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LETTER TO THE EDITOR

Misinformed users: improving informed decision-making on social media

Adam M. Peña[1,2]

1 Center for Medical Ethics & Health Policy, Baylor College of Medicine, Houston, TX, USA
2 Houston Methodist Hospital System, Houston Methodist Hospital System Biomedical Ethics Program, Houston, TX, USA
E-mail: adam.pena@bcm.edu

Dear Editors,

High-profile transplantation cases like Roel Marien continue to be the focus of international public debate on social networking sites (SNS) (e.g., Facebook) [1]. There has been little, if any, guidance from professional societies or agencies (e.g., UNOS, ESOT) about how to ensure the quality and reliability of information about organ donation and transplantation generally on SNS. Current regulatory frameworks do not address the potential impact of social media upon transplantation processes. This is problematic given that SNS is increasingly used as a vehicle for organ donation registration, via, for example, Facebook's "Organ Donor" feature [2].

If users are exposed to misinformation about organ donation and transplantation, a significant ethical concern regarding informed consent and refusal is raised. The modest goal of this commentary is to briefly suggest strategies for the use of SNS as a mechanism for registration in a way that could foster informed decision-making.

While the use of SNS can have a positive impact on organ donation initiatives (e.g., increased awareness of organ donation), SNS may also provide misinformation on a large scale [3]. For example, the Facebook forum, "Discussing Lung Transplantation and Sarah Murnaghan," provides heavily biased information about the controversial decision to allocate adult lungs into a pediatric patient. One user commented, "Everyone is…horrified at Sarah's outcome and no other child has gotten adult lungs (probably cause no one else wants to risk their child for an experiment) [4]." Given the efficiency and expediency of SNS, misinformation available to the general public is hard to control and can create confusion about transplant processes.

Under the current model in the USA, individuals who want to become an organ donor can designate their status by means of a donor card or a driver's license [3]. Recognizing the shortcomings of this approach, other authors argue in favor of improving existing mechanisms of registration [3]. With the pervasive use of social media, SNS have begun to serve as "more modern" mechanisms for consenting to be an organ donor [3,5]. A recent study concluded that one application generated a 21-fold increase in registrations over the baseline registration rate, proposing that SNS can increase donation rates [2].

Using SNS as mechanism of consent may promote uninformed decision-making, which could undermine autonomy-based principles [6]. National transplant societies and local health departments could collaboratively develop mechanisms to promote informed decision-making in the context of SNS:

1 National transplant societies could develop relevant criteria [7] for health departments to evaluate the credibility and quality of information on SNS within their respective countries (e.g., authorship).

2 National transplant societies could partner with SNS to create informational videos that automatically start once a user clicks on an SNS function as a mandatory step before a user can register online.

3 Built-in features on SNS could direct users to websites where information related to organ donation is subject to quality control (e.g., health department website).

These strategies would help protect the integrity of transplant medicine while utilizing SNS to buttress informed decision-making about organ donation and transplantation for users of SNS.

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