O MUNDO DA SAÚDE

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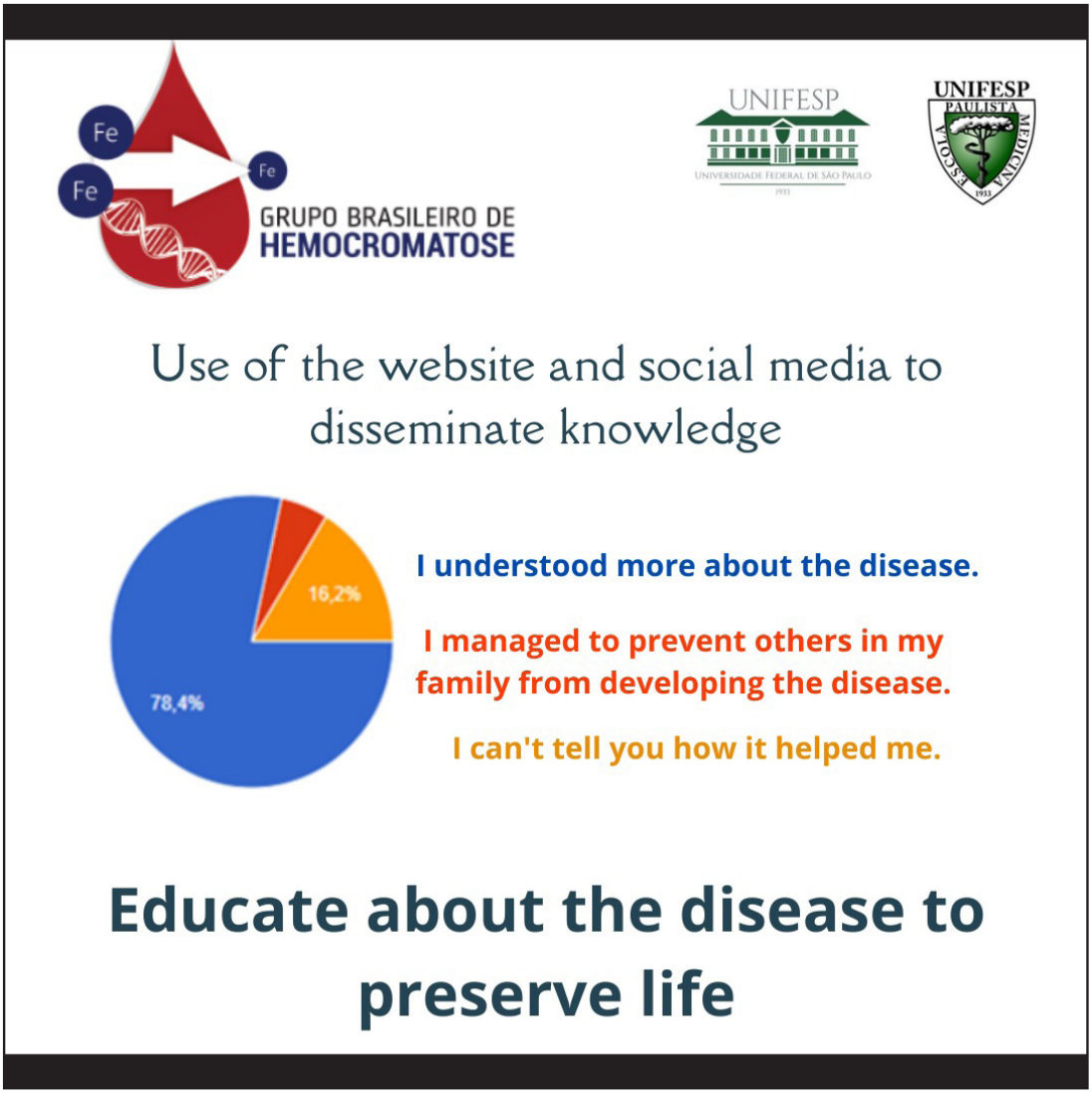
GBH (Brazilian Group of Hemochromatosis): educating about the disease to preserve life

Solange Rosanir de Lima[1] **Jennifer Saori Nakahara**[1] **André Machado Bottino**[1] **Silmara Rodrigues Machado**[2] **GBH**[3] **Paulo Caleb Júnior Lima Santos**[1,4]

[1]Escola Paulista de Medicina, Universidade Federal de São Paulo – EPM/Unifesp. São Paulo/SP, Brasil.
[2]Sociedade Beneficente de Senhoras, Hospital Sírio-Libanês. São Paulo/SP, Brasil.
[3]Grupo Brasileiro de Hemocromatose - Universidade Federal de São Paulo - Unifesp. São Paulo/SP, Brasil.
[4]Departamento de Farmacologia da Escola Paulista de Medicina, Universidade Federal de São Paulo – EPM/Unifesp. São Paulo/SP, Brasil.
E-mail: paulo.caleb@unifesp.br

