

Social Media Use Among Transplant Professionals in Europe: a Cross-Sectional Study From the European Society of Organ Transplantation

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Abstract

Objectives: Social media are Internet-based tools to gather and communicate information. Our aim was to survey transplant professionals in their attitude toward social media, to allow a better understanding of these technologies and their impact on health communication.

Materials and Methods: An online survey was distributed through the European Society for Organ Transplantation's social media platforms. Participation was voluntary and confidential. Participants were health care professionals working in organ transplant fields and actively responding to the link shared through the European Society for Organ Transplantation's social media platforms.

Results: In total, 190 health care professionals answered the survey: 70 (37%) were 35 to 44 years old, 105 (55%) were male, and 154 (81%) were white. The main training background was transplant nephrology (n = 42; 22%), with 115 participants (61%) working in academic centers. More than half (n = 102; 54%) used social media multiple times per day, utilizing Twitter or Facebook to connect with patients in equal amounts (n = 65; 34%) or WhatsApp (n = 53; 28%). To communicate about non-work-related information, most respondents (n = 124; 65%) chose WhatsApp, with 98 (52%) connecting through Facebook and

Instagram (n = 54; 28%). Of total participants, 77 (41%) actively used Web-based technologies for educational purposes. Respondents indicated that the main described risks associated with social media were breach of anonymity and confidentiality (n = 159; 84%), lack of authenticity (n = 77; 41%), lack of standard informed consent (n = 77; 41%), and organ trafficking (n = 71; 37%).

Conclusions: Transplant health care professionals recognize the role of social media platforms in promoting organ donation, sharing information, and providing knowledge for trainees or for research purposes. Future studies are needed to investigate how health care institutions and professional organizations could prevent risks related to social media use by professionals.

Key words: Awareness campaigns, Organ donation, Survey, Web-based technology

Introduction

In 2017, in the United Kingdom, 1574 people donated their organs after death and a further 1051 people were living donors. These generous acts have allowed 5090 recipients to benefit from a transplant, although 6044 patients have remained on transplant wait lists and a further 3404 patients had to be temporarily suspended from the wait lists.¹ Discussions have been ongoing on how to increase the current organ donation rate. Although one discussion is whether a legislation change with presumed consent to donate would be effective,² public campaigns to promote awareness about organ donation and transplant are definitely needed. Religious and cultural barriers currently represent 15% of the reasons against consent for organ donation in the United Kingdom,³ with this reason being highly prevalent among Black and ethnic minorities. The huge imbalance between the need for transplants and the availability of suitable organs with a compatible match could reach the 1574 Black

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and Asian individuals on wait lists, potentially filling the gap for the whole wait list.

Social media, Internet-based tools to gather and communicate and to share information, ideas, personal messages, images, and other content, can allow collaboration with other users in real time.⁴ The use of social media has proven to be an effective tool to promote positive health behavior changes, including reducing rates of smoking, alcohol abuse, and use of illicit drugs in the past.⁵⁻⁷ In the United States, the “Facebook effect,”⁸ prompted by members who can specify “organ donor” as part of their profile, has increased the number of new donor registrations by approximately 21-fold by the day after the implementation and by a 5.8-fold increase over baseline over a 13-day period. There is also growing evidence of the possibility to increase the number of living donors by providing guidance to kidney transplant patients in how to use social media to be advocates and to provide information about living kidney donation to their social network.⁹

In this study, our aim was to survey transplant professionals in their attitudes toward the use of social media, which would allow a better understanding of these technologies and their impact on health communication. An identification of the characteristics of current social media users will help monitor the growth of online technologies and inform health promotion communication efforts aimed at effectively utilizing these applications.

Materials and Methods

The link to a voluntary, confidential, online survey was distributed through the European Society for Organ Transplantation’s (ESOT) social media platforms of Facebook and shared via Twitter and LinkedIn, with 2 reminders over a 45-day period in summer 2018. Members of ESOT were also reached through mail addresses provided to the organization. The 28 questions were designed to understand the current use of social media among transplant professionals and whether these Internet-based applications could prove effective in increasing organ donation rates and/or could be utilized in other refractory public health problems in which communication and education are essential.

The data were analyzed through descriptive statistics with Survey Monkey (San Mateo, CA, USA) software.

Patients and public involvement

No patients or other participants, other than those already described, were involved in the study.

Results

In total, 190 participants answered the survey. As an online survey, it was not possible to determine how the Facebook, Twitter, and the LinkedIn platforms influenced the response rate.

