

## **LOW RATES OF ORGAN DONATION AND TRANSPLANTATION: CAUSES AND SOLUTIONS**

Peter M. Dimo \* & Delarise M. Mulqueeny

### **ABSTRACT**

Organ donation presents as a global public health, societal and educational challenge with a high number of patients with end-stage diseases being left in limbo due to the low rates of life-saving organ donation and transplantation. Organ transplantation is a definitive therapy for patients suffering from a wide range of end-stage diseases and organ failures which prolongs and improves their lives and wellbeing. Countries including South Africa struggle with low rates of organ donation and transplantation with the number of patients on organ donation waiting lists exceeding the number of available organs. Hence, the imbalance of organ supply and demand results in many patients dying prior to receiving life-saving organs. South Africa currently utilizes the opt-in system which assumes that all people do not want to be organ donors. This study's aim sought to explore and assess factors responsible for low rates of organ donations with its aim being achieved through the employment of a qualitative approach aligned to an explorative research design. Additionally, the eco-systems theory was adopted as the theoretical framework for this study. Purposive sampling was used to recruit thirty research participants. In-depths interviews with traditional leaders in rural areas who were 20 years and older were used to collect data that was later analyzed using a thematic content approach. The study findings highlighted the breeding grounds for low rates of organ donation and transplantation. These include the refusal to grant consent for organ donation, lack of knowledge surrounding the process, pursuance of the opt-in system of organ donation, attitudes and socio-cultural factors contributing to the chronic shortage of life-saving organs. Moreover, recommendations emanating from the findings could improve the rate of organ donation and transplantation.

**Keywords:** Organ donation, transplantation, deceased organ donation, living donation

### **INTRODUCTION**

Human organ donation is a life-saving miracle of modern medical science (Aniza, Naren, Masor, Suzana, Hani & Hasdy, 2017). Furthermore, the process is a precious, priceless gift as it has undeniably saved and improved the quality of many people's lives (Zwart, 2016). The study argues that organ donation and transplantation is a definitive therapy for the malfunctioning of organs such as the heart, kidney, liver and the pancreas as many countries are confronted with high incidence of end-stage diseases. Though organ donation is a highly supported humanitarian act universally, a chronic shortage of available organs for transplantation exists. This assertion is consistent with a study conducted by Kamin, Berzelak and Ule (2017) who postulate that the medical transplantation methods are socially accepted and people are willing to sign organ donor cards. However, the official figures for post-mortem organ donation remains stagnant. It is in the axiom of life, that sought after commodities and things are often in short supply. Consequently, the low rates of organ donation and

transplantation pose a significant healthcare crisis in developing and developed countries. This study's burning desire is to explore and assess the breeding ground for the low rate of organ donation with the objectives being:

- What factors are responsible for the low rate of organ donation?
- What measures can be implemented to improve organ donation awareness and increase organ donation rates?

Additionally, it recommends that the adoption of efficacious measures aimed at increasing awareness of organ donation and transplantation and ultimately escalating the rates of organ donation and transplantation.

### **Problem Statement**

Many countries are battling with end-stage diseases while there is chronic shortage of organs for organ transplantation. There is a widening gap between the demand and the actual supply of organs. Consequently, the majority of patients depart from the world of the living due to shortage of organs to improve and prolong life. Organ donation and transplantation are regarded as one of the successful medical advances and a definitive therapy with global support and many people embracing the process (Bahrami, Khaleghi, Khorsand & Afzalaghaee, 2017). It is viewed as a humanitarian intervention to assist individuals in the end-stage failure of human organs such as the heart, liver, lungs, pancreas and the kidneys which occur at an alarming rate. Despite its success, the global community is still confronted with and limited by a critical shortage of human organs to match the demand for transplantation. Moreover, Arora and Subramanian (2019) lament about the mismatch between the supply and the demand of organs for transplantation. Furthermore, approximately 120 000 patients in United States of America (USA) were added on the waiting list to receive life-saving organs in December 2017 (Organdonor, 2020). This concurs with Srivastava and Mani's (2018) assertion that a lack of education is a contributory factor limiting organ donation and transplantation. They firmly attest that the public's awareness of organ donation is low. Hence, inaccurate and inconsistent information and superstitions are distributed and embraced, resulting in negative attitudes towards the process. Moreover, many people distance themselves from organ donation due to misinformation and their socio-cultural roots.