Graphical Abstract



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Abstract

Hemochromatosis is a disease that is not widely known among the general population or healthcare professionals, particularly because its signs and symptoms are non-specific, making diagnosis challenging. It is caused by a deficiency of hepcidin, an important hormone responsible for iron homeostasis. Reduced production or activity of this hormone leads to increased intestinal iron absorption, resulting in iron overload in the body and, consequently, damage to various organs. Diagnosis and treatment are essential processes to ensure a better quality of life for patients. In this context, the objective of this university extension is scientific dissemination to promote advances for a more effective and safer treatment and diagnosis for patients. The methods involved using the website of the Brazilian Hemochromatosis Group (GBH) and social media to disseminate knowledge with a simple, didactic approach backed by scientific foundations to reach all interested parties. A Google® Forms questionnaire was also created to gather input for developing educational materials on the most requested topics in stage 1. In stage 2, we conducted a survey on the knowledge and perceptions of individuals who accessed these contents. The main results observed were engagement on social media and the GBH website by healthcare professionals, patients, and their families, who subscribed, followed, and expressed interest in learning more about hemochromatosis, in addition to providing feedback for future improvements to the extension project. Thus, the importance and scientific contribution of this health education model were observed, with the production of accessible, scientifically based materials. Based on feedback from the participants, the positive impact on patients and healthcare professionals from the actions carried out was evident. This enables the planning of new actions and approaches to continue with the purpose of disseminating information in a clear and objective manner, accessible to all.

Keywords: Health Education. Ferritin. Primary Iron Overload.

INTRODUCTION

Despite the democratization of information through the internet, there is notable misinformation in society on various topics, especially those related to health. Health misinformation involves the spread of incorrect information that negatively impacts the population's understanding and health decisions, affecting trust in professionals, adherence to treatments, and disease prevention.

In this context, we highlight hemochromatosis, a genetic disease with signs and symptoms that make its differential diagnosis with other conditions challenging. Additionally, it is not widely known even among healthcare professionals, underscoring the importance of developing information dissemination projects on this disease. Hemochromatosis mainly affects individuals of Caucasian ancestry; however, it is a disease with global prevalence, more frequent in Northern European countries or among their descendants, but also present in Brazilians due to extensive miscegenation and immigration[1-6].

Hemochromatosis is caused by a deficiency of hepcidin, an important hormone responsible for iron homeostasis. Reduced production or decreased binding activity of hepcidin with ferroportin results in increased intestinal absorption and thus iron overload in the body[1]. Without therapeutic intervention, iron overload leads to damage in multiple organs, liver cirrhosis, cardiomyopathy, diabetes, arthritis, hypogonadism, and skin hyperpigmentation[2]. The primary treatment involves efficiently and safely removing iron through therapeutic phlebotomies (also known as bloodletting)[2,3,5].

The clinical diagnosis of iron overload is the starting point for treating and monitoring the patient. Early diagnosis and treatment are essential to improve quality of life[1,4]. In general, it is recommended that patients with hemochromatosis follow a healthy, balanced diet[1,3].

The Brazilian Hemochromatosis Group (GBH) was created to increase awareness

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about hemochromatosis across various spheres. GBH is a university extension project with institutional and external collaborations, both national and international, and aims to promote advances and support for the diagnosis and treatment of this disease, assist in preventing disease development in relatives of patients, and enable the development of basic and clinical research in the context of iron metabolism and hemochromatosis.

The GBH is composed of undergraduates, postgraduates, patients, and healthcare professionals who contribute in diverse ways to a more comprehensive approach. They work on scientific platforms and social media (Website, Facebook, Instagram, and YouTube), creating content based on scientific studies in a contemporary, simple, and didactic language, with the aim of democratically spreading knowledge about hemochromatosis.

In this context, the goal of this university extension is scientific dissemination to promote advances for a more effective and safer treatment and diagnosis for patients with hemochromatosis. In this article, we describe the outreach actions and their impact on the public.

METHODOLOGY

The GBH was founded with support from Haemochromatosis International (HI), an alliance of international associations and groups focused on disseminating scientific and accessible knowledge about hemochromatosis to the public. The GBH has scientific collaborators who ensure the accuracy of the information to be shared and bring extensive experience in the field.

The topics for videos and content were developed based on the needs of those registered with GBH (subscribed through the website). In April 2021, we sent questionnaires via email to registrants and promoted them on GBH's social media channels to identify the main topics of interest. We received 37 responses, which served as the basis for topic selection and content creation.

The participants involved in production and development included professors, physicians, postgraduates, and undergraduates. The target audience consisted of patients, family members, healthcare professionals, and the general population.

