BRAZILIAN AND ECUADORIAN SOCIAL MEDIA USERS: A STUDY OF KNOWLEDGE, ATTITU-DES, AND BELIEFS TOWARD ORGAN DONATION

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RESUMEN

Varios estudios han declarado que las actitudes de las personas hacia la donación de órganos están influenciadas por factores como el conocimiento, la educación y la religión. Muchas personas podrían donar si supieran los beneficios de la donación de órganos en lugar de desperdiciarla. Esa es la razón por la que este estudio se propone determinar el conocimiento, las actitudes y las creencias hacia la donación de órganos entre los usuarios de redes sociales brasileños y ecuatorianos. Se realizó un estudio transversal, evaluado a través de una encuesta autoadministrada, anónima y validada, y distribuido a través de las redes sociales. Cuatrocientos ocho individuos participaron en esta encuesta, 72 (17.6%) eran brasileños y 336 (82.4%) ecuatorianos. Las edades de los participantes estaban entre 18 y 59 años; 360 (88.2%) participantes estaban dispuestos a donar un órgano, mientras que solo 300 (73.5%) estuvieron de acuerdo dar su consentimiento para donar los órganos de sus familiares fallecidos (p <0.001), y 48 (11.8%) de esas personas no estaban dispuestas tener una identificación de donante (p <0.001). Con respecto al conocimiento sobre la muerte cerebral, 320 (78.4%) considerarán que el corazón continuará latiendo y 306 (75%) afirman que las personas con muerte cerebral permanecerán en coma; 359 (88%) personas recibieron información sobre trasplantes y donaciones de órganos a través de la televisión, las redes sociales y los periódicos impresos. Con base en los resultados de esta investigación y analizándolos, podemos concluir que existe una gran disposición de la población estudiada para convertirse en donante de órganos y recibir más información sobre este tema.

Palabras clave: conocimiento, actitudes, creencias, donación de órganos, redes sociales.

ABSTRACT

Several studies have stated that people's attitudes towards organ donation are influenced by factors such as knowledge, education, and religion. Many people could donate if they knew about the benefits of organ donation instead of wasting it. That is the reason that this study sets out to determine the knowledge, attitudes, and beliefs toward organ donation among Brazilian and Ecuadorian Social Media Users. A cross-sectional study was conducted, assessed through a self-administered, anonymous and validated survey, and distributed through social media. Four hundred and eight individuals participated in this survey, 72 (17.6%) were Brazilian, and 336 (82.4%) Ecuadorian. The participants' ages were between 18 and 59 years old; 360 (88.2%) participants were willing to donate an organ, whereas only 300 (73.5%) agreed to give their consent to donate their deceased family member's organs (p < 0.001), and 48 (11.8%) of those people were not willing to have a donor identification (p < 0.001). Concerning knowledge about brain death, 320 (78.4%) will consider that the heart will continue beating and 306 (75%) affirm that people who are brain dead will remain in a coma; 359 (88%) people received information on transplants and organ donations through television, social networks, and printed newspapers. Based on the results of this research and by analyzing them, we can conclude that there is a great willingness of the studied population to become an organ donor and to receive more information on this topic.

Keywords: Knowledge, attitudes, beliefs, organ donation, social media







INTRODUCTION

Chronic diseases are replacing infectious diseases as the leading cause of morbidity and mortality worldwide, and they are responsible for about 70% of all deaths, with an estimated 38 million deaths annually (World Health Organization, 2019). About these deaths, 16 million occur prematurely (under 70 years of age) and almost 28 million in low-income countries and average income (World Health Organization, 2018). In the United States, heart disease, cancer and diabetes are leading causes of death and disability, and they are also leading drivers of the nation's more than U\$3 trillion in annual health care costs (U.S. Department of Health & Human Services, 2019). In the same way, some Southern Common Market countries, cardiovascular diseases, cancer and diabetes are the leading causes of mortality (MERCOSUR y Estados Asociados, 2011).

