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CHAPTER 8

Rare diseases: What information is available on social media?

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ABSTRACT

Rare diseases are those that affect up to 65 people per 100,000 individuals, that is, 1.3 people per 2,000 individuals, and are classified in their nature as: genetic and non-genetic in origin. Considering the difficult access to the correct diagnosis and treatment of rare diseases, the internet, through virtual social media, has been a tool for support and clarification of patients and families. The aim of this study was to verify the information available on rare diseases on the internet, using the virtual social media Facebook and Instagram and to evaluate the quantity and relevance of the published material. This is a cross-sectional, descriptive study, using social media Facebook and Instagram, data collection took place from September 7 to November 10, 2022, and this period was established for convenience. For research on social media, the words "rare diseases" were used; "rare diseases in Brazil" and the question: "What are rare diseases?". In the search carried out in the virtual social networks, profiles of support groups and associations with individuals with rare diseases (04), profiles that presented concepts and clarification about rare diseases (04), profiles that disseminated the laws of support for patients with rare diseases (04) and content producers (04) were identified. Virtual social networks are tools used on the internet, being useful and easy to access and with thousands of simultaneous accesses worldwide and with a wide range of information being shared every second. Unfortunately, on the other hand, it is observed that the publications are lacking in depth and, at times, in content quality. While there are pages and profiles dedicated to rare diseases, the vast potential of this digital environment remains underutilized.

Keywords: Rare diseases, Use of the Internet, Information Systems.

1 INTRODUCTION

Rare diseases are those that affect up to 65 people in every 100,000 individuals, that is, 1.3 people for every 2,000 individuals (Micheleti and Oliveira, 2023), being classified in their nature as:

genetic and non-genetic in origin (Brasil, 2014) and there are between 6 and 8 thousand rare diseases in the world, and for 95% of them, there is no specific treatment to date (Brasil, 2019).

In 2014, the Ministry of Health instituted the Guidelines for Comprehensive Care for People with Rare Diseases in the Unified Health System (SUS), which determines that Specialized Care Services and Reference Services for Rare Diseases will be components of the Health Care Network, in the National Policy for Comprehensive Care for People with Rare Diseases in the SUS. and should offer specialized and comprehensive care, being responsible for both prevention and therapy in these cases.

Thinking about the best approach to the patient with rare disease, two axes of rare diseases were listed, the first axis being composed of diseases of genetic origin: 1-Congenital Anomalies or Late Manifestation, 2-Intellectual Disability, 3-Inborn Errors of Metabolism; and the second axis formed by diseases of non-genetic origin, being Rare diseases of a non-Genetic nature - the following groups of causes were proposed: 1- Infectious, 2- Inflammatory, 3- Autoimmune, and 4 - Other Rare Diseases of Non-Genetic origin (Brasil, 2014).

In order to provide care to individuals with rare diseases or at risk of developing them, the network needs to be structured to ensure comprehensive and coordinated care, from reception and support to resolution and follow-up of the patient. However, families of people with rare diseases are treated unequally in health services, but not exactly because of prejudice, but often because the services do not have the technological resources to treat a rare condition or because professionals are not prepared (Luz, 2015).

In an attempt to fill the gaps found in health services, individuals who do not find answers to their questions turn to the internet, especially after the SARS-CoV-2 pandemic in 2020. Virtual social networks became part of the daily life of the population that was in social isolation, and in addition to entertainment, they were used to validate information (Nascimento, 2023).

The role of technologies and virtual social networks in the midst of the pandemic was significant and the use of technosociality, which can be delineated as the socialization of users through technologies, characterizes a change in society, in the individual and collective way of living (Maffesoli, 2016).

Nowadays, social networks are no longer limited to relationships, but also as a source of research and news, with interactivity and participation as attributes, enabling not only access to information, but the ability to produce it (Barros, 2022). It is estimated that social networks are relationship tools and are responsible for 62% of internet traffic and about 4 billion people have access to the internet, representing 52.63% of the world's population, with 476 million Internet users in Europe and 215 million Internet users in Latin America and in Brazil there are about 120 million active users (Netherlands, 2021).