In addition to content production and dissemination in stage 1, we conducted a survey on the knowledge and perceptions of individuals who accessed this content in stage 2.

RESULTS

Stage 1 - Content production and dissemination. Four tools were developed and used, including:

1. Website: The main platform is the website titled Brazilian Hemochromatosis Group (https://gbh.unifesp.br/), through which patients can find up-to-date information on the disease, clinical manifestations, scientific articles, and treatment. Additionally, the site offers a registration option for patients (or healthcare professionals, or family members).

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2. Social Media: Social media platforms have grown exponentially, especially during the pandemic[7]. Therefore, the project also utilizes profiles on Facebook®, Instagram®, and a YouTube® channel as means to expand knowledge about the disease to the general public. On Facebook® and Instagram®, posts are written in an easily understandable way, enabling anyone whether healthcare professionals or laypeople to grasp the subject matter.

a. Instagram:

Figure 1 - Screenshot of the GBH Instagram® Profile Homepage (@gbhemocromatose). Accessed in may 2023.

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b. Facebook

Figure 2 - Screenshot of the GBH Facebook® Profile Homepage (facebook.com/HemocromatoseBrasil). Accessed in may 2023.

c. YouTube:

On YouTube®, several videos about hemochromatosis can be found, recorded by professors and doctors, covering treatment, dietary care, and other topics relevant to the disease.

Figure 3 - Screenshot of the Videos Page on the YouTube® Channel (Brazilian Hemochromatosis Group). Accessed in may 2023.

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Stage 2 - we obtained the following responses from individuals who accessed this content. Through analyzing the form responses, we found that our primary audience consists of patients, who make up 94.6% of those who completed the questionnaires (Figure 4).

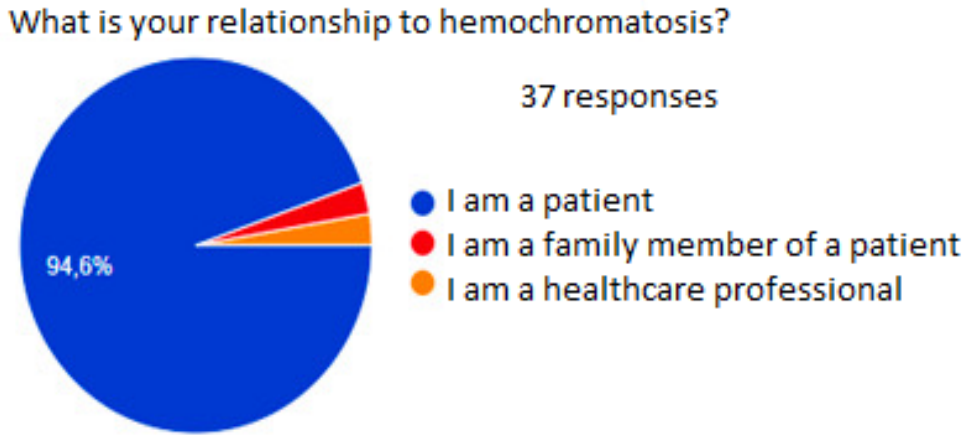

Figure 4 - Responses to the question about the profile of those following the GBH group's website. Responses obtained in april 2021.

The primary impact of GBH activities on its audience, according to the results obtained, was enabling a better understanding of hemochromatosis (Figure 5).

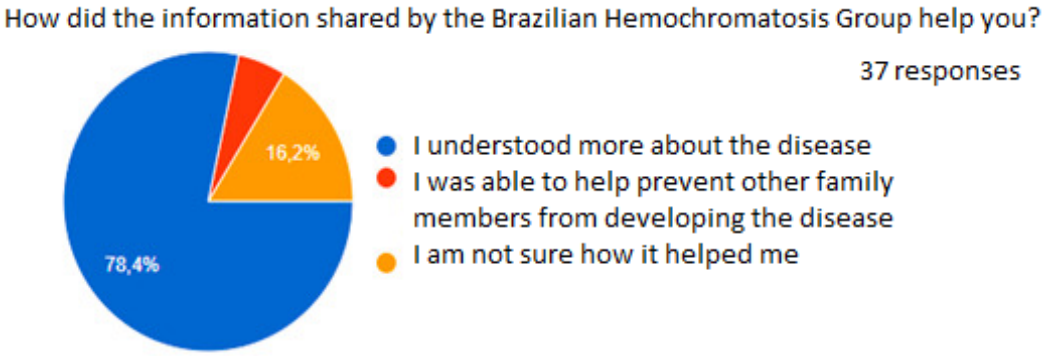

Figure 5 - Response to one of the questions applied via Google® Forms, quantifying the impact of the extension project on our audience. Responses obtained in april 2021.

