Kidney360

Impact of Social Media on Self-Referral Patterns for Living Kidney Donation

Bernard J. DuBray[1], *Saed H. Shawar*[2], *Scott A. Rega*[3], *Kristin M. Smith*[3], *Kaylin M. Centanni*[3], *Kara Warmke*[3], *Beatrice P. Concepcion*[2], *Gretchen C. Edwards*[4], *Heidi M. Schaefer*[2], *Irene D. Feurer*[5] and *Rachel C. Forbes*[1]

Abstract

Background As the organ-shortage crisis continues to worsen, many patients in need of a kidney transplant have turned to social media to find a living donor. The effect of social media on living kidney donation is not known. The goal of this study is to investigate the influence of social media on those interested in donating a kidney.

Methods Self-referrals for living kidney donation from December 2016 to March 2019 were retrospectively reviewed. Age, sex, race, and relationship of individuals petitioned through social media (SM) were compared with those petitioned through verbal communication (VC). Data were analyzed using chi-squared tests, with z tests of column proportions, and multivariable logistic regression.

Results A total of 7817 individuals (53% SM, 36% VC, and 10% other) were self-referred for living kidney donation. The analysis sample included 6737 adults petitioned through SM ($n=3999$) or VC ($n=2738$). Half ($n=3933$) of the individuals reported an altruistic relationship, and 94% of these respondents were petitioned through SM. Although univariate analyses indicated that SM respondents were younger, more likely female, more likely White, and more likely to have directed altruistic intent than those petitioned through VC (all $P<0.05$), multivariable logistic regression demonstrated that only decreased age, female sex, and relationship were significantly related to likelihood of SM use (all $P<0.001$).

Conclusions The use of SM to petition living kidney donors is prevalent and accounts for a greater proportion of respondents compared with VC. SM respondents tend to be younger, female, and altruistic compared with VC. Directed altruistic interest in kidney donation is almost exclusively generated through SM.

KIDNEY360 1: 1419–1425, 2020. doi: https://doi.org/10.34067/KID.0003212020

Introduction

Despite technologic advances in medicine and increased awareness of organ donation, substantial gaps exist between the supply and demand for kidneys needed for organ transplant (1). Although there are >60,000 active candidates waiting for a kidney transplant, only 22,003 kidney transplants were performed in 2018 (2). To narrow this gap, many efforts and initiatives have been implemented to increase the knowledge and awareness of individuals on the importance of donation, particularly living donation (3,4). Living-donor kidney transplantation represents the optimal therapy for patients with ESKD, with several clinical benefits compared with prolonged dialysis or deceased-donor kidney transplantation. These advantages include better patient and graft survival, improved quality of life, and reduction in wait-list time to transplant (5–7). Despite these benefits, living-donor transplants continue to represent a small proportion of transplants performed (8).

Living kidney donors can be further characterized on the basis of their recipient. Directed donors have an intended recipient, whereas nondirected donors do not. Those solicited to become donors by the recipient, or an agent of the recipient, are considered directed donors. Although all donations are considered an act of altruism, an altruistic relationship indicates the donor does not know the recipient (nonfamily, nonfriend, nonacquaintance).

A key component of the internet is social media (SM) and the networks it creates. SM has revolutionized the way we think and interact with each other. Platforms such as Facebook, Twitter, and Instagram are now used by at least one in four people worldwide (9). The Pew Research Center, which provides information on social issues and demographic trends, showed 72% of the public (>223 million people) use some type of SM in the United States. Facebook users alone totaled 2.7 billion people in October 2020, which is about a third of the total population of earth (10).

