E-Health

"I want your kidney!" Information seeking, sharing, and disclosure when soliciting a kidney donor online

Kaitlin Light Costello *, Angela P. Murillo

School of Information and Library Science, University of North Carolina at Chapel Hill, Chapel Hill, USA

ABSTRACT

Objective: This study investigates how people use the Internet to search for an altruistic kidney donor. Although many opinion pieces on this phenomenon have been written, this is the first qualitative study focused on online kidney solicitation from the potential recipient's point of view.
Methods: Eight participants – four who successfully found donors and four who were still searching – were interviewed, and inductive content analysis was performed.
Results: Three themes appear in our data: choosing to go online to find a donor, information hubs, and information flow. These themes emphasize the process of information seeking and disclosure when using the Internet to find an altruistic kidney donor.
Conclusion: The benefits from searching online are not limited to the possibility of finding a kidney donor. Our participants also experience a wide variety of socially supportive activities from their online networks. Additionally, our participants felt that the potential benefits of finding a donor online outweighed risks to their privacy.
Practice implications: Not all potential recipients will find a kidney donor online. Participants indicated that through sharing educational information, staying positive, and actively maintaining their online solicitation efforts they received numerous social benefits even if they did not find a kidney donor.

© 2013 Elsevier Ireland Ltd. All rights reserved.

1. Introduction

On November 1, 2013, there were 98,597 candidates in the United States waiting for a kidney transplant, according to the U.S. Organ Procurement and Transplantation Network (OPTN). In 2011, 5139 people died while waiting for a kidney, greatly surpassing the mortality rate for all other organs. The median waiting time for a deceased donor is 3 years across all blood types. Living donations are possible and commonly come from family or friends. The waiting list continues to grow, and efforts to increase the number of donors are ongoing [1]. The responsibility to find a living donor is the job of the recipient, and many turn to people in their social networks in order to find potential donors [2,3].

Increasingly, individuals create, manage, and define their social networks online [4]. As part of this trend, individuals with end-stage renal disease (ESRD) have begun to turn to the Internet in search of a living kidney donor. In this search, they may discuss their need on YouTube, Facebook, Twitter, Craigslist, personal blogs, and kidney matching sites (e.g. [5,6]). The number of kidney donors solicited online is growing, and this trend is expected to continue [7].

Opinion pieces about this topic have been written recently by transplant surgeons, medical ethicists, and nephrologists; nearly all of these articles explain the pressing need for research in this area [7–11]. However, to the best of our knowledge only one study has been conducted that investigates online kidney solicitation [12]. This prior study looked specifically at organ matching sites, not at activity within one's existing social networks. Our study furthers an understanding of how and why ESRD patients and their caregivers use the Internet to find a kidney donor through focusing on the information seeking and sharing aspects of the process.

2. Methods

As is common in exploratory research, the researchers chose several areas of the phenomenon to explore rather than identifying a central research question, including:

- The decision to go online to find a kidney donor.
- Information seeking, sharing, and management processes undertaken by potential recipients and/or caregivers online.

* Corresponding author at: School of Information and Library Science, University of North Carolina at Chapel Hill, 216 Lenoir Drive, CB #3360, 100 Manning Hall, Chapel Hill, NC 27599-3360, USA. Tel.: +1 919 962 8366; fax: +1 919 962 8071.
  E-mail address: kaitcost@unc.edu (K.L. Costello).

• The tension between disclosing personal health information online and maintaining privacy.

After obtaining approval from our Institutional Review Board (IRB #12-0821), we began by searching Google and Facebook for people currently looking for a kidney donor online and people who had successfully found a kidney donor online. The following search terms were used: "need a kidney," "looking for kidney donor," "kidney donor wanted," "found a kidney online," "donated kidney to stranger," and "found donor on Internet". These terms were selected because they either correspond with commonly used titles of Facebook groups for people searching for kidneys or because they are often found in news articles about recipients who successfully found donors online.

Potential participants were contacted privately via email or Facebook messages. English-speaking patients and caregivers managing the solicitation process over the age of 18 were eligible. Participants who successfully located a donor online must have posted their initial solicitation on Facebook, Twitter, Craigslist, or YouTube between the dates of April 1, 2002 and April 1, 2012. The date range was wide to ensure that enough participants would be eligible, since this practice is fairly new. Participants that were still looking for a donor online must have posted their initial solicitation on one of the above sites between April 1, 2010 and April 1, 2012. A shorter date range was selected in order to ensure that participants were still actively searching for a donor online. Participants were offered a VISA gift card as a token of appreciation for their time. The researcher was able to recruit eight total participants – four in each category – a sufficient sample size for an exploratory study [13].

