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Identifying Potential Kidney Donors Using Social Networking Websites

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Abstract

Social networking sites like Facebook may be a powerful tool for increasing rates of live kidney donation. They allow for wide dissemination of information and discussion, and could lessen anxiety associated with a face-to-face request for donation. However, sparse data exist on the use of social media for this purpose. We searched Facebook, the most popular social networking site, for publicly available English-language pages seeking kidney donors for a specific individual, abstracting information on the potential recipient, characteristics of the page itself, and whether potential donors were tested. In the 91 pages meeting inclusion criteria, the mean age of potential recipients was 37 (range: 2–69); 88% were U.S. residents. Other posted information included the individual's photograph (76%), blood type (64%), cause of kidney disease (43%), and location (71%). Thirty-two percent of pages reported having potential donors tested, and 10% reported receiving a live donor kidney transplant. Those reporting donor testing shared more potential recipient characteristics, provided more information about transplantation, and had higher page traffic. Facebook is already being used to identify potential kidney donors. Future studies should focus on how to safely, ethically, and effectively use social networking sites to inform potential donors and potentially expand live kidney donation.

Keywords

living donors; live kidney donation; Facebook; social networking; kidney transplantation; social media

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Introduction

For the appropriately selected end-stage renal disease (ESRD) patient, kidney transplantation is the best treatment, offering on average 10 additional life-years, a better quality of life, and lower medical costs compared to treatment with dialysis [1–3]. Despite efforts to increase community awareness of kidney donation and transplantation, there remains a growing gap between the number of kidneys needed and those available. Expanding live donor kidney transplantation (which currently comprises 40% of all U.S. kidney transplants) could narrow this gap [3]. However, rates of live kidney donation have declined in recent years, with a shift from genetically-related donors to genetically-unrelated donors [3–5].

Several barriers to live kidney donation exist, including reluctance to initiate conversations about kidney donation with potential donors, concerns of financial and health risk to the donor, and lack of knowledge about the kidney donation process[6–10]. Use of the internet to identify and educate potential donors may overcome some of these barriers; indeed, a few commercial websites have been established for the sole purpose of finding altruistic donors [11,12]. General social networking sites, such as Facebook (now boasting 955 million active users worldwide) [13], offer a free (and currently unregulated) platform for dissemination of information about live kidney donation to friends, family members, acquaintances, and even strangers. While there have been reports of kidney donations facilitated by social media[14], the use of social networking sites in identifying potential live donors has not been formally investigated.

With the hypothesis that social networking sites are already being used by transplant candidates to identify potential live donors, we studied the use of Facebook for this purpose. Our objective was to characterize Facebook pages created to find potential live kidney donors, transplant candidates using this modality, and factors associated with successful campaigns.

Methods

Data source

Data were obtained from Facebook, a social networking site that allows individuals to communicate and share information with pre-designated friends and/or the general public. Publicly available Facebook “pages” (personal websites) were identified using Facebook’s search engine. Information was abstracted from the page “wall,” an area where page authors and other Facebook users can read and post messages visible to the entire Facebook community [15].

Search and Abstraction Strategy

To avoid influence by existing social networks, a new Facebook user profile was created using the research team’s email address; this profile had no “friends,” no stated institutional or geographical affiliation, and was not a member of any Facebook groups. Therefore, only pages whose authors chose the most public settings were accessed. Pre-specified search terms included “kidney donor,” “need kidney,” “kidney donation,” “seeking kidney,” “find kidney,” and “kidney search.” To eliminate the possibility of temporal changes in Facebook, all searches were performed on a single day (October 3, 2011).

All search results were screened. Pages were included if they had a stated purpose of finding a live kidney donor for a specific person. We excluded non-English pages and pages that contained no information. Page links to other public Facebook pages related to identifying live kidney donors were investigated and included in the study if they fulfilled inclusion

criteria. The first 25 results were analyzed by 3 investigators (AC, EA, HT) to develop clear criteria for abstracted information to promote consistency and facilitate data organization[16]. Information was then abstracted by a single investigator (AC), and independently verified by another (HT) between October 3–26, 2011 (time was of the essence as Facebook is continuously updated). A kappa statistic was calculated to assess agreement between the two coders. Inter-rater agreement for abstracted categorical data was excellent (Kappa statistic = 0.99). Disagreements were resolved by an independent adjudicator (EA).

