

PROFESSION

Facebook grapples with rules for patients seeking organ donors

■ The social media site already has shown it can send the organ donation message in an unprecedented fashion. Now it's trying to standardize the process.

By KEVIN B. O'REILLY ([HTTP://WWW.AMEDNEWS.COM/APPS/PBCS.DLL/PERSONALIA?ID=KOREILLY](http://WWW.AMEDNEWS.COM/APPS/PBCS.DLL/PERSONALIA?ID=KOREILLY)) amednews staff — Posted July 1, 2013

Officials at Facebook are exploring how to help patients in need of organ transplants use the social networking service to ask for help.

The functionality, which could go live by the end of 2013, would involve a default format intended to make it easier for patients to raise awareness of their plight while avoiding any hint of coercion or financial exchange.

"I'm very excited about this next step in using social media to help with the organ donation crisis, in collaboration with Facebook, to help people on the waiting list," said Andrew M. Cameron, MD, PhD, surgical director of liver transplantation at the Johns Hopkins Hospital in Baltimore. He worked with Facebook Chief Operating Officer Sheryl Sandberg, a Harvard University classmate, last year to enable an option on Facebook's site in which users could tout their organ donor registration or easily register if they had not yet done so.

"We have this cohort of more than 100,000 people waiting for an organ, 18 of whom die each day," Dr. Cameron said, noting that 80% of wait-list patients need kidneys. "If we could help these people find living donors, we could really get to the heart of the problem of the kidney shortage. It's incredibly awkward for people to do that, and you're asking a lot of a patient to know how to make that request. If we could use that existing social network and help them structure the ask and tell their story on Facebook to say, 'Hey, I have organ failure, and here's how to learn what it's like. If you're interested, here's how to find out whether you'd be an appropriate donor.' "

There already is evidence that Facebook can have a dramatic impact in the organ donation space. The functionality unveiled May 1, 2012, that allowed users to add their organ-donor registration status as a "life event" on their profile pages was quickly used by about 100,000 people. But what was unclear until recently was how many Facebook users were prompted by the site to become newly registered donors.

21-fold boost in registration

More than 13,000 used the site's functionality to link to state organ-donor registration systems to sign up, a 21-fold increase over the baseline number of registrations, according to a study published online June 18 in the *American Journal of Transplantation*. Nearly 12,000 more signed up as donors the following day, and about 40,000 signed up in May 2012, the study said.

There is a big gap between people's general perception that it is a good thing to register as an organ donor and their actual willingness to do so, driven by lingering concerns that one's status as an organ donor will impede lifesaving efforts, Dr. Cameron said.

"These misconceptions are difficult to break down, and they are certainly difficult to attack in a DMV-like setting," he added. "Not much good happens at the DMV. You're tired, you've been waiting in a long line and you want to get out of there. And the clerk asks, 'By the way, can we have your organs?'"

Regarding the proposed new functionality allowing Facebook users with organ failure to tout their transplant needs, Dr. Cameron acknowledged the ethical objections raised to similar online personal pleas. Indeed, studies have found that users are already posting to Facebook, asking for organ donors.

“There cannot be any degree of coercion, and there cannot be any financial transaction in the context of a living donation,” he said. “So the reason to do this with a Facebook app is to standardize and oversee the appropriate ask and answer. … At Hopkins, we looked at 100 Facebook pages where people on their own asked for and got a kidney, and very few included information on the risk to the donor and what it entailed. It’s already happening now, and we need to participate responsibly before something bad happens.”

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EXTERNAL LINKS

“Social Media and Organ Donor Registration: The Facebook Effect,” *American Journal of Transplantation*, published online June 18 ([link: http://www.ncbi.nlm.nih.gov/pubmed/23777475/](http://www.ncbi.nlm.nih.gov/pubmed/23777475/))

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