

Participating in Organ Donation: Issues Among Black South Africans

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Received: October 13, 2018 Accepted: November 14, 2018 Online Published: December 13, 2018

doi:10.5539/gjhs.v11n1p71

URL: <https://doi.org/10.5539/gjhs.v11n1p71>

Abstract

The medical transplantation of human body organs remains the only efficacious therapy for patients who are confronted with the reality of death due to the breakdown of their vital body organs such as the heart, lungs, kidneys, pancreas, and liver. Nevertheless, their hopes of improving and prolonging their lives on earth are shattered by the consistent shortage and paucity of suitable organ donors. The scarcity of human organs is an issue of great concern in public health, both locally and internationally and the current outlook is bleak. This study seeks to explore factors that prevent black South Africans in Limpopo province from participating in organ donation. In a quest to explore factors that might impede black South Africans from participating in organ donation, a qualitative approach and explorative research design were used. Non-probability sampling was used to select 30 research participants. In-depths interviews were used to collect data and the data analysis method was a content analysis. The study was based on the theory of planned behaviour. The study established that the majority of black South Africans are not registered organ donors. A lack of awareness or educational, religious, and cultural backgrounds and myths regarding organ donation prevent black South Africans from registering and donating their organs. This study recommends further research into organ donation, and the development of a social work model to increase the awareness rate of organ donation in black communities. It calls for the evaluation of legislation that regulates organ donation and transplantation in South Africa.

Keywords: organ, organ donation, transplantation

1. Introduction and Study Background

The purpose of this study is to investigate factors that prevent black South Africans in Limpopo province in South Africa from registering as organ donors and donating their organs for transplantation. The medical transplantation of human body organs is the only efficacious medical intervention for patients who are confronted with the reality of death due to the breakdown of their vital body organs such as the heart, lungs, kidneys, pancreas, and the liver. Nevertheless, these patients' hopes of improving and prolonging the quality of their lives on earth are destroyed by the consistent shortage and paucity of suitable organ donors.

The scarcity of organs is an issue of great concern in public health and the current outlook is bleak. It is an indisputable fact that the success of any transplantation program is largely determined by the availability of committed and registered organ donors. There is no balance between the demand and the supply of human body organs. This view is supported by Merola, Pei, Rodriguez-Davalos, Deng, Mulligan, and Davis (2016), who report that more than 100 000 patients in the United States of America are added to the transplant waiting list in the hope of receiving an organ that could improve and prolong their lives. Furthermore, it is estimated that more than 7 000 patients die annually as a result of the shortage of organs. Australia has an organ donation rate of 15.1 per million populations, and this is the lowest and most unacceptable level or rate of donation (Hyde & Chambers, 2014). The imbalance between organ supply and the demand and the acute shortage of registered and committed organ donors are likely caused by the current system of organ donation in many countries, both locally and internationally. Organ donation is viewed as an altruistic act with most people feeling disinclined to participate. In South Africa, the Organ Donor Foundation (2016) reported that South Africa has over 4 300 patients who require an organ, and amongst these people who are waiting for life-saving organs are children who are forced to put their childhood interests and dreams on hold while they wait for a suitable organ. The reason for the current status quo regarding organ donation in South Africa is the opt-in system of organ donation, which does not bear positive results in terms of increasing the donor pool (Etheredge, Turner, & Kahn, 2013). According to previous organ donation studies,

insufficient human body organs and the unavailability of committed donors is occasioned by multidimensional aspects in various countries, and it would therefore be misleading to ascribe to global common reasons. Scientific investigations are the cornerstone of intervention programs in social work practice and medicine. Nevertheless, there is a chronic lack of scientific investigation in this area. Many studies have been done at a global level in countries such as the United States of America, Korea, New Zealand, and China. However, a few studies have been done in South Africa by researchers such as Muller (2013), Turner and Kahn (2014), Etheredge, Turner, and Kahn (2013), Venter and Slabbert (2013), and Slabbert and Venter who investigated organ procurement in Israel with the purpose of drawing lessons for South Africa. Scientific investigations on organ donation that have been conducted to date did not focus on the Limpopo province. Amongst the factors that prohibit people from participating in organ donation are: a lack of knowledge or awareness; socio-cultural factors such as culture and religion; negative attitudes and perceptions; and myths regarding organ donation. Moreover, demographic aspects, such as the age, sex, education, socio-economic status, knowledge, and personal experience of organ donation have been cited as factors that inhibit individuals from donating their organs. A lack of personal experience with organ donation is caused by the obvious absence of people who serve as role models in society, either as organ donors or as recipients of organs (Mithra et al., 2013; Philipson, Larsen-Truong, Pits, & Nonu, 2015).

