Social Media and Kidney Transplant Donation in the United States: Clinical and Ethical Considerations When Seeking a Living Donor

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A Twitter post showing a man in a sports jersey holding a sign telling of his need for a kidney went “viral.” After the sports team’s official account retweeted the original post, hundreds of thousands of Twitter users engaged with the tweet and many replied to the tweet asking about being a directed living kidney donor for the man pictured.

A waitlist patient’s Facebook post about their need for a living donor is seen by 100 local friends. Ten people contact the transplantation center mentioned in the post to initiate donor screening and evaluation.

Can both of these patients get the kidney they need by using social media?

**Social Media and Adults in the United States**

Social media encompasses a wide variety of internet applications that allow users to publish content and interact with networks of people. Examples of social media use and engagement range from updating one’s own profile and creating content to liking and commenting on posts, photos, and videos by others, as well as sharing and responding to third-party content and links. Pew research estimates that 68% of US adults use Facebook, and 88% of 18- to 29-year-olds use some form of social media. Importantly, the relative ease of access to social media enables users to share content that can quickly be spread to a large number of people. Although there are disparities in access to and use of technology, in the United States, the reach of social media and growth in smartphone use appears to have occurred with little difference based on gender, income, or education.

Recently, the kidney transplantation community has begun to explore outreach to and education of the general public through online platforms and social media. Studies have examined the effectiveness of social media in the organ donation sphere, from advocacy training programs to a smartphone application to guide Facebook posts on how to find a living donor. Such interventions have the potential to expand access to living donation by offering a virtual community for would-be recipients and candidate donors to communicate.

Social media has the potential to dramatically influence outcomes for kidney transplant waitlist patients by helping the search for a living donor as opposed to waiting for a deceased donor. Increased patient communication about the need for a transplant and a donor increases the likelihood of finding a living donor quickly, easily, and inexpensively through social media networks.

**Social Media as a Tool for Waitlist Candidates**

Social media platforms allow patients on the waitlist and their social network to be creative in coping with their experience and may even cause patient-created content to “go viral.” A majority of dialysis patients report feelings of isolation and up to 60% of solid-organ transplant patients experience depression, which has been associated with increased nonadherence to immunosuppression and graft loss. Facebook has the potential to empower patients with tools for self-care management, as well as help them forge relationships with providers and build a stronger community with fellow patients.

Targeted efforts to provide support to waitlist patients can improve their emotional well-being and thus help improve secondary health outcomes.

A widespread form of this support exists with Facebook groups, which are public or private communities that can cultivate spaces for like-minded people to virtually meet, share stories, and comment on similar challenges. Participating in groups gives patients the opportunity to ask questions of peers, share experiences, seek social support, and participate in activism. Previous studies have explored benefits of Facebook groups, although patient testimonials serve as the strongest evidence to the effectiveness of these efforts.
Using Social Media–Based Mobile Applications to Find a Living Donor

As the number of patients with chronic kidney disease increases, the shortage of organs available for transplantation becomes more severe. Posting on social media provides an outlet by which patients can speak to a broad audience. Our research group hypothesized that using social media to reach out to potential living donors would be more comfortable and less burdensome for waitlisted patients than navigating direct conversations with friends or family. Currently being evaluated in a research capacity, DONOR (www.thedonorapp.com) is a web-based application to enable waitlisted candidates to share their need for a live donor through social media.3,9 DONOR allows patients to create a story describing their need for a transplant, life with kidney disease, and life on dialysis (Fig 1). To our knowledge, DONOR is the only application designed for use on smartphones that was developed specifically for transplant candidates.10 Users can share their story through Facebook, Twitter, WhatsApp, text message, or e-mail. Patients can invite family members, friends, and other advocates as champions who can draft stories on behalf of a patient. When finished, analytics track user engagement with a story as a source of motivation for users to make updates to their story, thereby remaining involved with the story-writing process. In a pilot study among 54 adult transplant candidates without potential living donors at the time of enrollment, the majority of candidates using DONOR rated the technology “good” to “excellent” with regard to the installation process, readability, simplicity, clarity, and content. Compared with matched controls, candidates using DONOR were 6.6 times more likely to have a potential donor come forward on their behalf in the 10 months after enrollment.3

Mitigating Challenges and Harnessing Opportunities With Social Media

Disparities in patient access to tools and knowledge about how to effectively use social media must be considered. Likewise, unintended consequences of social media use for potential living donors should be identified and mitigated. Transplant hospitals that do not encourage the use of social media can inadvertently create more disparities in access.10 Age, among other disparities (eg, visual impairments), can influence how familiar patients are with technology or

Figure 1. The interface of the DONOR web-based application.
their knowledge about how to use specific platforms. Language barriers posed by English-only sites can deter users who have limited English fluency. The potential for competition for a limited number of living donors among a transplant candidate community can be problematic because transplant candidates and potential living donors can effectively “shop” to find their preferred donor or recipient. Advantages disproportionately flow to transplant candidates with the financial resources to buy technical support, those with a support network comfortable with technology, and those with more compelling or “attractive” stories. Although these individuals may not demonstrate a greater medical need, they perpetuate the “Beauty Pageant Effect.”

Social media provides a public forum in which undue influence, external pressure to donate, coercion, breaches in confidentiality, and attempted organ sales may arise to a larger degree than in traditional communications. While social media can circumvent anxieties of communicating with immediate social circles, increased risks may need to be assuaged. For example, to mitigate coercion risk, DONOR features content alerts that notify administrators of words or characters that may denote undue pressure (eg, pay, $, pressure, check, and dead). Location and other tracking data can be collected though apps and platforms. Privacy laws (eg, Health Insurance Portability and Accountability Act) require password-protected login for users and a method for users to eliminate all of their data. Finally, despite laws against the sale of organs, the risk for illegal activity exists. Ultimately, the transplant hospital is responsible for selecting appropriate donor candidates. Extensive psychological screening to assess motivation has been suggested for potential living donors coming forward from social media as one way to reduce risks for illegal activity and safeguard the integrity of the process.

Transplant hospitals and professionals hold a unique and powerful role to help patients effectively and ethically leverage social media to find a living donor, provide education, promote access, and address potential disparities at various stages on the path to a life-saving organ transplant.

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