All abstracted information was publicly available and further de-identified for the purposes of this study (i.e., no names or other identifying information was collected or stored in our records). No contact was made with any potential kidney transplant recipients or donors. This study was determined to be exempt by the Loyola University Health Sciences Division Institutional Review Board.

Data Collection

Personal information abstracted from each page included the potential transplant recipient's age, location, cause of kidney disease, blood type, dialysis and previous transplant status, and relationship to the page author. Abstracted page content included mention of paired kidney donation, the length/wait of the transplant list, and the risks and costs of donation; in addition, the provision of a transplant website, requests to sign up for the organ registry or donate money, and encouragement by the page author to "spread the word" (e.g., "Please like my page and invite all your friends!") were noted. Abstracted page traffic information included the number of wall posts by the page author and by others, and the number of "likes," a feature on Facebook that allows individuals to give positive feedback on a webpage[15].

Outcome Ascertainment

The primary outcome was donor testing. The outcome was adjudicated based on wall posts by either the author or other users (e.g., "Thanks to the 3 people who have stepped up and been tested!" or "I just had my blood tests done, let me know when you find out if I am suitable."). The secondary outcome was receipt of a live donor kidney transplant, which was also adjudicated from wall posts (e.g., "Thanks to Susan for donating her kidney to me!").

Covariates

Three composite variables were constructed to represent different characteristics of Facebook pages we thought might be important in successful campaigns: 1 – a personal information composite (representing the amount of personal information shared); 2 – a transplant information composite (representing the amount of transplant-specific informational page content); and 3 – a page traffic composite (representing the amount of page activity). For the personal information composite, pages were given a point for including each of the following: the potential recipient's photograph, age, cause of kidney disease, blood type, location, a link to a personal website, and mention of family's ability to donate (score 0–7; 7 = most information provided). The transplant information composite awarded a point for each of the following: mention of the length of the transplant waiting list, mention of paired kidney donation, and provision of a transplant website (score 0–3; 3 = all mentioned on page). For the traffic composite, pages were given a point for having each of the following: ≥ 25 wall posts by others, and ≥ 200 likes, corresponding to the highest quartiles of these variables (score 0–2; 2=highest page traffic).

Statistical Analysis

Page characteristics and composite variables were compared by primary outcome (having donors tested) using chi-squared or t-tests for categorical and continuous variables, respectively. Multivariate logistic regression was used to assess the relationship between primary and secondary outcomes and the three composite covariates, which were standardized to allow for easier interpretation. A sensitivity analysis was done expanding the secondary outcome to include any reported kidney transplants. Missing data were handled using complete case analysis. All analyses were done using STATA 11.1 (Stata Corporation, College Station, TX).

Results

Search Results

The initial search resulted in 131 pages. Pages were excluded for the following reasons: not related to kidney donation or no mention of a specific potential transplant recipient (22), no posted information (25), not in English (2), and removed from Facebook prior to data abstraction (4). From the remaining 78 pages, we identified an additional 13 linked pages that fulfilled our search criteria, for a total of 91 pages included in our study (Figure 1).

Page Characteristics

Of the 91 pages, 78% provided information about the relationship between page author and potential recipient. Thirty-seven percent of these pages were created by the potential recipient, 31% by the son or daughter of the potential recipient, and 32% by other family members or friends. Disclosure of personal information included the potential transplant recipient's photograph (76%), blood type (64%), cause of kidney disease (43%), age (33%), dialysis requirement (44%), history of transplant (14%), and location (71%); 14% provided a link to a personal website, and 25% mentioned the ability of family/friends to donate. Risks and costs of donation were infrequently mentioned (6% and 12%, respectively). Ten percent of pages asked people to sign up for organ registries, and 17% asked for monetary donations, either to the potential kidney recipient or to national organizations. There were offers to sell kidneys posted on 3% of the pages.

