ORGAN DONATION AND TRANSPLANTATION: IMPLICATIONS FOR SOCIAL WORK

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Abstract

Organ transplantation is a panacea for end-stage diseases and unfortunately, the number of patients that are on the waiting list is increasing. There is no equilibrium between the supply and the demand for organs. The chronic shortage of organs has detrimental consequences as the majority of patients depart from the world of the living without getting a life-saving organ. This study seeks to appraise the roles that are played by medical social workers in organ donation and transplantation. The ambition of this study was achieved through the employment of qualitative approach and explorative research design. Social marketing was used as the theoretical framework for this study. Purposive sampling and snow ball were used to select a sample of fifteen social workers. In-depth interviews were used to collect data which was analysed through thematic-content analysis. The finds that, the major roles of social workers in organ donation and transplantation are assessment, counselling, public education, advocacy, broker role. The study recommends that further research in organ donation and transplantation should be conducted, particularly in black communities. Public education on organ donation and transplantation should be taught in both primary and secondary schools.

Keywords: organ donation; transplantation; social work

Introduction and background of the study

The ambition of this qualitative study is to critically appraise the roles that are played by medical social workers in organ donation and transplantation within the health systems. The medical transplantation of organs is a wonderful therapy for patients that are suffering from end-stage diseases however, their hope of getting life-saving organs that could prolong and improve the quality of their lives psychologically, emotionally and physically is shattered by the chronic shortage of organs. According to Hernandez-Ibarra, Mercado-Martinez and Martinez-Castaneda (2017:54) many countries have made fruitless attempts to develop social policies, programmes and actions regarding organ donation and the medical transplantation of organs. Despite the availability of these good legislations and organ donation programmes, prospective organ donors are still reluctant to sign organ donor cards. Lack of registered and committed organ donors has detrimental consequences as the majority of patients depart from the world of the living without getting life-saving organs. Alwehaibi (2017:1) asserts that human body organs can either be donated by the living or deceased organs but organ donation is highly sensitive and a very controversial subjects. It is a subject that encounters strong controversial and problematic issues at the level of individuals, societies and humanity.

A healthy body is important for the normal functioning of individuals, groups and communities and this assertion supported by Selby (2014:) who declares that good health is an essential asset in people's lives. Good health from this perspective refers to a state of being in total physical, mental and social well-being. However, this is not the case with patients that are suffering from end-stage diseases. It is against this background that, this study seeks to establish and appraise the roles that are played by medical social workers in organ donation and transplantation. Social work is amongst

the health professionals such as psychologists, nurses and medical doctors that are involved in organ donation and transplantation. According to Hassan (2016:495) medical social work as a subdiscipline of social work came into existence because medical doctors and professional nurses wanted effective ways of making patients well and to keep them well. This paper contends that medical social workers have a critical role to play within the health system and one of their key responsibilities is to educate medical personnel's about the social welfare of clients holistically. Hassan (2016:495) declares that social work deals with the systemic treatment and solution of psycho-social problems of individuals, groups and communities. This view finds its support in Zastrow (2010: 10) who defines social work as a professional activity of helping individuals, groups and communities to enhance or bring back their capacity for social functioning and the creation of societal conditions that are favourable. Social workers are sufficiently equipped with knowledge about human development, behaviour, social, economic and cultural institutions and the interactions and relationships between these factors.

Problem statement

South Africa, like the rest of the world is confronted with an acute shortage of organs because the majority are not registered as organ donors. Organ donation is a highly sensitive subject that is surrounded by multifarious factors. Organ Donor Foundation (2018) reports that South Africa has more than 4300.00 patients that are expecting organs that could prolong and improve the quality of their lives and in addition to this predicament, only 0.2 % of the population is registered as organ donors. 0.2% is extremely insufficient to close the gap between the current demand and supply of organs and the majority of organ donation researchers boldly assert that there is a high volume of people in need of organs for transplantation than there are people who are willing to donate organs. It is an inevitable fact that, transplantation of organs cannot be done without the availability of registered and committed organ donors however Miller and Breakwell (2019:103) postulate that, the high demand for transplantable organs is not met by the supply of living or deceased donors. Many countries are fixing their hopes on living donors but Thompson (2017:36) is making organ donation coordinators aware that many patients are struggling to get a suitable living donor.