Demographics

Of total respondents, 70 (37%) were between 35 and 44 years old and 52 (28%) were between 45 and 54 years old (Table 1); 105 participants (55%) were male and 154 (81%) were of White ethnicity. The main training background was transplant nephrology (n = 42; 22%), followed by different transplant surgery subspecialties, including 25 (13%) with liver training, 20 (11%) with kidney training, and 18 (9%) with kidney-pancreas training. Most of the participating transplant professionals had worked in the

Table 1. Demographics of Survey Respondents

Characteristic	Percent	Number
Age		
< 25 years	1	1
25-34 years	14	27
35-44 years	37	70
45-54 years	27	52
55-65 years	17	33
> 65 years	4	7
Female	45	85
Ethnicity		
Caucasian/White	81	154
Asian/Indian	8	16
Arab	4	7
Asian/Mongoloid	2	4
Afro-Caribbean/Black	1	1
Hispanic	1	1
Mixed	3	7
Training background		
Transplant medicine: nephrology	22	42
Transplant surgery: liver	13	25
Nursing	11	21
Transplant surgery: kidney	11	20
Transplant surgery: kidney and pancreas	9	18
Research	9	17
Transplant medicine: hepatology	3	6
Transplant surgery: heart	2	3.5
Transplant medicine: cardiology	2	3.5
Transplant surgery: lung	1	2
Other	17	32
Years worked in the field		
≤ 5 years	16	31
6-10 years	27	52
11-15 years	19	36
16-20 years	15	28
21-25 years	13	24
26-30 years	4	8
> 30 years	6	11

field for 6 to 10 years (n = 52; 27%); 36 participants (19%) had worked in the field for 11 to 15 years, with 16% having less than 5 years of work in the field. The dominant country of work was as follows: 51 respondents (17%) in the United Kingdom, 19 respondents (10%) in The Netherlands, and 17 respondents (9%) in Italy.

Working institution

Of total respondents, 115 (61%) worked in an academic center, whereas 57 (30%) worked in a public hospital (Table 2); 70 respondents (37%) were consultants, and 36 (19%) were primary academic faculty members. The reported transplant volume of their institutions was 101 to 200 organs/year for 54 respondents (29%) and > 200 organs/year for 50

respondents (26%). The rate of living donor transplant was 10 to 30 organs/year in 25% of the cases (n = 48) or more than 50 organs/year in 24% (n = 45). Of total respondents, 113 (59%) stated that their working institution did not have an official social media platform to actively promote organ donation and transplant.

Social media usage

When respondents were asked how many times per day they connect through social media, more than half (53%; n = 102) answered that they do so multiple times per day (Table 3). The transplant professionals indicated that they usually connect for work-related information through WhatsApp (52%; n = 98), Twitter (51%; n = 97), and Facebook (41%; n = 77). They equally utilized Twitter or Facebook (34%; n = 65) and also used WhatsApp (28%; n = 53) to connect with patients. To communicate about non-work-related information, most respondents (65%; n = 124) instead chose WhatsApp, with others connecting with Facebook (28%; n = 54) or Instagram (52%; n = 98) or with Twitter as the fourth option (26%; n = 49). Online news about organ donation and transplant on social media were read multiple times per week in 36% of respondents (n = 68), with 15% (n = 29) of respondents involved in campaigns at least once per month and 12% (n = 29) once per week. The rate of attendance of scientific meetings was once a month in 72 responders (38%), with 77 (41%) confirming active use of these Web-based technologies during educational activities, such as conferences.

Table 2. Working Institution of Survey Respondents

Characteristic	Percent	Number
Workplace description		
Academic institute/university	61	115
Public hospital	30	57
Private hospital/clinic	2	4
Other	7	14
Current level of training/practice		
Consultant	36	70
Academic/university faculty	18	36
Coordinator	7	13
Research scientist	7	13
Fellow	6	11
Associate specialist	6	11
Trainee	5	9
Nurse	5	9
Medical student	2	3
Other health care professional	8	15
Transplant volume per year		
< 50 organs	24	46
50-100 organs	21	40
101-200 organs	29	54
> 200 organs	26	50
Living donor volume per year		
10-30 living-donor transplants	25	48
> 50 living-donor transplants	24	45
31-50 living-donor transplants	21	39
Did not perform living-donor transplants	16	31
< 10 living-donor transplants	14	27
Official institution social media page (Yes)	41	77
Possibility/ies for institutions to		
promote organ donation through social media		
Work with the local patient associations		
in social media organ donation promotions	75	142
Publish donation numbers performed at the institution every year	63	119
Organize campaigns based on historical cases aimed at promoting nondirected altruistic donation	57	
Write how they promote organ donation as an organization at different time points	50	95
Encourage personal case-based campaigns organized by individuals aimed at promoting themselves/family/friend as a recipient for directed altruistic donation	35	67
Organize personal case-based campaigns aimed at promoting specific recipients for directed donation	28	54