The consequence of insufficient information on organ donation is the subject being shrouded in superstitious beliefs that generate fear in the minds of uninformed people (Mithra et al., 2013). Knowledge is a powerful weapon that can be used to dispel myths and inform black South Africans. The researcher maintains that the success of any transplant program or intervention is determined by knowledge; it is the pre-requisite. Knowledge shapes people's mind-sets, perceptions, and attitudes, whether positive or negative and determines the organ behaviour of communities; it helps people to make choices, and unfortunately these perceptions are transmitted from generation to generation. It is unwise to only blame lack of knowledge as a barrier to organ donation. It is imperative to investigate and assess the type of information that people have regarding organ donation and to establish the source of such information. The researcher believes that either people have incorrect information regarding the subject, or they have the positive information that is not translated into action.

The current organ donation system in South Africa makes it extremely difficult to obtain informed consent from family members. The opt-in system of organ donation requires an individual to express their consent to become a potential donor, while the opt-out system of organ donation presumes consent unless an individual expresses their refusal to become a potential donor. The opt-in system gives prospective organ donors the freedom to indicate that they wish to voluntarily donate their organs for transplantation upon their deaths. However, both systems should be examined. Firstly, the opt-in system that is currently in operation in South Africa protects people against policies that might seek to increase the donation rates, e.g. where benefits are hinted at, such as proposals to compensate donors. However, the amount of patients who are patiently waiting without hope in many countries for life-saving organs increases on a daily basis. Unfortunately, some patients die without ever receiving organs. Therefore, the researcher boldly maintains that the system is not bearing fruits, and it costs the state significant financial resources. It costs money to take care of patients who are suffering from end-stage diseases, not to mention patients that are financially unable to afford dialysis. The researcher further proposes that all government legislation should have at their centre the welfare of the population and the intention to meet their needs within the state's available resources. In support of this view, Dukelow and Considine (2017) assert that the primary purpose of social policy is to understand the social and economic structures that are central to people's lives, their life chances, and their quality of life. In addition to this view, social policy is about the study of how human needs are met and how people and their governments respond to these needs. This is the core business of governments' legislation and policies. The National Health Act No. 61 of 2003 attempted to regulate donation of organs, tissues, and blood, but its silence regarding the welfare of people who intend to save people's lives by donating their vital organs while they are still alive or after their death does not provide clarity. Although it is unethical to sell or compensate organ donors, several studies have discovered that a token of appreciation could increase the rate of organ donation.

For the purpose of this study it will be called 'a token of appreciation', even though the correct terminology that should be used is 'compensation'. Fisher, Butt, Friedewald, Fry-Revere, Hanneman, Henderson, Ladin, Mysel, Preczewski, Sherman, Thiessen, and Gordon (2015:1881), support this notion and state that financial rewards for a direct living kidney donor has the potential to increase the supply of kidneys, and this would reduce the cost of dialysis in the case of renal failure. This is a valid proposition, because the process of organ donation and the medical transplantation of human body organs are associated with financial costs, and emotional and psychological aspects, but in South Africa financial incentives for organ donation are forbidden, and it is also against the legislation that regulates 119 of organs used for donation.

Many researchers have identified socio-cultural factors such as religion and culture as impediments that prevent

black South Africans from making significant contributions in organ donation. Black South Africans are highly religious and cultural people. Religion and culture provide their sense of identity and unconsciously regulates their behaviour and their perspective of life events as well as their importance. Any behaviour that is regarded as contrary to the culture or the religion of a particular community is not tolerated, and is viewed negatively. While this study doesn't seek to enter into a definition of culture, it cannot be repudiated is that culture is a dynamic, controversial subject that is often misunderstood. The researcher is in agreement with Telleria's (2015) definition of culture as a set of values, principles, and standards that shape and condition a group's behaviour.

