

Using Social Media/ Mainstream Media to Prompt Organ Donation/ Transplantation Education – Scientist Perspective on Chronic Kidney Disease (CKD)

Dr Shahid N Muhammad, *Specialist Biomedical Scientist, Chartered Scientist, University of the West of England (UWE), Dept. of Health and Applied Sciences, UK*

Correspondence: Shahid Muhammad, University of the West of England (UWE), UK
Email: shahid2.muhammad@live.uwe.ac.uk

Keywords: Healthcare, Scientist, Organ Donation, Transplantation, Education, Literacy, Perspective

Abstract

Introduction: The use of social media (SM) today provides unparalleled opportunities to provide and receive education, access to communication and engagement. SM/ mainstream media (MM) such as television, newspapers, magazines, and radio stations are also being used to prompt education surrounding specific Long-Term Conditions (LTCs). Certainly, use of SM is not limited by constraints of time and geography **Aims:** Three questions being proposed here: 1) Is there an Islamic stance on using SM/ MM to prompt organ donation/ transplantation education? 2) Can Muslims donate their organs? and 3) Does the Healthcare Scientist have a role providing the public education surrounding organ donation/ transplantation? Chronic Kidney Disease (CKD) will be used to provide a LTC example. **Review:** There is a need for multi-channel approaches so that the issue is a more widely known social norm in primary care, where healthcare scientists will know underlying pathologies. **Islamic Stance:** If a Muslim decides to donate an organ they must do so out of free will without being morally or socially forced and without economic pressures. If the deceased Muslim indicated during life (in a will) that they do not want to donate organs, then no one is authorized to do this on the deceased person's behalf. **The Healthcare Scientist's Role:** More educational campaigns via SM/ MM involving healthcare scientists and Muslim communities are required. **Discussion:** Bridging gaps in health literacy (HL) is also important. This is where healthcare scientists have an important role, to provide health science transparency where other health professionals are challenged. Clarity of terminology to help increase HL on topics relating to organ donation/ transplantation is now especially required owing to more time being spent online. **Conclusion:** 1) The Islamic stance on use of social media to prompt organ donation/ education has not been investigated. 2) Muslims can donate their organs, and 3) there is a role for healthcare scientists to provide education, however more research is required to shed light on what is the most effective approach for the healthcare scientist to become proactive.

Introduction

With exception to individuals with severe learning difficulties and neurological illnesses (which of course are devastating in their own right), there has never existed a human being who has not been aware not only of his body but also of his individuality, both physical and spiritual (Mauss 1998). Human beings are consciously aware of their own lives and, it's through understanding that awareness of a consciously constructed self is identified (Dunn 1998). The use of social media (SM) today provides unparalleled opportunities to provide and receive education, access to communication and engagement. SM/ mainstream media

(MM) such as television, newspapers, magazines, and radio stations are also being used to prompt education surrounding specific Long-Term Conditions (LTCs). These forms of education have not been explored in detail to prompt organ donation/ transplantation education using SM/ MM. Certainly use of SM is not limited by constraints of time and geography (Eysenbach and Till 2001).

Aim

Three questions are being proposed here:

- 1) Can Muslims donate their organs?

2) Is there an Islamic stance on using SM/ MM to prompt organ donation/ transplantation education?

3) Does the Healthcare Scientist have a role providing the public education surrounding organ donation/ transplantation? To answer these questions, the LTC, Chronic Kidney Disease (CKD) will be used to provide an example.

Social Media and Health Education

Social Media usage has grown exponentially, now representing one in five minutes spent online (Dunn 1998; Eysenbach and Till 2001; Eaton 1994; Nutbeam 2018; O’Kane 2015; Protheroe 2009) and patients/ carers and the lay general public accessing information combining key issues relating to organ donation/ transplantation through Mainstream Media. Using Social Media perhaps has several gains with standard forms of Mainstream Media where healthcare is concerned (Dunn 1998; Eysenbach and Till 2001; Eaton 1994), but both have advantages with regards to reach, accessibility and prompting organ donation awareness/ education. Using Social Media versus Mainstream media to prompt organ donation/ transplantation education offers wider opportunity in ways as previously unrealized (Dunn 1998; Eysenbach and Till 2001; Eaton 1994).