Potential transplant recipient characteristics

Fifty-two percent of potential recipients were female, mean reported age was 37 (range 2–69, standard deviation 16), and every United Network for Organ Sharing (UNOS) region except region 4 (Texas and Oklahoma) was represented. Eight pages reported international locations (England, Kuwait, India, and Canada). Reported causes of kidney disease included polycystic kidney disease (39%), congenital disease (18%), lupus nephritis (13%), diabetes mellitus (13%), IgA nephropathy (5%), and other causes (13%). Of the 58 pages reporting the individual's blood type, the most common blood type was type O (50%), followed by type B (29%), type A (14%), and type AB (7%).

Outcome incidence

A total of 29 (32%) pages reported donors being tested (Table 1), with one page reporting >600 people tested for a highly sensitized young child. Of the 13 pages that reported receiving a kidney transplant, 3 received deceased donor transplants, 9 received live donor transplants, and one page did not provide enough information to determine the donor type. Relationships between donor and recipient included: co-worker (1), wife's cousin (1), family friend (1), altruistic donors (4), and unreported (2) (Table 1).

Factors Associated with Having Potential Donors Tested

There was no significant difference in age between individuals who had potential donors tested and those who did not (35.0 vs. 38.6, p=0.6) (Table 2). Pages of successful campaigns more often represented US residents (100% vs. 79%, p=0.02), and provided more personal information (age, location, cause of kidney disease, blood type, photograph, personal website) (Table 2). Pages of individuals who had donors tested were more likely to provide a link to a transplant website (59% vs. 27%, p=0.01), encourage page visitors to "spread the word" (79% vs. 42%, p=0.001), have ≥ 200 "likes" (60.7% vs. 8.1%, p<0.001), ≥ 25 wall posts by the page author (69.0% vs. 3.2%, p<0.001), and ≥ 25 wall posts by others (72.4% vs. 4.8%, p<0.001).

Association of Composite Variables with Having Potential Donors Tested

Individuals who had potential donors tested had higher mean personal information (5.0 vs. 3.5, p<0.001), transplant information (1.2 vs. 0.6, p=0.01), and page traffic (1.3 vs. 0.1, p<0.001) composite scores than individuals who did not have donors tested (Table 2).

In multivariate analysis using standardized composite scores, the page traffic score (adjusted odds ratio (aOR) 3.8, 95% CI: 1.9–7.5, p<0.001) remained significantly associated with having potential donors tested whereas the personal information (aOR 2.1, 95% CI: 0.9–4.8, p=0.1) and transplant information (aOR 1.5, 95% CI: 0.8–2.9, p=0.2) composite scores did not (Table 3). Of note, these scores were significantly correlated with each other: personal and transplant information composite (r=0.3; p=0.006), personal information and traffic composite (r=0.5; p<0.001), transplant information and traffic composite (r=0.3; p=0.01).

Factors Associated with Receiving a Live Kidney Transplant

Individuals who received live kidney transplants had higher mean personal information (5.4 vs. 3.9, p<0.001) and traffic (1.9 vs. 0.3, p<0.001) composite scores than individuals who did not receive live kidney transplants. Mean transplant information composite scores were similar for both groups (1.0 vs. 0.8, p=0.5). In multivariate analysis using standardized composite scores, only traffic composite score (aOR 6.8, 95% CI: 1.5–29.7, p=0.02) was significantly associated with receiving a live kidney transplant. No association was found between personal information (aOR 1.7, 95% CI: 0.4–7.0, p=0.4) or transplant information (aOR 0.7, 95% CI: 0.3–1.6, p=0.4) and receiving a live kidney transplant (Table 4). In sensitivity analysis, expanding the secondary outcome to include all reported kidney transplants resulted in similar findings (data not shown).

