Exploring the Knowledge Levels, Attitudes and Beliefs of Patients’ Relatives Towards Organ Donation in the Intensive Care Units of Two Majors Hospitals in Trinidad

Philip Onuoha¹, Gloria Ramdeen-Mootoo¹, Ria Edwards¹, Rita Gobin¹, Dionne McConney¹, Alicea Greene-Nicholas¹, Dianne Ramoo¹ & Vanessa Young¹.

¹The UWI School of Nursing, The University of the West Indies, St. Augustine, Trinidad and Tobago

Correspondence: Philip Onuoha, The UWI School of Nursing, The University of the West Indies, St. Augustine, Trinidad and Tobago. Tel: 868-225-1026 Ext. 3029. E-mail: Philip.onuoha@sta.uwi.edu

Received: March 6, 2020   Accepted: June 5, 2020   Online Published: June 30, 2020
doi:10.5539/gjhs.v12n9p15          URL: https://doi.org/10.5539/gjhs.v12n9p15

Abstract

Purpose: To ascertain the Knowledge levels, Attitudes and Beliefs to toward Organ Donation by Relatives of Patients in the Intensive Care Unit at two Tertiary Care Hospitals in Trinidad.

Methods: A quantitative descriptive study in which the researchers’-designed and pretested self-administered questionnaire was used on a sample of 133 randomly selected patients’ relatives from two main intensive care hospitals units of Trinidad. The respondents were requested to give their consent after necessary ethical approval was received. Data entry was done manually but the analysis was done with the SPSS version 12 programme. Results were presented as frequencies.

Results: Demographic characteristics indicate that most were females, of African ethnicity, and Christianity as their main religion. The majority of participants had high level of knowledge (69.2%) while 57.9% of them had unfavourable attitude towards organ donation. Most (86.5%) had positive belief. It also showed that the respondents’ knowledge towards organ donation is significantly related to their age and religion, (P≤, 0.05) while their attitudes are significantly related to their gender and ethnicity (p≤0.05). Their belief is only significantly associated with their marital status.

Discussion: The findings of the study were compared with previous studies and the researchers showed how the relevant theories that guided the study were used to explain the findings.

Conclusion: Based on the findings, the researchers made a number of recommendations particularly related to public education in attempt to address the attitudes of the public related to organ donation in Trinidad and Tobago.

Keywords: organ donation, Caribbean, knowledge, attitudes and belief, health care

1. Introduction

1.1 Background

The practice of organ donation is an effective way of prolonging life. Although the access of patients to organ donation varies given their national situations, the cost of health care, the level of technical capacity and the availability of organs, the increasing yearly statistics of prospective recipients shows that persons are interested and accessing this service (WHO, 2016).

Cleveland Clinic (Cleveland Clinic, 2016) opines that organ donation is the donation of biological tissue or an organ of the human body, from a living or deceased person to a living recipient in need. This transplantation is necessary because the recipient’s organ has failed or has been damaged by disease or injury, and is often the only treatment for end stage organ failure, such as liver, kidney and heart failure. Organ transplantation is now seen as a preferred treatment modality for end-stage organ disease, and offers a better quality of life with better survival benefits (Cleveland Clinic, 2016).

In countries such as Spain, France, Sweden, and across Europe, organ donation is openly discussed with every potential donor or their relatives, as is, the accepted practice (BBC News, 2015). It has become one of the great advances in modern medicine. In these countries however, even in these countries the need for organ donors is
much greater than the number of people who actually donate. Statistics shows that every day in the United States 18 people die waiting for an organ to be donated to them and more than 100,000 men, women, and children await life-saving organ transplants (Cleveland Clinic, 2016).

