

ORIGINAL ARTICLE

## PARKINSON'S DISEASE: Innovations in Communication and Functional Health Education in Social Media

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Highlights:

- (1) Most content on PD in social media is generalist and outdated.
- (2) Well-founded educational videos expanded qualified access to information.
- (3) Professional curation is needed to ensure quality in health and PD information.

ABSTRACT

Parkinson's Disease (PD) results in the reduction of the individual's independence and functionality. Physiotherapy acts in the management of PD based on several strategies, such as health education. The objective of this study was to identify, analyze and develop innovative and educational content in health and analyze the metrics achieved in social networks. The research is exploratory, explanatory of content analysis and descriptive of data collection, divided into 6 phases: 1. Search for thematic materials on PD, 2. Definition of content to be produced, 3. Development of scripts, 4. Technical production, 5. Disclosure and 6. Analysis of metrics achieved. Most of the content found is of the generalist information type and the result of the achieved metrics yielded 373 views. It is necessary to advance in health education, mainly in the quality and depth of information.

**Palavras-chave:** physiotherapy; aquatic therapy; health communication; health education; parkinson's disease

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## INTRODUCTION

It is necessary to fully understand the different repercussions generated by chronic degenerative diseases, such as Parkinson's Disease (PD), in order to offer the best strategies for managing/living with this condition<sup>1</sup>. The current understanding about health has a biopsychosocial (BPS) concept, centered on the triad individual, environment and task. In this way it covers aspects of functionality in the domains: functions, structures, participation and activities, in addition to contextual factors, which include the environment and personal aspects<sup>2</sup>.

Parkinson's disease (PD) is a progressive and chronic neurological syndrome that leads to the degeneration of the neurons responsible for dopamine production, closely related to the movement regulation processes<sup>3</sup>. Individuals with PD go through a decline in brain functions and structures, generating interferences in the regulation of movement and psychological, emotional and autonomic alterations<sup>4</sup>. Thus, it modifies several aspects related to functionality, activities and participation<sup>5</sup>. The treatment of PD is based on a multiprofessional approach that involves the reduction/relief of symptoms, associated with a clinical approach that uses the administration of drugs to replace Dopamine<sup>6</sup>.

There is a lot of current evidence that drug treatment alone is not enough to address all the physical/functional aspects of the patients, besides not preventing the progression of the disease<sup>7,8</sup>. Within the BPS concept, non-pharmacological therapies such as physical therapy, based on therapeutic exercise and health education, associated with medication, are capable of promoting improvement/control of the progression of motor and non-motor symptoms and increasing the levels of understanding about PD<sup>9,10</sup>.

It is known that the processes involved in the displacements, such as costs, time dynamics and availability of family members/caregivers, can be potential complicating factors in relation to the adherence of patients to face-to-face interventions<sup>11</sup>. In this sense, despite being considered a global health crisis, the pandemic of Covid-19 has driven the organization and acceleration of health-related processes in a virtual/remote way, given the need for monitoring patients with chronic and progressive diseases, as is the case of people with PD<sup>11, 12</sup>. In addition, the increased levels of anxiety and stress during the pandemic, seem to be associated with the worsening of PD symptoms, having repercussions in the worsening of their general health status<sup>12, 13</sup>.

Health education strategies and various other services offered remotely have proven to be effective<sup>11</sup> and can assist in the process of understanding and managing chronic and progressive diseases, such as PD. Additionally, they take into account the functional and contextual aspects of the individual<sup>13, 14</sup>, as well as facilitate communication and strengthen the bond between professionals, clients/users, and caregivers<sup>15, 16</sup>. Thus, the objective of this study was to identify, analyze, and develop strategic, innovative, and educational content on functional health, aimed at people with PD, their families/caregivers/health professionals, and to analyze the metrics achieved on social media."

## METHODOLOGY

The research is characterized as exploratory explanatory content analysis and descriptive data survey, with a qualitative approach<sup>17,18</sup>. Conducted between August 2021 and March 2023, during the post-Covid-19 pandemic period, from a funding grant from the Institutional Program of Scholarships for Initiation in Technological Development and Innovation of the Federal University of Paraná (UFPR)

The study was divided into 6 phases developed by the authors: 1. Search for thematic materials about PD on social networks, bibliographic survey and analysis of the main contents found; 2. Definition of the type of content to be produced, delineation of themes and choice of social networks to be used;

3. Development and correction of scripts; 4. Technical production of materials; 5. Dissemination of content; and 6. Analysis of the metrics achieved on social networks.

