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## Use of Twitter in Communicating Living Solid Organ Donation Information to the Public: An Exploratory Study of Living Donors and Transplant Professionals

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### Abstract

**Background:** As transplant centers start leveraging Twitter for information dissemination and public engagement, it is important to understand current living solid organ donation-related Twitter use.

**Methods:** We identified public Twitter profiles available in 01/2017 that referenced living organ donation and analyzed use of donation-related Twitter handles, names, or profile information. Tweets were manually abstracted and qualitatively analyzed for common themes. Social media influence of those tweeting about living donation was evaluated using Klout score.

**Results:** We identified 93 donors, 61 professionals, 12 hospitals, and 19 organizations that met eligibility criteria. Social media influence was similar across these groups ( $p=0.4$ ). Donors (16%) and organizations (23%) were more likely than professionals (7%) or hospitals (0%) to include transplant-related educational information in their profiles ( $p=0.007$ ). Living donation-related tweets were most commonly donation stories (33%), news reports (20%), reports about new transplant research (15%), and sharing transplant candidates' searches for donors (14%).

**Conclusions—**This exploratory study of living donors and transplant professionals, hospitals, and organizations on Twitter provides insight into how the social media platform may be used to communicate about and disseminate information about living donation.

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## Keywords

education; donors and donation: living; media and social media; patient education

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## Introduction

Twitter is a free web-based social media and microblogging platform with over 330 million monthly active users.<sup>1</sup> It is used by 24% of adults in the United States,<sup>2</sup> as well as by professional organizations, politicians, news professionals, professors, scientists, and other leaders seeking to reach the general public. The appeal of Twitter is evident: it provides a vast, immediate audience and has become a main channel of news communication and information dissemination. Twitter hashtag campaigns have successfully engaged millions of users in activism or to bring awareness to a cause. A single campaign in 2013 about a young cancer patient fulfilling his dream generated over 1.7 billion social impressions over a period of two weeks.<sup>3</sup> By providing a high-speed, low-cost link to the general public, Twitter is becoming increasingly important for any industry that wishes to grow its influence.

The transplant community has begun to explore outreach to and education of the general public via online platforms and social media.<sup>4</sup> Multiple online resources have been designed to identify living organ donors<sup>5</sup> and provide donation education<sup>6</sup>, including educational Facebook pages created by transplant hospitals<sup>7</sup> and culturally appropriate and/or bilingual educational websites.<sup>8,9</sup> In addition, transplant hospital programs such as Live Donor Champion and the Facebook Donor App teach lay people to leverage social media to find living donors for transplant candidates.<sup>10–12</sup> Participants in the pilot Live Donor Champion program and Donor App program each had a six-fold higher likelihood than controls of finding a potential living donor ( $p < 0.001$ ),<sup>10,12</sup> underscoring the potential of peer-to-peer communication to increase the influence of the message (i.e. messenger effects).<sup>13</sup>

To better understand how Twitter is being used to facilitate online conversation about living organ donation, we sought to characterize the population of living organ donation-related users on Twitter in terms of affiliation (e.g. living donor, transplant professional, organization, transplant center), current education and advocacy efforts, social media influence, and tweet content. In particular, we focused the experiences of living organ donors and the communities they create online, and we compared their online presence to that of the professional transplant community.

## Methods

### Study Population

We searched the public profiles of Twitter users for terms identifying them as living solid organ donors. These terms included “living donor”, “live donor”, “living kidney donor”, “live kidney donor”, “living liver donor”, “live liver donor”, “kidney donor”, and “liver donor”. We also searched for Twitter users self-identifying as living lung or pancreas donors but were unable to identify any donors fitting those criteria. We excluded living donor transplant recipients, potential living donors (i.e. users who were considering or in

evaluation for living donation, but who had not yet donated), and bone marrow donors. Searches were made under the “People” tab in Twitter’s search function. Given the dynamic nature of social media content, all Twitter profile searches for living organ donors were conducted on a single day (January 13, 2017).

We also searched the public profiles of Twitter users for terms identifying them as organ transplant providers. These terms included “transplant surgeon”, “transplant nurse”, “transplant coordinator”, “transplant center”, “transplant hospital”, “transplant institute”, and “transplant program.” We excluded users who performed hair, stem cell or bone marrow transplants. All Twitter profile searches for transplant providers were conducted on a single day (January 19, 2017). The Johns Hopkins Institutional Review Board determined that this study was not human subjects research due to the public nature of the data used, and therefore it did not require IRB approval.

