Ethical implications of searching for a kidney donor online

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ABSTRACT
This paper describes an exploratory study investigating the ethical implications of searching for a kidney donor online. Semi-structured interviews were conducted with eight individuals – four people who found a kidney donor online and four people who were still searching – about the process of looking for an altruistic kidney donor on the Internet. To explore ethical issues discussed by participants, the interviews were coded using the resource-product-target model of information ethics. All three types of moral issues outlined in this model were present in the data. When viewing information as a resource, participants discussed their choice to go online to find a donor, the process of encouraging others to share their solicitation message, and ways of handling requests for payment in exchange for a donation. In the information-as-product perspective, people discussed the management of their online persona. Finally, the ramifications of patients and caregivers choosing to share personal health information online was discussed when participants considered information as a target. Several fruitful areas for future research are identified in this study, which is the first qualitative study investigating the phenomenon of searching for a kidney donor online – an area of great interest to information scientists, healthcare providers, medical ethicists, and chronic kidney disease patients.

Keywords
Information ethics, kidney transplantation, living donation, public solicitation, tangible support

INTRODUCTION
In the United States, there were 97,325 candidates on the waitlist for a kidney transplant as of August 23, 2013 (based on Organ Procurement and Transplantation Network data). These patients are typically on dialysis and will wait for an average of 1,100 days – just over three years – for a deceased donor kidney to become available (Danovitch, 2012). The number of people waiting for a kidney transplant is steadily increasing, while the number of donors – both deceased and living – has remained steady for the last 15 years (Organ Procurement and Transplantation Network, 2011). As such, efforts to increase the number of living donations are common (Shapiro & Breman, 2012). Living donor kidney transplants are also more successful: they last longer (an average of 13.8 years compared with 9.7 years for deceased donor kidneys) and can be performed preemptively – this means that the recipient is healthier and often not on dialysis when the transplant is performed, resulting in better health outcomes for the recipient (Organ Procurement and Transplantation Network, 2011). Living donor kidneys can either come from a related or an unrelated donor, although related donations are much more common. The burden to find a living donor is typically placed on the potential recipient.

Although living non-related kidney donation was once regarded with suspicion by medical ethicists and healthcare professionals, there has been a gradual acceptance of non-related kidney donations in the United States (Spital, 2000, 2003). It is now understood that living altruistic organ donors are not psychologically unstable or irrational; rather, they are likely motivated spiritual beliefs and a desire to help others (Henderson et al., 2003). Several studies have examined altruistic kidney donation from the donor’s point of view (Fellner & Marshall, 1968; Ross, 2002), and some have investigated the process of asking potential living donors to be tested to see if they are a possible match (e.g. Afifi et al., 2006; Waterman et al., 2006). However, these studies only examine how potential recipients discuss the issue with family or friends: to this researcher’s knowledge, to date no one has investigated how and why potential recipients ask strangers to be tested as kidney donors.

In recent years, people have turned to the Internet to aid them in their search for a kidney donor. Requests are made on YouTube, Facebook, Twitter, and on kidney matching sites, which are similar to dating sites (e.g. Block, 2010; Flood, 2009). This trend is growing as more recipients are successful (Williams, 2006) and at least 30% of transplant centers allow the practice, although this number is likely
higher now (Rodrique et al., 2007). One study examined the demographic characteristics of online solicitors on kidney matching sites and found that most individuals searching for a donor were white, married, over 40 years old, and on dialysis, although only .5% of the people on the waitlist were using the site they studied; however, the researchers did not investigate the motivations of solicitors (Rodrique, Antonellis, Mandelbrot, & Hanto, 2008).

Although the ethical issues of searching for a donor online have often been discussed (P. Brennan, 2006; Rodrigue et al., 2008; Wright & Campbell, 2006; Wright, 2008), no one has investigated the ethical questions that potential recipients face when making such a request. The resource-product-target (RPT) model of information ethics provides a framework for discussing these issues (Floridi, 2008). This poster presents preliminary data from a study on online kidney solicitation with a focus on these ethical issues.

METHODS
It is common in exploratory research to identify a general phenomenon without choosing a central research question; in this study, the phenomenon of searching for an altruistic kidney donor online was the central focus. The researcher investigated issues such as:

• What factors motivate people to go online to search for a kidney donor?
• How do searchers manage information during the process?
• What personal information do searchers share online as they search for a potential donor?

To locate participants, the researcher searched Google and Facebook for people who were looking for a kidney donor and for individuals who had successfully completed a donor search online, using the terms “need a kidney,” “looking for kidney donor,” “kidney donor wanted,” “found a kidney online,” “donated kidney to stranger,” and “found donor on Internet”. English-speaking patients and caregivers over 18 years old were eligible to participate in the study; they had to post their initial solicitation online between April 2002 and April 2012. Potential participants were contacted via email or direct message on Facebook or Twitter. The first four respondents in each group were enrolled in the study resulting in eight total participants. Each participant was offered a VISA gift card upon completion of the study. The University of North Carolina’s Institutional Review Board approved the study in April 2012 (IRB #12-0821).