Phase 1: searches were performed with the term “Parkinson’s Disease” in Google®, Facebook®, Instagram® and Youtube® and the first 5 links were selected. The searches were conducted in an anonymous tab for the Youtube® and Google® platforms, in order to reduce algorithm preferences of the researcher’s personal profile. The other searches were performed with the account of the Health and Functionality Lab – “Alegria em Movimento” – Federal University of Paraná (LAM-SF/UFPR), on Instagram® and Facebook®. The searches were performed in June 2022, on the same date for each social network. After, the collected data were gathered in Microsoft Excel® program, and the analysis of the main types of content found was performed.

Phase 2: definition of the contents, themes and social media used strategically in the LAM-SF/UFPR profile, based on discussions between health professionals with experience in Neurofunctional Physiotherapy, and specifically with PD research, and undergraduate students with research experience about PD and in Digital Marketing professional, based on the data found in the previous phase.

Phase 3: scientific initiation students, belonging to the LAM-SF/UFPR’s project “Parkinson’s Disease and Aquatic Therapy”, developed scripts based on technical-scientific knowledge, translated into a language accessible to the population, assisted by physical therapists, also specialists. The chosen themes were: general aspects of PD, repercussions on gait, balance, cardiorespiratory system and quality of life, themes related to the main research carried out by the group. The platforms chosen for dissemination were Youtube®, Facebook® and Instagram® for their easy usability and popularity among users. The social media used for publication belong to the profile of LAM-SF/UFPR (<https://www.instagram.com/lamsf.ufpr/>)

Phase 4: the technical production of the content was based on the recording and editing of short videos (3 to 5 minutes) for the Youtube® platform, based on the scripts previously produced, as well as the digital arts production for the Facebook® and Instagram® media.

Phase 5: the dissemination of the created contents occurred weekly from the digital products finalization and comprised the sharing of the productions on social media. In the case of Instagram®, the links with the videos were made available through the social-linking and social networking platform linktr.ee ([linktr.ee /lamsf.ufpr](https://linktr.ee/lamsf.ufpr)), on the bio page.

Phase 6: analysis of the metrics offered by the digital platforms themselves, regarding the profile and reach of the content produced. The Facebook® platform offers a space for ad pages and Instagram® accounts, categorized as “Business Profile” and Facebook Business®. The space provides information such as the “metrics” and “profile analysis” of both Facebook® and Instagram®, with the information: posts reach, user profile, number of shares, likes and engagement. Youtube® offers statistical tools that encompass the channel overview, reach, engagement and audience profile.

Data was manually extracted from the social media platforms into the Microsoft Excel® program, and analyzed regarding the profile of users reached, number of reaches and the content popularity at two points in time: 1. 30 days after the last video’s publication and 2. eight months after the last video’s publication.

## RESULTS

Regarding the search for materials related to the topic in phase 1 of the study, the results show that most of the produced content was found on Google®, Facebook®, and Instagram®. In terms of content type and format, the majority is general informational content in text format. Youtube® provides videos that are also mostly informative, with an average length of 12 minutes and 7 seconds.

In addition, the main authors of content production in the analyzed media include: virtual libraries, private companies, health professionals, students, academic leagues and/or universities.

Searches on Google® brought up the websites: *Biblioteca Virtual em Saúde – Ministério da Saúde* (Virtual Health Library – Health Ministry); *Dr. Drauzio Varella*; *Med Tronic*; *MSD manual versão saúde para a família* (MSD manual family health version); and *Veja Saúde* (View Health). All websites present generalist informative content and only the website *MSD manual versão saúde para a família* (MSD manual family health version), specified its content for non-health professionals. The main topics covered related to PD were: what it is, diagnosis, symptoms and treatment. Some information such as year of publication and the posts' author were not present in two of the five websites.