Concerning that, more than 60% of all death in Brazil is related to cardiovascular diseases, diabetes, cancer, and chronic respiratory disease (Ministério da Saúde do Brasil, 2013; Pan American Health Organization and World Health Organization, 2015). Ecuador has followed the same trend, given the increase registered between 2007 and 2011, to almost double the number of cases in the three primary diseases, diabetes me-Ilitus, hypertension and cerebrovascular disease (Pan American Health Organization and World Health Organization & World Health Organization, 2014; World Health Organization, 2013).

There is a gradual decrease in the quality of health of patients with advanced chronic disease (Amblàs-Novellas et al., 2016), which corresponds to patients with advanced organ diseases such as heart, lung, kidney and liver failure (Lunney, 2003). Saying that, in the absence of long-lasting artificial organ support or ineffective drug treatment, solid organ transplantation becomes a life-saving therapy in those patients (Grinyo, 2013). Transplantation is the transfer of human cells, tissues, or organs from a donor to a recipient to restore the function (s) of the body (World Health Organization, 2019). Organ donation is the process of giving an organ or a part of it to be transplanted to another person, either a deceased or living donor (Holman et al., 2013; Ríos et al., 2013).

In 2015, more than 126 thousand people worldwide had already received organ transplants, which means that there was an increase of 5.8% since 2014 (GODT, 2016). Scientific, technological and administrative advances have contributed to an increase in the number of transplants, although it is still insufficient in the face of high demand (Gross et al., 2001; Holman et al., 2013; Ríos et al., 2013). However, there is a growing discrepancy between the number of organ donors and potential recipients. For this reason, in 2016, more than 7,000 candidates to be organ recipients died while on the waiting list (UNOS, 2017). Few countries in the world have enough bodies to meet the needs of their citizens. Organ transplantation is estimated to cover <10% of global needs. Spain, Austria, Croatia, the United States, Norway, Portugal, Belgium and France stand out as countries with high rates of deceased donors (Garcia et al., 2012; GODT, 2016; Rudge et al., 2012). Spain has systematically registered the largest donation of deceased, a rate of 33-35 donors per million inhabitants and many countries around the world have been following the Spanish model (International Registry in Organ Donation and Transplantation, 2020; Matesanz et al., 2017).

It is striking to note that in Brazil, from 2010 to 2017, the effective donor rate grew 69%, from 9.9 per million inhabitants to 16.7 per million inhabitants, while the notification rate of potential donors increased 41% and the effectiveness of donation increased by 21% (ABTO, 2019). Ecuador has also made a significant advance in increasing the donation rate, going from 5.05 donors per million inhabitants in 2017 to 7.75 donors per million inhabitants in 2019 (INDOT, 2020); unfortunately, there is a huge deficit in the organ donation and transplantation system. Also, the population does not realize the importance and benefits of donation. Even though, since 2012, every Ecuadorian is by law a donor unless they sign to state that they do not want to, but the expected improvement has not materialized.

The issue of organ donation is complex and multifaceted, involving ethical, legal, medical, organizational and social factors (Wakefield et al., 2010). Countries around the world have reported that people's attitudes towards organ donation are influenced by factors such as knowledge, education, and religion (Haustein & Sellers, 2004; Irving et al., 2012; Kaur & Ajinkya, 2012; Morgan & Miller, 2002; Wakefield et al., 2010). Many people would be likely to donate if they knew about the benefit of organ donation instead of wasting it (Hyde & White, 2010); however, some still hold the belief that an intact body is essential to pass over into "the afterlife" (Alam, 2007). In Poland, due to misconceptions about brain death, the public did not have positive attitudes towards organ donation, as they were not willing to accept brain death as the death of a human being (Nowak et al., 2014).

Studies in Brazil demonstrate that disinformation is the main barrier in attracting donors (G. H. de F. Coelho & Bonella, 2019; Marodin et al., 2012). Although about 80% of public opinion related to donation for transplantation in Brazil is favourable, researches mention that distrust in the procurement and distribution of organs remains reasons to rethink the option to donate (G. H. de F. Coelho & Bonella, 2019; J. C. U. Coelho et al., 2007). In Ecuador, there is also a great willingness to be an organ donor and to receive more information on this subject, in addition to psychosocial factors and academic level influencing the decision to donate organs. However, that lack of studies about organ donation and transplantation in Ecuador has affected that it does not have the necessary interest in our population. Thus the lack of knowledge about it increases (Alvarez & Valencia, 2011).