In the Caribbean nation states, such as Jamaica, Grenada and Antigua, the practice of organ donation has not fully permeated the societies (Soyibo, 2012). Despite the existence of National Organ Transplant Unit (NOTU) in Trinidad and Tobago, organ donation numbers are still not encouraging. It remains a topic for national discussion, since relatives as well as potential donors continue to be apprehensive towards the advancement of this practice and the subject of organ donation is still seen as taboo. In many Caribbean cultures, persons are hesitant to remove necrotic tissues that may affect their health status, it becomes even harder to persuade individuals to donate their organs. Soyibo (2012) asserts that they should go back to their Creator just as they came, hence we surmise that their attitudes, beliefs and knowledge may contribute to their unwillingness to this practice. In Trinidad and Tobago the demand for organs for transplantation continues to exceed the supply. Further, due to the high prevalence of chronic diseases among the population, there is an increased number of individuals living with organ failure (Baal, 2011) while Pan American Health Association (PAHO, 2012), indicates that chronic non communicable diseases (CNCD’s) are collectively the leading cause of death in Trinidad and Tobago.

In 2011 Ministry of Health, Trinidad and Tobago, (2016) estimated that over 500 individuals were in need of kidney transplant and that over 900 persons are on the waiting list. Crime related deaths in Trinidad and Tobago in 2015 was 420 (Overseas Security Advisory Council for the United States Department of State Bureau of Diplomatic Security, 2016), while Arrive Alive (2015) informed that Trinidad and Tobago road fatalities numbered at 147 for the year 2015. We believe that these numbers represent the loss of viable organs that could have been beneficial to those recipients on the waiting list. This is in spite of the actions of National Organ Transplant Unit (NOTU) and their intervention.

The reality is that there is an almost universal shortage of donors (Rudge, 2012). The patients’ families play major a role in increasing the number of organs needed to meet the demands by the population. Families’ avoidance of giving consent for organ donation is an obstacle in this regard (Tahrekhani, 2016). In Iran, Yousefi, Roshani and Nazari (2014), indicated that the decision to donate an organ is a very tough one for some families. It indicated that certain factors including humanistic desires, immortality, culture making challenges, the satisfaction levels, the eternal honour of the deceased and the assurance of the relatives, all play different role in the relatives’ willingness to donate.

It is not clear what the situation is in Trinidad and Tobago as the authors are not aware of any study that attempted to determine what contributes to this lack of desire to donate organ. We envisage that ascertaining whether the knowledge levels of patients’ relatives are high or not, if their beliefs are positive or negative and if their attitudes are favourable or not towards organ donation will go a long way at determining what may be the contributory factors to the problem of scarcity of organs for many needy patients despite the numerous violent deaths that occur in the Island state.

1.2 Objectives

The specific objectives are to:

1. To determine the levels of knowledge of relatives of patients in the ICU on organ donation.
2. To ascertain if the beliefs of the relatives of patients in the ICU on organ donation are positive of negative.
3. To ascertain if attitudes of the patients relatives are favourable or unfavourable to organ donation.
4. To determine if the respondents’ (a) levels of knowledge, (b) beliefs and (c) attitudes are significantly associated with their demographic characteristics.

1.2 Research Questions

1. What are the knowledge levels of the patients relatives regarding organ donation
2. Are the beliefs of the patients’ relatives favourable or not regarding organ donation
3. Do the relatives of patients in ICUs in Trinidad have positive or negative attitudes toward organ donation?
4. Are the knowledge levels, attitudes and beliefs of the patients relatives at the ICU related to the demographic characteristics?

Adapting the Theory of Reasoned Action and the Theory of Planned Behaviour to underpin the study

The nature and relationship of the multiple factors that affect a range of health-related behaviours have led to the
development of many theories (Glanz, Rimer and Viswanath, 2008). Two of such theories are the Theory of Planned Behaviour (TPB) and the Theory of Reasoned Action (TRA). Humans behave in particular ways because of multiple influences from biological characteristics, environment, education and culture. Our study seeks to understand the relationship between knowledge, attitudes and beliefs of patients’ relatives in the ICU at the two major tertiary care hospitals in the Island of Trinidad and their willingness to donate. In effect, it seeks to explain the extent these variables may play a part where the patients’ relatives are related to organ donation.