A study conducted on college students in the US, demonstrated that social- based communication had the greatest impact for donor registration, and described that a social media campaign which used Facebook, and YouTube resulted in 9000 documented donor registrations. Within the student organisation, the organ donor registration was increased by 28% (D’Alessandro et al. 2012). Furthermore, whilst traditional online advertising offers the greatest message exposure, when combined with the use of social networking sites to promote donation, it resulted in an increase in request for organ donor cards and registrations (BBC News 2015). Thus, the use of social media alongside existing mass media donation campaigns can be seen to be highly effective in promoting organ donation. One LTC that surrounds organ donation/ transplantation quite heavily is Chronic Kidney Disease (CKD).

What is Chronic Kidney Disease (CKD)?

CKD is a long-term irreversible clinical condition and has been described as the gradual, and usually permanent, loss of kidney function over time. Early in the disease process, individuals with CKD often experience no symptoms and for a long time, it has been an under-diagnosed condition (Cameron et al. 2013). Even in the absence of symptoms, CKD appears to add significantly to the burden of cardiovascular disease (CVD) and death (Cameron et al. 2013). The rate of CKD is increasing worldwide, leading to greater need for kidney transplantation (Stefanone

et al. 2012). Transplantation is not a cure; however, it is cost effective compared with Haemodialysis (HD) in the treatment of this long-term condition (LTC) and achieves higher prognosis and morality (BBC News 2012). Currently living kidney donation accounts for about one-third of kidney transplants performed in the UK, with deceased donation forming the main source of kidney transplantation (Sissons 2011). This high need but low supply among minority ethnic populations presents problems in achieving an optimal match of blood group and tissue type where these are less common among the majority population, resulting in patients from minority ethnic groups/ Muslim faith spending an increased time on the transplantation waiting list (Stefanone et al. 2012; BBC News 2012; Sissons 2011). Table 1 summarises stages of CKD.

What is the Islamic Stance to surrounding organ donation/ transplantation Education?

From an Islamic perspective, organ donation/transplantation is a more recent phenomenon and started to preoccupy the minds of jurists since the 1950s (Saaleh bin Fawzaan bin Abdullaah al-Fawzaan 2015; Eaton 2000). Available Islamic literature to date does not provide detail with any indication that organ transplantation took place during the lifetime of the Prophet Muhammad (Peace be Upon Him). However, early discussions have some implications used as starting points by ‘today’s’ Muslims. One condition is that if a Muslim decides to donate an organ he must do so out of free will without being morally or socially forced and without economic pressures (Saaleh bin Fawzaan bin Abdullaah al-Fawzaan 2015; Eaton 2000). If the deceased Muslim indicated during life (in a will) that they do not want to donate organs, then no one is authorized to do this on the deceased person’s behalf Saaleh bin Fawzaan bin Abdullaah al-Fawzaan 2015; Eaton 2000).

Although other sociocultural confounders are likely to influence the decision-making process for Black and Asian Minority Ethnicity (BAME) communities, religion is an important aspect of the decision-making process for most individuals. To this end, healthcare professionals and service providers should also look to explore/ take advantage of SM/ MM to help facilitate discussions, raising education and providing evidence-based understanding for ultimate solutions (Morgan 2008a; Morgan et al. 2008b Morgan et al. 2013; Morgan et al. 2006). The use of SM/ MM would help 1) bring more rounded discussions to the organ donation/ transplantation debate, 2) help with prompting open dialogue with key faith authorities in positions of influence to generate a consensus for further all-inclusive frameworks/ guidelines, 3) prompt organ donation/ transplantation to specific diseases, 4) provide channels for engagement with individuals, families, and communities to discuss the some of the most sensitive issues, and 5) encourage personal decision-making by intellectual effort.

This may be a challenging subject to converse, but it is an important one because it has the potential to promote organ donation among an approximate fifth of the world population (Morgan 2008a; Morgan et al. 2008b Morgan et al. 2013; Morgan et al. 2006). Education surrounding organ donation/ transplantation thus needs to be enhanced through the very health professionals that support clinical decision making, the healthcare scientists. These health professionals need to provide a rounded perspective on this important topic where laboratory care and practice is concerned. However, what also needs to be highlighted is that this understanding requires discussion with Fiqh (Islamic Jurisprudence) (Morgan 2008a; Morgan et al. 2008b Morgan et al. 2013; Morgan et al. 2006). For every disease, there is a cure (definition of which is ambiguous from human thought to Divine knowledge). However, those who do not believe in mercy or practice it cannot expect to be saved by it (Eaton 1994; Eaton 2000). In terms of strategies to promote organ donation/ transplantation, there is a need for multi-channel approaches so that the issue it is a more widely known social norm in primary care (Morgan 2008a; Morgan et al. 2008b Morgan et al. 2013; Morgan et al. 2006). It is important that this subject area is linked to those LTCs that are indeed known to require organ transplantation for best prognosis/ health outcome (Morgan 2010; Department of Health 2008; Hostetter 2001). LTCs that healthcare scientists will know underlying pathologies.