Furthermore, Simmers (2004: 216) describes culture as the beliefs, attitudes, languages, symbols, rituals, behaviours, and customs that are specifically unique to a particular group of people and which are transmitted from one generation to the next. The important message for organ donation coordinators and policy makers is that culture has the power to influence the behaviour of people. Culture also provides them with the lenses through which they view and interpret important life events, and prescribes how they should behave in certain circumstances. Chavis (2011: 472) states that human beings possess cultural experiences that affect their behaviour. The socio-cultural aspects of a particular group of people or a community also influence the decisions that they take regarding organ donation. This view is supported by Tarus and Gavrilovici (2015: 72) who also point out that culture is a strong barrier to organ donation. Another barrier to organ donation is religion. It is closely linked with culture, but it is addressed independently in this study. According Afifi, Morgan, Stephenson, Reichert, Harrison, and Long (2009), religion is described as associate-based beliefs and practices relating to God or a higher power commonly associated with a church or organised group. In addition to this view the researcher asserts both religious and spiritual beliefs determine how people perceive health, illnesses, pain, and suffering, including life and death. The limited space of this study does not allow the researcher to identify and discuss all South African religions, but the researcher will refer to the dominant religion, namely Christianity, as many of South Africa's religions are based on Christian principles. Christians believe in life after death, and they believe that they must appear whole before their Maker. Many black South Africans refuse to participate in organ donation due to their religious beliefs, which is a contradiction of their Christian principles because Christianity advocates sacrificial giving that is influenced by love. Religion shapes the people's attitudes towards organ donation and also engenders strong feelings about organ donation. Religion also taps into the political world, and it is politically correct to acknowledge that South Africans practice all the major religions, such as Christianity, Muslim, Judaism, Islam and Buddhism.

2. Methods

Kara (2017) defines a methodology as a coherent and logical framework for research that is based on the views, beliefs, and values, and the purpose of this framework is to guide the researcher's choices. Furthermore, Thomas (2017) describes methodology as the general research strategy and the collection of research data, including the analytical techniques adopted in the research study. For the purpose of this study, the research methodology includes research approach and design, the type of research, population, sampling, data collection, analysis, theoretical framework, and ethical consideration.

2.1 Research Approach

In its quest to explore the socio-cultural factors that prohibit black South Africans from participating in organ donation, a qualitative approach was adopted. A qualitative approach is more appropriate, particularly when one is doing a ground-breaking study. There is a dearth of research on organ donation and transplantation, especially within the black community contexts. According to Brynard, Hanekom, and Brynard (2014), a qualitative approach allows the researcher to know research participants personally, to see them as they are within their natural settings, and lastly but crucially, to experience their daily struggles when they are confronted with real-life issues.

2.2 Research Design

The design of a study serves the purpose of explaining, in detail, the manner in which the researcher intends to conduct the research, namely, how questions will be asked in each research step (Sarantakos, 2013). Additionally, Gray (2014) defines a research design as an overarching plan for the gathering, measurement, and analysis of data. The nature and the purpose of this study called for an exploratory research design. The purpose of exploratory design is to gain an insight into a situation, person, or community. According to Bless, Higson-Smith, and Sithole (2013), exploratory research is preferred when limited knowledge or information exists about a particular subject. Babbie (2014) also proposes that this design is more suitable when the researcher examines a new subject or engages in a ground-breaking study. Research literature has proven that, many researchers are in agreement with the fact that, exploratory design is appropriate when there is a need used need to explore a subject under investigation using qualitative data before making an endeavour to measure or test it using quantifiable

approaches.

2.3 Type of Research

This study sought to find solutions that could remedy the acute shortage of organ donors for transplantation and the unacceptable imbalance between available life-giving organs and the actual demand for human body organs. This study can be classified as applied research, which is research that is implemented when there is a problem or a situation to be solved, however it serves two purposes, because it also generates new knowledge. According to Bless et al. (2013) and Brynard et al. (2014), the primary purpose of applied research is to assist in solving real problems that confront communities. Nevertheless, this is often achieved by applying basic research findings, as is argued in this study.

2.4 Population or Study Area

This study was conducted in Zebediela, which is in Limpopo province in the northern part of South Africa.

2.5 Sampling

Sampling refers to the scientific technique that is used to select a small group with the view of determining the characteristics of a larger group (Brynard et al., 2014). In scientific investigations, the research approach and the population under investigation determine the type of sampling method used. This study adopted a qualitative approach and therefore non-probability sampling was relevant. Babbie (2014) postulates that non-probability sampling is suitable for studies that are conducted in situations that do not permit probability sampling. Non-probability sampling methods, purposive and snowball, were used to select a total number of 30 research participants. Kara (2017) states that purposive sampling is used when researchers use their own judgment to decide which participants will contribute in the study. However, snowballing was also used because participants also assisted in identifying other participants who had valuable information for the study. According to Babbie (2014) snowball sampling is a nonprobability-sampling method that is often used in field research. Each participant interviewed is asked to suggest additional research participants for interviewing. Participants were requested to sign confidentiality agreements in order to protect the privacy and the confidentiality of participants. The sample included five traditional leaders, five traditional healers, and twenty ministers from various religions.