### Profile Content Analysis

Twitter users were included if their profiles contained text (were not blank), included relevant information in English, and indicated whether they were a living organ donor, transplant professional, center, or organization (Figure 1). Information provided in the Twitter profiles was used to determine if the user was a living organ donor, transplant professional, center, or organization. For living organ donors, we collected the type of donated organ, if specified. Users were recorded as being an “educator” for kidney donation if they listed themselves as an advocate or educator, included facts about organ donation or transplantation in their profile, provided links to transplant campaigns or informational websites, or used transplant-related Twitter hashtags. We also collected data regarding the use of organ donation and transplantation references, particularly living donation references, in a user’s displayed name or Twitter handle (i.e. username, in format @username). If users’ tweets were public, the dates of their most recent tweets were identified. Based on whether users had account activity (e.g. tweets or retweets) in the last six months, they were classified as active or inactive. We collected data about which Twitter users identified working in a communications and media or a healthcare profession. Information from Twitter profiles was gathered by one researcher for consistency (JR) and reviewed by a second researcher (AE) for confirmation.

### Social Media Influence

We used Klout scores, which have previously been used to examine Twitter users in the field of transplantation,<sup>14</sup> to measure the social influence of the users included in our study. Klout scores incorporate both the size of a user’s social media network and how other users interact with the content the user posts. Klout aggregates data about social media use over the past 90 days. This represents a longer timeline than we would have been able to independently analyze, as Twitter application programming interface allows data capture software such as NVivo (QSR International Pty Ltd.) to obtain a random tweet sampling from approximately the prior three weeks. Klout also combines many metrics – such as number of tweets, retweets, and followers - into a single score, making it easier to compare the social influence of different users. Klout scores range from 1 to 100, a higher score indicating the user has greater social media influence.

## Statistical Analysis

We compared the proportion of Twitter users in each group (donors, professionals, hospitals, and organizations) who were active or had specific profile content using Fisher's exact testing. Profile content analyzed included transplant-related names or Twitter handle (i.e. username), media-related careers, healthcare careers, and educational transplant-related information. The median Klout score for each group was compared using the rank sum test. All analyses were performed using Stata 14.1/MP for Windows (College Station, Texas).

## Thematic Analysis of Tweet Contents

Tweet content (Figure 2) was abstracted from the previously described tweets manually by a team of research assistants between May 2017 and August 2017. Tweets not related to living organ donation were subsequently excluded from further analysis. Two qualitative coders independently analyzed the tweets using NVivo 11 Pro (QSR International). Themes were derived inductively from the tweets. Discrepancies in coding were resolved through discussion, and remaining disagreements were mediated by the first authors. Tweet content was de-identified and links were removed for the purposes of publication; tweets are otherwise quoted verbatim including any grammatical or typographical errors.

## Results

### Study Population: Twitter User Profiles

Of the Twitter account profiles identified to include living organ donation-related information, 93 were for living organ donors and 92 for transplant providers (transplant professionals, hospitals, and other organizations). Among the Twitter users who were transplant providers, 61 were transplant healthcare professionals, including surgeons (56%), non-surgeon physicians (15%), nurses (21%), coordinators (5%), and other healthcare professionals (3%). Of the 34 transplant surgeons, 80% indicated the type of organ transplants they performed, with 89% listing themselves as abdominal organ transplant surgeons and 11% listing themselves as cardiothoracic (i.e. heart and/or lung) transplant surgeons. An additional 12 Twitter accounts belonged to transplant hospitals and 19 were for other non-hospital transplant-related organizations. Therefore, in our overall sample, 50% of users were living donors, 33% were transplant healthcare professionals, 7% were transplant hospitals, and 10% were other transplant organizations (Table 1).

### Living Donors: Profile Content and Activity

Among living organ donors, 81% had donated a kidney, 6% had donated a liver segment, and 13% did not specify the organ donated. Five percent of donors referenced organ transplantation in their profile name or Twitter handle (i.e. username). A total of 16% of living donors included organ donation-related education in their profiles (Figure 3). Thirty-seven percent of living donors listed a career in a media-related profession and 5% listed a career in the healthcare industry. Eighty-four percent of living donors were active users.

