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1.3 To share or not to share your donor status on Facebook: public benefits, private risks

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"Along with your alma mater, your hometown and your spouse's name, Facebook will also display whether you'd like to give a kidney when you die." (Cox 2012)

Abstract

In the spring of 2012, the social network Facebook opened up the biggest public campaign on organ donation. By enabling their users from the UK, the US and Australia (for a start) to create a "life event" based on their donor status, the expanding network has allowed millions of users to share information on their intentions to donate their organs after death. The announcement was received with excitement by well-known bioethicists, who praised the network for officially supporting the donor campaigns, however it has also elicited concerns.

In this chapter, we aim to thoroughly investigate the ethical arguments concerning both the benefits and the risks of such a world-scale campaign. There are several ethical issues associated with organ donation that are deeply challenged by this initiative, such as: consent for donation, privacy, confidentiality, anonymity, data protection, public solicitation. Arguments both pro and con are addressed and critically assessed. Although the initiative targets specifically donation after death, it could have unexpected implications on living donors as well, and these implications are also critically discussed.

Introduction

On May 1st, 2012, the popular social network Facebook allowed the public to share the users' donor status. This was done by allowing the users to select the status "organ donor" to their Facebook personal page (timeline) in the section "Life events"/"Health and wellness". The facility was rapidly extended to a list of countries that, as of August 2012, included: Australia, Brazil, Colombia, Denmark, Ireland, Netherlands, New Zealand, South Africa, Sweden, the United Kingdom and the United States. It is important to mention that the Facebook user was informed about the steps to officially register as a donor and was redirected towards the respective national registry.

The first striking issue in this campaign is the magnitude of people targeted by this initiative. There were 901 million monthly active users of Facebook¹ in March 2012. More than 200 million

¹ <http://www.howmanyarethere.org/how-many-facebook-users-are-there-2012/>

active users out of all the Facebook users are from the US, Brazil and the UK, where the update on one's donor status is available. This transforms the initiative of Facebook as the biggest campaign in favor of organ donation ever organized. In the first day of the campaign, 100,000 US users shared their status as organ donors, more than 22,000 followed the links to their national registries, and more than 6,000 new donors officially registered (Timpane 2012). Between May and mid September, 275,000 users posted their donor status (Schultz 2012). The potential is underlined both by the huge numbers of presumptive users, and by the fact that the pro-donation message was not a uniform, top-down one, as in most national campaigns. Instead of a single message, there were multiple personal messages coming from one's peers (Facebook "friends"). In this way, many individuals that are outside the target group of national campaigns were reached by tailored messages produced by their own friends.

However, the initial boom in registering as donors does not appear to have been sustained. At first, the initiative was applauded as it produced an impressive number of new donors. However, a few days later, at Donate Life California, the rate of registering donors was back to the low pace before the Facebook announcement (Sadler & Sadler 2012).

The context of this campaign is the current ever-increasing gap between the number of existing organs and the much larger demand of the patients. Thousands of individuals die as a result of the lack of organs, or desperately wait for an available one for many years. This chronic imbalance between supply and demand leads to negative phenomena such as organ trafficking and organ trade. Several organizations recommend that one efficient way to prevent organ trafficking is the legal increase of available organs, which can be stimulated by public campaigns.

Different campaigns have been recently designed to promote organ donation. Proposed by various institutions, they have especially targeted deceased donation, sometimes living donation, or fighting organ trafficking. Although campaigns are popular across Europe, and were disseminated through all available channels (traditional as well as new media), few systematic studies have been conducted concerning their impact. Existing studies show that, although the short-term impact of those campaigns is significant, the long-term effects are not that visible (Roels & Rahmel 2011). Being "in progress", the potential of the Facebook campaign is difficult to evaluate. For those unreachable via other traditional channels, the Facebook campaign could become the first opportunity to be informed about organ donation. However, more traditional campaigns (via school, church or the national media) could benefit from the fact that they are promoted by opinion leaders that are already well known and that could shape the attitudes of their followers.

The Facebook campaign can be analyzed in this particular context, and all its benefits and possible risks can be evaluated only having this context in mind. It should be noted that the Facebook campaign for increasing organ donation cannot replace or substitute legal procedures that have already developed for organ donation. The mere indication of the donor status on Facebook cannot be interpreted as consent. As an analogy, when one places the pink ribbon on her Facebook picture for raising consciousness for breast cancer, it does not refer to her health status nor to her willingness to participate in a relevant medical research.

