dated 31 August 2017, received 04 October 2017.

Please be advised that your request to conduct research titled; Development of a Programme in Promoting Uptake of Organ Donation among Xhosa Community/ People in Eastern Cape Province has been approved.

You may contact our Human Resources Section for any assistance that you may require. We wish you the best of luck in your endeavour.

Kind regards,

Mr M.A. Mene
Municipal Manager

Appendix G - Participant Informed Consent Form

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PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM

TITLE OF THE RESEARCH PROJECT: A programme for promoting the uptake of organ donation among Xhosa Community in the Eastern Cape Province.

PRINCIPAL INVESTIGATOR: Tobeka Dondashe Mtise, (200025376)

ADDRESS: 34 Coronation Road
Sunny ridge
East London
5201

CONTACT DETAILS: CELL: 082 487 2642
EMAIL: tmtise@ufh.ac.za

You are being invited to take part in a research project that forms part of my PhD in nursing. Please take some time to read the information presented here, which will explain the details of this research. Please ask the researcher any questions about any part of this research that you do not fully understand. It is very important that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you did agree to take part.

This study has been approved by the **University of Fort Hare Research Ethics Committee (UFH FHREC) (Ref No: SEE051SDON01)** and will be conducted according to the guidelines of the National Health Research Ethics Council. It might be necessary for the research ethics committee members or relevant authorities to inspect the research records.

What is this research study all about?

- *This study conducted in **OR Tambo and Chris Hani Districts of the Eastern Cape Province. The study seeks to develop a programme for promoting the uptake of organ***
- *To explore and describe the barriers contributing to the low uptake of organ donation among the Xhosa community.* *ow uptake of*
- *To develop a conceptual framework that informs the programme to promote an uptake of organ donation among this particular community.*
- *Lastly, to develop a programme that will promotes uptake of organ donation among the Xhosa community.*

Why have you been invited to participate?

copies in locked cupboards in the researcher's office, and for electronic data it will be password protected. Data will be stored for 5 years.

What will happen with the data/samples?

- *This is a once off collection and data will be destroyed by means of shredding the completed transcripts and recorded information will be deleted after 5 years*

Will I be paid to take part in this study and are there any costs involved?

Yes. You will be reimbursed to take part in the study for time inconvenience.

Whom can you contact for additional information regarding the study?

The primary investigator Tobeka Dondashe Mtise, can be contacted during office hours on her cellular phone 082 487 2642. The Supervisor, Prof E. Seekoe can be contacted during office hours at Cell: 076 150 6762. The Co-Supervisor leader Prof D.T. Goon can also be contacted during office hours at Cell: 079 857 2280.

How will you know about the findings?

- The findings of the research will be shared with you in a meeting form. A research report will be written, and a copy will be kept at the University of Fort Hare Library.

Declaration by participant

By signing below, I ……..…… agree to take part in a research study titled: A programme for promoting the uptake of organ donation among Xhosa Community in the Eastern Cape Province

I declare that:

- I have read this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions to both the person obtaining consent, as well as the researcher and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at (*place*) .....…..…….. on (*date*) ……...…….. 20....

....

Signature of participant **Signature of witness**

Declaration by person obtaining consent

I ..... declare that:

- I explained the information in this document to the participants
- I encouraged her to ask questions and took adequate time to answer them.
- I am satisfied that she adequately understands all aspects of the research, as discussed above
- I did not use an interpreter.

Signed at (place).....on (date).....20.....

....

Signature of person obtaining consent **Signature of witness**

Declaration by researcher

I …….declare that:

- I explained the information in this document to the participant.
- I encouraged her to ask questions and took adequate time to answer them.
- I am satisfied that she adequately understands all aspects of the research, as discussed above
- I did not use a interpreter.

Signed at (*place*) ……. on (*date*) ……..…….. 20....