### **Transplant Professionals, Hospitals, and Organizations: Profile Content and Activity**

Transplant-related names and Twitter handles were used by 7% of transplant professionals, and educational transplant-related information was provided in the profiles of 7% of transplant professionals (Figure 3). However, none of the professionals who referenced organ transplantation in their names or Twitter handles provided transplant-related educational information in their profiles. Seventy-six percent of transplant professionals were active users; this percentage was similar across the different healthcare professions: 76% of surgeons, 78% of non-surgeon physicians, 62% of nurses, 100% of coordinators, and 50% of other providers were active ( $p=0.6$ ).

Among transplant center Twitter accounts, 68% had transplant-related usernames, 58% had transplant-related Twitter handles, and 67% of accounts were active. No transplant centers included transplant-related educational information, including transplant-related links, hashtags, or facts, in their Twitter profiles (Figure 3).

Among other transplant organizations, 89% had transplant-related names, 79% had transplant-related Twitter handles, and 53% of accounts were active. Educational transplant-related information was provided in the profiles of 37% of organizations (Figure 3).

### **Dissemination of Educational Information and Activity among All Groups**

Living donors were significantly more likely than transplant professionals to list media-related affiliation in their profiles ( $p<0.001$ ) (Table 1). The proportion of active users was significantly higher among donors than transplant organizations ( $p=0.03$ ) but was similar among living donors, transplant professionals, and centers ( $p=0.3$ ). The social media influence, by Klout score, of users in each group was similar (Table 1).

Transplant centers (58%) and organizations (89%) were significantly more likely than living donors (1%) or transplant professionals (7%) to have transplant-related profile names ( $p<0.001$ ). Similarly, transplant centers (58%) and organizations (79%) were significantly more likely than living donors (4%) or transplant professionals (7%) to have transplant-related Twitter handles ( $p<0.001$ ; Table 1). Transplant organizations were significantly more likely to provide transplant-related educational information in their profiles than transplant professionals ( $p=0.003$ ) and transplant centers ( $p=0.03$ ). Transplant organizations and living donors provided transplant-related educational information in their profiles at similar rates ( $p=0.06$ ).

### **Thematic Analysis of Tweet Content**

The abstraction of all tweets from Twitter users included in the study resulted in 5,198 unique tweets. Of those, 81 were related to living organ donation and were coded for thematic analysis. In all, 12 themes were derived from the tweets (Table 2).

Of the tweets captured, those related to living organ donation were from 18 unique Twitter profiles. Of these, 6 (33%) were from abdominal transplant surgeon profiles, 5 (28%) were from non-hospital transplant-related organizations' Twitter profiles, 4 (22%) were from living organ donors, and the remaining 3 (17%) belonged to transplant hospitals. Among users included in our captured tweets, 6 (33%) included transplant-related educational

information, including transplant-related links, hashtags, or facts, in their profiles, 10 (56%) had organ donation or transplantation references in their displayed name or username, and median (IQR) Klout score was 41 (36–43) (Table 3).

The most common topic for living donation-related tweets was donation stories, accounting for 33% of all living organ donation-related tweets captured. Donation story tweets included: “Nanny donates part of liver to toddler she cares for” and “In gesture of love, Alaska pilot to donate kidney to flight attendant [link]”. News stories accounted for 20% of the living organ donation-related tweets captured. News story-related tweets included highlighting donation stories: “Seminole County deputy gets new kidney thanks to 8-person kidney exchange [link]” and promoting living donation: “Help us to reduce the waiting list. There is an opportunity for everyone with a desire to help [link]”. Additionally, 15% of the captured tweets were about organ-donation-related research. One user tweeted: “Understanding & communicating risks to living kidney donors is paramount for well-informed decisions #organdonation [link]”.

Tweets about patients needing a donor accounted for 14% of living organ donation-related tweets. One user tweeted: “Facing long waits with registries, kidney and liver patients make personal appeal to coworkers”. Tweets about transplant-related work occurring within transplant hospitals accounted for 14% of living organ donation-related tweets. One hospital live-tweeted several live donor kidney transplants: “Live #OrganDonation Tuesday again @[transplant center] First #kidney #Transplant done, starting the second @[transplant surgeon] @[transplant surgeon]”, while another tweeted about their staff: “Meet some of the Live Donor Team, [names], we are just some of the people who make up a great Live Donor Liver Transplant Team, there are many more... [link]”.