Organ donation is not completely a foreign subject in South Africa because the first heart transplant was performed in South Africa by Professor Christiaan Barnard. However, the majority of organ donation researchers continue to accuse lack of knowledge as the main cause of the scarcity of human body organs. This assertion is consistent with the findings of Mithra, Ravindra, Unnikrishnan, Rekha, Kanchan, Kumar, Papanna, Kulkarni, Holla, and Divyavaraprasad (2013:84) who state that transplantation programmes cannot be successful without awareness and the nurturing of positive attitudes towards organ donation. In addition to lack of information, people have wrong and misleading information about organ donation and transplantation.

This paper argues that, there is a strong correlation between knowledge and the rate of organ donation and further knowledge also influence organ donation behaviour of prospective organ donors. Lack of knowledge or awareness about organ donation does not affect lay people only but also health professionals who are expected to promote organ donation. Thompson (2017:36) sees lack of knowledge about organ donation and brain-death among professional as a matter that demands urgent attention. In addition to this, South Africa is currently using opt-in system of organ donation and organ donation is seen as an altruistic act. This type of a system is not able to bridge the gap between the demand and supply of organs as people are not obliged to donate their organs. A plethora of studies indicate that, it is difficult to obtain consent for the retrieval of organs from family members of the deceased. This assertion is supported by Albidin, Ming, Loch, Hilmi and Hautmann (2013:188) who claim that, the draught of organs is not the result of lack of suitable

organ donors but the failure to identify, obtain consent and the procurement of organs. Thompson (2017:36) reports that the consent rate for organ donation in South Africa was 18 % in 2017 and this is approximately 82 % of families that are not supporting organ donation.

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The aim of the study

The aim of this study is to explore and assess the roles of medical social workers in organ donation and transplantation and the challenges that they encounter in organ donation.

Research methodology

The research methodology of this study included the research approach, research design, population, sampling, data collection, analysis, ethical consideration and the theoretical framework. Babbie, Mouton, Voster and Prozesky (2018: 647) research methodology refers to the methods, techniques as well as the procedures that are used by scientific researchers in the process of implementing the research design or plan.

Research approach

The present study adopted a qualitative approach to explore and evaluate the roles of medical social workers in organ donation and transplantation within the health setting. According to Creswell, Ebersohn, Eloff, Ferreira, Ivankova, Jansen, Nieuwehuis, Pietrson and Clark (2016:309) qualitative approach in scientific studies is used to explore and to understand a central phenomenon which is the concept or process explored in qualitative investigations. Babbie, Mouton, Voster and Prozesky (2018: 270) indicate that qualitative studies are appropriate for the exploration of attitudes and behaviours that can be best analysed and be understood within their natural setting.

Research design

The exploration and assessment of social work roles was achieved through the employment of a phenomenological research. The majority of researchers use phenomenology to explore and understand life experiences of research subjects. Brink, Van der Walt and Van Rensburg (2012:121) indicate that, the intention of phenomenological investigations is to describe what people experience in regard to certain phenomena and the interpretation of those experiences and their meaning. This assertion finds its support in Creswell et.al (2016:77) who maintain that almost all phenomenological investigations are exploration into the structures of the human life-world, lived world experienced in everyday situations.

Population

Brink et.al (2012:131) define as research population as the entire group of people or subjects that is interest to the researcher and of great importance is, they should meet the inclusion criteria that the researcher is interested in studying. Sixteen medical social workers with two years working experience or more in medical setting participated in the present study.

