The Renal Health Instagram: An Analysis of Comments

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Abstract. Chronic kidney disease (CKD) is a Public Health problem affecting a considerable number of patients worldwide. CKD treatment is complex and requires patients' education. Based on this we have created technological tools, including an application for smartphones and a profile on Instagram (Renal Health) aiming to educate patients to self-monitor and cope with their disease, to increase adherence to treatment. In this study, we have analyzed the spontaneous feedbacks patients, and other people have posted on the Renal Health Instagram (comments) to investigate which information was needed the most by which types of patients. During the first 15 months since the release of this profile, there were 3380 followers, a total of 449 posts, with 36,079 "likes". Most of the followers were patients and parents, they gave spontaneous testimonials of their experiences with having kidney disease, and were thankful for the information provided and for the response we gave to their questions. From the analysis of the comments, we found that information on nutrition, physical activities and kidney transplant were the most discussed and valued. Our results also showed that the main use of this medium for dialysis and transplant patients was to share their experience. The Renal Health Instagram was considered a good digital platform of trusted information for both patients and the general population and also a space for sharing experiences in the context of kidney disease epidemics.

Keywords. Kidney disease, patient empowerment, internet, Instagram, education

1. Introduction

Since 1980 debates regarding health promotion are advancing in Brazil, with focus on the multi causality of diseases and the right to health, culminating in the creation of the Brazilian Unified Health System (SUS), which is now one of the largest Public Health Systems in the world, with free universal coverage [1]. Since the creation of the SUS,

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health education is valued, and patients are considered as crucial in the process of healthcare and the management of their care, to have an active role for achieving a good health condition [2].

This protagonism of patients in healthcare is crucial in the context of chronic disease, as in the case of chronic kidney disease (CKD). CKD is currently a worrisome Public Health problem, which affects approximately 11-13% of the general population. This reality is not different than in Brazil, where these rates have grown, having a 27% increase of patients on hemodialysis from 2012 to 2017, and in 2018 there were more than 130,000 people receiving dialysis [3]. The main causes of CKD are hypertension and diabetes, which are controllable, require patients' education and collaboration to change their habits. Therefore, educational measures are crucial, and technology can help.

Recent data shows that more than 70% of internet users claim to have searched for health information in the past year [4]. In Brazil, recent data from the Ministry of Planning, Development and Management showed that 74.9% of households have internet access, and 97% of the population has a smartphone [5]. Although there are many sources of information on the internet, many are neither trusted nor valid. Therefore, there is a need to create educational material, with a multidisciplinary team, which can be frequently updated [2, 6]. In this way, patients and people who connect with our social networks and other technological tools that we create can have easy access to qualified professionals, who cannot be so easily accessed in regions where access to health is limited, such as in poor and developing countries. In addition, one size does not fit all. Therefore, the aim of our study was two-fold: first, we aimed to analyze the effects of a recently created social network for patients with kidney disease (the Renal Health Instagram) through their spontaneous comments, using the internet and smartphones as a way of getting information for health education.

2. Methods

The Renal Health project started in 2015, aiming to develop technological tools for patients, and the public in general, to get information about kidney disease in Fortaleza, Brazil, including an application to help CKD patients in their treatment [6]. Although the fifth largest city in Brazil, Fortaleza, still faces several problems, including poverty, lack of sanitation, unemployment, and difficulties with access to health care, we have the possibility to offer technological tools to help people cope with chronic diseases, and they have easy access to the internet. All this makes health education essential to achieve better results in terms of decreasing the burden of chronic diseases. In the most recent official document about the mortality causes in Brazil, CKD appeared as the 10th most common cause of death in this region [5]. We created an Instagram profile and a YouTube channel to educate people, using not only text but also movies. We posted information about nutrition, medication use, physical exercises, and several other aspects of kidney diseases, prevention and treatment, on a weekly basis. The profile can be accessed through this link: https://www.instagram.com/renal_health/. We analyzed the spontaneous feedback people who follow the Renal Health Instagram profile have given from 1st June 2018 to 8th September 2019. Aside from analyzing all the feedback given in this period, including a quantification of the "likes", we specifically analyzed the posts that were most commented on, and what type of information was required the most by which type of kidney disease patients. An analysis of the testimonials and

acknowledgements was also done, in order to identify which groups of patients and people were most "reached" by the information provided by the Renal Health Profile so that in the future posts we could offer more tailored information based on these patients' needs. We have analyzed all the posts of the profile ("Renal Health" Instagram), as well as each comment and feedback, and made a classification based on the subject. It consisted of a content analysis. Subsequently, we have made a characterization of the socio-demographical profile of the followers.