[1]Division of Kidney and Pancreas Transplantation, Department of Surgery, Vanderbilt University Medical Center, Nashville, Tennessee
[2]Division of Nephrology and Hypertension, Department of Medicine, Vanderbilt University Medical Center, Nashville, Tennessee
[3]Vanderbilt Transplant Center, Nashville, Tennessee
[4]Division of General Surgery, Department of Surgery, Vanderbilt University Medical Center, Nashville, Tennessee
[5]Departments of Surgery and Biostatistics, Vanderbilt University Medical Center, Vanderbilt Transplant Center, Nashville, Tennessee

Correspondence: Dr. Bernard J. DuBray, Vanderbilt University Medical Center, 1313 21st Avenue South, 912 Oxford House, Nashville, TN 37232. Email: bernard.j.dubray@vumc.org

SM has influenced all aspects of modern-day life, including health and wellness. Recent studies demonstrate the positive effect of SM on smoking rates, alcohol abuse, nutrition, exercise, and preventive medical screenings (11). The US Food and Drug Administration has used SM to track the spread of communicable diseases and to monitor adverse medication events (12).

Information-technology applications within the realm of kidney donation have also proliferated, including patient-based website applications (13), telehealth for patient care (14), smartphone applications (15), online education modules, and post-transplant monitoring (16). The importance of SM for donation has been evaluated with living donors by the Johns Hopkins team partnering with Facebook. Facebook agreed to alter its timeline platform to allow Facebook members to specify their status as an organ donor in May 2012. This initiative was dramatically effective and led to improving the number of new donor registrations by approximately 21-fold the day after implementation, and by a 5.8-fold increase over baseline over a 13-day period. This phenomenon is called the "Facebook effect" (17).

In 2009, our center introduced an online referral form for living kidney donors that gathers data, including demographic, clinical, and social information, such as the relationship to their intended recipient (13). The aims of this study are to (*1*) evaluate and quantify contemporary utilization of SM by those who self-refer to be living kidney donors, and (*2*) characterize those who self-refer *via* SM compared with those who use verbal or standard communication. A better understanding of the utilization patterns of SM from those interested in donating a kidney may allow for increased conversion of interested donors into actual donors.

Materials and Methods

Individuals interested in kidney donation at Vanderbilt University Medical Center are directed to complete an online, living-donor referral form (Figure 1). Information collected from the referral form includes basic demographic information and medical history pertinent for screening potential live kidney donors. Data from individuals interested in kidney donation were collected and managed using Research Electronic Data Capture * REDCap) electronic data capture tools at Vanderbilt University Medical Center (Nashville, TN) (18). REDCap is a secure, website-based