The social network Facebook® brought the pages: “*Doença de Parkinson*” [Parkinson's Disease] (user doencaparkinson), “*Doença de Parkinson*” [Parkinson's Disease] (user DoencaDeParkinson), “*Grupo de Estudos na Doença de Parkinson*” [Parkinson's Disease Study Group] (user gedopabrazil), “*Doença de Parkinson*” Parkinson's Disease (user doencassncp) and “*A Doença de Parkinson em minha vida*” [Parkinson's Disease] in my life (user convivercomparkinson). Classified as medical services, community, college/university, community and book, respectively. The contents ranged from generalist informative, sentimental/personal exposition, in-depth informative for non-professionals and dissemination of literary work. The main topics addressed in the pages' posts ranged from general health information to information about PD.

On Instagram® we obtained the profiles: “*Liga da Doença de Parkinson*” [Parkinson's Disease League] (user ligadopa) “*FVJ – Doença de Parkinson*” Neurofunctional, FVJ – Parkinson's Disease (user doenca.de.parkinson20), “*Doença de Parkinson*” [Parkinson's Disease] (user bio\_parkinson), “*Neuropsi – Doença de Parkinson*” [Neuropsi – Parkinson's Disease] (user equipeparkinson\_indc) and “*Doença de Parkinson*” [Parkinson's Disease] (parkinson\_explica). The main types of the pages' owners are: academics, academic leagues, extension projects and/or institutes linked to universities. The page's contents are mainly informative/generalist.

As for the YouTube® searches, the following videos were recommended: “*Doença de Parkinson (aula completa)*” [Parkinson's Disease (complete class)] – *Dr Suhaila Smaili*” from *Neurofuncional* channel, “*Doença de Parkinson I Coluna #133*” [Parkinson's Disease I Column #133] from *Drauzio Varella* channel, “*Doença de Parkinson: tremores no corpo*” [Parkinson's Disease: body tremors] from *Doutor Ajuda* channel, “*O que é mal de Parkinson?*” [What is Parkinson's disease?] from *Hcor* channel, and “*Mal de Parkinson – Causas, sintomas e tratamentos I*” [Parkinson's Disease – Causes, symptoms, and treatments I] from *Sua saúde na rede* channel [your health on the net], respectively. Most of the videos featured informational type content and only one of the videos was a free online class – in-depth content. Three of the five channels were owned by health professionals, two being doctors and one physiotherapist, the other two channels belonged to associations (TABLE 1).

Table 1 – Results of searches on PD in Google®, Facebook®, Instagram® and Youtube®