International tweets about living organ donation accounted for 12% of captured tweets. One user tweeted: “Living donors were responsible for 25 kidney transplants in #Manitoba in 2016 [link]”. Tweets highlighting quotes from living organ donors accounted for 11% of captured tweets, including one user tweeting: “#shareyourspare Our live donor today said “I donated my kidney instead of my heart for #valentinesday2017 @[transplant center] @[transplantsurgeon]”. An additional 5 themes were derived from tweets, all with less than 5 tweets per theme (Table 2).

## Discussion

In this exploratory study of Twitter use among a subset of living organ donors and transplant professionals, hospitals, and organizations, we identified an existing, active social media community that publicly affiliates with living organ donation. While high proportions of donors and transplant organizations included transplant education related information in their profiles, this was seen significantly less frequently in the profiles of transplant professionals and hospitals. No profile of a transplant center account included transplantation-related educational information. Donation stories, news stories, and research articles were the most common topics tweeted about, and profiles from transplant surgeons and non-hospital transplant-related organizations accounted for over half of all profiles with a living-donation related tweet captured.

Twitter profile information is visible at the top of an individual's page indefinitely, unlike an individual Tweet, and provides an opportunity for users to craft online identities by listing descriptions or affiliations, information they wish to disseminate, or links to other websites. We have shown that both Twitter profiles and tweets are already being leveraged by users with strong connections to organ donation and transplantation to provide educational information, though this was more common among living donors and transplant-related organizations than among transplant professionals. We believe this represents an opportunity to direct interested users to reputable, vetted online resources that have been created by the transplant community.<sup>7-9,12</sup>

Additionally, our findings highlight how living donors have taken an active role as social media peer educators. One single-center survey reported that over half of kidney transplant candidates were willing to post information about living kidney donation on their social media accounts.<sup>15</sup> However, research into living donors' willingness to serve as organ donation ambassadors on social media is limited. In this study, we found nearly 100 Twitter users who identified themselves as living organ donors on their social media accounts; 16% of them already provided additional transplant-related information in their profiles. Transplant centers have an opportunity to reach Twitter-active donors to amplify messages about organ transplantation and donation. Examples of information that could be disseminated on Twitter include stories of waitlist candidates seeking a living donor, testimonials and experiences from prior living donors, instructions for how to register as an organ donor, or recent transplantation-related research findings. Furthermore, Twitter could be used to build a two-way dialogue with constituents, the media, and the community and advocate for prior living kidney donors (e.g. for financial support or healthcare coverage).<sup>16,17</sup>

This study had several important limitations. The Klout scores used to assess social media influence, while previously used in the field of transplantation, draw from sources beyond Twitter and do not reflect a user's influence on Twitter alone.<sup>14</sup> Since social media is a dynamic data source, we were only able to capture a limited snapshot of Twitter activity during data collection. For this reason, we defined active use as posting within the six months prior to the time of data collection. Given the rapidly changing nature of social media, this time frame, as well as the time passed since data collection in January 2017, is a limitation of this study. Our English language search terms likely enriched the proportion of Twitter accounts from English-speaking countries in our search and excluded users from countries where English is not the primary language. However, the users captured in our search are most relevant to United States-based efforts to improve knowledge about living organ donation and organ transplantation. We were limited by the feasibility of data abstraction to analyze twitter activity on only a single day. Our study was also limited to those Twitter users who explicitly identified themselves as living organ donors or transplant providers, as this represents an important subset of the Twitter community discussing living donation. This small, self-identifying population is likely biased towards high levels of engagement around living donation on social media. However, given the limited scope of our study sample, there is likely more engagement around this topic than was captured in this study, as there are likely many users engaging in discussion of living organ donation who have not included the search terms employed in this study in their profiles. The large number

of tweets captured in this study suggest that even Twitter users who self-identify as living organ donors or transplant providers are engaging in other issues beyond living organ donation. Furthermore, given the millions of monthly Twitter users, the number of Twitter users captured in this study was relatively quite small. Future research efforts could provide a more broad understanding of Twitter activity within the transplant community by including bone marrow/stem cell donors and those who do not identify as part of the transplant community in their profiles; using more specific search terms for transplant professionals, such as social workers, psychologists, and advocates; expanding the time frame in which Twitter activity was captured; and formally undertaking social network analysis. Lastly, as we had a finite sample of tweets included in this study, a saturation analysis, typically used in qualitative research, would have been of limited usefulness<sup>18</sup>. Further qualitative analysis of Twitter activity should aim to capture a larger volume of Tweets, allowing for a more thorough qualitative analysis.