Semi-structured interviews were conducted over the phone with each participant between June 2012 and October 2012. The interviews took approximately one hour and included questions like “Tell me a bit about why you decided to look for a kidney donor online,” “What kind of health information do you share online?” and “Do you share different information in different places online?” These interviews were recorded and transcribed, and pseudonyms were chosen for each participant.

To examine ethical issues discussed by participants, the transcripts were coded using deductive qualitative content analysis. The resource-product-target model of information ethics was used to code the data pertaining to information ethics from each transcript (Floridi, 2008).

RESULTS AND DISCUSSION
In the resource-product-target model of information ethics, there are three approaches to information ethics: those arising from viewing information as a resource, as a product, or as an interaction between an actor and their environment. It is essentially a schematic organization of the different types of information-ethics issues (Floridi, 2008). This section uses these three approaches to information ethics to describe the multitude of issues that arise when people try to locate a kidney donor online.

Information as Resource
Information is a valuable resource to be managed, which introduces many ethical questions. In this study, participants described many issues relating to information as a resource. Often, these issues are broken down into questions of availability, accessibility, and accuracy.

First, the availability of information – in this case, sharing the need for a kidney donor online – has ethical implications. In this study, sharing personal health information online – making it known that they needed a kidney donor – was a choice that participants largely felt like they did out of necessity. As Darren said, “[Finding a donor] is what you’ve got to do to survive, and that makes it really easy for me to justify [going online to look for a donor].” However, the choice to go online to solicit a donor was sometimes surprising. As Julio explained: “I never intended to be so forthcoming [about my illness online]. Then again, I never intended to have my kidneys fail.”

Second, the accessibility of that information also raises ethical questions. In this study, participants widened their social networks as a way to expand their search. One participant who worked at a large university had a personal policy of not friending students on Facebook until they graduated. However, he suspended this practice while looking for a donor: “It was against my better judgment,” he said, “but there’s a time in your life when you’ve got to say: ‘Judgment be damned.’” Participants also discussed how important it was for the information they shared to be accessed by as many people as possible, and they often encouraged this activity. Darren describes the process: “I said ‘even if you’re not interested in being tested, please do me a favor and forward the page.’ So you get this exponential effect.”

Finally, the accuracy of information was an issue. Participants noted exchanges that made them doubtful of the claims being made by potential donors. Bonnie
explains: “I had the sense of ‘I don’t know who this person is.’ I was a little apprehensive when someone came forward because as much as I wanted a donor… Facebook. Anyone can say anything on Facebook. I didn’t trust it until we had the surgery scheduled.” Philip chose not to respond to several “wackos that [he] didn’t deem… I didn’t want anything to do with.” This was particularly a problem with potential donors who wanted payment for their kidney, which every participant encountered even though it is illegal in the United States. The universal response was to block these potential donors; as Ryan said, “Once I understand what their intentions are, it's my ethics, my morals – if that is what their intentions are, I don't want to waste my time. There is no sense in me responding to them or having any further conversation.”

Information as Product
Individuals also produce information – often in response to using information as a resource – and this, too, has ethical implications. One of the frequently discussed issues in this approach to information ethics is the presentation of information. In this study, several participants discussed their presentation of self online. As Julio said: “I think that [sharing online] has helped me to, for better or for worse, build a brand of an injured person that does need help.”

Philip also described the process as a “campaign,” and Ryan discussed choosing what information to share as a “marketing strategy.”

These strategies employed by participants were often geared towards encouraging others to share their page; for example, Bonnie paid attention to which of her posts were shared more readily and changed her posting habits due to her observations. She posted more pictures of her husband and educational resources about kidney disease, for example, because these posts were more likely to be shared, effectively widening the audience for their search. Harriet also talked about posting pictures of herself: “I think posting pictures makes people contact me more, seeing that I am young. They say, ‘Oh, that’s a young girl. She’s been through so much.’”

Participants also discussed the need to stay positive online, because they were concerned that too much negative information would discourage sharing as it may be off-putting. As Ted said, “If I was having a really bad day, I couldn’t quite be negative. I had a sense of who was reading. Nobody had to have a bad day because of me.”

These findings highlight the concern that online kidney solicitations will become a “beauty contest” (Neidich, Neidich, Cooper, & Bramstedt, 2012). Patients who solicit donors online also must have the resources – including an Internet connection, time to post, and the savvy to build a personal brand that highlights the need for a kidney without being too negative about one’s dire condition – to effectively solicit a donor online. However, none of the participants were willing to consider paying for a kidney, despite claims that they would “do anything for a kidney,” as Bonnie put it. Future research applying marketing and advertising theories to questions of online organ solicitation would greatly benefit the ethical issues surrounding this aspect of the online organ solicitation process.