Therefore, before carrying out any campaign to promote organ and tissue donation and transplantation, it is necessary to know, in a broader way, the knowledge that people have on the subject. To achieve the donation of organs and tissues is essential to act on two levels; the general public and health workers. Educational programs have recently been suggested as a new approach to resolve organ shortages (Burra et al., 2005), especially on social media, which are contributing to spreading the information of this topic (Cameron, 2015; Desmon, 2012; Pacheco et al., 2017).

That is the reason that social networking sites are a common platform for promoting organ donation in the United States (Smith et al., 2016; Stefanone et al., 2012) and in some other European countries (Cucchetti et al., 2012). Consequently, organ donation campaigns that use social media have generated some promising results, such as increasing organ donor consent rates (Henderson et al., 2017; Rodrigues, 2014; Shi & Salmon, 2018b). Besides, health campaign designers promote organ donation on social media to facilitate information with the global environment. Also, organ transplant surgeons can have a significant influence on their direct connections, and that could also effectively participate in promoting organ donation on social platforms (Cheston et al., 2013; Shi & Salmon, 2018b). One of the most common platforms using in the United States is Facebook, used by 79% of all Internet users (Rodrigues, 2014).

For this reason, the purpose of this study is to determine the knowledge, attitudes, and beliefs toward organ donation between Brazilian and Ecuadorian Social Media Users. This paper will also analyze whether the willingness to donate is related to sociodemographic variables.

METHODS

Sample and Process

This is a cross-sectional study which it was assessed through a self-administered, anonymous and validated survey (Hajjar et al., 2016). It was distributed online for Brazilian and Ecuadorian social media users randomly via Google Forms on social media networks (Instagram, Facebook, and WhatsApp) conducted in June and July 2018, and 408 participants above 18 years old filled out this questionnaire. All participants received an online consent form, and it indicated the estimated time to complete it, the purpose of the study, and the participant's right to withdraw at any time without any penalty or loss of benefit. The questionnaire contained nine sociodemographic questions, ten questions related to the knowledge of organ donation, thirteen questions about attitude and beliefs associated with the willingness of donations, and seven questions about brain death.

Analytical Design

Frequencies and percentages have been used to describe all the variables of the questionnaire. To assess the association between sociode-mographic variables and the desire to donate, the Chi-Square test or Fisher's exact test has been used for tables with low frequencies. The Lilliefors-corrected Kolmogorov-Smirnov test was carried out to check if the age (in years) has a normal distribution. The Mann—Whitney U test was used to determine the association between age with the willingness to donate. The data were analyzed by the use of Statistical Package for Social Sciences (SPSS) version 25, and an alpha of 0.05 was used as the cutoff for significance.

RESULTS AND DISCUSSION

From a total of 408 participants, 72 (17.6%) were Brazilian and 336 (82.4%) Ecuadorian; 292 (71.6%) female, 114 (27.9%) male, and two (0.5%) preferred not to say. The majority of the participants were students (N = 208, 51%), followed by employees (N = 162, 39.7%), and other professions. Among them, 312 (76.5%) were Christian, followed by 72 Agnostic/atheist (17.6%), and others religions; 296 (43.6%) of the respondents had an income ranging between 0 and 3000 USD, and 112 (56.4%) had an income of more than 3001 USD. The minimum age was 18 years old, and the maximum was 59 years old (29.85 \pm 9.52 years old).

Also, 360 (88.2%) participants were willing to donate an organ. In contrast, only 300 (73.5%) agreed to give their consent to donate their deceased family member's organs (p < 0.001), and 46 (11.28%) of those people were not willing to have a donor identification (p <0.001). In addition, 48 (11.8%) people who were not willing to donate, only two (0.5%) mentioned that it was for religious reasons, 28 (6.86%) for fear of the operation, others for other factors. Concerning knowledge about brain death, 320 (78.4%) will consider that the heart will continue beating, and 306 (75%) affirm that people with brain death will continue in a coma. This attitude was associated with different psychosocial variables; 359 (88%) people received information on transplants and organ donations through television, social networks, and printed newspapers are shown in Table 1.