Both theories were founded on specific assumptions including that there was a causal chain that links behavioural beliefs, and normative beliefs to behaviour through attitudes and subjective norms. Both theories also focus on constructs that are concerned with individual motivational factors as determinants of the likelihood of performing a specific behaviour. Finally, they provide a systematic method of identifying those issues that are most important to a person’s decision about performing specific behaviours (Glanz et al., 2008). Since these theories came out of a need to understand the relationship between attitudes and behaviour (for example the knowledge attitudes and beliefs of patient’s relative towards organ donation), we believe their application to this study is appropriate.

The TRA was developed by Fishbein (1967) to better understand relationships between attitudes, intention and behaviours. Dillard & Pfau (2002) states, “the individual's intention to perform given behaviours is dependent on attitudes towards the behaviour and their subjective norms associated with the behaviour and determined by the individual’s beliefs about outcomes or attributes of performing the behaviour” (p.260). Thus, a person who holds strong beliefs that positively valued outcomes will result from performing the behaviour will have a positive attitude towards the behaviour. This can be applied to the process of organ donation for example where relatives who possess adequate knowledge, positive attitudes and beliefs towards organ donation would most likely positively consent to the process of organ donation.

The TPB developed by Ajzen in 1988, is an extension of the TRA. It includes an additional construct concerned with perceived control over performance of the behaviour. It asserts that a person will expend more effort to perform behaviour when his/her perception of behavioural control is high. Ajzen, (1991) states ‘TPB is designed to account for the range of personal and social influences that may impact on people's decision making’ (p.189).

TPB distinguishes between these three types of beliefs: behavioural, normative and control. According to Ajzen (1991), behavioural beliefs link the behaviour of interest to expected outcome which is belief that the behaviour will produce a given outcome. Normative beliefs refer to the supposed behavioural expectations of individuals or groups about whether or not significant people in their life would approve or disapprove of the behaviour and their motivation to obey with these expectations. Control beliefs on the other hand refer to an individual’s belief that he or she possesses the necessary resources, skills, and opportunities to aid or inhibit performance of behaviour. Thus, the more favourable the attitude and the subjective norm, and the greater the perceived control, the stronger the person’s intention to perform the behaviour in question should be (Hyde and White, 2009).

Thus we believe that the TRA and TPB are appropriate theoretical models that can be used to identify behaviour beliefs, normative beliefs and control beliefs that are relevant to the particular behaviour of the population under investigation (Glanz et al., 2008). These models have been used successfully to predict people's intentions and behaviours across the context of organ donation with varying results (Rocheleau, 2013).

2. Research Methodology

2.1 Design

A descriptive design was employed in the execution of the study (Polit and Beck, 2014). We investigated the issues of levels of knowledge, beliefs and attitudes of respondents towards organ donation in Trinidad.

2.2 Population/Sample

Patients’ relatives in the Intensive Care Unit (ICU) Departments at the Port of Spain General Hospital (POSGH) and San Fernando General Hospital (SFGH) in Trinidad were studied. These were those who are related by blood
or marriage, or who are the legal guardians of the patients admitted to the ICUs. This population was chosen because many patients in the ICU may have been identified as potential organ donors, but the relatives tend to show reluctance towards the donation of their relatives’ organs. With 9- and 6-bedded capacities at the POSGH and SFGH respectively, we estimated a sample of 90 and 60 respectively totalling 150 respondents. However, 133 representing 88.7% of the respondents consented and therefore were recruited for the study at 81 and 42 for POSGH and SFGH respectively.

2.3 Ethical Considerations

We received ethical approval from the University of the West Indies Ethics Committee, as well as the Ethics committees of the North West Regional Health Authority (NWRHA) and South West Regional Health Authority (SWRHA) prior to any data collection.