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Additionally, we also identified that the most common question is about the main precautions that patients with hemochromatosis need to take (Figure 6), indicating a need for better guidance on their clinical condition and the additional care it requires. Furthermore, we can highlight upcoming topics to be addressed, with both "Diet" and "Treatment" following at 18.9%. These are followed by "Cause of the disease," "Other," and "Diagnosis."

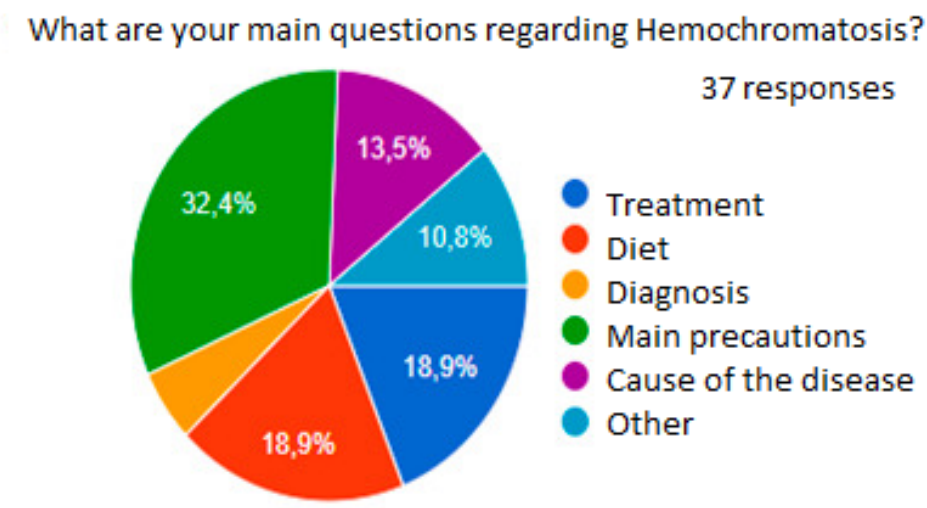

Figure 6 - Responses to the question applied via Google® Forms, identifying the topics (used in the creation of materials published on social media) of the main questions from those following GBH. Responses obtained in april 2021.

DISCUSSION

The primary impact observed was the engagement of healthcare professionals, patients, and their families, who contributed to the project not only by registering on the website and following GBH's social media but also by expressing interest in learning more about hemochromatosis and understanding it better. It was through responses to the questionnaires from those following GBH that all content produced in this project was planned and executed, allowing us to identify the typical profile of our audience and their main questions about hemochromatosis.

New health education initiatives, specifically on hemochromatosis, were planned and developed by GBH. The most notable of these was World Hemochromatosis Week, which took place in June 2021, during which new posts were created on social media (Instagram®, Facebook®, and YouTube®). During this period of new activities, we saw a significant increase in individuals following the project's content. Emphasis was placed on the scientific foundation of the content, even when presented in clear language, which helped enhance the impact of this extension activity on society and medical practice. This action presented a challenge that was met by the diverse team making up GBH, offering

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a variety of perspectives, from the more scientific-academic to community-oriented insights.

In addition to over 2,000 registrations on the GBH website, more than 900 views and interactions with our digital content, and over 700 followers on GBH's social media, personal accounts of learning and improved understanding of the disease based on the information we disseminate through GBH highlight the importance of projects like this, focused on health education.

Considering that health encompasses both individual and social aspects, GBH aims to extend knowledge not only for the diagnosis and treatment of patients with hemochromatosis but especially for the prevention of disease development. Another key aspect of GBH is its contribution to research development, both in basic and clinical areas, as seen in publications by GBH participants[8], improving understanding of iron metabolism and hemochromatosis. Through this, the group supports a better approach to health promotion and prevention of hemochromatosis and related complications.

This initiative has certain limitations due to its restricted reach to a digital audience, although the website includes partner centers that can be accessed in person. However, there are ongoing actions and expansion plans, such as updating existing physical materials to be distributed in person at blood centers, universities, and parks, promoting campaigns for continuous awareness.

CONCLUSION

Through this extension project, we are able to make a scientific and effective contribution to health education on hemochromatosis, a little-known disease. We produce accessible content with a solid scientific foundation, helping to improve early diagnosis and treatment. Based on feedback from participants, the positive impact on both patients and healthcare professionals from the actions carried out was evident. This allows for the planning of new actions and approaches, enabling us to continue with the goal of sharing information in a clear and objective manner, accessible to all.

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CRediT author statement

Conceptualization: Lima, SR; Santos, PCJL. Methodology: Lima, SR. Research: Lima, SR. Original draft preparation: Lima, SR. Writing-review and editing: Nakahara, JS; Bottino, AM; Santos, PCJL. Visualization: Santos, PCJL. Supervision: Santos, PCJL. Project administration: Santos, PCJL

All authors read and agreed to the published version of the manuscript.

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