Table 1. Variables related to willing to donate				
Variables	In favor	Not in favor	P-value	
	(n = 360; 88.2%)	(n = 48; 11.8%)		
Gender	Men = 102	Women = 36	0.769	
	Women $= 256$	Men = 12		
	Prefer not to say $= 2$			
Nationality	Brazilian = 64	Brazilian = 8	0.850	
	Ecuadorian = 296	Ecuadorian $= 40$		
Education	Primary or Secondary = 14	Primary or Secondary = 2	0.823	
level	Bachelor = 194	Bachelor =28		
	Master or $PhD = 152$	Master or $PhD = 18$		
Occupation	Employee = 170	Employee = 14	0.009	
	Student = 174	Student = 34		
	Retired/Not work = 16			
Religion	Atheist/agnostic = 68	Atheist/agnostic = 4	0.110	
	Religious = 294	Religious = 44		
Income per	$U\$ \ 0 - 500 = 160$	$U\$\ 0 - 500 = 18$	0.403	
month	U\$ 501 - 1000 = 70	U\$ 501 - 1000 = 14		
	U\$ 1001 - 3000 = 104	U\$ 1001 - 3000 = 14		
	$U\$\ 3001 - 5000 = 14$	$U\$ \ 3001 - 5000 = 2$		
	More than U\$ 5001 = 12			

Although 'Occupation' has statistical significance with the willingness to donate an organ (p = 0.009), the age (in years) has no significance (p = 0.204). The knowledge of brain death is showed in Table 2. 176 (43.1%) of people said that they do not know if the brain-dead people react if someone touches their eyeball. However, 306 (75%) stated that brain death is different from coma; 186 (45.6%) different from a vegetative state; and, 320 (78.4%) answered that it is possible that brain-dead people have their heart beating. Moreover, all the information on attitudes and beliefs towards organ donation is shown in Table 3.

Table 2. Knowledge about brain death

Knowledge about brain death		Frequencies	Percentage
1.	Does the brain-dead person	n react if someone touc	thes their eyeball?
I do not know		176	43.1
No		140	34.3
Yes		92	22.5
	2. Is brain dea	th different from a com	a?
I do not know		54	13.2
No		48	11.8
Yes		306	75.0
	Is brain death dif	ferent from a vegetativ	e state?
I do not know		90	22.1
No		132	32.4
Yes		186	45.6
4.	Can a person be brain-	dead even if the heart i	s still beating?
I do not know		54	13.2
No		34	8.3
Yes		320	78.4