.....	.....
Signature of researcher	**Signature of witness**

Appendix H – Transcript Sample

GROUP A: COMMUNITY MEMBERS

Raw data specific to the domain of inquiry, study and the discipline extracted	Meaning unit- Meaning close to text coded	Category-Condensed meaning unit Interpretation	Sub-Themes	Themes
I've never seen it; Didn't hear it; Heard people talking about it; We are in the dark; Heard from TV but can't say I have enough information about it; Donating organs what is it? Do not understand; There is no one who can reach out to us. There are few chances that they come to rural areas to teach us about organ donation; Little information about organ donation; I will not trust something I have not workshopped on; This is Nonqawuse; Flesh transplant is possible from one person to the other, in order to cover the place that has no flesh; If it is like donating blood, I can do it; How can one survive without a kidney? Can a person be an organ donor when he/she is dead; Where to go when we want to donate an organ; Only the kidney discussed, what about other organs	Never heard nor witnessed a person who went through organ donation. Not reaching out rural areas to educate about organ donation It is difficult to trust something you have never heard of (That is madness) Lack of understanding medical process and procedures Lack of Information regarding processes	No evidence of organ donation. Lack of information about organ donation. Inadequate information on organ donation programmes Poor understanding of organ donation Little information about organ donation Organ donation lacks credibility Lack of understanding medical procedures and processes Little understanding of organ donation Value organ donation Knowledge about organ donation.	Lack of knowledge and understanding of organ donation Invisibility of organ donation Poor network and infrastructure to reach out to rural community Lack of understanding of brain death Clarity regarding structures involved in organ donation and ethical issues around it. .	Understanding and perception of organ donation by all participants

Table 2.5: Example of the raw data extracted from the interview transcript, codes, categories, sub-theme and themes

IN LUMINE TUO VIDE BIMUS LUMEN
University of Fort Hare
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Appendix I - Translation Certificate

iiTranslation PTY LTD

086 126 6335
86 Bathurst Street, Grahamstown, 6140
Eastern Cape, South Africa
iitranslation.com
info@iitranslation.com

TRANSLATION CERTIFICATE

1. QUALITY ASSURANCE

Project Reference II-1

DOCREF#

6257

The following documents were translated

IsiXhosa total of 14455 words TRANSLATION COMPLEX
(XHO)(14455 WORDS)Main Document (FOR TRANSLATION).docx
DEDICATED AFRICAN LANGUAGE SPELLING CHECK
LINE-FOR-LINE CHECK ENGLISH COMPARISON

The translation was made by a fully qualified and experienced translator. CV is kept on file by the iiTranslation Company and will be available on request.

22 May 2018

Mr AK Sadian on behalf of iiTranslation Pty Ltd — *Date*

Appendix J - Independent Coder Certificate

FACULTY HEALTH SCIENCES

P.O. Box 1054
East London 5200
Tel: +27 (043) 7047475| Fax: 0866282026
Date : 28/12/2018

University of Fort Hare
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REGARDING: Co-coding of analyzed data.

This is to confirm that I, Dr. Daphne Murray co-coded and analyses data for PhD Student Tobeka Dondashe-Mtise. Student No: 200025376.The processes that I embarked on are as follows:
I read her methodology chapter to understand the approach and the design of choice for the study so as to understand the objectives and the questions the participants had to answer. I thereafter read how she delineated the meaning units from the data transcripts. I examined the analysed data to understand how segments of meaning units were clustered.Co-coded all data and presented Themes and Sub-Themes. I then made suggestions with regard to how the researcher and her supervisor could modify categorization of some information so as to come up with the final themes and sub-themes where applicable.

I do have experience in qualitative data analysis and have been utilized by the Faculty of Health Science to co-code analyzed qualitative data for several studies and projects.

Dr.D.Murray ..... DMurray 28/12/2018

1

Appendix K - Programme Review Sheet

REVIEW SHEET FOR THE PROGRAMME DEVELOPMENT IN PROMOTING UPTAKE OF ORGAN DONATION AMONG XHOSA COMMUNITY. (Adapted from the Checklist for Programme Report Content by Robertson & Wingate, 2017)

Please tick the most relevant response in the blocks as indicated below:

Citation Information	Health Education Programme in Promoting Uptake of Organ Donation among Xhosa Community. T. Dondashe-Mtise, E. Seekoe, DT. Goon, Faculty of Health Sciences, Department of Nursing Science, University of Fort Hare. 2020						
Description of the Context	The programme was developed in promotion of organ donation uptake for Xhosa people in the rural districts of the Eastern Cape Province. The programme was based on data derived from the situational analysis (Phase 1 of the Intervention Mapping Framework) and literature control.						
SCORE	Strongly Disagree ↔ Strongly Agree						
Rating Score	1	2	3	4	5	6	7
Domain 1: Programme Description							
1. The overall goal(s) and objective(s) of the programme is specifically described.							
2. Organisation(s) involved in the programme and its role(s) is clearly described.							
3. Intended beneficiary(s) for the programme designed to serve is clearly stated.							
4. Programme design is clearly described							
5. Context in which the programme operates is clearly described							
6. The programme' stage of maturity is clearly identified							
Domain 2: Evaluation Background							
1. Purpose and intended use of evaluation is clearly stated.							
2. Stakeholder engagement is clearly explained							
3. Responsiveness to culture and context is considered.							
5. Evaluation team composition and selection clearly described.							
Domain 3: Evaluation Methods							
1. Methods employed for programme review are clearly described							
2. The strength and the limitations of the programme clearly described.							
Domain 4: Recommendations							
1. Development process explained clearly							