We consider organ donation after death a very important individual decision that one must contemplate after understanding its details and implications. We agree with bioethicist Summer McGee when she states, in relation with the Facebook campaign: "It's a huge decision. This isn't just as simple as saying you went on a trip to Washington, D.C., last month or had a great dinner with friends last night, or to equate with a whole number of other things you put on your Facebook status" (McGee & O'Reilly 2012).

It is also important to understand the difference between registering oneself as a *to-be donor after death*, during one's lifetime, and actually becoming a *donor* either during one's lifetime (living donor) or after death, following the dying process in certain conditions (brain death or some specific forms of cardiac death). All categories are called "donors", although the difference between them is the difference between intention and fact. However, although Facebook officials speak

about deceased donors, the whole campaign does not distinguish between the various types of donors, which may result into involuntary confusions (D'Costa 2012).

1 Methodology

This chapter consists of an ethical analysis of the arguments concerning the opportunities offered by the organ donation campaign initiated by Facebook. A literature review was conducted in two databases, Academic Search Complete from EBSCO and PubMed, covering the period May 1st – September 1st, 2012. The review was not limited to peer review journals, but included also newspaper articles. All abstracts were evaluated and articles attempting to analyze the campaign (as opposed to those which only present the facts) were investigated, attempting to identify the major ethical issues touched by the campaign. An interview with a member of the Facebook Donation Campaign team, covering all ethical issues identified, was conducted by email.

From the literature review, several ethical issues arise connected to this initiative, although the campaign initiators have not considered all of them as being relevant. Thus, a member of the Facebook Donation Campaign team stated that "we see no risks in promoting organ donation"².

2 Consent for donation

One should note that the issue of consent matters in this campaign only for those users who have simultaneously updated their donor status and registered in their respective national donor registry. In fact, there are three categories of users:

1. The user has already registered as donor prior to the Facebook campaign, and merely updates one's status to reflect this situation;
2. The user decides to become a donor, updates one's status and follows the link to the national registry, where one also officially registers as donor;
3. The user updates one's status as donor, but does not do anything to officially register.

As one can note, the issue of consent is relevant only for individuals in the second category. The first category of users decided to become donors irrespective of the Facebook campaign, and the third category are only pseudo donors as they are not officially registered donors. However, the campaign data mentioned above indicates that there were a significant number of users in the second category in the very first days of the campaign. Their number is relevant to considering the issue of donation consent.

A 2011 study carried out in several countries revealed that the average visit on Facebook ranged between 18 and 38 minutes. In this time, an average user does plenty of things, such as checking the status updates of one's friends, following pages he/she likes, using a variety of applications, playing network games, updating his/her own status, etc. In these conditions, one hardly has time for considering the implications of a decision of such importance as to become or not a donor.

One critique of donation practices such as the US one (declaring one's donor status when applying for a driver's license) is that it does not allow users to really think about what it means to become a donor; they simply tick a box on a form. Do Facebook users have the opportunity to consider what it means to become a donor? The feature offered by Facebook to declare one's donor status does not address that, assuming that users will deduce it from informing one another about their motivation of becoming a donor, and eventually by following the link towards the national registry and finding official information on this matter on the registry page. From the message an-

² Personal communication, on-line interview with a member of the Facebook team, September 20, 2012.

nouncing the launch of the campaign, users could only understand that donation might be a heroic act, that it is life saving and that the rest can be accounted by the sharing power of the network (Zuckerberg & Sandberg 2012).

Consent for donation means also that no pressure to make a decision was inflicted from the outside. However, due to the campaign, the decision not to update one's donor status receives a sort of visibility that might inflict exactly the pressure one attempts to avoid: "if you don't check this box, you're instead marking an invisible box revealing that you're a selfish person, hoarding your personal organs like Gollum does his ring" (Hill 2012). Indeed, many sorts of pressures could lean the balance towards declaring oneself as donor, even if this is not really one's intention. What does it mean for someone to find out all his/her friends have declared themselves donors on Facebook? This sort of pressure is visible in articles asking why the Facebook founder, Mark Zuckerberg, has not instantly used the new feature, to update his own donor status (Hill 2012).

Bioethicist Arthur Caplan believes that pressure in this case is acceptable, because it does not force one to do something against one's will: "It's pressure, sure," says Caplan, "but coercion, no. It's opt-in; it's all up to you. And there are no penalties if you don't do it. It's quite clever: They're encouraging people to talk about it, create a community that values donation. Yes, if you saw all that around you and didn't share that, you might be uncomfortable, but no one is twisting your arm." (Timpane 2012).