Between June and October of 2012, participants were interviewed over the telephone for approximately one hour about their experiences soliciting a kidney donor online. The interviews were semi-structured and included questions such as "Tell me a bit about why you decided to go online to find a kidney donor" and "What kind of health information did you decide to share online?" These interviews were recorded and transcribed. Pseudonyms were assigned to each participant.

Inductive content analysis was chosen to analyze the interview data. In this method, the researchers develop codes and categories from the data rather than applying an existing framework [14]. It allows for flexibility in the design of research, which means that it emphasizes meaning, consequences, and context, making it ideally suited for questions about a phenomenon or process [15,16].

Codes were developed with a focus on themes related to information seeking, information sharing, and disclosure from each interview. The resulting codes were collapsed into three main categories throughout the process, and descriptions of each code and category were made. Both authors coded all of the interviews; in order to assess reliability, Cohen's kappa coefficients were calculated for each category.

3. Results

Three main categories were developed: choosing to go online to find a donor, information hubs, and information flow. To assess inter-coder reliability, Cohen's kappa (κ) was calculated on all of the interviews, which were first coded by one researcher and then coded by the second. The formula was weighted according to source size. The average κ coefficient for all of the codes was .8798, indicating substantial agreement – particularly for exploratory research. The weighted κ coefficients for each category were also substantial (see Table 1).

Table 1
κ for each category.

Category name	κ
Choosing to go online to find a donor	.8793
Information hubs	.8743
Information flow	.8914

3.1. Choosing to go online to find a donor

Participants had often not found a match in their face-to-face networks, so they turned to the Internet to widen their search. Most participants decided to go online after hearing success stories from others in traditional media outlets or through friends: "Seeing someone else do this on Facebook kind of inspired me and gave me some strategies and ideas on how to proceed," said Ryan.

Participants felt that creating and maintaining an online presence was low-stress and low-cost, especially when compared with asking people face-to-face. "Saying 'Can I have your kidney?' – those are really hard words to say," explained Ted. Darren agreed: "The Internet is a very good way to reach a lot of people and there is no expense. It's easy to do. It was hard to go up to somebody and say, 'Hey, would you consider, maybe, seeing if we're a match?' It wasn't hard at all to send out a message on the Internet, because I wasn't staring somebody right in the face and asking them this incredible imposition – to have surgery on my behalf." Julio thought that potential donors appreciated having the process mediated by the Internet: "Being able to get information online and not actually have to talk to me directly about it… has been helpful. I think if I didn't put that information online, that perhaps a number of people that are getting tested… well, that would be a much smaller number."

While healthcare providers encouraged participants to find a living donor, they did not recommend that patients use the Internet in their search. As Harriet explained, "They all encourage you to go find living donors, and they always say, go to your family. They don't ever encourage you to go online and look." In fact, some participants said that their healthcare providers actively discouraged it, as Philip explains: "A number of the healthcare providers were hesitant to recommend using the Internet because of all the pitfalls that can come from putting the word out, for fear that we would be susceptible to maybe somebody preying on people like us." All of the participants were offered a kidney in exchange for payment; the common response to these queries was to block the offending party. "I have no interest in participating in purchasing a kidney from someone. The easiest thing for me to do is to just shut that conversation down," explained Ryan.

After going online with their need, participants were met with an outpouring of support, ranging from simple messages of solidarity to offers to get tested as a potential donor. "My online presence," says Ryan, "has served tremendously in really building an overwhelming sense of support." Participants also described the large volume of potential donors contacting their transplant center: "We flooded the hospital's call center," said Ted. Even when the solicitation did not cause a magnitude of donor responses, as has occurred in Julio's case, "there's this immense amount of emotional support and affirmation, on a daily basis."

3.2. Information hubs

Julio explained the process of creating an information hub online: "I decided to run this like a campaign. I created a brand, a website – I created information hubs. I needed to have some sort of hub that was always available to get people information, even when I was unavailable to get it to them," he explained. The hub allowed him and other participants to take days off due to fatigue.