1

Overall programme assessment

1. Rate overall quality of this programme

1 Lowest Possible quality	2	3	4	5	6	7 Highest possible quality

2. I would recommend this programme for use.

Yes.
Yes, with modification
No
Notes:

Appendix L - Copy of Final Programme

PROGRAMME FOR PROMOTING UPTAKE OF ORGAN DONATION AMONG XHOSA COMMUNITY IN THE RURAL DISTRICTS OF THE EASTERN CAPE PROVINCE, SOUTH AFRICA.

Tobeka Dondashe-Mtise- M Cur (Nursing Administration), B Cur I et A, Dip Critical Care, Dip Midwifery, Dip General Nursing Science. Faculty of Health Sciences, Department of Nursing, University of Fort Hare.

Eunice Seekoe- RN, RM, RCHN, RPN, RNE, BA Cur (UNISA), MSoc Sc, MBA (UFS), DCur (UJ), Deputy Vice Chancellor Teaching Learning and Community Engagement. Sefako Makgato Health Sciences University.

Daniel Ter Goon- BSc Ed (BUK, Nigeria), M Tech Sport & Exercise Technology, D Tech Clinical Technology (TUT). Research Head Faculty of Health Sciences, University of Fort Hare

ACKNOWLEDGEMENTS

I thank in particular the following persons/officers for their assistance in the development of this programme for their input, reviewing and producing this document in particular:

- University of Fort Hare Research Ethics Committee for ethical clearance, Department of Health for granting permission to conduct the study;
- House of Traditional Leaders in the Eastern Cape Province for guidance to community entry;
- Office of the Traditional Health Practitioners in the Eastern Cape Province for their guidance in accessing traditional healers;
- Provincial Council of Churches for their guidance to access ministers of religion;
- Planning group that consisted of medical doctors, organ transplant coordinator, social workers and the critical care trained nurses, traditional leaders, traditional healers, ministers of religion and some of the community members;
- Participants in the research study (Xhosa community members);
- Expert Reviewer Panel: for accepting request to participate in programme review.

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LIST OF ACRONYMS

IMF Intervention Mapping Framework

ECP Eastern Cape Province

SA South Africa

WHO World Health Organisation

PHC Primary Health Care

MI Motivational Interviewing

IMB Information-Motivation-Behaviour- Skills Model

SCogT Social Cognitive Theory

HPT Health Promotion Theory

SDT Social Determination Theory

EXECUTIVE SUMMARY

The lack of a programme to promote the uptake of organ donation in the rural communities of Eastern Cape Province necessitated the development of a programme facilitate its practice and uptake. To accomplish this task, several steps were undertaken. The programme developed following the steps of Intervention Mapping Framework (IMF). The Intervention Mapping Framework was introduced by Bartholomew, Parcel and Kok (1998) with the purpose of providing programme planners with a structured process and theoretical applications for development of evidenced based programmes; and to make effective decisions at every step of development, implementation and evaluation (Bartholomew et al., 2011). The objective of this programme was to create awareness, and provide comprehensive knowledge to promote uptake of organ donation in order to improve the shortage of organ among rural Xhosa ethnic group in the Eastern Cape Province. This programme was developed based on the data derived from Phase 1 of the Intervention-Mapping Framework, which captures the situational analysis that generated qualitative findings from individual semi-structured interviews and focus group discussions with traditional leaders, traditional healers, ministers of religion and general community members of OR Tambo and Chris Hani Districts in the ECP. Phase 2, step 2, indicates the phase of developing the educational programme through collaboration with the stakeholders (Xhosa community with the planning group) using the findings from the data analysis of phase 1 with literature support. Also in phase 2 step 2, matrices of change objectives were developed from the data analysis in phase 1 for the programme. Perfomance objectives were derived from the matrices and important determinants in theories were selected. In Phase 2 step 3, programme ideas were generated with the planning group, theory based intervention method and practical applications that address change objectives were selected to complete the preliminary programme. Lastly, in Phase 3, step 4, themes emerged, the scope was desrcibed and the sequence explained. In addtion, the materials added to the programme were selected and the programme was described. The programme is intended for use by healthcare professionals or instructors in primary health care institutions (clinic catchment areas) and community centres to promote uptake of organ donation among Xhosa community. The programme aims to address and improve uptake of organ donation for Xhosa community members (traditional leaders, traditional healers, ministers of religion and the general community members). Based on the results of the situational analysis, recommendations on the knowledge of organ donation and implications for clincial, education, nursing and community/organisational practice were highlighted.