Sampling

Non-probability sampling was used to select sixteen medical social workers as Babbie et.al (2018:166) is of the conviction that scientific investigations are carried out in situations where researchers are not able to select the kinds of probability samples that are used in large-scale social surveys. However, non-probability sampling is accused of not accurately representing the entire population and in order to address this shortcoming, data was collected until a saturation point was reached. For the purpose of this study, purposive sampling was used to select sixteen medical social workers. This type of sampling is popular in qualitative studies and it is based on the assumption

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that, it is appropriate sometimes to choose research sample on the basis of a researcher's knowledge of the population, its elements, nature of the study and the purpose of the study.

Data collection

Qualitative data in this study was collected through unstructured interviews. According to Creswell (2016:93) unstructured interview is a conversation with a purpose that the researcher explores with the participants his or her views, ideas, attitudes and belies about certain phenomena. The advantage of using unstructured interviews to collect data according to De Vos et.al (2011:348) is that it is focused, discursive and it gives the researcher and the participant to explore an issue under investigation.

Data analysis

Babbie (2007) as cited in De Vos (2011: 399) describe qualitative data analysis as the nonnumerical assessment and interpretation of scientific observation for the purpose of discovering underlying meanings and patterns of relationships. It is also viewed as a scientific process that is aimed at bringing order and structure in the data. For the purpose of this study, thematic content analysis was used to analyse data. The findings of this study are discussed according to the themes that emerged during the interviews.

Theoretical frameworks

Social marketing was used as the theoretical framework for this study. Weyers (2011:16) defines social marketing as the design, implementation and control of programmes that are seeking to increase the acceptance of a social idea, a cause, a practice, a service, a profession or an organisation by a target group. According to Schwartz (1971) as cited in Gestao and Leopoldo (2017:15) Social marketing is a way of planning programmes in a large scale to influence voluntary behaviour in a determined segment of individuals, with social objective instead of a financial one as organ donation is seen as an altruistic act in many countries that are still using opt-in system of organ donation. In addition, Pecak and Ovsenik (2012:195) view social marketing as the application of commercial marketing strategies to analyse, plan, execute and assess programmes that are designed to influence the voluntary behaviour of the target audiences in order to improve their personal welfare and their society.

Organ donation and transplantation are sensitive subjects that are surrounded by multifarious sociocultural aspects. Furthermore, the majority of people still have little insight about organ donation and transplantation. Social marketing is a useful perspective because it intention is to change or modify social attitudes and concomitant behaviour. The goal of social marketing is achieved through the employment of marketing principles and its techniques to influence targeted individuals to accept and change their attitudes and behaviour for the benefit of all people.

Ethical consideration

The purpose of research ethics is to protect research participants. Permission to conduct with study was granted by North West University, Mafikeng Campus. All research participants participated in this study voluntarily. According to De Vos, Strydom, Fouche and Delport (2017:116) participation in scientific investigations should at all times be voluntary. Furthermore, they signed informed consent forms which were administered by research assistants. The informed consent made participants aware about the purpose of the study, rights of participants to withdraw from the study when they feel uncomfortable, benefits and risks that are involved in the study. Real names and identifying information of participants were not used in order to ensure confidentiality. All electronic information was kept and protected in a password protected computer. Confidentiality is

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a central principle in social work practice and education. Social workers in practice and research are legally obliged to respect the client's rights to privacy and keep information as confidential as possible, (Mbedzi, Qalinge, Schltz, Sekudu & Sesoko, 2017, 72).

Research findings

This study finds that medical social workers have a pivotal role to play in organ donation and transplantation. They are members of a multi-disciplinary team and their position is to educate the medical personnel's about the welfare of patients. This view is supported by Hassan (2016:495) by indicating that social work within the health setting deals with the systemic treatment and solution of psycho-social problems of individuals, groups and communities. Amongst the roles that they play in organ donation and transplantation are assessment of patients, counselling of patients and their families, public education on organ donation and transplantation, educating the patients family and medical personnel's about bio-psycho-social needs of the patients, crisis intervention, obtain consent from family members of the deceased. Medical social workers evaluate and monitor organ transplants programmes.