2.4 Instrument

Researchers’-designed questionnaire was used for data collection. The instrument consisted of Likert Scale type questions. The questionnaire was constructed in four sections, comprising a total of 29 questions. Section A consisted of 7 questions related to demographic data, section B consisted of 11 questions related to relative’s knowledge on organ donation, section C consisted of 4 questions to enquire the beliefs of relatives as it relates to organ donation, and section D consisted of 7 questions to determine the attitudes of relatives as it relates to organ donation. The instrument was pre-tested and adjudged to have the face and content validity.

2.5 Data Analysis

The data was collated manually, but analysed with the SPSS version 20. Descriptive Frequency tables were generated in response to objectives 1 to 3, while ANOVA tests were carried out to determine whether or not there are relationships among the knowledge levels, attitudes, and beliefs of the respondents and the respondents’ selected demographic characteristics.

3. Results

3.1 Socio-Demographic Characteristics

The result is presented according to the research questions. Table 1 illustrates the distribution of the research participants according to their socio-demographic variables. It shows that majority of the respondents were within the age group 28-37 (39.1%) followed by the age group 38-47 (30.1%). It also shows that the respondents were mostly females (67.4%), of African ethnicity (43.6%), Christians (63.9%) and married (35.3%).

To answer research questions 1, 2 and 3; Figure 1 illustrates the results. In the figure, it can be seen that 69.2% of the respondents have adequate to high knowledge levels. Also 86.5% of the respondents’ have positive belief while 57.9% of them have unfavourable attitudes towards organ donation.

The answer to research question 4 was illustrated in Table 2 that is indicating whether or not there is a relationship between (a) knowledge level of the respondents, (b) their attitudes and (c) their beliefs and the socio-demographic characteristics namely: (i) age, (ii) gender, (iii) ethnicity, (iv) religion, and (v) Marital Status. The result shows that the respondents’ levels of knowledge is associated with their age (p≤.035) and religion (p≤.015). It also shows that the subjects’ attitudes are significantly related with their gender (p≤.030) while their beliefs are significantly associated with their marital status (p≤.005).

| Demographic variables | f | %  |
|-----------------------|---|----|
| Age                   |   |    |
| 18-27                 | 18| 13.5|
| 28-37                 | 52| 39.1|
| 38-47                 | 40| 30.1|
| 48 and over           | 23| 17.3|
| Gender     |        |       |       |
|------------|--------|-------|-------|
| Male       | 48     | 36.1  |       |
| Female     | 83     | 62.4  |       |
| Other      | 2      | 1.5   |       |

| Ethnicity  |        |       |       |
|------------|--------|-------|-------|
| African    | 58     | 43.6  |       |
| East Indian| 39     | 29.3  |       |
| Chinese    | 9      | 6.8   |       |
| Mixed      | 24     | 18.0  |       |
| Other      | 3      | 2.3   |       |

| Religion   |        |       |       |
|------------|--------|-------|-------|
| Hindu      | 28     | 21.1  |       |
| Muslim     | 15     | 11.3  |       |
| Christian  | 85     | 63.9  |       |
| Other      | 5      | 3.8   |       |

| Marital Status |        |       |       |
|----------------|--------|-------|-------|
| Single         | 46     | 34.6  |       |
| Common law     | 20     | 15.0  |       |
| Married        | 47     | 35.3  |       |
| Separated      | 5      | 3.8   |       |
| Divorce        | 8      | 6.0   |       |
| Widowed        | 6      | 4.5   |       |
| Other          | 1      | .8    |       |

Figure 1. Knowledge Levels, belief and attitudes of participants towards organ donation
Table 2. ANOVA Related to Respondents’ Selected Socio demographic variables and their knowledge level, attitude and beliefs towards organ Donation

| Variable     | Knowledge | Attitude | Beliefs |
|--------------|-----------|----------|---------|
| Age          | 0.035*    | -0.242   | 0.147   |
| Gender       | 0.189     | -0.030*  | 0.079   |
| Ethnicity    | -0.062    | -0.046*  | -0.150  |
| Religion     | .015*     | -0.092   | 0.205   |
| Marital Status| 0.067     | -0.148   | -0.005* |

* P ≤ 0.05 significant level.