Discussion

This study demonstrates that a varied group of transplant candidates are already using social networking sites to locate live kidney donors. Furthermore, it suggests that the use of social networking sites may be effective in connecting potential donors to transplant candidates. Thirty-two percent of Facebook pages seeking live kidney donors reported testing of potential donors, and 10% reported receiving live kidney transplants. Pages waging successful campaigns tended to provide more information about the transplant candidate as well as live donor transplantation in general, and they experienced higher page traffic. Although only higher page traffic was associated with having donors tested after multivariate adjustment, this analysis was likely hindered by the relatively small sample size and collinearity between composite variables.

While our findings should be considered only hypothesis-generating, this study hints at the potential promise of social networking sites for increasing live kidney donation. Facebook has already proven highly effective in promoting deceased kidney donation. A Facebook

initiative launched on May 1, 2012 [17] resulted in 100,000 individuals declaring themselves as organ donors on Facebook, 10,000 signing up for their state organ registries through Facebook, and several state registries reporting significant increases in registered donors – all by the following day [18]. The potential for similarly facilitating live donor identification seems high: Facebook allows users to interact with people they already know, reconnect with old acquaintances, and meet new people. Information from a user can be transferred rapidly to friends (the average Facebook user has 229 friends) [19] or even strangers, who can respond and/or forward information to their own friends.

In addition to the ability to rapidly disseminate information to potential donors, social networking sites also allow for networking among those afflicted with disease[20–23]. Many individuals with kidney disease lack knowledge about transplantation in general [6,9], and misconception about live kidney transplantation is strongly associated with reluctance to initiate discussions about live kidney donation [9]. Furthermore, while reluctance to initiate discussions with friends or family about live kidney donation is common[10], this could be eased by a non-directed, public forum that does not require face-to-face contact or even initiation by the potential transplant recipient himself. In our study, 63% of pages were created by someone other than the potential recipient. Proxies working on behalf of intended recipients have had great success in other settings: in a pilot study, “live donor champions” (trained transplant candidate advocates) significantly increased the rate of donor testing and live donor transplantation compared to matched controls[24]. Live donor champions identified potential donors through the use of all manners of social media, including email, internet and local publications[24].

The use of social networking sites could be an effective method of addressing demographic and socioeconomic disparities in transplantation as well. Racial disparities have been well-documented at nearly every step of the transplantation process [25–28]. Specifically, live donor transplantation is less frequent among African-Americans[29]. Among adults who use the Internet, the Pew Internet and American Life Project reported that there are no significant differences in use of social networking based on race/ethnicity, household income, or education level[30]; this suggests that efforts to educate potential recipients regarding the use of social media could benefit all races and ethnicities. However, African-Americans and Hispanics are less likely to have access to the Internet compared to whites (74%, 73%, and 83%, respectively) [31], and more likely to have low health literacy[32]. Individuals with lower e-health literacy (the ability to use emerging information and communications technologies to improve or enable health and health care) may derive less benefit from social media campaigns[33]. Thus, improving access to internet as well as providing e-health education to high-risk groups may be important if social networking campaigns are to be successful in decreasing disparities in live kidney donation.

This study highlights certain ethical issues in the use of social networking sites to identify live kidney donors. First, misspecified privacy settings could result in the inadvertent sharing of private health information with unintended recipients[34]. However, the very existence of privacy settings on social networking sites may be considered an advantage, as traditional websites and other forms of media generally lack these capabilities. Second, the use of social networking sites could facilitate kidney donation in settings of coercion or monetary compensation[11]. We found explicit offers to sell kidneys on 3% of the pages – a percentage that likely underestimates the number of kidney offers for monetary compensation as Facebook users can delete posted messages. Further research is required to understand how social media may enable the illicit sale of organs and what the transplant community can do to address this pressing issue. Lastly, the use of social networking sites is unregulated, and information presented to potential donors may be incorrect or misleading. Educational efforts targeted to patients and their families interested in waging social

networking campaigns could decrease misinformation about risks and benefits of live kidney donation. In an ideal setting, social networking campaigns could even improve informed consent and voluntariness as potential kidney donors would be able to read information about the risks and benefits of donation at will, without immediate interaction with the potential recipient. Ultimately, the onus remains on transplant centers to provide accurate information about risks and benefits of donation as well as to assess for inappropriate motives for donation.