Islam and Definition of Knowledge (or Education)

Islam is commonly regarded as religion of ‘Law’, but above all it is the religion of knowledge. The Arabic meaning word for ‘law’ has the primary meaning for ‘understanding’ and thus relates to knowledge (Rispler-Chaim 2007; Ghaly 2008; Sheikh 2007; Alkhawari et al. 2005; Sissons 2011; Rocklinsberg 2009). In Islam, knowledge, intelligence and understanding define man as such. Man is not defined as a good or strong creature, or even as one who loves, but can be defined as one who understands or has the capacity for understanding (Rispler-Chaim 2007; Ghaly 2008; Sheikh 2007; Alkhawari et al. 2005; Sissons 2011; Rocklinsberg 2009). In other words, if man penetrates deeply into self – through all the layers of dreams and darkness – then comes out into the open and finds ‘everything’, that is knowledge. There are contentions but the question is then: who provides knowledge? It is Allah (God) alone and He alone deserves worship. In Islam, worship can also be defined as 1) Tawhid al-Rububiyah (or the unity of Allah’s Lordship), 2) Tawhid al-’Ibadah or the unity of Allah’s worship and 3) Tawhid al-Asma’ Wa’l-Siffat or the unity of His names and attributes (Rispler-Chaim 2007; Ghaly 2008; Sheikh 2007; Alkhawari et al. 2005; Sissons 2011; Rocklinsberg 2009). This is why the beloved prophet Muhammad (Peace be Upon Him) informed: ‘He, who knows himself, knows his Lord’. Science for a long time has been a foundation for

establishing knowledge/ education. What does Islam say about science?

Islam and Science

Islamic Science has always been holistic. This term, in which is of recent origin is ambiguous. Sometimes it refers only to the recognition of inter-independence between mind and body (Rispler-Chaim 2007; Ghaly 2008; Sheikh 2007; Alkhawari et al. 2005; Sissons 2011; Rocklinsberg 2009). If theory relates to ‘holism’ with reference to the Islamic perspective, then really it can only refer to the governing principle of Islam (Tawheed – oneness of Allah) and the unity of that He has created (Rispler-Chaim 2007; Ghaly 2008; Sheikh 2007; Alkhawari et al. 2005; Sissons 2011; Rocklinsberg 2009). It is through trials and tribulations, man matures and Allah (SWT)-willing, begin to face the reality of circumstances. Trials and tribulations free mankind from the illusions in which man seeks refuge (Rispler-Chaim 2007; Ghaly 2008; Sheikh 2007; Alkhawari et al. 2005; Sissons 2011; Rocklinsberg 2009). Any attempt to study phenomena (i.e. organ donation/ transplantation) without reference to the Qur’an is destined to failure because it has fragmented a link with reality (Rispler-Chaim 2007; Ghaly 2008; Sheikh 2007; Alkhawari et al. 2005; Sissons 2011; Rocklinsberg 2009). It is also quintessential to note that religious morality sets limits which do not change with passing public opinion (Rispler-Chaim 2007; Ghaly 2008; Sheikh 2007; Alkhawari et al. 2005; Sissons 2011; Rocklinsberg 2009). If man denies the world around him as a self-evident truth, then man is also denying that Allah (SWT) is a self-evident truth. Science has limitations – it is time bound (not timeless) and thus for the Muslim, the Qur’an is also ‘The Criterion’ (Al-Furqan) teaching to discriminate, not only between good and evil but also between shades of grey, the misnomers which are apparent in daily life (Rispler-Chaim 2007; Ghaly 2008; Sheikh 2007; Alkhawari et al. 2005; Sissons 2011; Rocklinsberg 2009). The Qur’an is multi-layered and multifaceted; it is distinct and is/ has always been (for the Muslims throughout history) a premise for decision-making.