| GOOGLE®                                                                                             |                                      |                                          |                                                                                                                                                                     |                                             |                                                                                                                                                                                                                                                                                                                           |
|-----------------------------------------------------------------------------------------------------|--------------------------------------|------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Page Name/Profile                                                                                   | Page type/profile                    | Author/Year                              | Contents of the publications                                                                                                                                        | Publication type                            | Link access                                                                                                                                                                                                                                                                                                               |
| <i>Biblioteca Virtual em Saúde – Ministério da Saúde</i> (Virtual Health Library – Health Ministry) | Government Information Site          | Not found/2019                           | Basic explanation of PD: what it is, diagnosis, symptoms and treatment                                                                                              | Generalist Newsletter                       | <a href="https://bvsm.sau.gov.br/doenca-de-parkinson/">https://bvsm.sau.gov.br/doenca-de-parkinson/</a>                                                                                                                                                                                                                   |
| <i>Dr. Drauzio Varella</i>                                                                          | Site about health-related content    | Maria Helena Varella Bruna/ not informed | Basic explanation about PD: what it is, symptoms, causes, treatment and recommendations.                                                                            | Generalist Newsletter                       | <a href="https://drauziovarella.uol.com.br/doencas-e-sintomas/doenca-de-parkinson/">https://drauziovarella.uol.com.br/doencas-e-sintomas/doenca-de-parkinson/</a>                                                                                                                                                         |
| <i>Med Tronic</i>                                                                                   | Healthcare Company                   | Not found/not informed                   | Basic explanation about PD: what it is, main symptoms (rest tremor, bradykinesia, rigidity and postural instability), causes and risk factors                       | Generalist Newsletter                       | <a href="https://www.medtronic.com/br-pt/your-health/conditions/parkinsons-disease.html">https://www.medtronic.com/br-pt/your-health/conditions/parkinsons-disease.html</a>                                                                                                                                               |
| <i>MSD manual (versão saúde para a família)</i> [MSD manual (family health version)]                | Manual for health information search | Hector A. Gonzalez-Usigli/ 2020          | Detailed explanation with plain language about: internal brain changes, causes, symptoms, treatment, diagnosis, and suggested links/websites with more information. | Generalist newsletter for non-professionals | <a href="https://www.msmanuals.com/pt-br/casa/dist%C3%A9rbios-cerebrais,-da-medula-espinhal-e-dos-nervos/doen%C3%A7as-do-movimento/doen%C3%A7a-de-parkinson-dp">https://www.msmanuals.com/pt-br/casa/dist%C3%A9rbios-cerebrais,-da-medula-espinhal-e-dos-nervos/doen%C3%A7as-do-movimento/doen%C3%A7a-de-parkinson-dp</a> |
| <i>Veja Saúde</i> (View Health)                                                                     | Virtual health journal               | Diogo Sponchiato/ 2021                   | Informative article with basic explanation about PD: main symptoms, diagnosis and treatment (drug and non-drug)                                                     | Generalist Newsletter                       | <a href="https://saude.abril.com.br/medicina/doenca-de-parkinson-o-que-e-e-quais-seus-tratamentos-e-sintomas/">https://saude.abril.com.br/medicina/doenca-de-parkinson-o-que-e-e-quais-seus-tratamentos-e-sintomas/</a>                                                                                                   |
| FACEBOOK®                                                                                           |                                      |                                          |                                                                                                                                                                     |                                             |                                                                                                                                                                                                                                                                                                                           |
| Page name (user)                                                                                    | Type                                 | Followers                                | Contents of the publications                                                                                                                                        | Publication type                            | Link access                                                                                                                                                                                                                                                                                                               |
| <i>Doença de Parkinson</i> [Parkinson's Disease] (@doencaparkinson)                                 | Medical Services                     | 1.083                                    | Health newsletters (various topics besides PD)                                                                                                                      | Generalist Newsletter                       | <a href="https://www.facebook.com/doencaparkinson/">https://www.facebook.com/doencaparkinson/</a>                                                                                                                                                                                                                         |
| <i>Doença de Parkinson</i> [Parkinson's Disease] (@Parkinson'sDisease)                              | Community                            | 1.531                                    | Poems, chronicles and short stories (various themes beyond PD)                                                                                                      | Personal/Sentimental Exposure               | <a href="https://www.facebook.com/DoencaDeParkinson">https://www.facebook.com/DoencaDeParkinson</a>                                                                                                                                                                                                                       |