Discussion of findings

The findings of this study are discussed according to the following themes that emerged during qualitative interviews;

Assessment

All research participants indicated that assessment of prospective organ donors and their family members is very crucial in organ donation and transplantation. Assessment is the cornerstone of social work intervention and practice. Social work assessment involves gathering of data, organizing and making professional judgement about information. According to Fook (2016:49) assessment in social work involves making a professional judgement about the problematic aspects of a situation in order to act effectively to address the problems with and within the situation while Parker (2017:15) defines social work assessment as making sense of events and statements, arriving at an overall picture and an understanding of what is happening and giving some thought as to how the situation has come about. This paper further contends that assessment helps social workers to understand the situations they are dealing with and to individualize problems and it helps them to come with appropriate intervention strategies. Organ donation and transplantation involve the screening of prospective organ donors and recipients. Fisher and Lu (2013:9) state that the prerequisite of successful transplant is pre-transplant screening. The purpose of screening is to rule out malignancy or infections that could be transmitted to the recipients. It is the responsibility of medical social workers to do document analysis by deeply scrutinizing the medical records of prospective organ donors. Social work screening is imperative because it takes a holistic view of a person into consideration. Organ donors and recipients are not assessed in isolation from their families and environments. It is further contended that, people are best understood within the contexts of their families and environments. In support of this view, Corey (2013:397) maintains that a family system perspective holds that individuals are best understood through assessing the interactions between and among family members and it is also argued that actions one individual has an influence on all family members and their reactions ultimately have a reciprocal effect on the individual.

Counselling of patients and their family members

Social workers spent majority of their time offering counselling to patients and clients through casework method of intervention. Organ donation and transplantation of organs are often accompanied with shock that affect the social functioning of patients and their family members. The

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long waiting periods have negative psychological, emotional and physical damage. According to Kumar (2013:103) patients are overpowered by various mixed feelings, shock, and disbelief. Therefore, professional counselling is required to strengthen patients, especially strengthening of the social support that patients have. According to Ntshwarang and Malinga-Musamba (2016:221) the primary purpose of counselling is to ensure personal growth in order to enhance support during crisis situation and improve problem-solving. It provides clients with the opportunity to discover diverse ways of addressing their predicaments and the identification of resources according to the assets-based and strengths-based perspective. It is the responsibility of the social worker to assist clients to identify with the clients' available resources. The challenges that people are facing in life cannot be addressed without knowledge of and availability of resources. According to strengthsbased perspective people live in environments that are full of resources and sometimes people have limited information about available resources. Social work counselling is of great significance to facilitate change, assist clients to accept new situations and subjugate dramatic moments and it is imperative to understand that the ultimate goal of counselling is to help clients so that they can help themselves. Social work counselling in organ donation and transplantation is influenced by theories such as ecological system theory as social work practice in informed by its theory. According to Rogers, Whitaker, Edmondson and Peach (2017:198-199) ecological theory views society where people live as a network and it orients a social worker to understand people and their environments including the nature of their transactions.

Grief counselling

All participants indicated that, they offer grief counselling in organ donation. The majority of prospective organ recipients die before they receive life-saving organs. According to Pomeroy (2011:101) grief may be defined as, a multidimensional experience as a result of a loss of a person including an object. Within the context of organ donation emphasis will be placed on the loss of a person though loss of an object is also important. Grief is viewed as a multidimensional phenomenon because it touches several aspects such as cognitive, physical, social, behavioural, and spiritual components. Death and Medical diagnoses are psychologically, emotionally and physically depressing particularly the malfunctioning of human body organs that could lead to death. These assertion finds its support in Kubler-Ross (1969) as cited in Baier and Buechsel (2012:28) who declare that the phases of grieving are shock and denial, anger, bargaining, depression and, finally, acceptance. This paper further argues that it is imperative to acknowledge that death affect the entire family as a unit or system as social work is one of the helping professions that is concerned with the welfare of the family as a whole. A family in Social Work practice is defined, understood and analyzed from a holistic perspective. A person is analyzed in relation to his or her environment and the family. It is therefore important to involve the entire family as a system in grief-counselling.