Considering virtual social networks as potential tools for the dissemination of knowledge, considering the intensification of their use after the COVID pandemic, this study aimed to verify the information available on rare diseases on the internet, using the virtual social media *Facebook and* Instagram *and to evaluate the quantity and relevance of the published material.*

2 METHODOLOGY

This is a cross-sectional, descriptive study using the virtual social media *Facebook* and *Instagram*. Data collection took place from September 7 to November 10, 2022, and this period was established for the convenience of the authors. For research on social media, the words "rare diseases" were used; "rare diseases in Brazil" and the question: "What are rare diseases?", these are not called descriptors, as they are not standardized terms defined by experts to identify subjects published in scientific articles, but words that could identify the profiles in the aforementioned networks.

The participants in this research were the social media themselves, who presented the data used as results.

For the search, the contents or profiles should be related to the theme of rare diseases and/or answer the question: what are rare diseases? Profiles or content found that were not related to rare diseases were not included in the study.

Regarding research conducted on social networks, it is important to highlight that, in the case of public and open profiles, it is not required to obtain a Human Research Ethics Committee (UNICAMP, 2016). The data obtained were meticulously organized and subjected to a qualitative analysis, in which the content published on virtual social media platforms was presented in the form of categories.

3 RESULTS AND DISCUSSION

In the search carried out in the virtual social networks, profiles of support groups and associations with individuals with rare diseases (04), profiles that presented concepts and clarification about rare diseases (04), profiles that disseminated the laws of support for patients with rare diseases (04) and content producers (04) were identified.

For this reason, The results were separated and presented in categories, which were called: Category 1 - family support; category 2- content producers; Category 3 - Produced Content and Category 4 - Laws to Support People with Rare Diseases.

3.1 CATEGORY 1 - FAMILY SUPPORT

In this category we will present the creation of the institutions/associations, their objectives and check the reach on social media. Associations are groups of people who come together voluntarily because they share interests and goals. They play an important role in the development of a society because they constitute a common voice (Lima, 2018). Associations on social networks aim to help family members to "guide" themselves in search of medical care or support networks.

Sometimes, rare diseases are difficult to diagnose and cure, the support of other families becomes important for the sharing of anxieties and doubts, making the experiences of other people serve as encouragement for parents of children with rare diseases, their families and those who seek information about some type of rare disease (Luz, 2015).

Among the organizations we have the "Rare Team", being a NGO (Non-Governmental Organization), created in 2022, with page both in the *Facebook e Instagram,* and in the *Instagram* They have 234 followers and 9 publications, formed by women activists in favor of rare diseases.

Another association, "Casa Hunter", also a non-profit organization, was created in 2013 and is made up of researchers and health professionals, as well as parents of children with rare diseases. The institution's goal is to welcome patients with rare diseases and their families, promoting activities aimed at diagnosing, preventing, and treating rare and related diseases. Her Instagram page *has more than* 13,000 followers and 2,039 publications, and on Facebook she has more than 17,000 followers, making daily publications to raise awareness of each rare disease in order to encourage actions to combat prejudice.

The "Association of Relatives, Friends and Carriers of Serious Diseases - AFAG" is a national non-profit association that fights for the defense of the rights of people with rare and serious diseases, using *#SomosTodosRaros,* arose from the work of lawyer Dr. Maria Cecilia Mazzariol Volpe, who was diagnosed with colon cancer and decided to combine her personal experience with her professional qualification. In addition, it aims to research, seek and fight for all the rights of the sick citizen. Her Instagram page has 2.7 thousand with 1,022 publications and her *Facebook* with 19.8 thousand followers.

The NGO "Instituto Amor e Carinho – IAC" was created in 2018 and aims to welcome patients with chronic, serious diseases with mobility disabilities, bringing them to knowledge and interacting with the best professionals, thus reducing the time to search for solutions, increasing assertiveness in diagnoses and ensuring a better and higher quality of life for patients and their families. Her *Facebook* page has 751 followers and her *Instagram* has 775 followers (with 213 publications), however her posts are not frequent.

These associations help the entire population, not just the friends and family of people with rare diseases. In most cases, rare diseases are difficult to diagnose and cure, and the support and experience of other families is an important tool for sharing anxieties and doubts, making the experiences of other people serve as encouragement for parents of children with rare diseases, family members and those who seek information about some type of rare disease (Lima, 2018).

3.2 CATEGORY 2 - CONTENT PRODUCERS

The content produced for the internet is all the material aimed at achieving results. Entertainment on social networks is the most accessed and because of this, some content producers use *Instagram* and *Facebook* for greater reach. According to Luca (2018), reports from *We Are Social* and *Hootsuite* show us that Brazilians spend an average of 9 hours a day on social media. And knowing the strength that these channels have in the life of society, some researchers and websites in the scientific and academic area are using them in favor of scientific dissemination.