There were several limitations to our study. Our sample size was small, and we were unable to report on the use of privately shared Facebook pages used to identify live donors. Information on outcomes was gathered from publicly shared Facebook pages, with no independent mechanism of verifying whether donors were actually tested or transplants received. Donors may have been identified through means other than Facebook, and Facebook pages could have simply reported their success. More broadly, page authors have the ability to delete and edit posts, which could affect our findings, especially if alterations happened more frequently after donor testing or transplantation. Pages with more posts may have simply been more likely to share information about donor testing and eventually transplantation. As such, our findings should not be interpreted as causal; higher page traffic does not necessarily result in a successful Facebook campaign. Nonetheless, while our analyses must be considered hypothesis-generating, to our knowledge this remains the only study that evaluates the use of social networking sites to identify live kidney donors.

Conclusion

Social networking sites may be a powerful tool in expanding live kidney donation. Facebook is already being used to identify live kidney donors by a wide range of potential transplant recipients. Future studies should focus on how to safely, ethically, and effectively use this modality to increase kidney donation.

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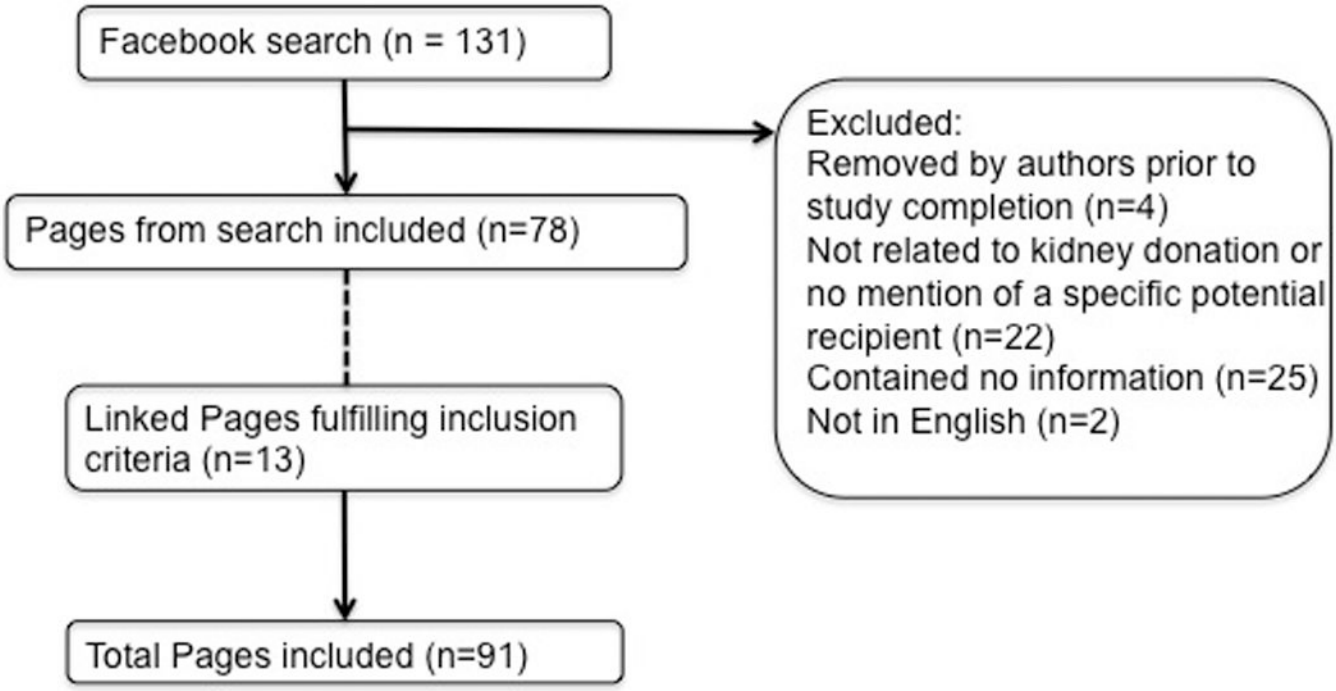