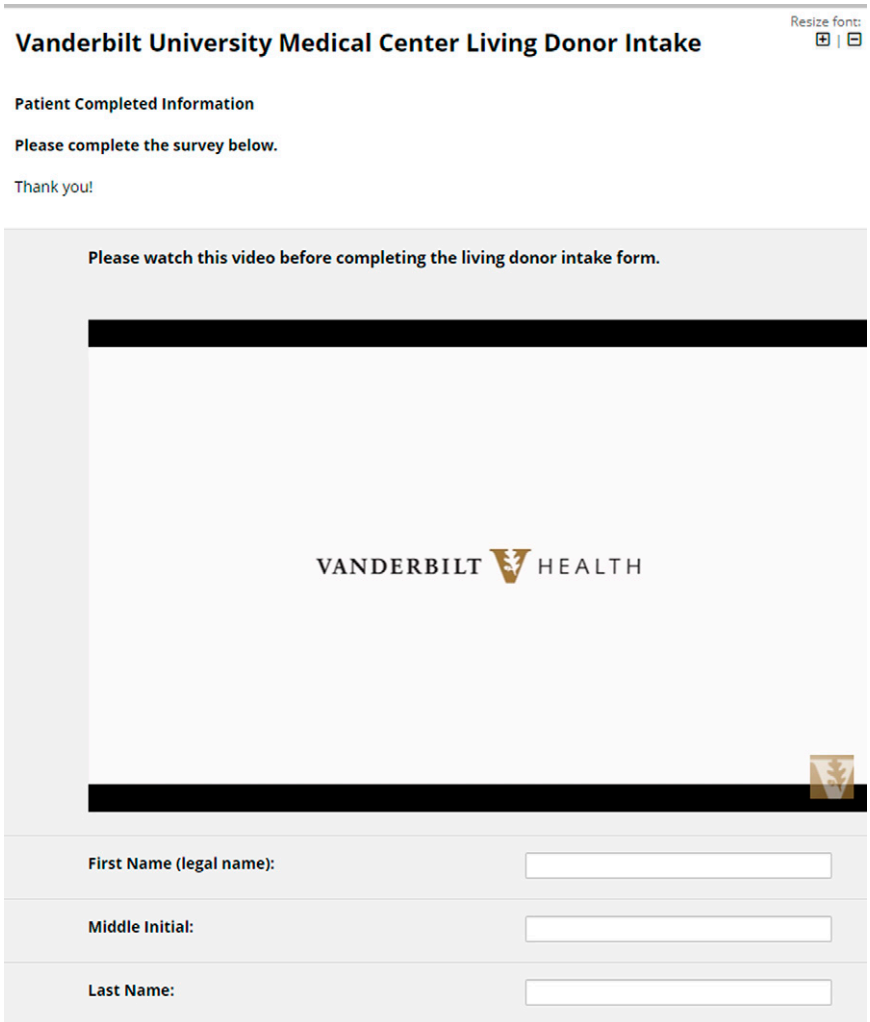

Figure 1. | **Vanderbilt University Medical Center living-donor intake form.**

Table 1. Characteristics of referrals

Characteristics	Social Media (n=3999), n (%)	Verbal Communication (n=2738), n (%)	P Value	Total (n=6737), n (%)
Sex[a]			<0.001	
Male	670 (17)	815 (30)		1485 (22)
Female	3312 (83)	1913 (70)		5225 (78)
Age (yr)			<0.001	
18–39[b]	2881 (72)	1362 (50)		4243 (63)
40–59[b]	1001 (25)	1111 (41)		2112 (31)
≥60[b]	117 (3)	265 (10)		382 (6)
Race			<0.001	
White[b]	3699 (93)	2363 (86)		6062 (90)
Black[b]	180 (5)	301 (11)		481 (7)
Asian	16 (0.4)	18 (0.7)		34 (0.5)
Other/unknown	104 (3)	56 (2)		160 (2)
Relationship			<0.001	
Immediate family[b]	7 (0.2)	605 (22)		612 (9)
Friend[b]	487 (12)	1334 (49)		1821 (27)
Other relative[b]	51 (1)	527 (19)		578 (9)
Directed altruistic[b]	3179 (80)	214 (8)		3393 (50)
Other/unknown[b]	275 (7)	58 (2)		333 (5)

Table entries are n (column %).
[a]n=6710.
[b]Column percentages differ (P<0.05).

application designed to support data capture for research studies.

After institutional review board approval, intake forms from December 2016 to March 2019 were retrospectively analyzed. Adults (≥18 years) petitioned through SM were compared with those petitioned through verbal communication (VC). The respondents' answer to the question "How did you hear that this person needed a kidney?" defined the cohorts, which were considered directed on the basis of solicitation. The SM cohort comprised those who were petitioned through "web-based services that allow individuals, communities, and organizations to collaborate, connect, interact, and build community" (19). These services included Facebook, Twitter, and Instagram. The VC cohort comprised those who were verbally petitioned by the potential recipient, a family member of the potential recipient, or a friend of the potential recipient.

Characteristics of respondents included age (in years, and stratified as 18–39, 40–59, ≥60 years), sex, race (White, Black, Asian, Other/Unknown), and relationship to recipient (immediate family, friend, other relative, altruistic, other/unknown). Directed altruistic donor referrals did not know their intended recipient. Differences in categoric variables between SM and VC cohorts were analyzed using chi-squared tests with z tests of column proportions. Multivariable logistic regression was used to evaluate the effects of age, sex, race, and relationship on the likelihood of SM use. Data were analyzed using IBM SPSS statistical software (version 25; IBM, Armonk, NY) and statistical significance was interpreted if nondirectional P values were <0.05.