Four profiles of female content producers were found, one nurse, two doctors and one patient with a rare disease. It is observed that the contents produced are simple and didactic so that lay people can have access and understand the information, but not all profiles are exclusive of publications on rare diseases.

For Gacia (undated), the internet is a medium that can lead us to a growing homogenization of culture in general and is also a channel for the construction of knowledge based on the transformation of information. Electronic networks are establishing new forms of communication and interaction where the exchange of group ideas, essentially interactive, does not consider physical and temporal distances.

3.3 CATEGORY 3 - CONTENTS

The total content found corresponds, on average, to 6,500 publications on the two viral social networks. Despite the amount of published materials, the problem found is that there is no periodicity in the publications and no way to "supervise" or correct the publications, and content with untrue information can be published on the internet.

Currently, Instagram *is one of the most used social networks by the general population, but when evaluating the number of media users and the number of profiles and content related to rare diseases, the percentage is small.*

In view of the study, a comparison was made between Facebook and *Instagram* and it was observed *that Facebook* has more users disseminating information about rare diseases, it is in this social network that the associations are more active and make daily publications. There are also several private communities in which family and friends expose the situation of the rare patient. Unlike *Instagram*, which has few professionals who disseminate information about rare diseases.

Regarding content, only one content producer was found that brings direct information about rare diseases, with clear and objective publications, but it is still not enough to clarify the doubts and curiosities of the population that seeks that information.

3.4 CATEGORY 4 - LAWS TO PROTECT PEOPLE WITH RARE DISEASES.

This category reveals that on social media have been found pages or profiles that have published laws to support people with rare diseases.

The SUS has its bases established in Arts. 196 to 200 of the Federal Constitution. According to article 198 of the Federal Constitution (1988), health is a right of all and a duty of the State, guaranteed through social and economic policies aimed at reducing the risk of disease and other health problems and at universal and equal access to actions and services for its promotion, protection and recovery.

According to Aith (2014), the objectives of the SUS must be achieved in accordance with fundamental principles and in line with guidelines expressly established by the Constitution and the Organic Health Law (Law 8080/90).

Brazil adopts the National Policy for Comprehensive Care for People with Rare Diseases, which since 2014 has organized the care network for prevention, diagnosis, treatment and rehabilitation. The SUS provides care for prevention, diagnosis, treatment and rehabilitation of people with rare diseases, in addition to treatment of symptoms. All this care is done through individualized evaluations of multidisciplinary teams in the various health services in the country, such as primary care units, university hospitals, specialized rehabilitation centers and home care. Since the creation of the policy in 2014, SUS has incorporated 19 diagnostic tests, in addition to organizing the care network. (Brazil, 2021).

The municipality of Maringá, in the north of the state of Paraná, instituted Law No. 10,793 on January 14, 2019, which provides for priority care for patients with rare diseases and establishes guidelines for the promotion of education for rare and genetic diseases at the municipal level, in addition to providing other measures, This law institutes the Municipal Week for Attention to Rare Diseases, to be held annually in the last week of February. (PREFEITURA DE MARINGÁ, 2019).

On March 3, 2022, the Federal Government, through the Ministry of Health, launched the Rare Handbook, which establishes the monitoring of people with rare diseases in health services, hospitalizations, emergencies, trips, vaccination campaigns, enrollments in daycare centers, schools, associations or when there is a demand for social assistance services. The document also provides information on the adequate, safe, comprehensive, and free diagnosis and treatment performed in the Unified Health System (SUS) for rare diseases. (Brazil, 2022).

4 FINAL THOUGHTS

Virtual social networks are tools used on the internet, being useful and easy to access and with thousands of simultaneous accesses worldwide and with a wide range of information being shared every second. Association pages are important in expanding support networks for patients and their families, since the content published on social networks can help clarify doubts, due to health professionals who use *Facebook and* Instagram *pages as promoters and disseminators of knowledge.*

Unfortunately, on the other hand, it is observed that the publications are lacking in depth and, at times, in content quality. While there are pages and profiles dedicated to rare diseases, the vast potential of this digital environment still remains underutilized. Even with access to information at everyone's fingertips, the production of content on rare diseases remains limited and needs greater engagement.

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