Information as Target
Information ethics from the target perspective is concerned with the interaction between an individual and their information environment; often, issues of privacy, confidentiality, and intellectual property are the focus of this approach. In this study, there were two moral issues that fit the information-as-target category: those related to caregivers sharing health information online for potential recipients, and those related to the ramifications of sharing personal health information online.

The participants that were caregivers for potential recipients discussed the privacy of their loved ones, who were all waiting for kidney transplants. These potential recipients were either too ill to manage the search process or were uninterested in looking for a donor online because they doubted the efficacy of the endeavor. An interesting aspect of personal health information disclosure online from the caregivers perspective was noted: since the information is not about them, they may have different privacy boundaries than the patients themselves. For example, Bonnie said: “I didn’t mind that it was personal information about my husband’s health, because I honestly would have done anything I had to do to get him a kidney. I didn’t care who I told, whatever, I just needed as many people as possible to know that he needed a kidney.” However, Bonnie’s husband was skeptical about the process, and she described him as a private person. Sharon also noted that her daughter was unhappy with some of the information that she shared online.

Several of the potential recipients also discussed the ramifications of looking for a donor online. In particular, many of the recipients who successfully located a donor online became objects of a great deal of media attention, making a great deal of their personal health information public knowledge. Darren explains: “There was all sorts of television coverage and newspaper coverage. It’s really weird, because I shared all these really intimate details of my life, and I don’t know if I want the whole world knowing all this weird stuff that went on with me.”

Both of these issues are concerned with personal health information privacy. Although there has been some research done that investigates disclosure of personal health information from patients to caregivers (Checton & Greene, 2012) and the disclosure of health information by caregivers to providers (Parrott, Duncan, & Duggan, 2000), to this researcher’s knowledge there are no studies that examine health information disclosure by caregivers online. This finding highlights the need for research in this area.
CONCLUSION
By applying the resource-product-target model of information ethics to the phenomenon of people using the Internet to search for a kidney donor, several issues were identified. Although many medical ethicists have discussed the myriad issues surrounding soliciting a kidney donor online, to this researcher’s knowledge no one has specifically examined the issue from the perspective of information ethics to date. Furthermore, no one has discussed these ethical issues with solicitors themselves.

This paper represents a preliminary step toward a more complete understanding of the ethical implications of searching for a kidney donor online. Several fruitful areas for future research were identified in this paper, including questions about the presentation of self online; the “beauty contest” aspects of solicitation; the application of advertising and marketing theory to online organ solicitation; and personal health information privacy online, both from the perspective of the patient and the perspective of the caregiver.

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REFERENCES


**Information ethics: Searching for a kidney donor online**

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**background**

98,024 people are currently waiting for a kidney transplant in the United States.

4,059 people died waiting in 2012.

Living donor transplants are more successful, but the burden to find a matching living donor is placed on the potential recipient.

**Some individuals go online to search for altruistic kidney donors.**

This trend is growing, but we know little about the phenomenon, especially from the recipient’s point of view.

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**method**

8 people*

4 currently searching
4 found a match online

*purposeful sample identified via Google and Facebook searches

Interviewed for 60-90 minutes

Interviews were recorded, transcribed, and participants were assigned.

Transcripts were coded using deductive qualitative content analysis and the resource-product-target model of information ethics.

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**Resource Product Target model of information ethics**

**any technology that radically modifies the ‘life of information’ is bound to have profound moral implications for any moral agent.**

( Floridi, 2008)

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**What ethical issues do potential recipients face as they seek and share information while looking for a donor online?**

**resource**

**management of information sought**

**product**

**presentation of information shared**

**target**

**effect of actions on information environment**

**people asking for payment**

Once I understand what their intentions are, it’s my ethics, my morals – if getting paid [for their kidney] is their intention, I don’t want to waste my time.

(Ryan)

**building a brand**

I think that [sharing my need online] has helped me to build a brand of an injured person that does need help, for better or for worse.

(Julio)

**caregiver disclosure**

I don’t mind that it was personal information about my husband’s health, because I honestly would have done anything I had to do to get him a kidney. I didn’t care who I told.

(Bonnie)

**information accuracy**

Anyone can say anything on Facebook. I didn’t trust it until we had the surgery scheduled.

(Bonnie)

**monitoring tone**

If I was having a really bad day, I couldn’t quite be negative. I had a sense of who was reading.

(Ted)

**sharing over time**

I shared all these really intimate details of my life, and I don’t know if I want the whole world still knowing all this weird stuff that went on with me.

(Darren)

**widening social network**

[Friending some people] was against my better judgment, but there’s a time in your life when you’ve got to say: “Judgment be damned.”

(Darren)

**information shared**

- Personal health information
- Photographs
- Testimonials from friends
- Educational materials
- Kidney-related news
- Pages for other seekers

**going viral**

They had never had a response to candidates for donation in the history of their transplant department. There were over 100 legitimate requests for applications.

(Philip)

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