### **REVIEW OF LITERATURE**

ODT is a process whereby individuals agree to donate a healthy organ that is then transplanted to the body of a person with either a damaged, failed or dysfunctional organ. ODT is a process whereby individuals agree to donate a healthy organ that is then transplanted to the body of a person with either a damaged, failed or dysfunctional organ. Human organ donation is a medical process whereby potential organ donors who have the legal capacity to consent or agree to donate or transplant healthy organs into the body of people with failed or dysfunctional organs (Jawoniyi, Gormley, McGleenan, Noble, 2017). Organ malfunctioning is a consequence of diseases, trauma and the excessive use of alcoholic, drugs and prescription drug use, misuse or abuse. Kiani, Abbasi, Ahmadi and Salehi (2018:2) report that the high and increasing incidence of chronic diseases such as hypertension, diabetes, obesity, and kidney disease elevate organ transplant needs. As an interventional strategy, organ transplantation is a definitive effective therapy for end-stage diseases and an efficacious treatment to improve

patients' survival and quality of life (Keten, Isik, Ucer, Keten, Ersoy and Olmez, 2017). The kidneys, liver, heart, pancreas and the lungs are organs that can be transplanted. The study contends that the success of organ transplantation in countries is determined by the model used. Such models include the presumed consent model which is commonly known as opt-out model and opt-in model. According to Rodriguez-Arias and Morgan (2016) the opt-in model of transplantation encourages people to become potential organ donors by establishing organ donation as the default option to save lives. Etheredge, Penn and Watermeyer (2019) describe this model as a system where all countrymen are presumed to be potential organ donors unless they indicate their objection in writing through official channels. On the other hand, the opt-in model of transplantation legally permits the harvesting of organs from those wanting to donate their organs, (Simkulet, 2017). This model is used in many countries and is based on fundamental human rights.

Organ donation is a humanitarian or an altruistic act as individuals are not coerced to donate their vital life-giving organs. However, the opt-in system is a model whereby citizens are registered as potential organ donors, (MacKay & Robinson, 2016). Nevertheless, the opt-in model is not without criticism with researchers levelling accusations that the model contributes to the current acute shortage of organs for transplantation because prospective organ donors are not legally obliged to donate. Conversely, Etheredge et.al (2019) offer a different view by advising organ transplantation coordinators to consider diverse unique contextual circumstances under which organ donation takes place within health institutions. This assertion aligns with the sentiments of Kamin, Berzelak and Ule (2017) who indicate the complexity of organ donation and the highly contested nature of the process and subject. This is due to the exchange of organs from one person to another and it being characterized by a network of complicated and emotionally charged relations between potential donors, organ recipients, power, family and medical team members and psychological and social complexities. It is not the intention of this paper to discuss the models of organ donation and typologies of organ donors in detail but to briefly discuss the types of organ donors.

According to Merola, Pei, Roddriguez-Davalos, Deng, Mulligan, and Davis (2016) as cited in Dimo (2018) the success of organ transplantation is limited by the unavailability of organs for transplantation. Additionally, the ministries of health in various countries are confronted with ever increasing waiting lists for organ donations. These findings are in agreement with Guttman, Siegel, Appel and Bar-On's (2016) study that affirms the humanitarian aspect of organ donation due to its potential to save lives. Nonetheless its usefulness is limited by the number of available organs for transplantation.

According to Ketel et.al (2017) in 2017, the United States of America had approximately 123025 patients requiring organ transplantation, while 3517 patients awaited life-saving organs, with only 7282 organ transplantations being performed. Unfortunately, the waiting lists are motionless as new patients are added daily. Arora and Subramanian (2019) also highlighted that in December 2017, United States of America added 120 000 patients on the organ donation waiting list. It is alarming to realize that, 16473 donors accounted for 37795. In addition, India had a donation rate of 0.8 per million populations, (Mohan & Aswathy, 2019:1). Furthermore, Miller and Breakwell (2018) report that more than 6500 patients are on the waiting list in United Kingdom (UK) with approximately 1000 dying before they receive a life-saving organ to improve their quality of their life.

Organ donation in many countries is incapacitated by close family members or next-of-kin's hesitancy to grant consent for organ harvesting despite the deceased organs wishes (Dimo, 2020). This can be attributed to the procurement of organs in the opt-in model requiring

the informed consent of the deceased's gatekeepers or family deciding in favour or against the donation and health professionals not having the legal power to harvest organs (Cotrau, Hodosan, Vladu, Daina, Negrau, Daina, Pantis & Vernic, 2020). The model elevates the family in organ donation and transplantation, despite the prospective organ donor's willingness and commitment to donate organs. Mbedzi et al. (2015) as cited in (Dimo, 2020) state that family members possess the capacity to determine what is best for their deceased family members and social workers, doctors, and nurses are ethically bound to respect the choices of their clients or patients. These assertions find support in dos Santos, dos Santos, Lira and de Moura (2019:579) who declare that the authorization for the removal of organs for transplantation should be finalised by the close members. When the family lack good understanding of the organ and tissue donation process, they become hesitant to engage in this life-saving process.