Keywords: organ donation uptake, health education community programme, Xhosa community, programme development, Intervention Mapping Framework.

1. INTRODUCTION

The researcher as an experienced critical care nurse observed with concern the behaviour of Xhosa people with relatives admitted in an intensive care unit and later declared brain stem dead. Upon the brain stem death confirmation of a patient in a clinical setting, it may be possible to use the dying person's organs for transplantation, which often save the lives of others. However, breaking the bad news such as death or brain stem death is a key performance area for any critical care nurse/clinician; and it is an important element of the family approach. Experience has shown that critical care nurses are afraid and nervous to approach the Xhosa family members of the patient declared brain dead, to consider organ donation, and the Xhosa family members of the patients who receive haemodialysis therapy. Refusal by family members to engage in discussions relating to organ donation with critical care nurses at such delicate periods results in critical care nurses fearing even to raise the matter of organ donation with Xhosa families. Apparently, there is insufficient uptake of organ donation among Xhosa community. Anecdotally, they also exhibit fears regarding decision to donate organs, based probably on limited knowledge concerning the advantages of organ donation.

Intervention is needed to improve the uptake of organ donation among this ethnic group. Firstly, an educational programme cannot only improve the knowledge of brain death but will assist Xhosa people to understand and commit to organ donation and transplantation at large. Secondly, this educational approach programme will create awareness of organ donation and transplantation among Xhosa community, thereby increasing the registration for organ donation and decreasing the number of people on waiting list for organs. Xhosa people will be the recipient, direct beneficiaries of the programme.

The likely homogeneity of organ matching among the Xhosa people warrant investigation. Anecdotal evidence indicates that, Xhosa people in the Eastern Cape Province are embroiled in fears and would refuse to talk or discuss what they consider as a sensitive subject; the issue of organ donation. The beliefs and fears the Xhosa people regarding organ donation, that affects the low uptake of organ donation has not been explored. Understanding the barriers or inhibitors to

organ donation among the Xhosa people would provide insights to developing intervention programmes to improve and promote the uptake of organ donation in the clinical setting.

However, there is no programme available to help improve and promote the uptake of organ donation among Xhosa community in the rural districts of the Eastern Cape Province; therefore, this study seek to fill this gap.

The programme for the development of organ donation is built on four domains: Programme Description; Evaluation Background; Evaluation Methods, and Recommendations.

2. DOMAIN 1: PROGRAMME DESCRIPTION

2.1. *Goal of the programme*

The goal of the structured health education programme among Xhosa community is to raise awareness of organ and tissue donation, encourage Xhosa people to commit, dedicate and oblige themselves (to reflect on their personal attitudes, feelings and thoughts) towards organ and tissue donation. Understanding the attitude and knowledge of Xhosa people that affect their willingness to commit as an organ donor is crucial to develop effective educational programme in the selected districts of the Eastern Cape Province, South Africa (SA). Attitude correlates strongly with commitment towards organ donation (Tam, Suen and Chan, 2012:1199).

The overall theme/subject is comprehension and overview organ and tissue donation.

The objectives of the programme are that, by the end of the programme, Xhosa people will:

- Have better knowledge and improved understanding of organ and tissue donation
- Changed attitude towards uptake of organ and tissue donation (alleviation of fears and dismissal of myths)
- Maintain regular health check-up in promotion of healthy lifestyle for future organ donation
- Embrace promotion of the uptake of organ donation, uptake through visible interventions
- Changed attitude towards uptake of organ and tissue donation (alleviation of fears and dismissal of myths)
- Accept societal, cultural and religious beliefs around organ donation (stand up against social stigma, cultural and religious barriers towards organ donation).

Healthcare professionals in the planning group should be able to:

- Use reasonable collaborative team approach in health education
- Implement interventions in a real community setting (community meetings for persuasive communication; group meetings for problem solving; self-talk for cognitive behavioural restructuring; support groups for social support; role model stories for symbolic modelling)
- Implement community- focus health promotion/ group method (group discussion, role play brainstorming, workshop/ seminar, demonstration, mini lecture, problem solving, panel discussion and field trip/ mini tour: and
- Use motivational interviewing

Underlying assumptions of the programme

For this programme, it is expected that:

- Xhosa community members with lack of knowledge and understanding of organ and tissue donation will be introduced to different teaching methods and approaches that will facilitate learning and change in behavior.
- Xhosa community members to affect a change in health behavior while the healthcare professional will need to exhaust the possibilities of the Xhosa community member's intrinsic factors through engagement of Xhosa people to participate in demonstrations, discussions, role-playing and giving homework to discuss organ and tissue donation at home to encourage thoughtfulness and self-confidence.
- Xhosa community members who discuss organ and tissue donation may understand it better and develop confidence in decision making to behavior change.
- Motivational interviewing will create comprehension to organ and tissue donation.
- Healthcare professionals will hearten Xhosa community members to put forth their self-realization and self-regulatory process to affect their results.
- Healthcare professionals delivering the programme will give appropriate and passable information to Xhosa community members in enabling change of attitude and allow real life story telling by Xhosa people who experienced organ donation and transplantation.
- Attitudinal change communication will modify Xhosa community members' tradition, cultural and religious beliefs, attitudes perceptions, core system of thought and behavior through tailored messages and supportive environment.
- Comprehension into a health problem would be gained through a dialogue and persuasive between healthcare professionals, traditional healers, and traditional

leaders since community as the society's responsibility views the health of individual.

- Positive attitude, listening skill and self-efficacy will be developed.
- Outcome expectations will be realized

2.2 Organization(s) involved in the programme and its role(s)

The Department of Health (DoH) in the Eastern Cape Province should approve the implementation of a health structured educational programme in promoting uptake of organ donation. Primary health care level, general health services are preventive, promotion, curative and rehabilitation are provided by the local government (World Health Organisation, Primary Health Care, 2019), and thus PHC serves as an entry point into health delivery system because facilities are located in communities for proximity and utilisation. Therefore, healthcare professionals with community clinic committee will collaboratively work with the community organisation to facilitate awareness of organ donation in the community. Community leaders, traditional health practitioners and ministers of religion will collaboratively facilitate the implementation of the programme in promoting uptake of organ donation. The nurses, doctors, organs transplant coordinator, social worker, psychologist are the healthcare professionals that will be offering the programme. Healthcare professionals may consult other healthcare professionals with expertise in offering education of organ and tissue donation.

2.3 Intended beneficiary(s) for the programme designed to serve

- All adults, both males and females (above the age of 18 years) and belong to Xhosa ethnic group (traditional healers, traditional leaders, religious leaders and general community members).
- Xhosa community members across socioeconomic position.
- More than once attendance is encouraged, as continuous learning is imperative to understand organ and tissue donation.
- Family members of Xhosa people who currently diagnosed with any type of organ failure, on hemodialysis in case of kidney failure and on waiting list for an organ.
- Informing of Xhosa community about the programme at a diagnosis of organ failure, diabetes mellitus, hypertension and renal failure by the healthcare professional with an

emphasis to stimulate their zeal and interest to obtain more knowledge about the complications of their chronic diseases.

Xhosa community members who donated an organ or a tissue before and who had undergone organ transplant to be utilized as visible mentors/ supporters/ advisers.

2.4 Programme design

Phase 1 Step 1 of the adapted (IMF) was achieved through objective 1 of the study which is termed by Bartholomew, Parcel and Kok (1998:545) as proximal programme objectives. The situation analysis was a key aspect of programme development to understand the context, to fill in the gaps and to gather more knowledge about the phenomena under study as the programme was developed as an intervention to the identified problems and specific requirement of the target group being studied (Perez & Cannella: 506). This situation analysis enabled the researcher to gain an insight into the current situation and what ought to be, which was in terms of promoting uptake of organ donation. Xhosa community were accessible and showed readiness to participate in the programme. During this phase, data collected from Xhosa community (general members of the community, traditional healers, ministers of religion, and the traditional leaders) was analysed, and the findings discussed with relevant literature.

Results of the situational analysis are triangulated in Table 1.1

2.5 Context and duration in which the programme operates

"The context are circumstances that form the setting for an event, statement or idea and in terms of which it can be fully understood" [Accessed June 2020] www.doceonline.com>dictionary>context. The programme is planned to be offered in the rural community health catchment areas and in rural community centers with the assistance of traditional leaders, religious ministers and traditional health practitioners of the selected rural sub district in the Eastern Cape Province. It is regarded as a compulsory programme for all the Xhosa community members. However, Xhosa community members should be encouraged to attend since a single education programme will not be effective in motivating the clients to change the behavior and decide to be organ donors. Duration of the programme is the length of time that the programme lasts [Accessed June 2020] (dictionary.cambridge.org/dictionary/English). Some institutions have formal policies that define hour credit and its application to courses and a programme. The credit hours viewed frequently as a proxy for the how much content students understand and the amount of time student learning that has taken place, credit hour also used to define the length of the programme of study (Lake Michigan College, revised 2018). Therefore, the duration of the programme is long term, will depend on the knowledge and understanding of organ and tissue donation by the Xhosa community members. Implementation and evaluation of the programme will be completed later (postdoctoral).