Public education on organ donation and transplantation

The majority of research participants indicated that public education is one of their role and responsibility in organ donation and transplantation. A plethora of researchers continue to accuse lack of insight about organ donation as a barrier to organ donation and transplantationhe subject of organ donation within black communities is highly misunderstood and people have wrong information about organ donation. Organ donation is also a subject that is not regularly discussed in families because it involves death. According to Nicholus, Rautenbash and Mainstry (2010:117) social workers are aware that knowledge is a powerful that can be used to change the mindset, attitudes, and perceptions of as majority of people lack the knowledge to address their concerns. The majority of prospective organ donors are not partaking in organ donation as a result of negative attitudes and perceptions that came through lack of knowledge or misinformation. Public education is essential to make people aware about organ donation and transplantation and this study maintains

that knowledge precedes action in organ donation and transplantation. The use of social marketing theory in this study is justified and expedient. According to Demsa and Ovesenik (2012:195) social marketing is used as a tool to efficiently and effectively challenge diverse socially undesirable and unacceptable behaviour.

Obtain family consent in organ donation

Organ donation involves surrogate decision making at the end of life. It is the responsibility of surrogates who are appointed on the basis of biological relationship with the deceased to take decisions on behalf of incapacitated patients as South Africa is still using the opt-in system of organ donation. According Bhatia and Tibballs (2017:953) this kind of a system requires an individual to register to donate after death. In organ donation the next-of-kin will include a spouse, parent and siblings (Anker, Akey & Feeley, 2013:836) however Shaw and Elger (2014:96) discovered that family refuses to give consent as a result of false belief, cognitive bias and misunderstanding. Social workers have the responsibility to obtain family consent for the retrieval of vital body organs from the deceased organ donor.

The family of the deceased plays a vital role in organ donation despite the legal evidence that authorizes the retrieval of body organs. It is the responsibility of social workers, medical doctors and professional nurses to facilitate the process of obtaining informed consent. Informed consent or self-determination are the corner stones of social work practice and intervention. Informed consent means clients should be involved in the decision making and nothing should be done without them. The majority of studies in organ donation and transplantation have reported that, families decline to give consent for the retrieval of vital body organs from the bodies of their deceased family members. Failure to obtain informed consent is determined by a number of aspects such as lack of awareness about organ donation, socio-cultural factors, lack of knowledge about brain-death and myths about organ donation. Furthermore, the timing of requesting informed concerned is critical as the family is expected to take the hardest decision at a time when it is grieving for the departure of its family member from the world of the living. Organ donation and transplantation are highly sensitive subjects that are not discussed in families and prospective organ donors often fail to communicate their intentions of being organ donors.

Evaluation and monitoring of transplant programmes

Social workers who are involved in organ transplantation have the responsibility to monitor and evaluate organ donation and transplantation programmes and all social workers were in agreement with this finding. Evaluation is extremely imperative in social work practice. It is through evaluation that social workers can measure whether their intervention strategies are yielding anticipated outcomes. Evaluation will be used interchangeably with assessment as they have the same meaning. In social work profession, assessment help social workers to understand the problem they are dealing with which will result in the design and implementation of appropriate intervention strategies. The primary purpose of organ transplantation programmes is to increase the volume of organ donors and to safe lives. Effective and objective evaluation helps social workers to identify the unintended consequences of programmes. According to Kettner, Moroney and Martin (2017: 10) programmes that are effective and efficient invite social service professionals to develop a wellresearched understanding about social problems that are affecting people, people in need and human services. Social workers working in organ transplantation should understand diverse contexts within which they promote organ donation and transplantation. A plethora of scientific evidence indicate that organ donation is affected by a multifaceted of social, religious, cultural as well as environmental factors. It is therefore expedient for social workers to for social workers to make



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attempts to understand these factors through research but research is an area that is neglected in social work practice. Ideally, social work intervention should be driven by research.

