FAMILY DECISION-MAKING ABOUT ORGAN DONATION: A SYSTEMATIC REVIEW

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ABSTRACT
The family is an important factor that influences an individual’s decision for organ donation. The number of studies addressing the family’s role in organ donation is limited. It is imperative to explore these studies and offer recommendations that may help in addressing organ shortage. 15 studies with more than 2100 participants were selected for a systematic review. The studies were accessed by searching three databases: MEDLINE, Elsevier, and PsycINFO. This systematic review indicates that knowledge about brain death and the circumstances surrounding organ donation and transplantation are the most important factors that affect a family’s decision regarding organ donation. Educational efforts targeting the family should be initiated, which can then guide the family’s decision on organ donation. We suggest that educational efforts be consistent with other factors such as religious beliefs that influence the family’s decision.

Keywords: deceased donation, family decision, family education, living donation, organ donation

Introduction
Many factors are considered when an individual is making a decision on organ donation. A systematic review of 18 studies involving 1,019 participants revealed that there are eight main factors that influence an individual’s decision regarding organ donation. They are relational ties, religious beliefs, cultural influences, family influences, body integrity, interaction with the health-care system, knowledge about organ donation, and reservations about the process of organ donation (1).

Of these eight factors, the family is the most important. It is universally accepted that the family is responsible for shaping an individual’s ethical considerations. Consequently, it can have a bearing on a person’s willingness to donate organs. There have been only a very limited number of studies focusing on the family as the fundamental decision-making institution on organ donation. This paper aims to examine how the family institution plays a role in influencing the decision to donate organs.

There are three main reasons why we should focus on providing the family with information on organ donation if we are to improve organ donation. Firstly, the family can influence an individual to become a related living organ donor. Families are genetically and emotionally related to the patient, and they are often referred as potential donors before an appeal for organ donation is made to the public. Secondly, the family can provide the ethical basis and influence on an individual’s decision to donate organs. The family, for instance, can influence the individual to sign up for organ donation. Thirdly, the family plays a major role in deciding on deceased organ donation. In this context, the family is the final decision maker and have the legal right to overrule the consent of the deceased for organ donation made whilst still living. This is the legal procedure in most of the countries with organ donation systems (2). In Malaysia, for instance, the Human Tissue Act 1974 stipulates that the family’s consent has to be taken before procuring organ(s) from the body of their loved ones, even when the deceased had registered to donate his organs before his death.

Taking into account the above arguments, it is thus imperative that we analyze the literature on the influence of the family in organ donation. Three things are of interest to us. We would like to identify from the literature the various factors that determine families’ decision about encouraging living related organ donation. We would also like to examine the significance of the role various family members play in allowing relatives to pledge for organ donation. Finally, we would like to locate in the literature
This paper provides a precise summary of recent literature findings on family's decision making on organ donation. The studies included in this article were randomly selected from the limited number of available studies pertaining to the scope of this research. A wider systematic search of the literature may provide a more comprehensive review on this topic. We believe however that our review provides important guidelines for future research in this area.

Conclusion
We conclude that the improvement of organ donation rates through the family channel requires adequate and appropriate efforts to educate people about organ donation and transplantation, especially on brain death and the circumstances surrounding the issue. The lack of knowledge is the factor which may impede organ donation, whether living or deceased. In the case of living donation, more often than not, emotional factors influence not only an individual to become an organ donor but also a family's decision to put pressure on the prospective donor. However, the review suggests that emotional factors must be complemented by knowledge of living donation.

In the case of deceased organ donation, it is most important to educate the family members about the definition and condition of brain death, besides disseminating information regarding organ donation, such as body integrity, religious acceptance toward organ donation, as well as the process of organ procurement. Choosing the right time to request the family's consent to donate their loved ones' organs is crucial in this context.

Given our understanding of the importance of knowledge in influencing a family's decision and acceptance toward organ donation, it is of fundamental concern to tackle the issue of dispersing information to the family members. We suggest that future studies focus on answering the question of 'what are the appropriate educational methods to enhance family knowledge about organ donation and transplantation?'

Acknowledgments
The authors would like to thank Mr. Khaled Tafran who helped in preparing this manuscript and The Ministry of Education, Malaysia, and University of Malaya for funding the research under the Exploratory Research Grant Scheme and the University of Malaya Research Grant Scheme. This study has been granted with Exploratory Research Grant Scheme 2012 (Project No: ER019-2012A) and University of Malaya Research Grant Scheme 2013 (RG490-13HTM).

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