2.6 Data Collection

Unstructured interviews or in-depth interviews were used to collect data as these interviews are suitable for exploratory or qualitative investigations (Brink, Van der Walt, & Van Rensburg, 2012). This is a method that allows research participants to talk freely about events, behaviour, and beliefs in relation to the topic under investigation, and it has the potential to produce more in-depth information than any other data collection method (Mitchell, 2012; Brink et al., 2012). Field notes and audio-tapes were used to record data after obtaining permission from the research participants. The interviews were designed to elicit participants' views, perceptions, knowledge, and attitudes regarding organ donation. Data in this study was collected until saturation point was reached

2.7 Data Analysis

For the purpose of this study, thematic content analysis was used to analyse data. Codes and themes were generated from the transcribed data according to Creswell (2014) and Bless et al.'s (2013) guidelines. Data analysis simply refers to the scientific process of bringing order and structure to the data. Babbie (2014) defines data in qualitative research as the non-numerical examination and interpretation of observation, with the intention of discovering underlying meanings of and patterns in relationships.

2.8 Theoretical Framework

Teater (2010) states that theory is an important ingredient in social work practice since it guides the manner in which social workers view and approach individuals, communities, and the society. It is a tool that helps social workers to predict, explain, and assess situations and behaviours, and it also provides a rationale as to how social workers should react and intervene. The theory of planned behaviour (TPB) was used to explore factors that influence the organ donation behaviour of black South Africans. The TPB is an appropriate conceptual framework for understanding and predicting social, health-related behaviours (Ayodele, 2015). This view finds its support in Ayodele (2017) who further confirms that the TPB provides a conceptual framework for understanding and predicting social, health-related behaviour. The theory posits that behavioural intention is a function of attitude, subjective norms, and perceived behavioural control. This theory has three important constructs, which are presumed to be key in influencing the intentions of people to perform a certain behaviour. The first construct is the favourable or unfavourable assessment of a behaviour. Secondly, subjective norms are considered to be perceived

pressure to perform or not to perform certain behaviours. Lastly, behavioural control is perceived as how easy or difficult it is to perform certain behaviours. According to the TPB, registration of organ donors and organ donation discussions are determined by intention, which is mostly influenced by subjective norms and attitudes toward organ donation.

2.9 Ethical Considerations

The basic purpose of research ethics in scientific investigations and social work practice is to protect research participants. Social work is arguably more ethics-based and directly concerned with values and principles. De Vos, Strydom, Fouche, and Delport (2013) add that scientific investigations should be based on mutual trust, acceptance, cooperation, promises, and well-accepted conventions and expectations between all parties involved. The researcher was given permission by the Ethics committee to conduct the study. All research participants participated in this study voluntarily and signed an informed consent, which indicated the purpose of the study, and identified the researchers, their expertise, and qualifications. It also clearly highlighted the benefits and risks of study participation. All research participants signed confidentiality agreements to safeguard confidentiality. According to Sarantakos (2013), when confidentiality is ensured, the researcher may keep names linked to the data, however the information that is made available for public consumption cannot include the respondent's name. In adhering to these constraints, the researcher used symbols and numbers to identify the research respondents. All collected electronic data was stored on a password-protected device and the only person with access to data was the study leader who also signed informed consent. Acknowledging all information sources prevented the occurrence of plagiarism.

3. Results

The results of this study are presented according to the themes that emerged during the interviews. Among the 30 research participants, only nine admitted that they had never heard of organ donation and/or transplantation. The study established that all participants are not registered as organ donors. It also emerged that they have neither the direction nor knowledge as to where and how they could register as organ donors. Their attitudes towards organ donation were positive, but six participants indicated that organ donation is unwarranted in back communities. The majority of participants, that is all of them, clearly declared that they would not give consent for the retrieval of body parts from their family members who are registered as organ donors. Although financial incentives did not form part of the study, it kept on emerging from the majority of participants, because the participants were given the opportunity to express themselves. There was a general view that hospitals might be selling their organs while participants themselves don't benefit from the process. Among the factors that prevented the participants from participating in organ donation was lack of awareness or education, even though it was only a small segment of the sample that mentioned a lack of knowledge. Culture and religion are still cited as deterrents to organ donation and registration. Organ donation is still shrouded in myth. Participants feared that if they registered as organ donors, they would be susceptible to poor health care and body mutilation.

4. Discussion

The main themes that emerged during the interviews are lack of knowledge, attitudes towards organ donation, consent in organ donation, financial incentives, culture and religion, fear of poor health and body mutilation. The findings of this study are discussed according to the themes that emerged.

