Social Media and Organ Donation

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ABSTRACT
This research paper is on the subject of how the emergence of social media and the increasing need for organs through donation have intertwined and the effect the former has had on the latter. With social media already changing the modern world, it has the potential to transform science, especially organ donation. With the demand for donated organs being exceptionally high, social media is being used to increase awareness for the matter and to find more willing donors. This paper will discuss how social media has already changed organ donation, current initiatives and what future influences social media might have on organ donation and ethical issue associated with the subject.

INTRODUCTION

Background: Social Media

Over the past decade, the emergence of social media has been something of a revolution in the way it has changed many people’s day to day lives. People are constantly using the medium to further their social connections and in many cases, it has now been integrated into their daily routines. So what is social media? Social media is defined as the collective of online communications channels dedicated to community-based input, interaction, content-sharing and collaboration [1]. It is a platform which enables a wider connection to people and organisations from around the world, providing the possibility of finding people and things you might not have necessarily found without such resources. Popular social media include websites such as Facebook, Twitter and LinkedIn. Publicising a cause has never been easier, with over 2 billion Internet users worldwide (which is 37.3% of the world’s population) [2], simply uploading to the Internet has the potential to reach out to millions.

Social media websites often use cookies to determine what ‘pops’ up on screen when a certain person uses the website. This can be used to tailor what displays when a certain person accesses the website, for example a person might be interested in medicine so the advertisements being shown will be medicine related. Using cookies is a great way to target a certain group of people and increase their awareness on a subject, e.g. attempting to increase the number of organ donors of South Asian or Black ethnic origin by showing certain advertisements relating to organ donation when a person of these ethnicities log in.

In medicine, social media is changing the way many are now addressing issues regarding the area; recent research has shown more than 40% of consumers say information found via social media affects the way they deal with their health, also “90% of respondents from 18 to 24 years of age said they would trust medical information shared by others on their social media networks” [3]. This shows, medically, the information being passed through social media is affecting people’s mentality towards medicine; moreover their opinions towards certain matters are changing as well as taking the relevant action, whether this is the correct action or not depends on the reliability of the source used. At one time, the first thing a person would do would be to book an appointment with their local GP, now in many cases their first thought is to use social media to find information. Furthermore, current research has shown “18 to 24 year olds are more than 2 times more likely than 45 to 54
year olds to use social media for health-related discussions”[3]. The future of medicine is now shifting towards a more technological base, with younger generations already using the platform for health reasons; the trend in medical social media use is only going to increase. However this is not the whole story, as medical practices are now using social media to promote their practices. Natasha Burgbert recently reported after a year of promoting their practice, there has been an increase in new patient traffic into the practice. “On average 1 new patient family per week came into the practice because of our social media presence, I know this because they tell me ‘I am here to see you today because I found you on Facebook” [10]. One can see social media has already had an effect on practice enhancement, and the results are now showing. Practices are raising local awareness of their practice and by doing so, people now have more information and are therefore able to make an informed decision as to whether they go to the practice or not. This same method is being also being used to promote so many other areas of science, including the matter of organ donation.

**Background: Organ Donation**

Organ donation is the process in which a person will donate organ/s, these organs are then transplanted to someone whose own organs are damaged and are in need replacing. Organs that can be transplanted include the kidneys, liver, lungs, pancreas, and small bowel. Most organs are donated after death; however it is possible to donate a kidney while alive. One in four of all kidney transplants are from a living donor. These donors are usually close relatives of the patient as their blood group and tissue type have to be compatible. To become an organ donor, you have to join the Organ Donor Register (details on how to join the Organ Donor Register can be found on [http://fleshandblood.org/resources/](http://fleshandblood.org/resources/)). Every year thousands of people around the world are in need of a donated organ, in the UK, the waiting list is at 7,026 at the time of writing [4]. Furthermore, last year more than 1,300 people waiting for a new kidney either died or become too sick to undergo a transplant [5]. This is an underlining problem, with only 31% of the UK’s population having joined the Organ Donor Register, and over 1000 people dying each year waiting for that life saving transplant, the need for organ donors is growing.

