

Public knowledge and attitudes regarding organ and tissue donation: an analysis of the northwest Ohio community

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Abstract

Residents of Ohio, a midwestern state of the United States, were surveyed to determine their knowledge and attitudes toward organ and tissue donation. Sources of information on donation and the role of health care providers were also explored. One thousand participants were randomly selected from northwest Ohio to receive a survey distributed by mail. A total of 383 valid questionnaires were obtained. Respondents were knowledgeable about donation, with a mean correct knowledge score of 86%. However, four questions were answered incorrectly by nearly 25% or more of participants, indicating deficits in the community's knowledge. Over 96% of respondents had favorable attitudes toward donation. Both knowledge and attitudes were positively associated with willingness as well as commitment to donate. Health care providers were infrequently reported as sources of information on donation, yet nearly 60% would like their provider to discuss donation. Misconceptions represent potential barriers to donation. Therefore, public education should focus on the knowledge areas that show deficits. Results of the present study suggest that health care providers can play a critical role in educating patients about donation.

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1. Introduction

Organ and tissue transplantation has become a common lifesaving and life-enhancing procedure with excellent results. The improved success rate of transplants due to advances in technology and immunosuppression as well as the trend of a population that is living longer have contributed to a substantial increase in the number of patients awaiting transplantation [1]. In the United States, the number of individuals waiting for an organ transplant far surpasses the number of donor organs recovered each year. As of October 2003, there were over 82,000 patients on the National Organ Transplant Waiting List [2]. Transplantable tissues are also in demand to improve the quality of many patients' lives.

A solution to the high demand and critical shortage is to increase the number of organs and tissues recovered from

donors. Both cadaveric and living donor transplants are currently performed in the United States. According to the Organ Procurement and Transplantation Network (OPTN), there were 25,451 organ transplants performed in the United States in 2003, of which 18,648 were from cadaveric donors and 6803 were from living donors [3]. It is noteworthy to mention that since 2001, the number of living donors has exceeded the number of deceased donors each year [4]. However, since one cadaveric donor often provides multiple organs and tissues, cadaveric donation remains the major source of organs and tissues available for transplantation. While the scope of the present study was limited to aspects of cadaveric organ and tissue donation, the findings have implications for living donation as well.

With respect to cadaveric donation, researchers have reported that only 40% of all potential organ donors and 24% of potential tissue donors actually become active donors [5]. These statistics reveal inefficiency in the organ and tissue procurement process. Unfortunately, a major factor limiting the number of organ and tissue donors is the low rate of

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consent by families of potential donors. Siminoff et al. [5] found that more than 50% of families refused to grant consent for donation. While a survey of the general public suggests that nine out of 10 Americans support the concept of organ donation, many remain reluctant to donate their own organs or those of a deceased family member [6]. Numerous factors have been found to be associated with families' decisions to grant consent for donation including positive beliefs and attitudes toward organ donation and prior knowledge of the patient's wishes regarding donation, either through a signed donor card or prior discussion about donation with the patient [7]. Family sociodemographics and discussion with the family of topics such as the costs of donation, impact of donation on funeral arrangements, and the option for the family to choose which organs to donate also were found to be directly related to the donation decision [7]. Therefore, it appears that knowledge and attitudes regarding organ and tissue donation play a significant role in the decision to donate.

Studies have shown that Americans have many misconceptions and lack specific knowledge of organ and tissue donation and transplantation [1,6,8,9]. Common misconceptions involve fear of bodily disfigurement or fear that potential donors will not receive the same life-saving measures as others. There are mistaken beliefs that signing a donor card or granting consent for donation on a driver's license is all that is necessary to ensure a person's wishes, that brain death is reversible, that rich and famous people receive preferential treatment on the transplant waiting list, and that most religions are generally opposed to donation. Many also incorrectly believe that there is an age limit on organ donation, that people with medical conditions cannot be donors, and that a donor's family will have to pay extra medical bills associated with donation. Due to the numerous misconceptions, many donation and transplantation organizations including the United Network for Organ Sharing have compiled educational materials covering the common myths and the actual facts about the process [10–12].

Researchers have assessed not only the public's knowledge regarding donation but also correlations with willingness to donate. Accurate knowledge of how to make arrangements to donate, the role of next-of-kin, and the body's normal appearance after donation as well as the willingness to accept a donated organ have been found to be positively associated with the intention to donate [1]. Knowledge of organ donation facts has also been shown to be positively correlated with attitudes toward donation, willingness to donate one's own organs or those of a deceased family member, and request for a donor card when given the opportunity to do so [9].

Public attitudes toward donation have also been explored in the literature. In a national survey, 85% of the American population supported the concept of organ donation [6]. Nearly all Americans felt that organ donation allows something positive to come from a person's death, and a majority believed that donation helps families cope with

their grief [6]. Positive feelings about organ donation have been found to be derived from personal satisfaction, beliefs in the humanitarian benefit of donation, and feelings of pride in being a donor, while negative feelings have reflected fears of body mutilation and of receiving inadequate medical care [13]. Individuals with both strong positive attitudes and weak negative attitudes toward donation have been found to be the most willing to commit to donation and sign a donor card [13].

Researchers have reported considerable variation in the willingness and commitment to donate among various subgroups of the population, and the trends are consistent with the sociodemographic composition of the group of actual organ donors [14]. Regarding ethnicity, Caucasians have been found to be more willing to donate organs [6,14] or commit to donation by signing a donor card [15] than other ethnic groups. The two largest minority cultures in the United States, the African American and Hispanic communities, are the focus of a number of studies in the literature on organ and tissue donation. A study of attitudes, beliefs, and behaviors toward donation among African Americans found that nearly 87% of respondents support donation [16], yet significantly lower consent rates for organ donation among African American families as compared to Caucasians have been reported [8]. The Hispanic community is also reluctant to donate as compared to Caucasians [6]. However, Hispanics are more likely than African Americans to express their support and willingness to donate organs as well as to grant consent for the donation of a deceased family member's organs [6].

Religious beliefs also have been implicated as a potential barrier to donation. Despite the fact that organ and tissue donation is supported by all major religions [10–12], individuals often cite religious beliefs as their reason for choosing not to donate organs or tissues [6,17]. Compared to Caucasians, a greater percentage of African American and Hispanics feel that organ donation is against their religion [6], although there are no documented religious conflicts with organ donation and transplantation within these cultures [18].

Other demographic variables associated with willingness to donate organs and tissues are age and educational level. Research has shown that individuals 35–44 years of age and those with higher educational levels were more willing to donate organs than those of other groups [6,14,19]. Regarding gender, no statistically significant difference has been reported in the willingness to donate among males and females [6,14].

The lives of thousands of individuals can be saved or enhanced through an organ or tissue transplant. However, until the number of organ and tissue donors increases to meet the growing demand, transplantation will be limited to a small percentage of those individuals in need each year. There are many possible mechanisms to solve this dilemma, one of which involves public education. A thorough understanding of the public's knowledge and attitudes

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