4.1 Knowledge About Organ Donation

This study adopted the theory of planned behaviour as its theoretical framework. TPB is used to understand and predict health-related behaviour. It is believed that, all behaviour is learnt and people behave according to the information or knowledge they have. It was found that organ donation was not an entirely foreign concept to the participants, as the majority of them admitted to knowing about it, albeit that their knowledge is limited. Historically, organ donation is not a foreign concept in South Africa, since Dr. Christiaan Barnard performed the first heart transplant in South Africa in 1967. Nonetheless, despite a sound history of organ transplantation, many researchers identify a lack of knowledge regarding organ donation as an impediment to the low rate of organ donation. Black South Africans have limited knowledge regarding organ donation therapy, and little insight into the plight of patients with end-stage organ failure (Paterson, 2013; Stein, 2011). These findings are supported by Perenc, Radochonski, and Radochonski (2012) who also identified a lack of knowledge regarding organ donation as a major barrier to people registering, donating, and discussing their intention to donate their organs. Conversely a small segment of the research sample reported that they had never encountered organ donation. Despite the scant insight that people have regarding organ donation, South Africa has the lowest donation rate. This finding is consistent with the findings of the study conducted by Organ Donor Foundation (2014). Indeed, a lack of

knowledge and the identification of donors are the thorny issues that have impacted on the success of organ transplantation.

4.2 Registration as Organ Donors

Knowledge precedes action in terms of organ donation however all research participants who took part in this study are not registered as potential organ donors including those who have little insight about organ donation. Therefore, it can be hypothesised that being informed about organ donation does not guarantee registration. Of great importance was the participants' admission that the knowledge that they had was insufficient, and it also emerged that none of the participants were prepared to register as donors. This confirmed the basic philosophy of the theory underpinning this study, that is that people choose to behave how they behave, and they are influenced by their intentions (Ayodele, 2017). This was proved by the participants' reluctance to participate in organ donation due to the absence of financial incentives for donors. Three respondents declared that organ donation is unwarranted in black communities.

4.3 Attitudes Towards Organ Donation

The majority of participants had positive attitudes towards organ donation, but their attitudes did not translate into positive actions of registering and declaring their intention publicly or to their families. The researcher maintains that there is a missing link between positive attitudes about organ donation and the actual registration. Although positive attitudes are vital in organ donation, they do not always lead to high volumes of donors.

4.4 Socio-Cultural Aspects

The recruitment, registration, and donation of organs appear to be influenced by socio-cultural aspects such as culture, religion, and demographic aspects such as gender, level of education, and socio-economic status. Socio-cultural aspects have been found to be factors that are influencing the organ donation behaviour of black South Africans. Few participants reported that their religions do not allow them to partake in organ donation and transplantation. Bresnahan, Guan, Smith, Wang and Edmundson (2010) believe that solid reasons are available that can make one to believe that spiritual beliefs have an inhibitory impact on organ donation because many studies proved the existence of a close relationship between cultural values, spiritual beliefs and how these factors are manifested in organ donation behaviour.

4.5 Informed Consent

It also came to light that participants are neither psychologically nor mentally prepared to give consent for the retrieval of body organs from their family members. The current system of organ donation is altruistic in nature, however the possibility family members of not honouring the intentions of their deceased family member are significantly high because the remaining family members appear to have more legal powers than the deceased, even though they signed legal documents regarding the donation of their organs.

5. Conclusion

The lack of organ donors and organs are issues of great concern in South Africa as the majority of South Africans are not registered organ donors. Poor knowledge and lack of information, socio-cultural aspects, fear of body mutilation, and myths are barriers that prevent black South Africans from participating in organ donation. Organ donation is a highly misunderstood and significantly sensitive issue that is not encouraged in black families.

5.1 Recommendations

This study recommends the evaluation of legislation responsible for the regulation of organ, tissue and blood donation. In the light of this study's findings, it is suggested that the presumed model of organ donation be accepted and implemented in South Africa, since the current opt-in system does not yield positive results. The study invites the Ministry of Basic Education to consider the inclusion of organ donation in its curriculum, as this will help children to become knowledgeable about organ donation during the early stages of their development. The study encourages different stakeholders, such as religious organisations, non-profit organisations, government departments, the private sector, and international organisations to join in regularly increasing public awareness of organ donation, including holding compulsory workshops in places of work. The study invites researchers to conduct more studies in this area, particularly in black communities. The Organ Donor Foundation is respectfully advised to open and activate satellite offices in all the nine South African provinces, as it is not currently visible in other provinces, particularly in Zebediela in the Limpopo province. The electronic method of registering organ donation is not accessible to all members of the population due to participants' financial inability to access the internet and information.

Acknowledgements

The researcher would like thank the North West University for their financial support and the research participants for participating in this study.

Competing Interests Statement

The researcher declares that he does not have competing interests for the publication of this study.

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