|                                                                                                     |                                              |                     |                                                                                         |                                            |                                                                                                                 |
|-----------------------------------------------------------------------------------------------------|----------------------------------------------|---------------------|-----------------------------------------------------------------------------------------|--------------------------------------------|-----------------------------------------------------------------------------------------------------------------|
| <i>Grupo de Estudos na Doença de Parkinson</i> [Parkinson's Disease Study Group] (@gedopabrazil)    | College and university                       | 726                 | Information about PD, movements about the research group, extension projects and events | In-depth information for non-professionals | <a href="https://www.facebook.com/gedopabrazil/">https://www.facebook.com/gedopabrazil/</a>                     |
| <i>Doença de Parkinson</i> [Parkinson's Disease] (@doencassncp)                                     | Community                                    | 618                 | PD Newsletters                                                                          | Generalist Newsletter                      | <a href="https://www.facebook.com/doencassncp/">https://www.facebook.com/doencassncp/</a>                       |
| <i>A Doença de Parkinson em minha vida</i> [Parkinson's Disease in my life] (@convivercomparkinson) | Book                                         | 627                 | Information about PD-related literary work                                              | Disclosure of literary work                | <a href="https://www.facebook.com/convivercomparkinson/">https://www.facebook.com/convivercomparkinson/</a>     |
| <b>INSTAGRAM®</b>                                                                                   |                                              |                     |                                                                                         |                                            |                                                                                                                 |
| <i>Liga da Doença de Parkinson</i> [Parkinson's Disease League] (ligadopa)                          | Academic League – University of Fortaleza    | 901                 | Generalist newsletter and updates/movements about the academic group                    | 77                                         | <a href="https://www.instagram.com/ligadopa/">https://www.instagram.com/ligadopa/</a>                           |
| <i>FVJ – Doença de Parkinson</i> [FVJ – Parkinson's Disease] (doenca.de.parkinson20)                | Physical Therapy Students                    | 132                 | Generalist Newsletter                                                                   | 13                                         | <a href="https://www.instagram.com/doenca.de.parkinson20/">https://www.instagram.com/doenca.de.parkinson20/</a> |
| <i>Doença de Parkinson</i> [Parkinson's Disease] (bio_parkinson)                                    | High School Students                         | 16                  | Generalist Newsletter                                                                   | 8                                          | <a href="https://www.instagram.com/bio_parkinson/">https://www.instagram.com/bio_parkinson/</a>                 |
| <i>Neuropsi – Doença de Parkinson</i> [Neuropsi – Parkinson's Disease] (equipeparkinson_indc)       | Institute of Neurology Deolindo Couto – UFRJ | 57                  | Not applicable                                                                          | 0                                          | <a href="https://www.instagram.com/equipeparkinson_indc/">https://www.instagram.com/equipeparkinson_indc/</a>   |
| <i>Doença de Parkinson</i> [Parkinson's Disease] (parkinson_explica)                                | Extension Project – UCSAL                    | 31                  | Generalist Newsletter                                                                   | 15                                         | <a href="https://www.instagram.com/parkinson_explica/">https://www.instagram.com/parkinson_explica/</a>         |
| <b>YOUTUBE®</b>                                                                                     |                                              |                     |                                                                                         |                                            |                                                                                                                 |
| <b>Profile name/Type or owner</b>                                                                   | <b>Video Title</b>                           | <b>No. of views</b> | <b>Video Content</b>                                                                    | <b>Video duration time</b>                 | <b>Link access</b>                                                                                              |

|                                                                                                                    |         |                                        |        |                                                                                                       |
|--------------------------------------------------------------------------------------------------------------------|---------|----------------------------------------|--------|-------------------------------------------------------------------------------------------------------|
| Neurofuncional / Profissional de saúde fisioterapeuta [Neurofunctional / Physiotherapist Health Care Professional] | 113.691 | Online Classroom (specialized content) | 39'30" | <a href="https://www.youtube.com/watch?v=SyNWpzjJsHo">https://www.youtube.com/watch?v=SyNWpzjJsHo</a> |
| "Doença de Parkinson (aula completa) – Dr Suhaila Smaili"                                                          |         |                                        |        |                                                                                                       |
| Parkinson's Disease (full lecture) – Dr. Suhaila Smaili                                                            |         |                                        |        |                                                                                                       |
| Drauzio Varella/ Profissional de saúde médico [Drauzio Varella/ Medical Health Professional]                       | 86.920  | Information content                    | 2'07"  | <a href="https://www.youtube.com/watch?v=fbJGN9dPM-s">https://www.youtube.com/watch?v=fbJGN9dPM-s</a> |
| "Doença de Parkinson I Coluna #133"                                                                                |         |                                        |        |                                                                                                       |
| Parkinson's Disease I Column #133                                                                                  |         |                                        |        |                                                                                                       |
| Doutor ajuda/ Profissional de saúde médico [Doctor Helper/ Medical Health Care Professional]                       | 32.679  | Information content                    | 8'33"  | <a href="https://www.youtube.com/watch?v=FCursydkzGM">https://www.youtube.com/watch?v=FCursydkzGM</a> |
| "Doença de Parkinson: tremores no corpo"                                                                           |         |                                        |        |                                                                                                       |
| Parkinson's Disease: body tremors                                                                                  |         |                                        |        |                                                                                                       |
| Hcor/ Associação beneficente [Hcor/ Charity Association]                                                           | 78.517  | Information content                    | 3'50"  | <a href="https://www.youtube.com/watch?v=dxBh208BhaA">https://www.youtube.com/watch?v=dxBh208BhaA</a> |
| "O que é mal de Parkinson?"                                                                                        |         |                                        |        |                                                                                                       |
| What is Parkinson's disease?                                                                                       |         |                                        |        |                                                                                                       |
| Sua saúde na rede/ Associação de medicina [Your Health on the Net/ Medical Association]                            | 168.316 | Information content                    | 10'37" | <a href="https://www.youtube.com/watch?v=oPp0YuCBkIM">https://www.youtube.com/watch?v=oPp0YuCBkIM</a> |
| "Mal de Parkinson – Causas, sintomas e tratamentos"                                                                |         |                                        |        |                                                                                                       |
| "Parkinson's Disease – Causes, symptoms and treatments"                                                            |         |                                        |        |                                                                                                       |