2.6 The programme' stage of maturity

The programme will be the new initiative to the rural districts. The programme will be evaluated after the implementation. Evaluation results will be effected to improve the programme overtime.

3 DOMAIN II: EVALUATION BACKGROUND

3.1 Purpose and intended use of evaluation

Programme evaluation will offer a way to understand and improve Xhosa community health and development practice utilizing useful methods. A subset of all the stakeholders that was identified as a planning group in the early development of the programme will be designated to maintain frequent interaction with the primary intended users (Xhosa people) to be sure

that evaluation addresses their needs and values. Programme evaluation will be conducted to find out what works and what does not work. Both process and outcome evaluation will enable the evaluator to provide answers to basic questions about the programme effectiveness regarding participant benefit and satisfaction attainment from the programme. As the programme is educational in nature, formative evaluation will focus on improving the uptake of organ donation by adopting more open ended questions to collect data aiming at identification the strengths and weaknesses of the programme. Ongoing feedback will guide the adjustments of the programme in complex environment on developmental evaluation. Lastly, summative evaluation will be conducted after the programme has been implemented to critic the efficacy or the value of the programme.

3.2 *Stakeholder engagement*

Stakeholder participation in the development of programmes is a vital part of the IMF (Ceptureanu & Luchian, 2018:11). Xhosa community members, traditional healers, ministers of religion, traditional leaders and health professionals represented the stakeholders as they worked with the researcher in the planning and the development of the programme. The researcher and the stakeholders formed a planning group committed to reach a mutual goal. To institute acknowledgement and special connection between the stakeholders, a casual workshop was held, and a friendly atmosphere created where all the participants were individually welcomed. The roles, responsibilities of each participant, and the time assurance accentuated. Valuable contributions of each member of the group was acknowledged. The planning group allowed time to introduce themselves and to share their stories regarding their experiences regarding organ donation. Healthcare professionals were allowed time to describe the core principles of their concerns to Xhosa people in uptake of organ donation and their expectations about the outcome of workshops on Xhosa community regarding the desired behavioural change towards organ donation.

3.3 Responsiveness to culture

"Culture is a cumulative body of learned and shared behavior, values, customs, and beliefs common to a particular group or society" (Frierson, Hood & Hughes, 2002: 63). A cultural responsive evaluation was employed. A culturally responsive evaluation fully takes into account the programme culture by grounding the analysis of impacts through a bird view (lenses) in which the culture of Xhosa community considered as an important factor. To

accomplish this objective, a culturally sensitive evaluation was undertaken by creating a multi ethnic evaluation team to increase the chances of hearing the voices of the Xhosa people. The evaluation team were aware of and responsive to the culture of Xhosa people and the stakeholders' culture as it narrates to and effects the programme. Considerable attention was given to the identification of the stakeholders (stakeholder group representative of population the programme will serve) that are culturally responsive in providing sound advice on framing of questions to disseminating of evaluation results. For this programme, for evaluation to be effective, all key voices were accurately heard and listened to.

3.4 *Evaluation team composition and selection*

Evaluators have no vested interest in the programme being evaluated and their work was conducted impartially without potential negative effects. Evaluation of this programme was conducted by a well-qualified evaluation team. Evaluators were selected on the basis of competence and by means of transparent process and should possess different types of expertise. An experienced member of the team in the area of the study with sound knowledge of the subject reviewed the programme. In addition, an evaluation specialist experienced in applying specific methodologies reviewed the programme. The team possessed a broad knowledge and understanding of the economic and social development issues and the challenges within the Xhosa community. The review team were familiar with the cultural, tradition and the characteristics of the Xhosa community, and therefore, they were well-quipped to understand and respect the local customs, beliefs and practices throughout the review process. The number of reviewers was depending on the size of evaluation (Guidelines for Selection of Evaluation Consultants for project evaluations, 2011).

4 DOMAIN III: EVALUATION METHODS

4.1 Methods employed for programme review/evaluation

Accreditation is voluntary process of evaluation. The goal of this review was to ensure that this programme meet appropriate standard of quality and integrity. Three external review panel members were appointed based on the criteria explained on composition of the evaluation team. A letter requesting participation in the review panel was emailed with the consent attached to the reviewers of the programme. Upon the signing of the consent, a draft programme and the checklist was then emailed to the expert panel reviewers.