4. Discussion

The main findings of this study suggest that the knowledge levels of the respondents are generally high, and so is their positive belief in organ donation. However, they have higher unfavourable attitudes than their favourable attitudes.

Cumulatively, respondents with medium and high level of knowledge represented 69.2% of the population. This showed that generally there was a fairly good awareness level on the issue of organ donation. This supports the National Survey of Organ Donation Attitudes and Behaviours (2012), Jacob, Dana, Robinson, Perryman, and Thompson, (2008) that reported general high knowledge levels on the subject. On the attitudes, Zimberan (2015), had indicated that body image is becoming a significant reason for not engaging in organ donation which perhaps explains the result that 57.9% of the respondents have unfavourable attitudes to organ donation. This however is inconformity with a number of other scholars’ findings. For example, Mithra et al. (2013) indicated that although there is high level of awareness about organ donation, there are also a high proportion of the participants who do not have positive attitudes towards organ donation in south India. This study found that belief in organ donation is positive thus confirming findings from any other studies namely Zimberan (2015), Falomir-Pichastor, Berent and Pereira, (2010), Zhang et al. (2007), and El-Shoubaki (2005).

Overall, this study has shown that the patients’ relatives at the 2 major general hospitals have high knowledge, and positive beliefs but did not have favourable attitudes. From the theoretical background, humans behave in particular ways because of multiple influences from biological characteristics, environment, education and culture. We note that the TRA and TPB had explained how the concepts such as knowledge, attitude and beliefs regarding organ donation could be motivational factors which act as determinants of the likelihood of performing their specific behaviour such as decision to donate organ. We are of the view that all these 3 concepts are necessary when determining behaviour and posit that when any or a combination of any of the 3 is low, the effect will affect the degree of the expected behaviour. We believe that this is one of the extensions of the theories as explained by Glanz et al., (2008). Thus, in this study as the attitudes of the patients’ relatives remain low, irrespective of the knowledge levels or beliefs, we expect that the decision of the patients’ relatives at the 2 hospitals to donate organs will be negatively affected. This conclusion further agrees with other authors’ findings (Zhang et al., 2007; El-Shoubaki, 2005; Oliver et al., 2012; Irving, 2012)

5. Recommendations

We recommend an exploration of this attitudinal barriers to organ donation to include personal experiences on this sensitive topic of organ donation with an aim to influencing changes in personal attitude, values and opinion as they relate to the need for organ donation.

In Trinidad and Tobago, we recommend that the way forward is to create an enabling environment that will assist individuals and the public to change their attitude towards the topic of organ donation.

6. Conclusion

Our study comes at a time in Trinidad when organ donation is still in its teething stage despite the establishment of NOTU in 2006. The study identified factors such as knowledge, attitudes and beliefs of the researched population towards organ donation and showed that its attitude towards donation was not a favourable one. However, the way forward for the deceased donation programme is to create an enabling environment in the public that may change their general attitude towards it.
7. Limitations

We note that this study has some inherent limitation issues including but not limited to use of only 2 hospitals in Trinidad to the exclusion of the twin Island, Tobago, the manner of sampling patients’ relatives when their loved ones were in critical situation, and the general sensitive nature of the topic under investigation. The investigators however, underwent some training in Ethics, a requirement for granting ethics approval by the University of the West Indies, were very diligent, used all necessary skills and expertise in data collection, treatment, analysis and interpretation. We still recommend more inclusive studies before findings can be generalised to the population of Trinidad and Tobago.

Competing Interests Statement

None.

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