LEGEND: PD, Parkinson's Disease

Source: The authors (2023).



Regarding the productions and dissemination of video content produced by LAM-SF/UFPR, referring to phases 2 to 6 of the study, the data provided by Youtube® were analyzed from the first video's publication (05/24/22) until one month after the publication of the last video (07/07/22). The sum of the number of views of the five videos yielded 257 views, as well as a total viewing time of 4.7 hours and the average duration of views was 1 minute. The total impressions refers to the number of times the thumbnails of the produced videos are shown to the viewers, with the total of 619 times, as well as the click-through rate on impressions corresponded to 8.5%, which means how often the viewers selected another related video after seeing an impression. The content also had a 100% approval rating by the audience: "liked" ratio: 83/ "disliked": 0.

Eight months after the last video was published, the data was extracted again, so the sum of the number of total views yielded 379 views, display time of 6.8 hours and average duration of views of 1.04 minutes. The total number of impressions was 1,396, click-through rate on impressions was 8.8% and audience approval was 100%, analyzed by the ratio "like": 95/ "dislike": 0 (Table 2).

Table 2 – Total metrics – PD contents produced for Youtube® by LAM-SF/UFPR

| Time (months) | Views (n) | Total Display Time (hours) | Average Viewing Duration (minutes) | "I liked it" (n) | "I didn't like it" (n) | Comments (n) | Total impressions (n) | Click-through rate on impressions (%) |
|---------------|-----------|----------------------------|------------------------------------|------------------|------------------------|--------------|-----------------------|---------------------------------------|
| 1             | 257       | 4,7                        | 1                                  | 83               | 0                      | 9            | 619                   | 8,5                                   |
| 9             | 379       | 6,8                        | 1.04                               | 95               | 0                      | 0            | 1.396                 | 8,8                                   |

Source: The authors (2023).

Regarding the origin of the information traffic, the main identified data refer that 36.9% originated from external sources, that is, websites and apps that incorporate or include links to access the video, 20.1% search on Youtube® itself, 14.8% channel pages, referring to traffic coming from the Youtube® channel itself. In addition, 100% of viewers originate from Brazil (Table 3).

Table 3 – Metrics on PD content produced for Youtube® by LAM-SF/UFPR

| Variables                             | %    |
|---------------------------------------|------|
| <b>Registration</b>                   |      |
| Subscribers                           | 23,5 |
| Not enrolled                          | 76,5 |
| <b>Device</b>                         |      |
| Mobile                                | 82,9 |
| Computer                              | 15,3 |
| TV                                    | 2,1  |
| <b>Sharing</b>                        |      |
| WhatsApp®                             | 77,8 |
| Directly from the system share dialog | 7,4  |
| Copy to Clipboard                     | 7,4  |
| Twitter®                              | 3,7  |
| Another                               | 3,7  |

LEGEND: details of the channel's subscribers/non-subscribers ratio, devices used to access the contents, as well as the way in which they are shared.

Source: The authors (2023).



Regarding the total views and total impressions of each produced video, the content with the greatest reach is entitled “*Equilíbrio Postural e Quedas na Doença de Parkinson*” (postural balance and falls in Parkinson’s Disease), while the video with the highest average percentage viewed, which refers to the average time spent watching/viewing the video, is “*O que é a Doença de Parkinson*” (What is Parkinson’s Disease?) (Figure 1).

