

Insides Trading: What Impact Will Facebook Have on Organ Donations?

People are turning to social media to bridge the chasm between those in need of life-saving organs and those who can help. This offers hope but also introduces risks

By Larry Greenemeier | Tuesday, May 29, 2012 | 6 comments

Since launching in February 2004, Facebook has proved highly effective at creating opportunities for the average Web user to create campaigns that reach a mass audience. Most recently such opportunities have extended to organ donation, an area that could benefit from the social network's attention—controversy over its recent initial public offering aside, Facebook's membership is more than 900 million and growing.

Indeed, with demand for healthy organs for transplantation growing worldwide, Facebook has already become a popular channel for people soliciting kidneys, livers and other potentially lifesaving organs. Earlier this month the social network began offering members the ability to identify themselves as organ donors on their Facebook pages and to locate state organ-donation registries if they would like to become donors.

Last October a team of researchers at Loyola University Medical Center began tracking how Facebook was being used as a tool for connecting potential donors with those in need of an organ. The researchers focused on kidney solicitations in particular and studied 91 Facebook pages seeking kidney donations for patients ranging in age from two to 69. Of the Facebook pages studied, 12 percent reported receiving a kidney transplant and 30 percent reported that potential donors had stepped forward to be tested to determine whether they were compatible, the researchers recently reported at a meeting of the National Kidney Foundation. One page reported that more than 600 people had been tested as potential donors for a young child.

There was a broad range in terms of how much personal information people disclosed. Some Facebook pages simply asked people to donate, without providing any other information. Other pages provided great detail about patients who needed kidneys, including explicit medical histories and family photos as well as emotional accounts of hospital stays, emergency room visits, financial problems and the difficulties of living on dialysis, according to the researchers led by Alexander Chang, nephrology fellow at Loyola University Chicago Stritch School of Medicine.

The research findings also raised ethical concerns: 3 percent of the pages received offers to sell kidneys, mostly from people in Third World countries. Would-be donors typically asked for \$30,000 to \$40,000, even though selling organs is illegal in most countries. In addition, only 5 percent of pages mentioned the risks of kidney donation (such as possible internal bleeding and/or infection as a result of the surgery) and only 11 percent mentioned associated costs.

Scientific American interviewed Chang to find out more about his team's reasons for examining Facebook as a means of soliciting



VITAL SIGNS: Last October a team of researchers at Loyola University Medical Center began tracking how Facebook was being used as a tool for connecting potential donors with those in need of an organ.

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kidney donations, the potential impact that social networks could have on the organ-donation shortfall and the possible dangers posed by using Facebook to match those in need of an organ transplant with potential donors.

[An edited transcript of the interview follows.]

What inspired you to study social media—Facebook, in particular—as means for soliciting living kidney donors?

As a nephrology fellow, I became interested in this issue as the transplant waiting list continues to grow and is outpacing the donor pool (from both deceased and living kidneys). The only really growing segment of the donor pool is coming recently from donors not related to the patients receiving the kidneys, and it seemed to me that social media must be an extremely easy way for people to search for kidney donors, as people are connected via Facebook to large numbers of friends, family and acquaintances they would not normally interact with in person or even by telephone or e-mail. As I could find no research on the subject, I thought it would be important to characterize what people are currently doing and how they are going about doing it.

Are you and your colleagues also looking at other organs (the liver, for example) being solicited via Facebook?

We specifically looked at kidney donors, as this is my interest as a nephrologist but also because the issues of kidney donation are quite unique, as living liver donations do not occur very often (and incur more risk to the donor) and bone marrow donations usually entail very little risk to the donors.

What was your process for searching Facebook for kidney donors?

We created a search on October 3rd, 2011, and looked for terms including "kidney donor," "need kidney," "kidney donation," "seeking kidney," "find kidney" and "kidney search." We found 131 pages in English. Of these pages, only 78 specified the purpose of finding a kidney for a specific person. We found an additional 13 pages that had the purpose of finding a kidney for someone, linked from these 78 pages, giving us a total of 91 pages for our study.

What conclusions can you draw at this time about how much Facebook use contributed to making successful solicitations?

Since these are just publicly accessible pages on Facebook, certainly this is just a snapshot of how people are using Facebook, as Facebook gives users the option of making pages "private," and people may also be sending messages directly to their friends via the social networking site. Such messages would not be included in our study. Since we only studied 91 pages, and our information was only derived from what was shared by the Facebook page to the public, this work should be considered hypothesis-generating.

What I can say is that it is clear that social media are being used by people to look for kidney donors, and the transplant medical community needs to be prepared for this and some of the special issues its use may create. Moreover, people of all stripes and ages are using social media in this manner.

Based on the small sample, the study found that patients successful in soliciting people to be tested for donation were more likely to be white and received more than 50 messages posted by people visiting their page. Might the use of social media impact communities that generally have less access to organ donors?

We know that there is decreased access to organ transplantation in the African-American community, stemming from many issues including the overall health of different communities, natural distrust of the medical community engendered by previous past experiences (such as the Tuskegee syphilis study), and different views on organ donation in general. The majority of pages identified in my study were created by individuals for [other] individuals who are not ethnic minorities. But, theoretically, social media could have a positive impact on organ donation in minority communities as more and more people start to use social media.

Facebook's recent organ donor initiative began the day after Loyola researchers had concluded their study. What impact might Facebook's involvement have on organ donation?

This study was not designed to encourage people to solicit living kidney donors, but to merely examine what is going on the world of social media. I was actually surprised how few people even mentioned that people should, at the very least, sign up for their state's organ donor registries. So when Facebook announced their initiative I was very pleased, as I think we should be concentrating on maximizing the deceased donor pool first. Although the risks of donating a kidney are low, they are present, and I think anybody considering this option needs to be well informed of the risks.

Your research turned up Facebook pages created for the purpose of selling organs, which is generally illegal. Does the use of social media to solicit organ donations raise any new ethical concerns?

I think the ethical concerns are important; the use of social media in living kidney donation solicitation will magnify the issues that already face the transplant community. For instance, to accept an anonymous donor, it is necessary to make sure there are no ulterior motives (that is, financial or otherwise) that exist. The vast majority of the Facebook pages examined did not make mention of risks of donation or potential financial costs, such as the possibility of the donor having to take two weeks off of work as they recover from the surgery. While potential donors will receive this information eventually when they go to the transplant center, I think that mention of these risks and costs is well deserved, especially when one is asking someone for such a serious gift.

Anyone using Facebook to publicly solicit for kidneys may find themselves the target of individuals wanting to sell their kidneys, usually from Third World countries. I think that if someone wanted to use Facebook safely to inform their loved ones that they were in need of a kidney transplantation, they should be very careful about sharing their information, and know exactly who they want to share their information with. I would not encourage someone to make this type of request public, as it may attract people who want to donate kidneys solely for financial benefit. Rather, using social media may be an effective way to inform friends and family of the need for a kidney, and then a much more formal discussion can be initiated.

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