As mentioned before the lack of donors is the main cause. Results from a recent survey highlighted the problem. Of the sample surveyed, 96% of them believed donating organs is the “right thing to do” however 70% of the people who said this had not joined the Organ Donor Register (see Figure 1). One can connote from these results that those who are in favour but have not yet joined the register either do not feel strongly enough about it to join or just haven’t thought about doing it as of yet. This may be because they haven’t had enough encouragement to sign up, or it may be as simple as they don’t know how to
become an organ donor. This is why raising awareness can be so important to increasing the number of donors, and as mentioned in the background to social media, there is now the possibility of really increasing that consciousness, a possibility that would have been difficult to achieve before the rise of social media.

Another problem present is less than 2% of registered organ donors are from South Asian and Black communities. However, a person of South Asian or Black origin is 3 times more likely to need an organ transplant. Because of this, the waiting time is two times longer as a transplant is more likely to be successful if donor and recipient have the same ethnic origin [7]. The organ is rejected if the receptor genes do not match. Transplant rejection occurs when a transplant recipient’s immune system attacks the transplanted organ or tissue. The immune response may be triggered when antigens enter the body; this happens when the antigens are recognised as being ‘foreign’ so it is attacked. Thus when a person receives a transplanted organ, the immune system may recognise it as foreign and attack it. To help prevent this, the recipient must take immunosuppressant medicines which weaken the body’s immune system, decreasing the body’s ability to attack foreign antigens. However, this will also decrease the ability to fight infections making the risk of having a transplant that much greater. If donor and recipient are of different ethnic origins, rejection chances increase as the antigens on the cells of the organ is different to that of the rest of the recipient’s body. Action needs to be taken to get not only increase the number of organ donors on the register but also concentrate on increasing the number of South Asian and Black donors.

Due to the lack of organs available, illegal organ trade is now increasing. People are now attempting to exploit the lack of organs by advertising and attempting to sell them illegally for money. It is estimated a new organ is sold ‘every hour’ [8] and 10,000 illegal black market operations involving human organs take place each year. Furthermore, since there is now such high demand, organs are being sold for extremely high prices, e.g. a heart can be sold for up to £1 million. This coupled with the current economic climate means that illegal organ trade will only continue growing. People are being murdered or put into serious condition for the reason that the value of organs is now at such a level, people are willing to do anything to obtain more money.
DISCUSSION

Social Media has given the organ donation cause a surge of volunteers since the topic of organ donation was taken to Facebook and Twitter. NHS Organ Donation has 108,232 and 13,000 followers on these sites respectively [1,2] and activities include particular cases of patients and awareness days, for example, World Kidney Day on 13th March 2014. Most developed countries have similar web pages aiming to recruit potential organ donors, such as the USA which has the OrganDonor.gov Facebook page with 109,000 members [3].

Raised support and awareness has shown in register figures, with 1,012,000 members of the British public signing onto the register between the 1st April 2012 and the 31st March 2013, bringing the total to 19,532,836. Therefore 5.18% of people on the Organ Donor Register signed up during that 11 month period which is a significant proportion and has been aided by social media. Beforehand, adults could ‘opt-in’ to the register and were encouraged when:

- Registering for a driving licence
- Registering with a GP
- Registering for an European Health Insurance Card (EHIC)

Although this managed to gather many applications, typically 12% of the population in European countries [4], a great many have been added to the register. Now nearly 20 million, one in three people, have agreed to donate an organ in the event of their death.

The most widespread activity carried out by social media was achieved by personal ambition of Mark Zuckerburg, founder of Facebook, and Sheryl Sandberg, COO of Facebook. On 1st May 2011 they announced Facebook would facilitate an individual’s wish to become an organ or blood donor on the website. The New York Times claimed it could have ‘potentially a profound affect’ on numbers and Andrew M. Cameron who is liver transplant surgical director at John Hopkins Hospital said ‘it will be an historic day in transplantation… and may well eliminate the problem’ of donor shortage. The change allows Facebook users to find a quick link to their countries donation website and within five minutes they can volunteer for the register and share their decision with friends online.

Director of the initiative, Sarah Feinburg, estimates 300,000 users have participated since 1st May 2011 and has observed a leap forward in donors. For example in California typically 70 people register per day but after the day of announcement 3,900 were witnessed signing up.