However, authors writing on the topic of social pressure consider that the consequences of accepting to post about one's donor status helps normalize this behavior and may in fact impose this type of behavior through the means of peer pressure in clustered networks, such as Facebook. Becoming an organ donor should remain a matter of personal choice, not a matter to be judged upon (D'Costa 2012).

3 Privacy and confidentiality

In social media the question of privacy has always been an important ethical and legal concern. This form of communication is meant to share information quickly and easily with a broad public, on the other hand, access and misuse by third parties pose challenges to privacy protection.

So no wonder that the founders of Facebook have been accused of changing repeatedly their policies on privacy and on failing to inform their users about the exact nature of the changes. Although users can modify the settings retrospectively, there were voices accusing the network for imposing unnecessary complications for its users and for making them involuntarily divulge private information. Studies show that, despite the subjects' concerns about privacy issues, their behavior varies, and that very young users together with older users are especially vulnerable because of their inability to understand the complications of privacy settings (Brandtzaeg et al. 2010).

Moreover, the update on donor status is by default both public and starred (highlighted), which confers it a special status among the rest of information provided by the user (for instance, on Timeline it is displayed on the whole page, not only on one column).

Facebook emphasizes the power of sharing a piece of news with the rest of one's friends. However, there are authors who rightly note that: "no posting on any social media site is private" (Bergeson 2011). Even if a user chooses to share one's donor status with only a couple of friends, either of the friends could decide to share the status update and make it public across his/her friends and so on and so forth.

Legally speaking, a mere sharing of the donor status via Facebook would not constitute a valid consent. A valid consent presupposes information, a certain procedure and signature. However, indication of the donors' status on Facebook may pose certain risks of safety and privacy. For instance it might be that desperate organ seekers will look and will try to contact those who participate in

the campaign. And direct communication between potential organ donors and recipients evidently has some risks of coercion. In case of opting-in systems, the position in the campaign (donor status) might help the relatives to support organ donation.

However, Facebook posts on issues different from organ donation have already had unexpected consequences for users. Thus, small issues such as sharing the pictures after a party or posting job-related comments has already had some negative outcomes for some users – for instance, there were cases of individuals being dismissed from employment after posting things that were considered offensive or inappropriate (Bergeson 2011). We cannot but ask: what unexpected consequences could sharing one's donor status have? An unplanned consequence, due to the terminological confusion (would-be donor after death/possible living donor) could be the unintended invitation to public solicitation. Thus, one would-be donor on Facebook may receive messages from people believing they wish to become living donors, people asking for their help in this matter.

As a general rule, medical decisions are confidential; all physicians are bound to respect patient confidentiality and not divulge information to third parties. In this case, a decision with medical implications is shared with virtually everybody on the network. We have to see whether there are risks from sharing what could be regarded as confidential information, especially considering the fact that many people are unaware of the consequences about sharing sensitive health information on the social media sites (Househ 2011).

4 Anonymity and data protection

An important principle of organ donation after death is anonymity (the donor family does not know where the organ goes, the recipient does not know to whom the organ belonged), which is preserved for at least a period after donation. However, a trend facilitated by recent communication technologies is to share data on donors and recipients via alternative mediums³. By comparing Facebook posts from donors and recipients, one could hypothetically trace the links between them. This is facilitated by the fact that the network aims at registering only real-life persons, identified by their real names, and continuously fights against fake profiles, treating them as "undesirable"⁴.

One has to account that breaching anonymity in the donation process may lead to unwanted consequences. Thus, either the threat of possible financial settlements or the psychological discomfort of identification between recipient and donor may arise (Mamode et al. 2012). This is why anonymity is still regarded as a basic requirement for the process, and any attempt that questions or undermines it should be explained.

Data protection is a sensitive and complex issue on Facebook. On the one hand people may develop easily a fake digital identity with a false name, location and picture. On the other hand, Facebook offers different types of privacy protection based on the individual choice: with whom one is willing to share a range of information.

According to the campaign initiators, "Information on organ donor status is protected the same as all the other information provided by the users, we protect our users' account from unauthorized third party access"⁵. However, all data provided by the users enters into a huge data system with extremely rich information that is hard to approximate: "Sharing your data with the social network additionally entails releasing that data to an unknown sum of other corporations" (Mahdawi 2012). Recent history has shown that huge databases can be accessed in order to reveal things about

³ For instance, on www.donadona.nl families of deceased donors and recipients can search for themselves and meet.