The Healthcare Scientist’s Role surrounding Education for Muslim Patients

Muslims are the most ethnically diverse faith group in the UK (Sheikh 2007). The limited health data shows that Muslims are about twice as likely to self-report poor health and disability as the general population (Wakefield et al. 2001; Wakefield et al. 2011; Sharif 2012; O’Leary et al. 2015). Available Islamic literature to date does not provide detail with any indication that organ transplantation took place during the lifetime of the Prophet Muhammad (Peace be Upon Him). However, early discussions have some implications used as starting points by ‘today’s’ Muslims (Wakefield et al. 2001; Wakefield et al. 2011; Sharif 2012;

O'Leary et al. 2015).

Within Islam there are varying schools of thought when it comes to organ donation/ transplantation (Morgan 2008a; Morgan et al. 2008b Morgan et al. 2013; Morgan et al. 2006; Wakefield et al. 2001; Wakefield et al. 2011; Sharif 2012; O'Leary et al. 2015). Muslims in the UK believe that their religion prohibits organ donation despite efforts of outreach groups to dispel this myth (Morgan 2008a; Morgan et al. 2008b Morgan et al. 2013; Morgan et al. 2006; Sharif 2012; O'Leary et al. 2015). In a study which asked the question: what are your thoughts on organ donation and transplantation? Most Muslim participants were unwilling to discuss organ donation with their families (Sharif 2012). The current emphasis in UK health education material would-be donors to 'tell' their relatives of their plan needs to be worded more sensitively to consider the shared nature of decision-making within Muslim families (Sharif 2012). Whilst these are some perceptions on organ donation and transplantation, they do not represent the wider Islamic world. There is no one faith that can claim privileged status regarding the complex and challenging questions of organ donation (Morgan 2008a; Morgan et al. 2008b Morgan et al. 2013; Morgan et al. 2006; Wakefield et al. 2001; Wakefield et al. 2011; Sharif 2012; O'Leary et al. 2015). If policymakers want to see an increase in organ donation from the Muslim population and decision process, NHS Trusts need to accommodate Muslims in other ways (Sheikh 2007). Healthcare scientists could be proactive in this area of healthcare providing more informed understanding surrounding tests behind the scenes. Specifically, there has been more effort to understand Muslim perspectives but there needs to be further cohesion between those producing policy and Muslim involvement (Morgan 2008a; Morgan et al. 2008b Morgan et al. 2013; Morgan et al. 2006; Wakefield et al. 2001; Wakefield et al. 2011; Sharif 2012; O'Leary et al. 2015).

An understanding of patient (or individual) attitudes toward self-management and technology could inform unbiased, patient-centered interventions. Moreover, literature informs that the use of SM, in particular (and perhaps more generally) provides a gateway for knowledge gathering and decision-making (Baker et al. 1999; Williams et al. 1998; Muhammad et al. 2015; Nutbeam et al. 2000). SM also influences technology adoption for health self-management and shaping the development for assessing the appropriateness of SM-mediated interventions for patients/ individuals where sharing experiences are involved. Overall, a greater education of SM on health, organ donation, transplantation can help both clinicians to leverage patient values and strategies for enhancing both important decisions making and prompting education since this technology is now almost 'everyday language' (Baker et al. 1999; Williams et al. 1998; Muhammad et al. 2015; Nutbeam et al. 2000). This work encourages health

professionals and policy makers to ensure there is wider coverage of sensitive issues such as organ donation and transplantation through SM/ MM so that the general public and those from the Muslim population can make more informed decisions under more challenging circumstances (Morgan 2008a; Morgan et al. 2008b Morgan et al. 2013). Certainly SM applications have their place and it's important that such topics are discussed to encompass the Muslim population. In Islam, organ donation/ transplantation is allowed as Allah (SWT) informs that for every disease, there is a cure. More educational campaigns via SM/ MM involving healthcare scientists and Muslim communities are required. Those who do not believe in mercy or practice it cannot expect to be saved by it (Eaton 1994; Eaton 2000).