However, after an initial peak in donors, the numbers started to level to normal rates seen before Facebook became actively involved. Figure 3 allows us to see this pattern which has been repeated across the developed world, and France. The UK has seen a similar peak after the social media initiative which has managed to raise awareness.
Case Study

Social networking is attempting to plug the gap of a lack of donors for ethnic minorities, who have to wait a year longer on average in the UK. Figures from the NHS show 31% of patients waiting for a transplant are from a black or Asian background but just 6% of donors in 2013 were from ethnic minorities. The problem was taken to Facebook and has received many shares because they used the example of Alicia Warren, whose donated organs saved five strangers lives [6]. There is a shortage because organs can be rejected by a patient if the receptor genes do not match and welcome the organ because they are matched by blood and tissue types, it will be rejected and destroyed if it is viewed by the body as a foreign body, making it vital to have a donor with similar genes which makes inter-racial donation rare. As mentioned in the introduction, immunosuppressant drugs can be taken but these have side effects and do not always succeed. Therefore, the Internet can be used to tackle specific aspects of the donor problem and make a difference in the quest to end the shortages. Websites can use cookies to target certain minorities by discovering popular websites and inserting Organ Register adverts into these websites in an attempt to ‘fill the gap’ on the donor register.

Another example is not only the donation side of the campaign, but the organisation behind it. The NHS Facebook group does not just look for donors but also prospective volunteers which can be trained to become advisors at organisation gatherings. Such as the British Kidney Patient Association which had publicity on Facebook looking for fresh volunteers to discuss important topics and also improve quality of life for patients on the organ donor register. So donors are not the only focus of internet campaigns it is also the ‘behind the scenes’ work that needs volunteers which can be obtained from the internet [7].
Advantages and Disadvantages

A large disadvantage of the Internet is although it is far reaching, there is a proportion of the population which it does not reach. Only 65% of the UK population has used Facebook in the last month which means 35% does not use Facebook regularly therefore have a smaller chance of viewing the new initiative [7]. However, Huffington Tech said Facebook attracts 22 million unique visitors per day which indicates the organ donor initiatives have wide reaching audiences, despite a lower percentage using it monthly [8]. An added disadvantage is many users of social networking sites are under the age to begin thinking about organ donation. There are no precise figures due to individuals lying about their age online but BBC believes 43% of 9 to 12 year olds and 88% of 13 to 16 year olds use social networking sites [9]. Implications of this mean many of the potential pool of organ donors that can be accessed through social networking and the Internet are too young to begin to think about donating as a driving licence is a common way to sign people up early on. Therefore figures are deceiving as we have shown although it is not all bad news as 74% of 21 to 24 year olds use Facebook regularly [10].

With the inclusion of the internet and social media to the organ donation scheme there have been sharp increases in the last five years. An 11% increase in deceased donors since between the years 2012-2013, a 50% increase from the 2008-2009 figures has ultimately meant lives have been saved by social media’s inclusion into the organ donation frame. These are obvious dividends of the internet and social media inclusion into recruitment campaigns and it is impossible to tell what the current figures would be if they were not involved but all we can see is the dramatic increase in which the internet has played a key part. The only danger is the NHS relies too heavily on these methods of registration and slackens off on the non-internet ideas as a result which would become a destructive influence to those who are not familiar with the internet [11].

But the worst effect the internet can have is the confirmed ‘boom’ in the illegal organ trade which has been witnessed across the world. The World Health Organisation has discovered that wealthy patients are able to order organs over the internet with £84,000 for a kidney and £1 million for a heart. The Independent has revealed that one illegal organ is donated an hour which amounts to one in ten of all donations. It has become so widespread over the internet that a 24 year old Russian attempted to sell a kidney on eBay, before it was taken down by the site [12].
Ethical Issues

Most world religions encourage organ donation, but Jehovah’s Witnesses prohibit organ transplants because of their view from the Old Testament that one person’s blood should never enter another’s body [13]. Many prospective donors are put off by qualms they have about the actual donation once they have died. For example, will the doctors fight to save me? Will I be left disfigured? Is it possible for my family to see the body after donation? These worries are enough for some people to avoid donation altogether but all the answers are available readily on the NHS website [14]. The opt-out system which many countries have in place allows for many people to ignorantly donate their vital organs after death without knowing about it or making an informed decision, they would have to sign a form to get off the organ register in those countries such as Austria. Therefore registering online is one of the most ethical ways of doing it because people make the decision themselves.