⁴ Mark Sweney, "Facebook quarterly report reveals 83m profiles are fake", *The Guardian*, August 12 2012, <http://www.guardian.co.uk/technology/2012/aug/02/facebook-83m-profiles-bogus-fake>

⁵ Personal communication, on-line interview with a member of the Facebook team, September 20, 2012.

users in unprecedented ways. For instance, the store Target found out about female customers' pregnancies before their families knew about it (Robertson 2012). It is very hard to predict how the information about one's donor status could be interpreted and (especially) mis-interpreted when put together with other information.

5 The issue of public solicitation of organs from living donors

"No doubt you will soon be able to tag your superfluous kidney in the new owner's photo albums" (Mahdawi 2012)

Although the current Facebook campaign is related to deceased donation only, the ambivalence of the words "organ donor" could lead to confusions between deceased donors and living ones. Also, there are already cases of recipients who found living donors with the help of Facebook, after posting about their search for kidneys. One can wonder whether it is possible to prevent a feature such as sharing one's donor status into transforming into a search for organs online. One can always report unwanted posts or messages on Facebook, but in this case approaching someone to trade one's organ is clearly illegal and it should receive special attention from the campaign initiators. A study presented at a meeting of the National Kidney Foundation (US) revealed that 3% of the patients soliciting live donations via Facebook pages received offers from organ sellers (Tucker 2012). This percentage is worrying and it should be addressed especially having in mind the Facebook campaign – for instance, by adding a button "report illegal content" in relation with comments or messages concerning one's donor status.

The fact that Facebook should target living donors as well, and not limit to the deceased donors, has already been discussed. Thus, transplant surgeons comment that the number of deceased donors has flattened in recent years due to the fact that the general conditions that may lead to a person become brain dead (e.g. traffic accidents, overdoses) have decreased. Therefore, the only way to supplement the list of donors is by adding living donors (Tan, quoted in O'Reilly 2012). However, directly targeting to-be living donors via Facebook announcement could be risky and could boost cases of organ selling and organ trafficking.

6 Conclusions: public benefits, private risks

An issue that benefitted from public scrutiny was whether the Facebook campaign is actually of help for increasing the number of donated organs and decreasing the number of patients on the waiting list. Leaving aside the theoretical benefits of having more people announcing to their friends about their future donor status, the practical issues for medical professionals are:

1. Is it acceptable for a clinician to use information of one's donor status from a social media site?
2. How can one use this information and how is it related to the actual system of assigning the donor status after one's death?

To answer these questions is no simple matter. The social media sites have recently spurred into the attention of physicians as possible practical tools to enhance communication with stakeholders. Few systematic studies have been done on this matter and the results are so far ambivalent. A meta-analysis from 2011 has discovered that the interest of health science students is more pronounced in social media than that of professional clinicians, who report having established a Facebook account in smaller numbers (13-47%) (Von Muhlen & Ohno-Machado 2011). Other studies report that the medical faculty members differ from students in evaluating the information about patients from social media sites: while students report conducting searches on Facebook for the profiles of

their patients, faculty members seem more reluctant to do such searches and to rely on information provided by patients on their Facebook profiles (Jent et al. 2011).

Concerning the Facebook feature of declaring one's donor status, bioethicists are even more reluctant to recommend using it as a way to overcome families' decisions towards organ donation from a deceased relative. Instead, they recommend the feature to be used in order to facilitate the intra-familial conversation on intentions to donate, thus preparing families to be more informed about their loved ones' decisions in the event of dying (McGee & O'Reilly 2012). Although the suggestion might seem paternalistic for those pleading for the importance of autonomous decisions. The suggestion is probably closer to the Facebook feature of encouraging conversations on various topics, and it might help families accord with the decision of one's member to become a donor.

The benefits of this campaign are clearly **public** (the users are informed about the donation issues, they might want to know more about them, they might want to get involved, a lot of publicity goes around the initiative, etc) while the risks for users are **private** (individual threats due to breach of confidentiality and data protection issues). The balance between benefits and risks depends on the perspective from which the user is considered: if they are considered as an autonomous individual who decides what risks can be assumed, then the benefits clearly outweigh the risks; if the user is considered vulnerable and ignorant towards the risks (due to the lack of information, due to the fact that they are unable to grasp the context, due to the failure to anticipate the consequences of breaching confidentiality, privacy, anonymity in the social media context) then the risks might outweigh the benefits. In any case, the balance must be established.

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2 Donation practice as a public policy issue