Results

The initial respondent cohort included 7817 persons who self-referred for living kidney donation during the study period. Of these, 4174 (53%) were petitioned through SM, 2828 (36%) through VC, and there were 815 (10%) for whom the contact mechanism was unknown, which resulted in

Table 2. Multivariable model of the likelihood of social media use

Model R^2=0.68 (P<0.001), N=6710	Estimate	P Value	Odds Ratio (95% CI)
Age (yr)	−0.022	<0.001	0.98 (0.97 to 0.98)
Female sex (ref: male)	0.328	0.001	1.39 (1.15 to 1.67)
Race (ref: White)		0.67	
Black	−0.148	0.37	0.86 (0.62 to 1.19)
Other/unknown/Asian	0.022	0.93	1.02 (0.64 to 1.62)
Relationship to recipient (ref: immediate family)		<0.001	
Friend	3.320	<0.001	27.67 (13.01 to 58.85)
Other relative	2.017	<0.001	7.52 (3.38 to 16.73)
Directed altruistic	6.933	<0.001	1025.45 (479.29 to 2193.97)
Other/Unknown	5.848	<0.001	346.69 (155.80 to 771.44)
Constant	−3.718	<0.001	

Ref, reference.

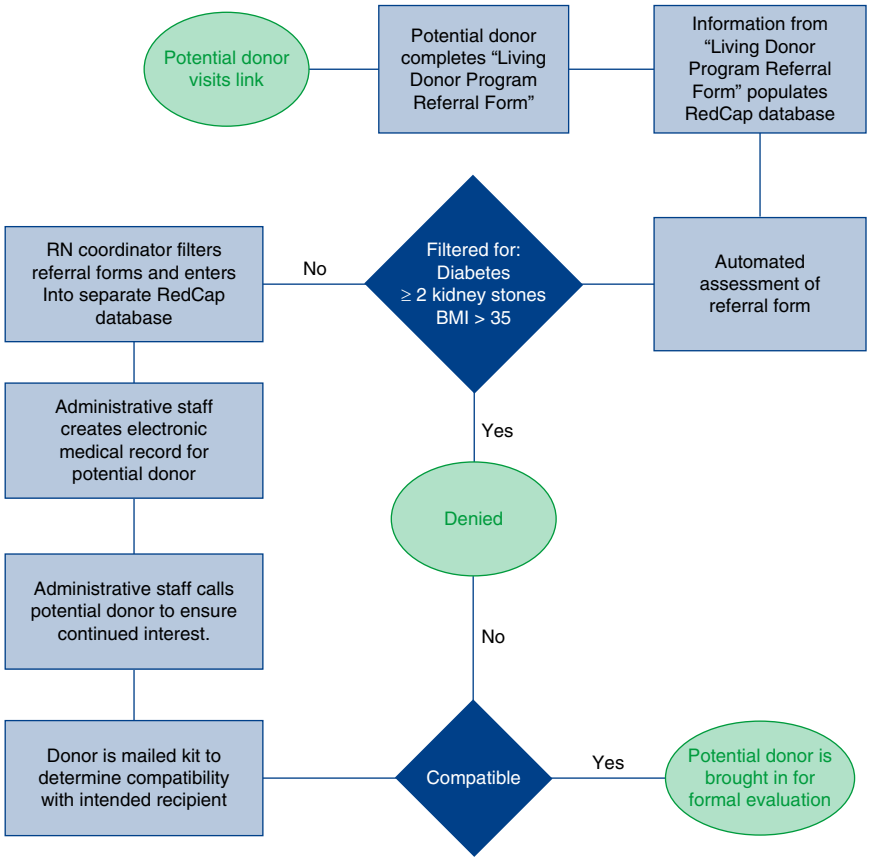

Figure 2. | **Standard living-donor request process map.** BMI, body mass index; RN, registered nurse.

a minimum percentage petitioned through SM of >50%. Age was reported to be ≥18 years in 7490 (96%) of respondents.