Future Developments

In the future social media could go even further and become more active by making it compulsory for over 18s to have an option to like the page when they sign up meaning most of the 500 million Facebook users worldwide would have to view the National Organ Donation page, therefore spreading word and guaranteeing more donors because raised awareness is the most effective method of increasing registered donors. The internet as a whole could do more to offer help by lowering or even eradicating advertising costs for Organ Donation initiatives and a welcome progression would simply be more coverage on donations within news websites such as BBC News which has become very popular online along with newspapers like the Telegraph and the Guardian being the 20th and 14th most visited websites in the UK respectively [15]. Organ Donation UK Twitter page has only 13,000 followers which is significantly lower than the Facebook number so there is potential for the website to accommodate for more followers because it could be just as influential as Facebook if it gained equal support.

With Google, BBC and Wikipedia all in the top ten most popular websites in the UK, these are the websites that can have the broadest viewing so could utilise that power for the donation cause. For example, Google has ‘doodles’ which are headers it puts on the main website when a significant day of the calendar arrives such as International Woman’s Day, 8th March and St. David’s Day, 1st March. Google and other websites have the ability to raise huge awareness by advertising National Transplantation Week via these methods from the 7th to the 13th July this year.

The police would have to work on closing down any website suspected of any illegal organ trading activities as to prevent organisations profiteering from desperate donors who sell their organs for a share of the money. There are security measures that can block the websites and the police can identify the address therefore stopping some of the trade itself.
Social media websites have access to a user’s address therefore they have the ability to identify areas where there is a below average number of donors and concentrate efforts on these regions, thus maximising the number of people on the register by targeting weak spots geographically by advertising in these areas or informing hospitals to educate the habitants. Similarly, the internet could be used to show people via social media the plights of people on the registers that live near them because that will make more of an impact on the human emotionally therefore are more likely to take notice and sign themselves up. There is proof in this now it has come to light that thousands of people signed up in North Devon following a teenage girl in Barnstaple being given a new lease of life after a double lung transplant. More cases such as this need to be publicised so the successes of transplants can become inspiration for potential donors [16].

**CONCLUSION**

Ultimately, the internet and social media has revolutionised organ donation worldwide by widening the potential audience and emphasising the problems at present on a general and personal level, making a more compassionate appeal for organs. We have seen what the situation was before social media became popular and have then evaluated what has changed since the internet has become available. Individual initiatives such as the one by Facebook.com have been responsible for huge rises in organ donation and the potential for the future remains promising. With the possibility for compulsory viewings of National Donation pages and also wider coverage on the increasingly used newspaper websites along with usage of cookies allowing us to track internet user patterns and then act upon the information provided, to target specific groups of people, especially people who are of South East Asian or Black origin.

It is also an ethical solution with no major disadvantages other than registers becoming reliant on the internet which also demonstrates the successes it has had. By looking at the results we can see the positive impact and extent of the overhaul caused by the inclusion of the internet into the frame.

The benefits of using social media outweigh the issues of utilising its powers to increase awareness and educate the people of the world by demonstrating the need for more organs through specific examples and cases of genuine patients on the organ donor register, however the figures of usage for social media sites are misleading because underage user numbers on the social medium. Although there is the risk it could boost the illegal organ trade by false identities which has been made easier by the internet, however this risk that will always be present whenever social media is involved. Precautions must be taken however it will not affect those who are more conscious of the official donation sites and the current dangers associated with the internet. Therefore, one can conclude social media will be a force for good when recruiting organ donors.
REFERENCES

Introduction


Discussion

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[8] http://yougov.co.uk/news/2012/02/17/social-media-growing-uk/ (Facebook disadvantages with users)
[9] http://www.huffingtonpost.co.uk/2013/08/14/facebook-uk-usage-statist_n_3753561.html (The advantage of Facebook)

(2) http://www.nhs.uk/Livewell/Donation/Pages/Ethicsandworries.aspx (Possible ethical issues)
(3) http://www.alexa.com/topsites/countries/GB (Most visited websites in the UK)
(4) http://www.northdevongazette.co.uk/news/thousands_sign_organ_donor_register_in_north_devon_1_3517629?utm_source=facebook&utm_medium=social&utm_content=09_april_post&utm_campaign=bau (North Devon sign up increase)