Self-Referral Patterns of Living Kidney Donors via Social Media: Examining an Expanding Platform

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Kidney transplantation remains the therapy of choice for eligible patients with ESKD. Unfortunately, obtaining a deceased donor kidney transplant entails a lengthy wait for patients on dialysis. Living donor kidney transplant allows patients to receive a higher-quality kidney transplant in a shorter time, and has been endorsed by the American Society of Transplantation as a priority (1). However, living donor kidney transplants continue to represent a minority of kidney transplants performed in the United States (2). There are many potential barriers to living donation, but one of the main reasons is identifying a healthy and willing living donor (3,4).

The internet and social media present an opportunity for educating the public, sharing outcomes, and disseminating individual stories of transplant donors and recipients via official transplant center social media accounts on Facebook, Twitter, and Instagram. However, the effect of social media on living kidney donation has not been well studied. In this issue of Kidney360, DuBray et al. (5) publish their study of self-referral patterns of potential living kidney donors at Vanderbilt, with the goal of better quantifying the role of social media in self-referral, and characterizing those who self-refer as a result of social media versus direct verbal communication from the recipient. All potential living donors at Vanderbilt are asked to contact the program via an online living donor form, which also asks how the potential donor heard the recipient needed a kidney. A total of 7817 people self-referred for living donation over the 3-year period studied, with 53% (4174) of those having been petitioned or asked via social media.

The authors found that potential living donors who self-referred due to social media were younger (aged <40 years) and more likely to be female compared with those who were asked verbally by the recipient. Additionally, of those who self-referred due to social media, an overwhelming majority (80%) were what the authors termed “directed-altruistic” donors, meaning they were not related to, or friends with, the recipient to whom they were interested in donating. This remained true even after adjustment for age and sex. In contrast, those potential donors who self-referred after verbal communication were more likely to be related to, or a friend of, the intended recipient, and over the age of 40.

The study highlights the role social media can have in increasing living kidney donation in this era. Over a 3-year period, there were >3000 potential living kidney donors who came forward and were not related to, or friends with, their intended recipient, but had found the recipient via social media. This was compared with only around 200 directed-altruistic donors via verbal communication over the same period.

Whether the magnitude of the effect of social media on potential living donors will be found consistently at other centers remains to be seen. This study was also not able to further characterize motivation for wanting to donate, or how the donors chose their potential recipients. Furthermore, it did not indicate what proportion of patients who self-referred were evaluated or successfully donated a kidney.

The use of social media to obtain a living donor transplant has some unique potential logistic issues and ethical considerations for transplant centers. As discussed by the authors in this study, having multiple potential donors come forward for a recipient (i.e., viral posts) may lead to a strain on resources for the transplant center to identify a suitable donor and will likely require each center to have a process in place to successfully navigate this, while encouraging other potential donors to consider an alternative recipient or participate in nondirected donation. Use of social media to obtain a living donor kidney transplant may also disadvantage those who are older, or who have visual disturbances or language barriers, although it offers an alternative platform to those who do not have family or friends who are willing or able to donate a kidney (6). Consideration of coercion or other gain among those who come forward via social media will also need to be addressed, and this was a concern among members of the American Society of Transplant Surgeons in a survey on using social media to increase living kidney donation (7). Furthermore, the potential donors in this study who came forward as a result of social media were more likely to be younger and female, a demographic that already disproportionally makes up living kidney donors (2).

In summary, this study by DuBray et al. (5) quantified the role of social media in self-referral at their transplant center, and characterized potential donors who self-referred due to social media versus direct verbal communication from the recipient. Although...
further research is needed, and the ethics surrounding using social media to find a donor should be addressed, social media has the unique potential to widely disseminate the stories of those in need of a kidney transplant, raise awareness of living donation, and make living donor kidney transplant an option to many more patients than previously possible.

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Author Contributions
E. Joachim wrote the original draft, and reviewed and edited the manuscript.

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