Table 3. Social Media Usage

Response Choice	Percent	Number
Connection frequency		
Multiple times per day	53	102
Once to twice daily	18	34
Multiple times per week	12	22
Once to twice per week	3	6
Multiple times per month	3	5
Once to twice per month	2	4
Less than once per month	9	17
Social media platform(s) for work-related information		
WhatsApp	52	98
Twitter	51	97
Facebook	41	77
LinkedIn	34	65
Skype	23	43
Instagram	17	33
iMessage	15	29
FaceTime	12	23
Viber	8	15
Pinterest	3	5
Snapchat	2	4
Other	10	19

Table 3 (Cont.). Social Media Usage

Response Choice	Percent	Number
Social media platform(s) for communication with patients		
Facebook	34	65
Twitter	34	65
WhatsApp	28	53
Skype	11	20
LinkedIn	9	18
Instagram	8	15
iMessage	7	13
Viber	5	9
FaceTime	4	8
Pinterest	2	4
Snapchat	0	0
Other	21	40
Social media platform(s) for non-work-related information		
WhatsApp	65	124
Facebook	52	98
Instagram	28	54
Twitter	26	49
iMessage	21	40
FaceTime	17	32
Skype	11	21
Viber	9	17
LinkedIn	6	11
Pinterest	6	11
Other	5	9
Snapchat	4	7
Frequency of news read on social media about organ donation and transplant		
Multiple times per day	20	38
Multiple times per week	36	68
About once per week	19	36
About once per month	11	22
Once or twice	9	17
Other frequency	5	9
Frequency of direct involvement in organ donation campaigns through social media		
Multiple times per day	3	6
Multiple times per week	8	16
About once per week	12	22
About once per month	15	29
Once or twice	42	80
Other frequency	20	37
Frequency of direct involvement in scientific meetings about organ donation and transplant		
Multiple times per day	2	3
Multiple times per week	8	16
About once per week	8	15
About once per month	38	72
Once or twice	27	52
Other frequency	17	32
Frequency of social media during educational activity		
Multiple times per day	40	77
Multiple times per week	9	17
Once or twice	36	68
Other frequency (please describe)	15	28
Donor information sharing		
Donor should remain anonymous	63	
If donors and recipients agreed, it should be permissible to meet before or after surgery	24	45
Prefer not to say	5	10
Other	8	15

Social media risk

When asked if inappropriate or illegal cyber content was encountered on social networking sites in relation to organ donation and transplantation,

110 respondents (58%) said that this never happened to them, whereas 57 (30%) affirmed to have seen it once or twice (Table 4). Of total respondents, 140 (74%) felt that patient privacy/anonymity could be violated if transplant information related to the date of transplant and modality of donation was shared through social media. A further 120 respondents (63%) stated that the donor should remain anonymous, with 24% (n = 45) supporting meeting with the recipient if both parties agree. Respondents were invited to disclose the main worry about social media use for organ donation and transplantation. The answers were as following: breach of anonymity and confidentiality (84%; n = 159), lack of authenticity (41%; n = 77), lack of standard informed consent (41%; n = 77), organ trafficking (37%; n = 71), difficulty of being up to date with technology with rapidly changing social media platforms (24%; n = 46), and difficulty in recruitment and voluntary participation (16%; n = 32).

Table 4. Social Media Risks

Response Choice	Percent	Number
Frequency of inappropriate content on social media related to organ donation and transplant		
Multiple times per week	1	2
About once per week	2	3
About once per month	5	9
Once or twice	30	57
Never	58	110
Other frequency	4	8
Privacy violation through social media (Yes)	74	140
Main worry/ies about social media use for organ donation and transplant		
Breach of anonymity and confidentiality	84	159
Lack of authenticity	41	77
Lack of standard informed consent	41	77
Organ trafficking	38	71
Rapidly changing social media environment and difficulty of being up-to-date with technology	24	46
Difficulty in recruitment and voluntary participation	16	31

Social media benefits

Of total survey respondents, 164 (86%) thought that social media campaigns could help pediatric patients to become familiar with the organ donation/transplant process and 166 (88%) stated that social media could influence minorities to change their unfavorable attitudes toward organ donation with regard to cultural and religious barriers (Table 5). Most respondents (66%; n = 125) supported the use of social media technologies in an encrypted form as helpful during transplant procedures. Respondents were invited to state the main benefits that their institution could gain from the use of social media in organ donation and transplant. These were (1) work