The living organ donation community on Twitter is actively engaged in discussion of issues related to living donation, but is relatively small. Information and discussion about living organ donation could reach a wider audience via Twitter if these resources are shared beyond the community of those self-identified with organ donation. Furthermore, while living donors and transplant-related organizations used links, hashtags, and text to spread transplant-related information, transplant professionals and transplant centers were less likely to utilize Twitter as a platform for transplant education by including transplant-related information in their profiles or tweeting about living donation. Given that the donors, professionals, transplant hospitals, and organizations in our study self-identified with living organ donation in a public, searchable forum, the population represents an online community who could be better engaged and activated by the transplant community. We view this study as a starting point for the growing conversation around social media use and how it can or should be leveraged in transplantation.

Ultimately patient demographics found on Twitter might present an opportunity to contact those patients or members of the public where they already are. We recommend transplant professionals and hospitals begin to actively explore their comfort with engaging on Twitter, establish themselves as a credible source of information about transplantation for patients and the public, and begin to disseminate high-quality and patient-centered information about living donation.

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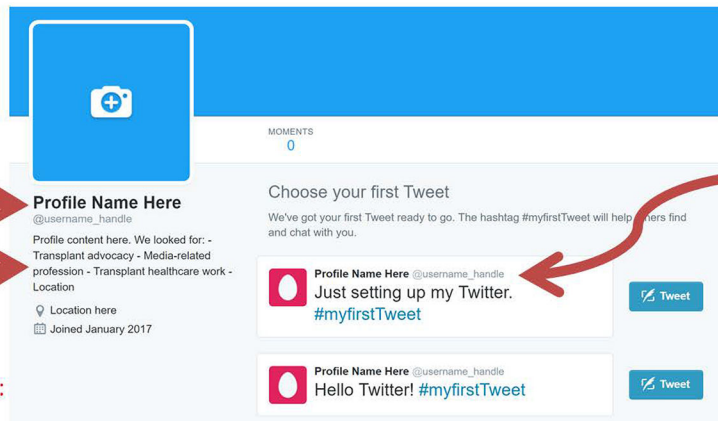
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Check for transplant references in:

- User name
- Twitter handle



Check the date of last post to determine if user is "active"

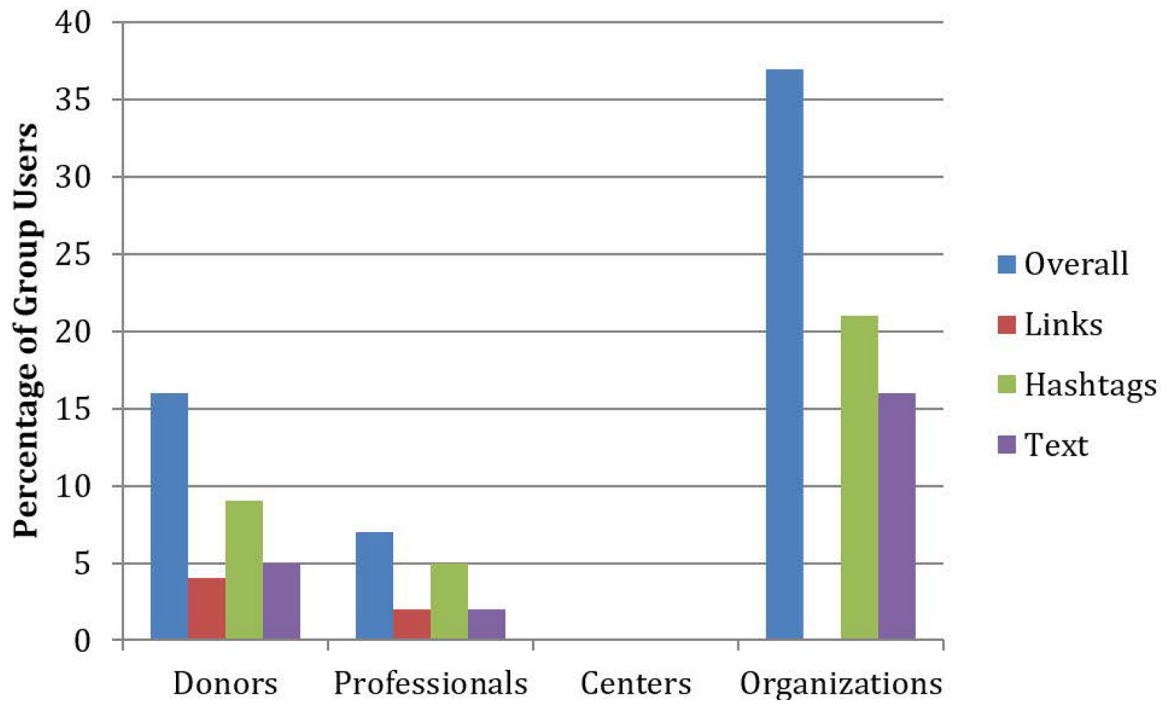
Pull profile content:

- Educational information
- Career

**Figure 1.** Sample Twitter profile outlining how data was collected.



**Figure 2. An example of a Tweet.**  
“Tweet Text” was abstracted for content analysis.



**Figure 3.**  
Inclusion of educational information by user group.

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**Table 1.**

Profile content of living donation-related Twitter users by group.

Profile Content	% of Users in Group				p
	Donors (N=93)	Professionals (N=61)	Hospitals (N=12)	Organizations (N=19)	
Transplant reference in:					
Name	1	7	68	77	<0.001
Username/Twitter handle	4	7	58	71	<0.001
Transplant-related information	16	7	0	23	0.007
Media-related work	37	3	N/A	N/A	<0.001
Active user *	83	77	67	58	0.03
Klout score, median (IQR)	41 (30–47)	41 (34–45)	37 (33–42)	33 (24–45)	0.4

\* Active users had posts, retweets, or other content generated in last six months and publicly available.

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**Table 2.****Thematic analysis of 82 tweets about living organ donation.<sup>a</sup>**

Theme	Number of tweets	Number of unique Twitter users	Representative tweet
Donation Stories	27	7	Husband Celebrates 20 <sup>th</sup> Anniversary In Hospital By Donating Kidney To Wife [link]
News stories	16	6	Organ donation to be featured on BBC Radio Scotland's Kaye Adams this morning. Listen to [name's] remarkable donation story #WeNeedEverybody
Research	12	4	Important article I published re: surgical technique to use living donor kidneys with benign tumors for transplant [link]
Patient needs a donor	11	3	These special grandchildren and [name's] daughter are seeking a living kidney donor for their grandfather [link]
Inside transplant hospitals	11	3	Live #OrganDonation Tuesday again @[transplant center] First #kidney #Transplant done, starting the second @[transplant surgeon] @[transplant surgeon]
International	10	7	Domesticating Organ Transplant: Familial Sacrifice and National Aspiration in Mexico [link] (via... [link])
Quotes from living donors	9	4	A living kidney donor writes: 'We need to encourage more donors – living or deceased' (via @thejournal_ie)
Thanking living donors	4	4	Living donors were responsible for 25 kidney transplants in #Manitoba in 2016. [link] #heros
Pediatrics	4	3	LDLT important option for children as deceased donor population is older & more obese#liveliverdonor
Books and movies about living donation	3	2	Aunt's life-saving transplant inspired Derry teen to make film [link]
Living donor chains	3	2	Seminole County deputy gets new kidney thanks to 8-person kidney exchange
Anniversaries	2	2	Can not believe this was a year ago, great moments with lovely people [link]

<sup>a</sup>Tweets are copied including grammatical errors but with names and links removed.

**Table 3.**

Profile content of 18 Twitter users that had living donation-related tweets.

<b>Profile Content</b>	<b>N (%)</b> <b>N=18</b>
Abdominal Transplant Surgeon	6 (33)
Non-hospital transplant-related organization	5 (28)
Living organ donor	4 (22)
Transplant hospital	3 (17)
Transplant-related information	6 (33)
Transplant reference in name/username	10 (56)
Klout score, median (IQR)	41 (36–43)

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