4.2 The strength and the limitations of the programme

Upon consideration on the complex and evidence based intervention mapping framework and the processes involved in the development, the extent of the research requires more human and financial resources as well as time to include many participants in other districts to cover entire province. There is need to evaluate the implementation of the programme in future. The strength of the programme will be clearly stated based on the outcome of the evaluation.

5 DOMAIN IV: RECOMMENDATIONS

5.1 Development process

Recommendations often derived from evaluation on how a program can be improved, and how the risk of a programme failure can be reduced or whether the programme can be implemented, or should continue if already implemented. Therefore, recommendations, comments and suggestions follow the programme review or evaluation by the expert panel.

5.2 The recommendations from the expert panel

Reviewer one:

- Talk to Theory of change, including Health Human Rights

Researcher's note: The educational programme was planned to have an emotional impact on behaviour; therefore, theory-guided behavioural constructs to enhance changes in the Xhosa community were derived from theories of behaviour change self-determination theory, social cognitive theory and information motivation and behavioural skills model, Health promotion theories and Leininger's theory for environmental determinants. All these theories are embedded under the theory of change.

- Describe the role played by the Department of Social Development, as they are the social support.

Researcher's note: The nurses, doctors, organs transplant coordinators, social workers, psychologists are the healthcare professionals that formed part of the planning committee and will be offering the programme. As the need arises and the emergence of new developments, healthcare professionals may consult other healthcare professionals in providing education on organ and tissue donation.

Reviewer two:

- How would the researcher motivate the targeted beneficiaries to firstly attend the programme, secondly to maintain their attendance for the entire duration of the programme?
- Suggested beneficiaries to take part in a programme instead of providing information in motivating beneficiaries
- The programme should be tailored for all

Researcher's note: Traditional leaders as custodians of African culture and tradition, stakeholders in the programme should play a leading role in motivating Xhosa people to participate in organ donation, same as encouraging the attendance for the entire duration of the sessions.

Reviewer three:

- To clarify the Xhosa community, clearly define/ or explain this from the onset to indicate that the researcher is examining particular cultural and spiritual beliefs (citing sources) among isiXhosa speaking communities.
- Describe the meaning of ethnic group (to engage anthropological literature on this to define this clearly).

Researcher's note: Xhosa people are members of Native communities inhabiting in the Eastern Cape Province, South Africa, and their primary language is isiXhosa. Community is a social group determined by geographic boundaries, and the Xhosa community is the central subgroup with their own distinct but related heritages (Pauw, 2018).

5.3 Programme summary

This section provides a summary of the programme in promoting uptake of organ donation among the Xhosa community people. A copy of the final programme will be attached as (annexure).

5.3.1 Programme title

Programme In Promoting Uptake Of Organ Donation Among Xhosa Community In The Rural Districts Of The Eastern Cape Province, South Africa.

5.4 Editorial independence

The responses from the Xhosa community members (traditional leaders, traditional health practitioners and religious ministers), suggestions brainstormed by the planning group of health professionals and the community members formed the basis of the development of this programme. The supervisor and the co-supervisor of the study were instrumental in the conception and the design of the programme. Although, funding was received from the institution (Seta). This programme is editorially independent of the funding body. No conflict of interest applies to the development of this programme. No changes were made to this programme as the reviewers recommended it.

Appendix M – Editing Certificate

SPELL CHECK
PROFESSIONAL LANGUAGE EDITING & TRANSLATION SERVICES
Tanya-Lee Stewart
Bachelor of Arts in English & Linguistics
spellcheck1977@gmail.com / +27 84 556 7745

EDITING CERTIFICATE

09 March 2022

To whom it may concern

DECLARATION OF LANGUAGE EDITING

Re: A programme for promoting the uptake of organ donation among Xhosa Community in the Eastern Cape Province

This serves to confirm that I, Tanya-Lee Ruby Stewart, a SATI-registered language editor and translator, undertook the language editing of the above-mentioned document on behalf of:
Miss T Mtise, student number 200025376, for the purpose of meeting the submission requirements of a PhD degree *(Doctorate in Clinical Nursing (Intensive Care))* at the University of Fort Hare.
Do note that I make no claims to the substantive matter covered by the document and have not altered the intent or research content drafted by the author(s). Furthermore, I can only provide a guarantee of linguistic accuracy, provided the relevant track changes/suggestions were accepted and my advice followed.