The success and failure of organ donation is determined by the quality of knowledge that people have on the process and individuals' attitudes and perceptions which provide the basis for them to make decisions and take actions regarding the process (Okere, 2017). This assertion is emphasized by Dimo (2018) who reiterates that people act, behave, and take decisions based on the information at their disposal. This study contends that the quality of information at people's disposal may negatively or positively influence their attitudes, behaviour, and perceptions. Moreover, inaccurate information on organ donation and transplantation barricades people from participating in the process. According to Mithra et al (2013) as cited in Dimo (2019) the consequence of insufficient information on organ donation is superstitious beliefs that generate fear in the minds of uninformed and misinformed people. Hence, quality information is a prerequisite for a valuable and balanced family discussion on organ donation. Consequently, health care workers are expected to advocate for and pioneer organ donation and transplantation by disseminating accurate information to educate patients and their families regarding same. However, Handa, Vir Singh, Dhiman, Ghai and Agnihotri (2018) speculate that disparities in knowledge on organ donation exists and the unwillingness of health care workers to donate. Krupic, Westin, Hagelberg, Skoldenberg and Samuelsson (2019) speculate that though many people support the organ donation process, they are not adequately informed about the process and hold on to beliefs that are contrary to organ donation.

The spiritual and religious beliefs of individuals shape and provide meaning to people's lives, including the time of death and the care that must be taken to deliver the body of the loved ones. Buthelezi and Ross (2011) express awareness of the influence of religion in organ donation and argue, that the process is complex and influenced by human beings, religious beliefs and affiliations. Bresnahan, Guan, Smith, Wang, and Edmundson (2010) as cited in Dimo (2018) believe that spiritual beliefs have an inhibitory impact on organ donation. Though religions such as Christianity, Jewish Buddhism and Hinduism do not forbid organ donation as they associate it with charity, many studies have found some religions disallow and hinder organ donation. This is despite the lack of specific religious prescriptions and policies for organ donation. Religious and spiritual beliefs are determinants in the patients' worldview about health, illnesses, pain, suffering including life and death. Additionally, the Muslim religion forbids organ donation and transplantation as their teachings state that Muslims have been entrusted with their physical bodies and therefore cannot donate what does not belong to them. The above demonstrates that investigations have proven the existence of close relationships between cultural values and spiritual beliefs, and how these factors affect individuals' views and perceptions of organ donation.

This study contends that culture is positioned as a strong barrier to organ donation as individuals possess cultural experiences that affect how they behave. It includes values, beliefs, attitudes, languages, symbols, rituals, behaviours and customs that are specifically unique to a particular group of people and transmitted from one generation to the next generation. According to Dimo (2019) organ donation and transplantation are surrounded by sociocultural subjects. Hence, organ donor and transplantation coordinators should be aware that culture, religion and traditions are vital contributory factors that determine and influence people, their families, communities and the worlds in which they live (Swadimath & Joshi, 2017).

## **THEORETICAL FRAMEWORK**

Organ donation is a social and health phenomenon earmarked by a high demand and an acute shortage of organs, resulting in promoters encountering obstacles. The Departments of Health (DOH) in many countries face challenges when recruiting and retaining potential organ donors. Hence, the importance of investigating and understanding the motivations behind organ donations from a cross-cultural perspective. Hence, social marketing being adopted as the theoretical framework for this study. Social marketing refers to the application “of commercial marketing technologies to the analysis, planning, execution, and evaluation of programs designed to influence the voluntary behaviour of target audiences in order to improve their personal welfare and that of their society” (Andreasen, 1994: 108). Social marketing was described by Kotler and Zaltman, (Correio, Pereira, Resende & Rezende, 2017). Social marketing is way of planning programs on a huge scale with the intention of influencing voluntary behaviour in a determined segment of individuals, with a social objective at the behest of a financial one. This marketing strategy is based on the assumption that people will adopt behaviour changes when barriers of a concept are reduced and benefits highlighted according to their specific needs (Mostafa, 2017). Marketing principles and techniques are used to influence a target audience to voluntarily accept, change or abandon a behaviour for the benefit of other people, groups and the community as a whole.