3. Results

Since the first publication in the Renal Health Instagram profile on June 1st, 2018, we have gathered a total of 3380 followers. In total there were 449 posts: 14 (3%) about medication, 63 (14%) about nutrition, 9 (2%) about excesses, 123 (17,39%) about kidney disease and comorbidities, 70 (15,59%) about treatment stimuli, 55 (12,2%) about kidney transplants and organ donations, and 35,78 % others. Virtually all posts received "likes" and comments. A total of 36,079 likes have been observed, and the post that has received the highest amount of "likes" (n=837) was one regarding organs' donation.

Of a total of 1381 comments, these comments were performed by 469 profiles, of these are 80 (17%) men, 350 (74.6%) women and 39 (8.3%) profiles without gender, noting the prevalence of women among the comments made. One hundred eighty-five (185) comments were posted regarding congratulations and acknowledgements on the profile (Figure 1). People were thankful for the fact that our profile is interactive, and all questions are answered. We have identified 95 patients with kidney disease, mainly CKD. Of these, 73/95 (63.1%) spontaneously reported their illnesses in their comments, being on 60.2% dialysis, 21.9% transplanted patients, 6.8% glomerulonephritis, 5.4% kidney stones and 5.4% renal cysts. In total, 95 patients had posted spontaneous testimonials about their diseases and experiences with having CKD, and the difficulties they had faced. Also, 28 acquaintances of patients with kidney diseases had posted comments on our publications, most regarding questions to help them cope with the care of their children.

Table 1. Types of themes posted in the Renal Health Instagram, June – September 2019.

Posts category	Number of posts
Medication	14
Nutrition	63
Excesses	9
Kidney disease and comorbidities	123
Treatment stimuli	70
Kidney transplants and organ donations	55
Others	115
	449

Figure 1. Testimonials of patients following the Renal Health Instagram, showing the impact on their habits and lifestyle. On the right side, a testimonial showing a patient's lifestyle change, and on the left, a tattoo with our project's logo in a patient's arm in a sign of gratitude and comprehension of the aims of the project.

The most commented posts were: 32 posts with comments on nutrition, followed by kidney transplants (with 29 comments), totalling 61 comments. From 90 comments that were posted in the groups of 45 patients on dialysis, there were 14 comments covering the questions on this topic, 68 comments of personal experiences on the subject, and finally eight comments on the importance of this information. In the group of 12 patients having kidney transplantation, 11 comments demonstrated their happiness after the transplant and their experiences, followed by one comment covering a question about their happiness after the transplant and their experiences. We have also identified other health professionals interacting with the profile, declaring that it was useful to help them to give advice to patients. And finally, this platform had crossed the borders, since we have also identified comments by people from other parts of the world, such as other South American countries, the Middle East and Europe.

Table 2. Types of comments from 45 dialysis patients posted in the Renal Health Instagram, June – September 2019.

Types of comments from dialysis patients	Number of posts
Questions on the topic	14
Personal experiences on the subject	68
About importance of this information	8

4. Discussion

The Renal Health Instagram showed to be a valuable digital platform for patients with kidney disease and surpassed the initial objective of the researchers, which was to provide information to patients and caregivers. Our results showed that methods of dialysis and treatment of chronic kidney disease were the most important information for the patients with dialysis and transplantation, followed by nutrition. Our results also showed that the main use of this media for dialysis and transplant patients was to share their experience.

Currently, Medicine and healthcare, in general, cannot be practised without technology and connecting with patients. According to Meskó (2017), there are very interesting new terms in Medicine, for example, the "e-patient", which can be defined as the patient who is "empowered, engaged, equipped, enabled, equal, or expert", and "Participatory Medicine", which is "a model of cooperative health care that seeks to achieve active involvement by patients, professionals, caregivers, and others across the continuum of care… to increase patient satisfaction and improve the cost of care" [7].

The use of social networks, such as the Renal Health Instagram, by patients and the general population, as a way of getting trusted information for health education is benefic, and a real way of connecting patients and the healthcare team in a trusted relationship. Using these platforms, a broader audience can be reached, cross the borders, as the internet can be easily accessed from any part of the world. As technological tools may empower patients with information and abilities to cope with

chronic diseases, medical recommendations might be better followed and therapeutic goals achieved. It is expected that treatment's adherence increases, and therefore complications might decrease, and outcomes might improve. Clinical trials are needed to test this hypothesis.

There are few studies analyzing the impact of the use of Instagram on patients' health education. In a study regarding the use of this social media in the area of Orthopedics, posts on Instagram were predominantly from patients, and fewer were made from doctors [8]. These posts had in the majority of cases positive comments [8]. Another study evaluated the experience of patients using social networks regarding Twitter and Instagram to discuss their experience about a specific surgery (Gamma Knife stereotactic radiosurgery), and the authors evidenced that the main use of these media was to share patients' experience [9], which is accordance with our findings for transplant and dialysis patients. To the best of our knowledge, this is the first study to extract information need for specific types of CKD patients using comments of the provided general information for CKD patients in an internet social network. Future studies are needed to analyze bigger dataset to identify the specific information needs of CKD patients.

5. Acknowledgements

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