Table 5. Social Media Benefits

Response Choice	Percent	Number
Could social media use for pediatric patients help familiarize them with the organ donation/transplant process? (Yes)	86	164
Could social media campaigns influence minorities to change their unfavorable attitudes toward organ donation, countering cultural and religious barriers? (Yes)	87	166
Could the use of social media in an encrypted form be helpful during transplant procedures? (Yes)	66	125
Possibility/ies for institutions to promote organ donation through social media		
Work with local patient associations in social media organ donation promotions	75	142
Publish donation numbers performed at the institution every year	63	119
Organize campaigns based on historical cases aimed at promoting nondirected unspecified donation	57	
Write how they promote organ donation as an organization at different time points	50	95
Encourage personal case-based campaigns organized by individuals aimed at promoting themselves/family/friend as a recipient for directed unspecified donation	35	67
Organize personal case-based campaigns aimed at promoting specific recipients for directed donation	28	54

with local patient associations for organ donation promotions (75%; n = 142), (2) publish the number of donations every year at institutions (63%; n = 119), (3) organize campaigns based on historical cases aimed at promoting nondirected altruistic donation (57%; n = 109), (4) show how organ donation is promoted at an organizational level at different time points (50%; n = 95), (5) encourage personal case-based campaigns organized by individuals aimed at promoting themselves or family/friends as recipients for directed altruistic donation (35%; n = 67), and (6) organize personal case-based campaigns aimed at promoting specific recipients for directed donation (28%; n = 54).

Discussion

This survey, conducted through ESOT’s social media platforms, illuminated the current use of social media among transplant professionals. More than half of the participants, irrespective of level of training and experience, stated a connection through Web-based technologies multiple times per day as possible ways to communicate about work-related information (Twitter, Facebook, and WhatsApp) but also about personal content (WhatsApp, Facebook, and Instagram) and engagement with the patient community (Twitter or Facebook equally). Similar findings have been described in a survey recently conducted through the American Society of Transplant Surgeons,¹⁰ in which 61% of the respondents supported information sharing via social media to communicate with family and friends (76%), surgeons (59%), transplant professionals (57%), transplant recipients (21%), living donors (16%), and candidates on wait lists (15%).

Social media have infiltrated all of our lives, both personally and professionally. Different social media

platforms could be used for different purposes: Twitter is a Web service microblog that allows subscribers to send short messages to other subscribers who could redistribute to their own personal network. Facebook is maintained by an individual or a group of individuals and allows regular entries of commentaries and events to be traced through the timelines of members. It is very useful to group people on a particular topic and has been proven to facilitate direct interactions as distant mentoring.¹¹ WhatsApp allows private and direct messages in an encrypted form between users connected generally through their mobile devices. Finally, Instagram is mainly focused on sharing photos, to capture a momentum.

Apart from the positive effects of social media in the health care arena, there is also a concern for risk. According to our survey, the greatest perceived barrier to social media use in organ donation and transplant is the breach of anonymity and confidentiality (84%). Of the respondents, 64% stated that donor information should remain anonymous, although 24% agreed with the possibility for the donor and the recipient to meet before or after surgery, if both parties agreed. A recent study showed that a strict policy on anonymity is deemed unnecessary in most cases.¹² These results therefore challenge current policy and education from an institutional point of view with respect to anonymity of the transplant process. In our study, we described the potential benefits with use of instant social media communication methods that are unique for the transplant arena. These consisted of working with local patient associations in promotion campaigns (75%; n = 142), publishing transplant procedures performed at the institution every year (63%; n = 119), and organizing focused campaigns based on historical cases, particularly for nondirected

altruistic donations (57%; $n = 109$) but also for directed altruistic donations. There is still a shortage of living donors throughout the world. In our study, the most common reported living donor rate is 10 to 30 living donors/year, a small number compared with the actual number of recipients on wait lists.¹ This was reported in The Netherlands ($n = 19$) and Italy ($n = 17$). However, in the United Kingdom, there is a vivid community of networks and online patient associations that offer support for overcoming the cultural and religious attitudes that often encumber living kidney donations. In our study, 19 respondents from the UK stated that living-donor transplants in their institution equaled more than 50 organs during 2017, which are encouraging data. Communication through social media has offered an effective method to discuss refractory public health problems in which communication and education are essential.¹³ Novel applications of social media may prove effective in increasing organ donation rates, particularly when active educational programs are scarce.¹⁴ The survey respondents were keen for the use of social media to approach children; in addition, 86% approved social media for communication in the Black community and 87% approved social media in the Asian community. The "Orgamites" (Figure 1 Top) are already an example of how electronic campaigns could help to break through this barrier by targeting children, with images that allow children to understand organ transplantation and donation in an amusing and engaging way. Moreover, the children, once they become adults, will pass the message on to the next generation, helping to make organ donation the social norm. A similar educational campaign has been designed to promote organ donation in Black and Asian communities (Figure 1 Bottom) by the National Health Service Blood and Transplant in the United Kingdom, as in fact demographic characteristics should not be considered a barrier to increase the organ donor pool.¹⁵