Crisis intervention

The majority of social worker were in agreement with the fact that they do crisis intervention. The discovery of malfunctioning of vital body organs such as the kidney, liver, pancreas and the heart come as a shock to majority of people. This situation is caused by costly medical expenses as majority of people are not working and as result they discover their medical conditions when the damage has already been done. To add salt on the wound, their situation is worsened by the unavailability of organs. The unavailability of human organs affects families and patients on the waiting list psychologically and emotionally. According to Kumar (2013:103) patients are overpowered by various mixed feelings, shock, and disbelief. Within the context of organ donation and transplantation a crisis may be seen as, a precipitating event and the perception of an event that causes distress and the inability of an individual's coping methods and it eventually causes a person experiencing the precipitating event to function at very lower than before the event. Patients on the waiting list for organs are facing death as a result of shortage of organs and some depart from this world while still waiting for lifesaving organs. The period of waiting for transplant is life threatening and it depletes the psychological and coping mechanisms of patients and their families. Furthermore, it is financially costly to take care of patients who are on dialysis as a result of malfunctioning of organs. It becomes the responsibility of medical social workers within the health settings to step in through holistic social work interventions that are targeting the entire family as a system.

Conclusions

The aim of this study was to assess roles and responsibilities of medical social workers in organ donation and transplantation. Indeed, many countries in the world including South Africa are finding it difficult to close the gap between the demand and the supply of organs for donation and transplantation. Medical social workers are among a group of medical professionals that are entrusted with the responsibility of saving lives. Their responsibility within medical teams is to assess holistically prospective organ donors, their immediate families as well as patients that are hoping to receive organs that could change their lives. Social workers are known as helping professionals that are able to go beyond institutional borders. This is demonstrated by their ability and willingness to involve the family in their intervention. In social work practice an individual should be assessed and be understood within the context of his or her family. They offer counselling services that are aimed at strengthening the coping mechanisms of patients and their families. Furthermore, lack of organs for transplantation result in death and it is therefore vital for medical social workers to provide grief-counselling to the bereaved families as death brings anger and hopelessness. It is the responsibility of medical social workers to educate the public about the importance of donating organs and also to register as organ donors. The majority of studies that are conducted on organ donation are still blaming lack of knowledge about organ donation as the culprit of chronic shortage of organs. South Africa is still using the opt-in system of organ donation and we don't have a guarantee that health profession will be allowed to harvest organs from the registered donor.

It is the responsibility of social workers to obtain consent from the family of the deceased patients. However, they don't always win the case as the decline rate is very high. Lack of organs for transplantation and committed organ donors is sign that organ transplants programmes are not producing what the Departments of Health in many countries are hoping for to assist them to close the widening gap between the demand and the supply of organs. Social workers are shouldering the

responsibility of evaluating organ transplants programmes to identify what is not working well and to discover new strategies to remedy the situation. The amount of space does not allow the researcher to discuss many roles that are played by medical social workers in organ donation and transplantation but lastly social workers are involved in crisis intervention as the discovery of malfunctioning of vital body organs bring discomfort and distress in people's lives. Their situation invites social workers with their unique skills, principles, knowledge and their knowledge of resources to intervene.

Recommendations

Based on the findings and the conclusions of this study, it is respectfully recommended that, more studies on organ donation should be done as there are few studies that are conducted in this field. Public education seems to be the primary methods of educating the general public about the importance of organ donation however; lack of knowledge on organ donation is still accused of lack of organs. It is therefore recommended that more and regular public education campaigns should be done. The Department of education is requested to intervene through including organ donation and transplantation in school curriculum so that people have knowledge at an early stage. It is also vital to acknowledge that the government and the ministry of health of health could intervene through policies that are favour of organ donation and transplantation. This study does not claim that South African policies are antagonistic towards organ donation but the current system that is in use is unable to close the widening gap between the demand and the supply of organs. It is therefore recommended that it is a high time to review policies that are regulating the donation of organs. The availability of social workers in health setting is of great importance as there is a need to go beyond the hospitals and do research and educate the public in order recruit more organ donors. It is therefore important to employ more social workers in order to strengthen the available work force.

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