## **RESEARCH METHODOLOGY**

The current study employed a qualitative, explorative design (Gray, 2018, Creswell, Ebersohn, Eloff, Ferreira, Ivankova, Jansen, Nieuwenhuis, Pietersen & Clark). As purposive sampling is used in special situations where the sampling is done with a precise purpose in mind, this technique was best suited to guide the participant selection process (Creswell et al., 2016). The inclusion criteria prescribed that the 30 participants be traditional leaders from a rural area who were twenty years and older as they had the legal capacity to consent. Thirty in-depths interviews using a semi-structured script with auxiliary questions were the data collection instruments used to facilitate participants freely and voluntarily expressing their views on the phenomenon under study. The dual-recorded interviews were later transcribed into text by a research assistant. Thereafter, the responses to the interview questions were read several times by the author to attain a comprehensive overview of the transcripts to gain context and subsequently the data underwent coding and analysis. The data was manually analysed by the researcher and an academic peer who was well versed in data analysis. The data analysis process comprised of three phases: description, analysis and interpretation with thematic content analysis being employed.

## **Ethical Considerations**

Permission to conduct this study was granted by the North West University Higher Degrees Committee prior to commencement of the data collection process. Additionally, all participation in the study was voluntary with participants expressing their willingness to participate by signing the informed consent form. Hence, no participants were coerced into participating. The informed consent form indicated the purpose of the study, the benefits and risks of participating in the study and participants right to withdraw from the study at any time. Furthermore, participants were assured of confidentiality and symbols and pseudo names were used to protect their anonymity. Passwords were used to protect electronic information and field notes were kept in a locked cabinet and will be destroyed five years later.

## **DISCUSSION**

This study's findings are discussed under six themes that emerged from the interview data. These include; Lack of information on organ donation, registration as an organ donor, refusal to give consent for harvesting organs, religious factors, cultural factors and social factors.

### **Theme 1: Lack of Knowledge about Organ Donation and Registration of Donors**

From the onset of the interviews, all the research participants revealed that, they were not organ donation literate and had limited insights on the process surrounded by misinformation and myths. These finding concur with those findings of Bharambe, Arole, Puranam, Manvikar and Rathod (2016) study, whose contention is that organ donation and transplantation cannot be successful without comprehensive awareness of the process. This is due to the process being influenced by factors such as education, superstitions, myths and a lack of awareness regarding organ donation. Their declaration finds its support in Sukalla, Wagner and Rackow (2017) who also highlight prevalent reasons for the individuals' reluctance to donate organs. These reasons include inadequate knowledge and misinformation concerning brain death with contributes to the instilling of fears and myths around organ donation. Though this study submits that knowledge paves the way for action and awareness and is crucial for the success of organ transplantation programmes, a lack of education is not solely responsible for the shortage of available organs. The findings highlighted a plethora of barriers and factors for organ shortages. Worth noting is that all the study participants were not registered and reluctant to register as potential organ donors due to a lack of comprehensive information about organ donation. The findings further highlighted that prospective organ donors were unaware of where and how to register as organ donors with the majority indicating that a hospital was the institution to register their intentions to be organ donors. This study safely deduces that inadequate information on organ donation and transplantation constituted a primary barrier. Hence, the importance and relevance of alleviating people's misinformation, fears and myths about organ donation and transplantation through the provision of accurate, current and accessible information.

### **Theme 2: Refusal to Provide Consent**

Obtaining the consent of the familial gatekeepers for the harvesting of organs for transplantation constituted a major challenge as participants openly declared that, they would

never allow health professionals to harvest organs from their deceased family members. The genesis of their reluctance to grant consent can be attributed to socio-cultural aspects and inaccurate information. In addition, brain-death is a controversial subject with many people having little insight on this subject. According to Virginio, Escudeiro, Christovam, Silvino and Oroski (2014) it is estimated that between 10 % to 15 % of individuals who die in hospitals are potential organ donors. However, without the involvement and buy-in of the family, vital body organs cannot be harvested as the process involves surrogate decision making at the end of life as they are appointed on the basis of their biological relationship with the deceased. Hence, they take decisions on behalf of incapacitated patients. The next-of-kin in the context of organ donations include a spouse, legal guardian, parent and sibling (Anker, Akey & Feeley, 2013). To harvest individual's vital body parts for organ donation and transplantation, patients have to be declared brain-dead. All participants expressed that, they did not understand brain-death and expressed conviction surrounding that. This finding is consistent with the findings of Lewis, Lord, Czeisler and Caplan's (2016) study that reported that the majority of people are not familiar with the legal and medical definition of brain-death and struggle to differentiate between brain-death and coma. Their lack of awareness on this subject makes them suspicious and not trusting of medical personnel.