donation 1. Source	s of information that has	ard about organ donation
News (Internet, newspapers)	356	87.3
Family	22	5.4
University	14	3.4
Hospital	12	2.9
Friends	4	1.0
2. Effe	ct of organ donation on	the recipient's health
Beneficial effect	338	82.8
Harmful effect	18	4.4
do not know	42	10.3
No effect	10	2.5
<i>3</i> .	Import organs from a	
Yes	288	70.6
No	120	29.4
	 Willing to donat 	
Yes	360	88.2
No	48	11.8
	5. If no, wh	
Afraid of operation	14 12	29.16
Afraid of losing a life I do not know	12	25 25
	6	12.5
Donate just to close relative Religion	2	4.17
religion Inadequate knowledge	2	4.17
	6. If yes, who	
After death	174	48.33
Both of them	152	42.22
During life	34	9.45
		r "both of them", why? 186
More humanity	109	58.6
Others will be happier	40	21.51
Cause no problem	23	12.37
Organ donation is easier for me	14	7.52
8.	What organs will don	
Kidney	194	23.80
Bone marrow	116	14.23
Liver	92	11.29
Pancreas	62	7.61
Cornea	58	7.12
Heart	58	7,12
Lungs	54	6.63
Bones	37	4.54
do not know	144	17.67
9.	If the answer is "after	r death", why?
Cause no problem	60	34.48
Others will be happier	58	33.33
More humanity	56	32.19
	What organs will you do	
Heart	123	13.50
Kidney	114	12.51
Cornea	108	11.86
Pancreas	90	9.88
Lungs	81	8.89
Bone marrow	50	5.49
Bones	50	5.49
Liver	79	8.67
All organs	216	23.71
11.	Who are you willing t	
Parents	340	19.72
Sons and daughters	302	17.52
Brothers and sisters	300	17.40
Friends	268	15.55
Relatives	266	15.43
Non-relatives	248	14.39
		ple not to donate organs?
nadequate knowledge	140	34.3
Afraid of losing a life	48	11.8
Afraid of operation	48	11.8
Like to donate to close relative only	16	3.9
All of the above	124	30.4
do not know	32	7.8
		ncrease the number of donors?
Health education	250	61.3
Privileges for donors	54	13.2
Media (TV/newspapers)	42	10.3
Social media	36	8.8
do not know	26	6.4
	you willing to have/sigr	
Yes	328	80.4
No .	80	19.6
	15. If "no", wh	
Do not have enough information abou	t 11	13.8
organ donation	10	45.0
Fear of complications after organ	12	15.0
donation		
Lack of family support	12	15.0
Lack of incentives	12	15.0
Religious reason	17	21.3
Worries about receiving inadequate	16	20.0
nealth care after donation		
		dead, would you consent to donate
If you have a famil	his/her organs?	

Our study suggests that the majority of the media users have a positive attitude toward organ donation, and most of them (80.4%) were willing to donate organs. However, the level of knowledge about which organs could be transplanted, the concept of death, and the transplantation law were low. In the group of nondonors, 25 (51.1%) justified as a lack of confidence in the health system and 9 (17.7%) as a concern about organ removal before death.

Although organ donation and transplantation are mostly influenced by several factors about people's attitude, such as religion (Alvarez & Valencia, 2011; Holman et al., 2013; Kaur & Ajinkya, 2012; Ríos et al., 2013, 2015), our study did not demonstrate a statistically significant between being religious and the decision to donate organs (p = 0.11). Moreover, this partially corroborates with our findings that states that 'Occupation" has a statistical significance to willing to donate (p = 0.009). Furthermore, the vast majority of people believe that the number of donors could increase is with health education 250 (61.3%), and the last chosen was social media 36 (8.8%), which suggests that information campaigns should be promoted from all possible areas.

From researches that have been done, the attitude for donation extends somewhere in the range of 50% and 80% (Haustein & Sellers, 2004). There is limited familiarity with the matter of both donation and replacement among the Latin American populace. Remarkably, solidarity and decent obligation are regularly expressed as tenacities behind individuals being supportive of donation. Notwithstanding, among the people who have had access to social media, the influence is very positive, and they demonstrate a progressively ideal demeanour toward donation and organ transplantation (Cheston et al., 2013; Haijar et al., 2016; Henderson et al., 2017; Shi & Salmon, 2018b). In this manner, an absence of awareness and a more noteworthy measure of hesitation are likewise a conspicuous component that is related to limited social media use (Aykas et al., 2015; Cheston et al., 2013; Pacheco et al., 2017).

As found in this investigation, one cannot make speculations given that critical contrasts have been found between the various nationalities. Along these lines, an increasingly positive attitude toward donation has been found among the respondents of Brazilian nationality (Ríos et al., 2015). The majority of these people also have completed their University education, and this increases their exposure to social media and the information available in regards to healthcare matters (Ríos et al., 2015). Hence, they are in support of the processes. In Ecuador, organ donation has not been of great interest to the population, even though few investigations attempt to determine positive and negative aspects that may affect the decision to donate organs (Alvarez & Valencia, 2011). Psychosocial aspects are undoubtedly the most influential factors (Falomir-Pichastor et al., 2013). Still, we can not mention that in our research because there is no significant association was found in all variables, except for occupation. Although on March 4, 2011, the Organic Law of Donation and Transplantation of Organs, Tissues, and Cells in Ecuador established that each Ecuadorian and foreign resident are donors, it is estimated that more than eight hundred people are on the waiting list for the reception of organs (INDOT, 2020).