The analysis sample included 6737 adults who were petitioned *via* SM or VC, which represents 86% of the initial respondent cohort (Table 1). SM respondents were significantly more likely to be female compared with VC respondents ($P<0.001$). The distribution of respondents differed between SM and VC for all age groups ($P<0.001$), with the majority of SM respondents being ages 18–39; whereas VC respondents were more evenly distributed between the 18–39 and 40–59 age groups. Half (50%) of persons who self-referred for living kidney donation reported an altruistic relationship. Among these 3393 individuals, 94% were petitioned through SM, which represents a significantly higher (all $P<0.05$) use of the SM route among directed altruistic donors compared with those whose reported relationship to the recipient was immediate family (1%), friend (27%), other relative (9%), or when the relationship was other/unknown (83%).

Additional univariate analysis (Table 1) indicated that (*1*) SM respondents were more likely to have directed altruistic intent than those petitioned through VC (80% versus 8%, $P<0.001$); (2) VC respondents tended to be family members or friends of the intended recipient, whereas proportionally fewer SM respondents reported this relationship ($P<0.001$); and (3) White respondents were more likely to have been petitioned for living kidney donation through SM. However, the comprehensive multivariable logistic regression demonstrated that only younger age, female sex, and relationship to recipient were significantly related to the likelihood of SM use (Table 2). After adjusting for age and sex, although friends and other relatives were more likely to use SM than immediate family (odds ratio 95% CI, 3.4 to 58.9), directed altruistic donors were overwhelmingly more likely to use SM (odds ratio 95% CI, 479 to 2194) (all $P<0.001$ compared with immediate family).

Discussion

These findings demonstrate that SM is an important source for living-donor referrals. More than half of all self-referrals to our living kidney donor program were made through SM, with more than half of those referrals being directed altruistic respondents. Direct VC by family or friends continue to be important factors for those self-referring as living donors.

Our study found females between the ages of 18 and 39 were more likely to self-refer for kidney donation through SM, and those ≥40 years of age were more likely to use VC. This is not unexpected because SM use in the younger cohort is more pervasive (20). Additionally, increased interest among women reflects known sex imbalances in living kidney donation (21). Multivariable analysis showed that, after adjusting for age and sex, there was no effect of race on the likelihood of SM utilization. These data also