### **Theme 3: Religious Factors**

The majority of the study participants assert that organ donation is not permitted within their religious beliefs and affiliations. This confirms the declaration made by Krupic, Sayed-Noor and Fatahi (2017) regarding the high and low degrees that religious and socio-cultural factors play in preventing people from subscribing to organ donation. These views are also in one accord with the findings of Uskun and Ozturk (2013) which assign the decision to donate organs for transplantation squarely upon the educational, socio-economic status, religious and cultural characteristics of individuals. Furthermore, Potter, Perry, Stockert and Hall (2011) articulate that, religious and spiritual beliefs are determinants of the patients' worldview about health, illnesses, pain and suffering including life and death. It is in the light of these views that, this paper submits that religious beliefs play a pivotal role in the formation of attitudes and perceptions towards organ donation. Furthermore, they prescribe how people behave.

### **Theme 4: Cultural Factors**

South Africa is a multicultural country with culture playing a pivotal role in the lives of many South Africans (Brom, Anderson, Channing & Underhill, 2020). According to the United Nations Educational, Scientific and Cultural Organization (1982) as cited in Kreitzer (2012) culture is viewed as a complex phenomenon of distinctive socio-cultural, material, intellectual and emotional characteristics that characterize a particular society or group. Moreover, it includes the modes of life, fundamental human rights of human beings, their value systems and traditional beliefs. More importantly, culture is a world view that enables black people to locate themselves within a diverse universe. The majority (28) of the participants indicated that their culture did not allow them to partake in organ donation. Tarus and Gavrilovici (2015) concur on the significant role that culture plays in individuals and families decision to donate organs. These views find support in Shaw (2015) who highlights the importance of culture in transmitting different beliefs about organ donation and transplantation. Additionally, culture is responsible for the formation of identity and the prescription of behaviour and also contributes

towards the formation of attitudes towards the process. It is therefore imperative for organ donor coordinators, medical social workers, medical doctors, and professional nurses to approach organ donation with a culturally sensitive and competent lens. Suppes and Wells (2018) advise on the importance of understanding the community and the diverse racial and ethnic groups that form that community, their traditional beliefs about illness and the different healing methods practised in those communities.

### **Theme 5: Social Attitudes**

All research participants declared a positive attitude towards organ donation. Nevertheless, attitudes do not equate to an increase in the volume of prospective organ donors who have signed the organ donor card. However, positive attitudes do play a pivotal role in facilitating the process of signing informed consent and partaking in organ donation. Muliira and Muliira (2013) maintain that social attitudes have an enormous impact on organ donation because attitudes are intertwined with the traditions of people, teachings and their heritage as well. Hence, positive attitudes are essential as they constitute the pillars of successful organ donation and transplantation.

## **CONCLUSION AND RECOMMENDATIONS**

The study concludes that organ donation presents as a global public health challenge due to a high number of patients living with end-stage diseases. Hence, they are in limbo whilst awaiting life-saving organs to prolong and improve the quality of their lives. Unfortunately, the success of organ transplantation depends on the availability of organs. In addition, a lack of accurate information, refusal to grant permission to harvest vital organs by family members, socio-cultural aspects, religion and social attitudes continue to exacerbate the disinclination to donate organs. The findings of this study calls for further research in organ donation and transplantation with the dissemination of information regarding organ donation and transplantation being intensified. Furthermore, this study submits that, it is imperative to recognise the socio-cultural and religious characteristics of diverse communities when developing organ donation programmes aimed at enhancing their success. Though most researchers are proponents of the opt-out model, this study declares the prematurity of recommending such measures. This position is influenced by the advice of Etheredge et al., (2019) who argued that challenges arise due to the implementation of the opt-out model not being comprehensively explored. A recommendation is the use of children as information sources as they are good messengers. In conclusion, this study proposes that the Department of Education (DOE) considers the inclusion of organ donation and transplantation in life-skills education.

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## **ABOUT THE AUTHORS**

### **DR DIMO, PETER MASIBINYANE (CORRESPONDING AUTHOR)**

Department of Social Work  
Faculty of Arts, University of Zululand  
Private Bag X1001, KwaDlangezwa 3886, South Africa  
DimoP@unizulu.ac.za or charismadimo@gmail.com

### **DR MULQUEENY, DELARISE, M.**

Department of Social Work  
Faculty of Arts, University of Zululand  
Private Bag X1001, KwaDlangezwa 3886, South Africa  
MulqueenyD@unizulu.ac.za