It is believed that the population does not recognize the importance and benefits of the donation. Unfortunately, there are no other studies related to the factors toward organ donation in Ecuador. Although around thirteen thousand organs and tissue transplantation were carried out in Brazil in 2019, more than 30 thousand are in a waiting list (ABTO, 2019). Although about 80% of Brazilians in some communities are willing to donate an organ, the lack of knowledge about this topic and the locating and distribution of organs remain reasons to rethink the option to donate are the main barrier (G. H. de F. Coelho & Bonella, 2019).



Opportunely, in the United States, Facebook users started the first discussion about the benefits of organ donation and the idea to register as organ donors (Desmon, 2012). In general, online platforms assume a central role in the general wellbeing sector and can improve public commitment for organ donation. The same number of persons is getting to be acclimated with surveying health-related data on the internet (Sussman et al., 2018). Social media has been broadly utilized for imparting health data (Cheston et al., 2013). People sign in to online platforms to communicate with each other to boost their self-esteem and to find information relating to different medical problems (Desmon, 2012; Pacheco et al., 2017). As to gift, online life has additionally been comprehensively received for correspondence at the emergency clinic, network, and grassroots levels (Henderson et al., 2017). Nevertheless, serving as a setting for data exchange, social media is vital for the advancement of health treatments. Data interchange happens through online platforms like Instagram, Facebook, and WhatsApp (Cameron, 2015; Hajjar et al., 2016; Shi & Salmon, 2018a).

Several areas deserve further research in opinion leadership on the topic of organ donation on social media. Social media education campaigns may likely include social statements and family discussions about organ donation and increase consent rates that require different interventions. More research is needed in Brazil and Ecuador to examine the content of the most compelling message (i.e. benefits, dispel myths, necessity) in social media posts. The effectiveness of content and message may also vary depending on the type of social media (i.e. text, photo or video posts) and platform (i.e. Facebook, Instagram, YouTube) and requires further investigation.

CONCLUSIONS

Based on the results of this research and by analyzing them, we can conclude that there is a great willingness of the studied population to become an organ donor and to receive more information on this topic, especially on social media. As we mentioned previously, psychosocial factors can influence the decision to donate organs, and we also determine through the obtained results that education is undoubtedly an influential factor. Besides, it has seen in several studies that the donation rate in Brazil and Ecuador is increasing; there is also a growing demand for donors in both countries. Although they have enacted clear legislation on organ donation and transplantation, there is a significant cultural attitude of the general population, given by different factors that limit this decision. Undoubtedly, the different cultural beliefs of a population will significantly influence the decision of people towards the donation. Negatively the erroneous ideas of myths, fears and taboos created by the same people based on ignorance influence not donating their organs. Also, we can conclude that the lack of studies about organ donation and transplantation in Ecuador, mainly, has influenced that it does not have the necessary interest in our population and therefore increases its ignorance.

LIMITATIONS

There are several limitations to this study. One of them is the small sample of Brazilian people, which we cannot compare precisely the factors towards organ donation with the Ecuadorian group. Besides that, the multiple questions made it difficult to analyze because the amount of time spent to do dummy variables were significant. Also, we did not receive all the questionnaires that we have sent. Additionally, we did not identify the reason which caused the lack of participation of both groups. Furthermore, we believe that Brazilians and Ecuadorians are not yet awa-

re of the power that social media can have to pass on information regarding the suffering of patients who are on the waiting list for an organ.

AVAILABILITY OF DATA

Free and limited use of bibliographic resources were used. The information collected is available upon request to the principal author.

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CONTRIBUTION OF THE AUTHORS

Sueny Paloma Lima dos Santos: Manuscript writing, work design, data analysis and interpretation of the data. María José Fernández-Gómez: Manuscript writing, revision criticism of the manuscript, approval of the final version. Javier Martín-Vallejo: Manuscript writing, revision criticism of the manuscript, approval of the final version. Waseem M. Hajjar: Manuscript writing, revision criticism of the manuscript, approval of the final version. All authors read, and they approved the final version of the article.

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