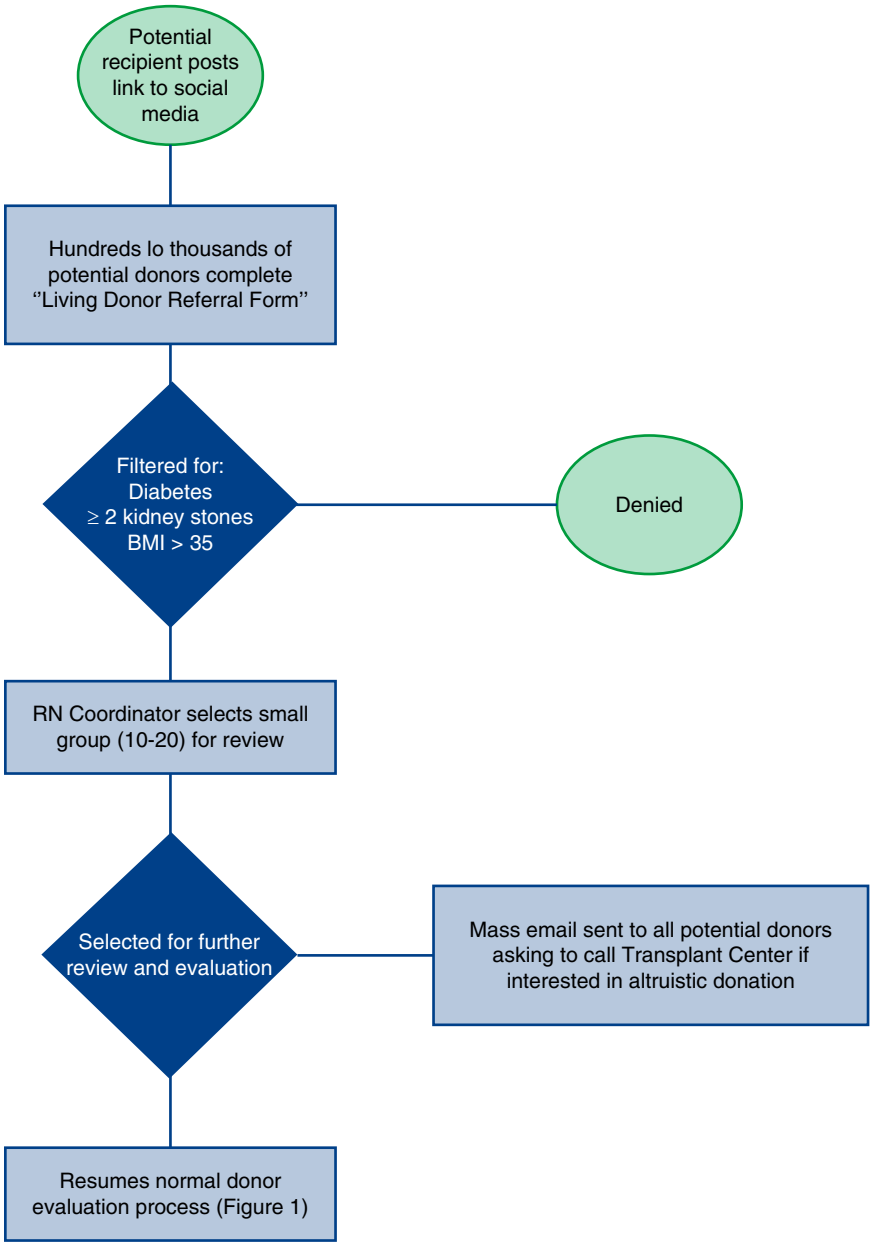

Figure 3. | **Social media surge living donor request process map.** BMI, body mass index; RN, registered nurse.

suggest SM is reaching a large and steadily growing number of persons who may be willing to be nondirected donors, as evidenced by the overall proportion of directed altruistic respondents who were petitioned through SM compared with VC. These data do show a benefit in using SM to increase living kidney donor referrals.

Our online self-referral process linked to a REDCap database is a unique resource among transplant centers. It allows for the ability to collect and analyze meaningful variables that affect the process of living donation. With an improved understanding of who is interested in becoming a living kidney donor, we can design protocols and processes aimed to reach specific groups of individuals. However, there are limitations to the study. First, this represents a single-center study and the results may not be representative of other geographic areas. Additionally, once a recipient has an approved living donor, we do not continue evaluating additional donors. Therefore, we do not know how many additional donors would have been approved for other recipients. We recently implemented a process *via* email that contacts those who have self-referred for a patient who has found a living donor. Instructions to contact our center are provided should individuals want to continue their evaluation as a nondirected donor.

SM surges or viral posts, defined as a large number of electronic donor requests at one time (>20–1000 s), pose logistic challenges in identifying suitable donors for the intended recipient, while not missing the opportunity for possible nondirected donors. Through engagement of key stakeholders and staff, we have now developed

a mechanism for processing living-donor requests after a SM surge to expand our donor pool by more readily identifying a donor for the intended recipient and engaging with altruistic donors, while minimizing the burden on staff, to allow for a streamlined operational efficiency during these times. The surge protocol now follows up with all of those who completed the online form with an email asking them to respond if they would like to continue with the living kidney donor process, although their intended recipient has already found a donor. With these processes, we hope to promote and support the use of SM in our living-donor referral program, and better engage directed altruistic donors to proceed with nondirected donor evaluation and donation (Figures 2 and 3).