Discussion

The Holy Qur'an and teachings of the Prophet Muhammad (Peace be Upon Him) inform that suffering in this life is short-term. Attachment (worldly life) is, at best a very brief, and Islam never condemns what is natural to the human creature. Attachment becomes a grave sin when it leads to forgetfulness of what is again, in the words of the Qur'an 'better and long-lasting' (Eaton 1994; Eaton 2000). Patients/ carers and the lay general public use the internet/ SM to access information relating to organ donation/ transplantation. Using SM perhaps has several gains compared to traditional forms of MM where healthcare education is concerned (Nutbeam 2018; O'Kane 2015; Protheroe 2009), but both have advantages with regards to reach, accessibility and prompting organ donation/ transplantation education. In relating, health literacy (HL) is also important (Baker et al. 1999; Williams et al. 1998; Nutbeam et al. 2000; Nutbeam 2018; O'Kane 2015; Protheroe 2009) thus bridging gaps in understanding of specific areas of health. This is where healthcare scientists have an important role, to provide health science transparency where other health professionals are challenged. Clarity of terminology to help increase HL on topics relating to organ donation/ transplantation is now especially required owing to more time being spent online (Nutbeam 2018; O'Kane 2015; Protheroe 2009). Using SM versus MM to provide wider education surrounding organ donation/ transplantation is still unique, however, healthcare scientists should seek opportunities to help raise more education surrounding this sensitive topic in this faith population (Nutbeam 2018; O'Kane 2015; Protheroe 2009).

Conclusion

So, 1) Can Muslims donate their organs? Yes, Muslims can donate their organs. Whilst there are some perceptions on organ donation/transplantation where Muslims can't donate, these do not represent the wider Islamic world. A campaign promoting the need for increased blood and

organ donation from Black and Asian Minority Ethnicities (BAME) and Muslim faith was published (Muhammad et al. 2015). There is no one faith that can claim privileged status regarding the complex and challenging questions of organ donation/ transplantation (Department of Health 2008; Rispler-Chaim 2007; Ghaly 2008; Sheikh; Alkhwari et al. 2005; Sissons 2011; Rocklinsberg 2009). 2) Is there an Islamic stance on using SM/ MM to prompt organ donation/ transplantation education? The Islamic stance on use of either SM/ MM would be positive to prompt organ donation/ transplantation if this helps to increase life expectancy. If policy-makers want to see an increase in organ donation/ transplantation from the Muslim population and a more inclusive process, NHS Trusts need to involve Muslims to help inform practice (Sheikh 2007; Morgan 2008a; Morgan et al. 2008b Morgan et al. 2013; Morgan et al. 2006). Specifically, there needs to be further cohesion between those producing policy and Muslim involvement. 3) Does the Healthcare Scientist have a role providing the public education surrounding organ donation/ transplantation? The answer is yes, however more research is required to shed light on what is the most effective approach for the healthcare scientist to become proactive surrounding education for Muslim patients. The proliferation and wide usage of SM in combination to education of disease states via MM of over the past decade has created opportunities for healthcare scientists to seek wider opportunities to contribute and inform practice.

Summary

Discussions need to be balanced to help to make informed decisions and healthcare providers to prompt the right choices in care plans (Black et al. 2010). At the same time, an increase in life expectancy is worthless if additional years do not lead to an increasing education of the Divine reality (Eaton 1999; Eaton 2000). Practice and research now need to identify novel ways to deliver sensitive education. Healthcare scientists could help provide education through SM/ MM groups like the Renal Patient Support Group (RPSG), for example. With over 8000 members, the RPSG is perhaps one of the best examples through SM where shared-decision making can become more informed; real-life stories are being shared (RPSG 2019).

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Table 1: Stages of Chronic Kidney Disease (CKD)

| CKD Severity | CKD Classification |
|----------------|---|
| Stage 1 | Kidney damage with normal or raised GFR (greater than 90 ml/ min/ 1.73m ²) |
| Stage 2 | Kidney damage with normal or raised GFR (60-89 ml/ min/ 1.73m ²) |
| Stage 3 | Moderately impaired GFR (30-59 ml/ min/ 1.73m ²) |
| Stage 4 | Severely impaired GFR (15-29 ml/ min/ 1.73m ²) |
| Stage 5 | End Stage Renal Failure or GFR (less than 15 ml/ min/ 1.73m ²) |

Table adapted from (*Chronic Kidney Disease in England 2012*)

Table 1: CKD is classified in five stages, according to the level of kidney damage and the ability of the kidneys to filter blood. The glomerular filtration rate (GFR) measures the amount of blood that passes through the tiny filters in the kidneys, called glomeruli, each minute. As the disease progresses, the GFR falls. Stage 3 is divided into two parts - stages 3A and 3B (but classification for these two subdivisions are not outlined here).