

Online Organ Solicitation: Finding a Kidney Donor Using the Internet from the Solicitor's Point of View

Background: As of January 20, 2012, there are 90,621 people in the United States waiting for a kidney transplant, based on current U.S. Organ Procurement and Transplantation Network data. In the last year, many people have been removed from the list after successfully receiving a kidney from an altruistic donor solicited online. These donors are both genetically and emotionally unrelated to the recipient, and are giving a kidney to a stranger. Solicitors find matches online through websites like thekidneyregistry.com, personal blogs, and Facebook. The number of kidney donors solicited online is almost certainly growing; this growth is expected to continue. Opinion pieces concerning donations solicited online have been written by nephrologists, transplant surgeons, and medical ethicists in recent years; nearly all of them call for further research on the myriad practical and ethical issues surrounding the topic. However, the amount of research in this area, especially from the point of view of the potential recipient, is paltry to date.

Objective: This exploratory study will explain, describe, and explore the online kidney solicitation process from the solicitor's point of view. Topics addressed include how individuals make the decision to look for a donor online, how they feel about the process, what tools they use to manage the online solicitation process, what other channels they are using to look for a donor, and how this process has affected their experiences as a transplant patient. The objective of this research is to develop a descriptive theory of online organ solicitation. This research has many practical applications: it will provide recipient-based evidence about the process for medical ethicists concerned with genetic unrelated donors, will aid in the development of online interfaces for organ sharing, and will provide a base of knowledge for potential solicitors.

Methods: 12 individuals will be interviewed twice and the content of their online solicitations will be harvested. Participants are either currently looking for a kidney donor online or have successfully solicited a donation from an online donor. Their personal blogs or Facebook pages have been located via Internet searches. Initial interviews are 30 to 45 minutes in length and semi-structured, allowing topics of interest to evolve and emerge. Transcriptions of the interviews are analyzed using grounded theory methods, particularly inductive coding and the constant comparative method. After the initial interview, online content from participants' solicitation pages will be harvested and also analyzed inductively. A second interview focuses specifically on the content posted online. Interviews will evolve to explore significant actions and processes that have newly surfaced in the data as analysis takes place. From the codes, a theory of online organ solicitation will emerge. This theory will be validated using data triangulation, member checking, and peer debriefing, all commonly employed techniques in grounded theory work.

Results: Research in progress.

Conclusions: Research in progress.