Figure 1.
Study Flow Diagram

Table 1

Reported Outcomes of Facebook Pages Seeking Live Kidney Donors for Specific Individuals

Reported Outcomes	**N = 91**
Potential donors tested	29 (31.9%)
Received a kidney transplant	13 (14.3%)
Received a living kidney transplant	9 (9.9%)
Relation to recipient:	
Co-worker	1 (1.1%)
Wife's cousin	1 (1.1%)
Family friend	1 (1.1%)
Altruistic donor	4 (4.4%)
Unreported	2 (2.2%)

Table 2

Characteristics by Primary Outcome (success in having donors tested)

	Donors Tested (n=29)	No Donors Tested (n= 62)	P value
Potential Donor Characteristics			
Age, mean (SD)	35.0 (17.3)	38.3 (15.7)	0.6
Female	55.2%	50.0%	0.6
US resident	100.0%	79.5%	0.02
Personal Information Reported			
Age	48.3%	25.8%	0.04
Location	89.7%	62.9%	0.01
Cause of kidney disease	62.1%	33.9%	0.02
Blood type	79.3%	56.5%	0.04
Photograph of potential recipient	90.0%	69.4%	0.04
Link to personal website	31.0%	6.5%	0.01
Mention of family/friends ability to donate	34.5%	21.0%	0.2
Currently on dialysis	48.3%	41.9%	0.6
Previous transplant	20.7%	11.3%	0.3
Transplant Information			
Mentioned paired kidney donation	27.6%	17.7%	0.3
Mentioned the length of the waiting list	31.0%	17.7%	0.2
Link to appropriate transplant website	58.6%	27.4%	0.01
Mentioned risks of donation	10.3%	3.2%	0.2
Mentioned costs of donation	17.2%	9.7%	0.4
Web Traffic Information			
≥ 200 likes	60.7%	8.1%	<0.001
≥ 25 wall posts by page author	69.0%	3.2%	<0.001
≥ 25 wall posts by others	72.4%	4.8%	<0.001
Encouraged others to “spread the word”	79.3%	41.9%	0.001
Composite Scores [¶]			
Personal information score, mean (SD)	5.0 (1.1)	3.5 (1.2)	<0.001
Transplant information score, mean (SD)	1.2 (1.0)	0.6 (0.8)	0.01
Page Traffic score, mean (SD)	1.3 (0.9)	0.1 (0.4)	<0.001

[¶]The personal information score gave a point for including each of the following: photograph of the potential recipient, age, cause of kidney disease, blood type, location, link to a personal website, and mention of family/friends’ ability to donate (score 0–7; 7=most personal information provided).

The transplant information score gave a point for: mention of length of transplant waiting list, paired kidney donation, and provision of a transplant website (score 0–3; 3=all factors used in page). Page traffic score gave a point for each of the following criteria: ≥ 25 posts by others, and ≥ 200 likes (score 0–2; 2=highest traffic).

Abbreviations: SD (standard deviation)

Table 3

Multivariable Model including Composite Scores with the Outcome of Having Donors Tested

Standardized Composite Scores	OR (95% CI)	P value
Personal information Score	2.1 (0.9–4.8)	0.07
Transplant information Score	1.5 (0.8–2.9)	0.3
Page traffic Score	3.8 (1.9–7.5)	<0.001

Table 4

Multivariable Model including Composite Scores with the Outcome of Having a Living Kidney Transplant

Standardized Composite Scores	OR (95% CI)	P value
Personal information score	1.7 (0.4–7.0)	0.5
Transplant information score	0.7 (0.3–1.6)	0.5
Page traffic score	6.8 (1.5–29.7)	0.02