There are ethical implications of SM use and identifying living kidney donors. The "identifiable victim effect" suggests individuals act differently toward identified victims rather than "statistical" victims (22). Through a personalized approach, SM platforms evoke empathy that could manipulate an individual's decision to donate. This underscores the importance of the psychosocial aspect of the donor evaluation. Given that petitions through SM are relatively young and female, special consideration should be given to overall readiness to donate in terms of age, lifelong follow-up, and other issues, such as postdonation pregnancy. Black and older individuals use SM disproportionately less; therefore, future research to understand attitudes and digital behaviors of these groups may be beneficial in obtaining increased living-donor interest and transplant.

Overall, SM seems to be an important mechanism for increasing living-donor awareness and interest, and ultimately may be an avenue to increase nondirected kidney donation. The processes we have created to further engage interested directed altruistic SM referrals will be further evaluated to assess transplant rates. Our data suggest that SM represents an effective tool to increase directed altruistic kidney donors' interest, especially among females <40 years old. The transplant community should consider SM and the effect that it has on living kidney transplantation. With further investigation and ethical considerations, SM represents a valuable resource for educating and engaging living kidney donors, the majority of whom are directed altruistic donors.

Disclosures

All authors have nothing to disclose.

Funding

This work was supported by Vanderbilt Institute for Clinical and Translational Research grant UL1 TR000445.

Acknowledgments

Portions of this article were presented as an abstract (number P-56) at the American Society of Transplant Surgeons 20th Annual State of the Art Winter Symposium.

Author Contributions

K.M. Centanni, B.P. Concepcion, B.J. DuBray, G.C. Edwards, I.D. Feurer, R.C. Forbes, H.M. Schaefer, K.M. Smith, and K. Warmke reviewed and edited the manuscript; B.P. Concepcion and B.J. DuBray were responsible for investigation; B.J. DuBray was responsible for data curation; B.J. DuBray and I.D. Feurer were responsible for validation; B.J. DuBray, I.D. Feurer, R.C. Forbes, and S.A. Rega were responsible for methodology; B.J. DuBray, I.D. Feurer, R.C. Forbes, and S.H. Shawar wrote the original draft; B.J. DuBray and R.C. Forbes were responsible for visualization; B.J. DuBray, R.C. Forbes, and S.H. Shawar conceptualized the study; I.D. Feurer and S.A. Rega were responsible for formal analysis; and R.C. Forbes provided supervision.