Social media can also be used to increase the number of living donors by, for example, helping potential donors during follow-up. Current mobile health applications allow health care professionals to gather relevant information from healthy living donors without the cost associated with losing a day of work to visit the hospital when they are not unwell. This has been shown to increase engagement and willingness among living donors.¹⁶

Figure 1. Examples of Social Media Campaigns



(Top) The targets of the campaign from Orgamites® are children, to confront and learn about organ donation in an amusing and engaging way. (Bottom) National and Health Service Blood and Transplant aims to campaign for organ donors in Black and Asian communities. Permission to reprint the images has been previously addressed.

An interesting finding of our survey was the awareness of social media's educational role among medical professions. Of survey respondents, 61% who were working in academic institutions connected through their mobile applications multiple times per day during scientific meetings. Knowledge is power and thus should be shared.¹⁷ Higher ranked residency programs are in fact more likely to have a social media page to promote and facilitate teaching activities.¹⁸ E-learning modalities, podcasts, live surgery platforms, and microblogs are some examples of how interaction and collaboration could be facilitated across the globe, overcoming costs related to traveling and attending conferences but still able to facilitate research collaborations among professionals living in different time zones. Furthermore, in the era of patient reported outcomes, social media can play a major role in patient recruitment for research, to align medical decisions with patient expectations.¹⁹ However, we found a main concern among survey respondents to be the lack of a standardized consent obtained through Internet-based technologies (41%; $n = 77$). The informed consent is required to share decision making between health care professionals and patients,²⁰ but it may be difficult to gain deep understanding with only Web-based information.

The use of encryption when sharing organ donation and transplant information was also considered useful by 125 (66%) of total responders.

In fact, a study has already indicated a benefit in transmitting histologic information through smartphones.²¹ How many times during organ procurement or in difficult situations during surgery would added assistance from a colleague have been beneficial, even just to have an extra pair of eyes? Communication via smartphones provides a reliable, simple, and inexpensive method to consult with other colleagues. The ability to transmit images from local hospitals to experts in real time has the potential for a more accurate assessment of organ quality and may help to optimize the transplant process.

Although social media has many positive attributes, it also has its dark side with practical and ethical concerns around the appropriate use in the context of organ transplantation.²² There are common aspects between social media and the transplant world: they both interconnect people inside a community, with personal relationships to be regulated to preserve privacy and confidentiality. They both share the burden of the validation of the source, to ensure transparency of the shared content or graft in the case of the organ donation. The difference is that, in transplant, there is already a system in place with several quality controls, from the donor to the recipient, certifying the validity of the process. However, in social media, the readily accessible information that reaches the public is more doubtful. The lack of formal peer review and unedited or curated content could lead to a risk of misinformation with fake news and spread of biased, selected, or incorrect data.¹⁷ This needs to be particularly considered when using social media for ethical and educational matters, including in organ donation campaigns. Furthermore, the same respect for colleagues and patients that is applied in face-to-face hospital communication should be employed on Internet platforms, with no acceptance for inappropriate and unprofessional behavior.²³

Limitations

The representativeness and transferability of the results were hindered because the survey was limited to participants who responded to social media requests through ESOT; therefore, the findings are reflective of professionals active on social media and may not represent the entire organ donation and transplant workforce in Europe or the country of origin outside Europe of participants.

Conclusions

Health care professionals in organ donation and transplantation recognize the emergent role of social media platforms in increasing the number of living donors, in disrupting barriers to promote organ donation, in sharing information in an encrypted form, in providing knowledge and educational content for trainees and colleagues across the world, and in providing knowledge for research purposes. Future studies are needed to investigate how health care institutions and professional organizations could set up rules and standards across different social media applications to facilitate the positive aspects while minimizing or preventing the risks related to the inappropriate use and issues around breach of confidentiality with regard to social media.

Recommendations

Our reported survey posits the current use of social media for health care professionals working within the organ donation and transplant fields in Europe and in the possible countries of origin of respondents outside of Europe. Our findings should be explored further by investigating how social media may continue to change, influence, and affect the field of transplant to better understand the mechanisms and modes of communication and involvement while exploring potential barriers. Finally, the social media community should work together to produce rules and targeted action plans addressing the barriers described and to facilitate progress.

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