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## **“Talk Is Cheap”: the Discrepancy Between Self and Next-Of-Kin Organ Donation Decisions**

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This research suggests that to increase organ donations we should focus on family members who are responsible for making the donation decision in real time. Two studies support this prediction demonstrating the gap between individuals’ willingness to donate his organs and his willingness to donate organs of his relatives.

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# “Talk is Cheap”: The Discrepancy between Self and Next-Of-Kin Organ Donation Decision

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## EXTENDED ABSTRACT

The medical demand for human organs suitable for use as transplants far exceeds the supply. Policy makers are trying to increase donation rates; despite the efforts to better understand individuals' decision-making process and to increase donation rates, the percentage of the people whose organs are donated post mortem remains relatively low.

In this project, we adopt a new perspective to the study of organ donations, and suggest that in order to increase post mortem organ donations, we should shift our focus away from the individual, and consider instead those who have the final word—the individual's family members. Specifically, we propose that there is a discrepancy between individuals' willingness to sign up as organ donors, and their willingness to donate organs of their loved ones. Importantly, we postulate that people are more likely to agree to donate their own organs than they are to donate the organs of their deceased relatives, and set out to find factors that can diminish this gap.

Generally, most individuals express positive attitudes toward organ donation (Moloney & Walker, 2002; Radecki & Jaccard, 1997; Singh, Katz, Beauchamp, & Hannon, 2002). There is evidence that a wide range of beliefs potentially underlie donation decisions, and that these beliefs largely fall into one of the categories of religious, cultural, knowledge, altruistic, and normative beliefs. However, an important problem is that the final decision whether to donate an individual's organs after his or her death is in the hands of someone else (close family), this requires that we consider the importance of these individuals in the decision making process. The fact that the actual donation decision is made by other people might explain the discrepancy between positive attitudes towards organ donation and the actual donations. Even when a patient has a signed organ donation card, the Organ procurement organization (OPO) often seeks family permission to proceed with donation. The Uniform Anatomical Gift Act (1968, revised 1987) established that a signed organ donation card is sufficient to proceed with donation, and it has been confirmed recently that such documents function legally as advance directives. In the United States, however, it is customary for the OPO to request permission from the next-of-kin due to fear of litigation (Hanto, Peters, Howard & Cornell, 2005).

Research on medical decisions shows that what may seem reasonable for one may be seen differently when acting on behalf of another, even when beliefs and values are similar (Raymark, 2000; Zikmund-Fisher, Sarr, Fagerlin and Ubel, 2006).

We conducted two studies to test whether the proposed gap between individuals' willingness to donate her organs and her willingness to donate organs of her relatives, exists. We also used this study to explore potential factors that could drive this discrepancy. In the first study we asked two different groups of participants to provide their attitudes and preferences with respect to donating their (Self), or their relatives (Relative) organs. Participants in the second studies were asked to provide responses for both Self and Relative organs.

### Study 1

In this study, we randomly assigned participants (108 undergraduate students in a major Israeli university) into one of four experimental conditions that manipulated decision type (Choice vs. Advice) and perspective (Self vs. Relative). First, participants read

an introductory neutral text about organ donations. Next, they faced simulated organ donation decisions.

The findings support our initial hypothesis in that participants' willingness to register as a donor was significantly higher than their willingness to consent donating a relative's organs (81% vs. 68%, respectively;  $F = 4.475, p < .01$ ). In contrast, participants were equally and highly likely (both 96%) to advise a friend they should register as donors and consent to donate a relative's organs. A series of binary logistic regressions revealed that of a host of potential predictors of likelihood to register/recommend organ donation, only prior discussion of the topic with family member was significant.

### Study 2

In the second study, we measured participants' ( $N = 117$ ; MTurk) willingness to register as organ donors and the likelihood they would agree to donate organs of a close relative. Interim findings show that 29% of respondents who were not already registered as organ donors (49%), are willing to register, 58% are undecided, and only 13% refuse. More importantly, consistent with the findings of Study 1, our data revealed a gap between participants' willingness to donate their organs and their willingness to donate the organs of their relatives/close others. While refusal rate to register as donors was at a mere 13%, refusal to consent to donate a relative's organs was higher, at 22% ( $\chi^2=19.53, df=1, p<.001$ ). Interestingly, 23% of individuals that have already registered as organ donors or expressed willingness to do so stated that they will refuse to donate a relative's organ after his or her death.

In sum, the findings presented herein provide good evidence for our assumptions and initial predictions. We found that there is a significant difference in individuals' willingness to donate their organs and their willingness to donate organs of their loved ones. This finding has major implications for anyone wishing to increase the number/percentage of organ donations, as the relatives of the deceased individuals often have the final word. There are various factors that could underlie the observed discrepancy, some of which are highlighted by our findings (e.g., religious beliefs, education). Additional research is required in order to better understand the relative impact each of these factors play in decreasing willingness to donate a relative's organs, and to further explore other potential factors such as uncertainty about one's preferences and predicted regret. Identifying the barriers to organ donation would allow us to prescribe potential approaches and interventions that could help health practitioners and policy makers increase the number of organ donations.

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