References

1. Langone AJ, Helderman JH: Disparity between solid-organ supply and demand. *N Engl J Med* 349: 704–706, 2003 10.1056/NEJMe038117
2. OPTN/SRTR 2018 annual data report: Introduction. *Am J Transplant* 20[Suppl s1]: 11–19, 2020 10.1111/ajt.15671
3. Lentine KL, Schnitzler MA: The economic impact of addressing the organ shortage with clinically high-risk allografts. *Mo Med* 108: 275–279, 2011
4. Treat E, Chow EKH, Peipert JD, Waterman A, Kwan L, Massie AB, Thomas AG, Bowring MG, Leeser D, Flechner S, Melcher ML, Kapur S, Segev DL, Veale J: Shipping living donor kidneys and transplant recipient outcomes. *Am J Transplant* 18: 632–641, 2018 10.1111/ajt.14597
5. Rodrigue JR, Schold JD, Mandelbrot DA: The decline in living kidney donation in the United States: Random variation and cause for concern? *Transplantation* 96: 767–773, 2013 10.1097/tp.0b013e318298fa61
6. Kostro JZ, Hellmann A, Kobiela J, Skóra I, Lichodziejewska-Niemierko M, Dębska-Ślizień A, Śledziński Z: Quality of life after kidney transplantation: A prospective study. *Transplant Proc* 48: 50–54, 2016 10.1016/j.transproceed.2015.10.058
7. Wolfe RA, Ashby VB, Milford EL, Ojo AO, Ettenger RE, Agodoa LY, Held PJ, Port FK: Comparison of mortality in all patients on dialysis, patients on dialysis awaiting transplantation, and recipients of a first cadaveric transplant. *N Engl J Med* 341: 1725–1730, 1999 10.1056/NEJM199912023412303
8. Hart A, Smith JM, Skeans MA, Gustafson SK, Wilk AR, Castro S, Foutz J, Wainright JL, Snyder JJ, Kasiske BL, Israni AK: OPTN/SRTR 2018 annual data report: Kidney. *Am J Transplant* 20[Suppl s1]: 20–130, 2020 10.1111/ajt.15672
9. Whiteman H: Social media: How does it affect our mental wellbeing?, 2015. Available at: http://www.medical-newstoday.com/articles/275361.php. Accessed June 15, 2020
10. Aslam S: Facebook by the numbers: Stats demographics & fun facts, 2017. Available at: https://www.omnicoreagency.com/facebook-statistics/. Accessed June 15, 2019
11. Kazley AS, Hamidi B, Balliet W, Baliga P: Social media use among living kidney donors and recipients: Survey on current practice and potential. *J Med Internet Res* 18: e328, 2016 10.2196/jmir.6176
12. Graham-Brown MPM, Oates T: Social media in medicine: A game changer? *Nephrol Dial Transplant* 32: 1806–1808, 2017 10.1093/ndt/gfx276
13. Moore DR, Feurer ID, Zavala EY, Shaffer D, Karp S, Hoy H, Moore DE: A web-based application for initial screening of living kidney donors: Development, implementation and evaluation. *Am J Transplant* 13: 450–457, 2013 10.1111/j.1600-6143.2012.04340.x
14. Forbes RC, Broman KK, Johnson TB, Rybacki DB, Hannah Gillis AE, Hagemann Williams M, Shaffer D, Feurer ID, Hale DA: Implementation of telehealth is associated with improved timeliness to kidney transplant waitlist evaluation. *J Telemed Telecare* 24: 485–491, 2018 10.1177/1357633X17715526
15. Kumar K, King EA, Muzaale AD, Konel JM, Bramstedt KA, Massie AB, Segev DL, Cameron AM: A smartphone app for increasing live organ donation. *Am J Transplant* 16: 3548–3553, 2016 10.1111/ajt.13961
16. Karl BC, Finkelstein SM, Robiner WN: The design of an internet-based system to maintain home monitoring adherence by lung transplant recipients. *IEEE Trans Inf Technol Biomed* 10: 66–76, 2006 10.1109/TITB.2005.855531
17. Cameron AM, Massie AB, Alexander CE, Stewart B, Montgomery RA, Benavides NR, Fleming GD, Segev DL: Social media and

organ donor registration: The Facebook effect. *Am J Transplant* 13: 2059–2065, 2013 10.1111/ajt.12312
18. Harris PA, Taylor R, Thielke R, Payne J, Gonzalez N, Conde JG: Research electronic data capture (REDCap)--a metadata-driven methodology and workflow process for providing translational research informatics support. *J Biomed Inform* 42: 377–381, 2009 10.1016/j.jbi.2008.08.010
19. Sloan L, Quan-Haase A, editors: *The SAGE Handbook of Social Media Research Methods*, London, Sage Publications, 2016 10.4135/9781473983847
20. Chou W-YS, Hunt YM, Beckjord EB, Moser RP, Hesse BW: Social media use in the United States: Implications for health communication. *J Med Internet Res* 11: e48, 2009
21. Prasad GVR: Understanding the sex disparity in living kidney donation. *J Eval Clin Pract* 24: 999–1004, 2018 10.1111/jep.13015
22. Moorlock G, Draper H: Empathy, social media, and directed altruistic living organ donation. *Bioethics* 32: 289–297, 2018 10.1111/bioe.12438

Received: May 20, 2020 **Accepted:** October 16, 2020

See related editorial, "Self-Referral Patterns of Living Kidney Donors via Social Media: Examining an Expanding Platform," on pages 1337–1338.