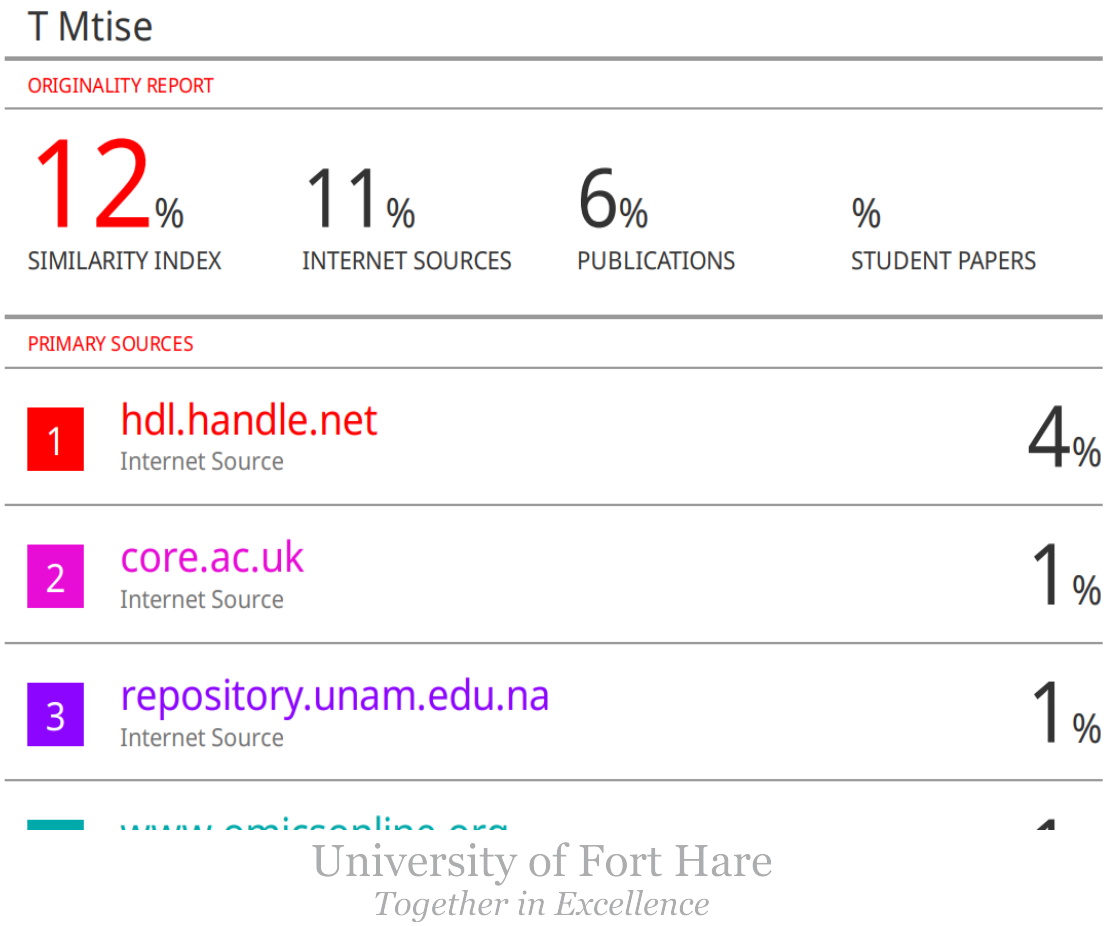
All changes and corrections were suggested by means of "track changes", "colour-coding", and e-mails. However, the implementation thereof was left entirely up to the author. As such, I do not accept responsibility or liability for any inaccuracies, both linguistically and content-related, that may be present.

Should you have any queries, please contact me through the email address and telephone number provided in the above letterhead.

Yours sincerely

TR Stewart
Member: South African Translators'
Institute SATI registration no: 1003470

Appendix N – Turnitin Report



T Mtise

ORIGINALITY REPORT

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Appendix O – Editing Certificate

MJR
EDITORIAL CONSULTING

Date: 29 December 2024

DECLARATION OF EDITING

I, Professor Margaret Williams, hereby declare that I edited the thesis's language as detailed below. The thesis is for submission purposes to fulfil the Doctor of Nursing degree requirements in the Faculty of Health Sciences at the University of Fort Hare. It has been edited for English language, grammar, syntax, punctuation, and spelling, followed by format/technical edits.

TITLE

A programme for promoting the uptake of organ donation among Xhosa Community in the Eastern Cape Province

AUTHOR

TOBEKA MTISE

University of Fort Hare
Together in Excellence

Disclaimer: The author, T Mtise, is free to accept or reject my changes to the document after I edit and proofread it. However, I am not responsible for revisions made to the document after I edited and proofread it on 31/12/2024.

Signed:



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