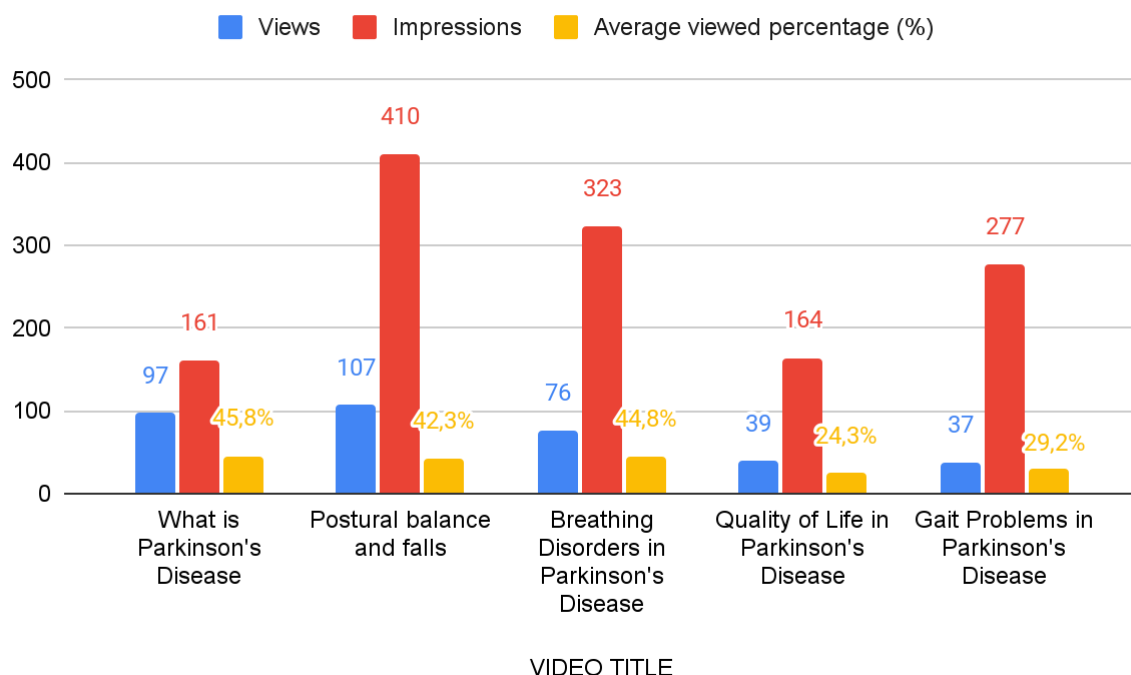


Figure 1 – Total views, average views and impressions on Youtube® of LAM-SF/UFPR PD contente.

LEGEND: average percentage viewed over total video time, total views and impressions (how many times thumbnails of your video were shown to viewers. Includes only impressions on YouTube®, not on external sites or applications).

Source: The authors (2023).

Regarding the data from the social media Facebook® and Instagram®, referring to the posts promoting the videos produced and published on Youtube®, the content with the greatest reach on both Facebook® and Instagram® was the video “*O que é a Doença de Parkinson*” (What is Parkinson’s Disease?) (Table 4).

Table 4 – Reach/interactions of PD outreach content on LAM-SF/UFPR social media profiles

| Publication                                                                                                    | Facebook® Search | Likes | Instagram® Search | Likes |
|----------------------------------------------------------------------------------------------------------------|------------------|-------|-------------------|-------|
| <i>O que é a Doença de Parkinson?</i> (What is Parkinson’s Disease?)                                           | 18               | 3     | 330               | 73    |
| <i>Equilíbrio Postural e Quedas na Doença de Parkinson</i> (postural balance and falls in Parkinson’s Disease) | 15               | 2     | 194               | 48    |
| <i>Problemas de Marcha na Doença de Parkinson</i> (Gait Problems in Parkinson’s Disease)                       | 12               | 1     | 165               | 23    |
| <i>Alterações Respiratórias na Doença de Parkinson</i> (Respiratory Changes in Parkinson’s Disease)            | 9                | 2     | 151               | 30    |
| <i>Qualidade de Vida na Doença de Parkinson</i> (Quality of Life in Parkinson’s Disease)                       | 11               | 1     | 148               | 29    |

Source: The authors (2023).

## DISCUSSION

With respect to the results obtained in phase 1 of the study, regarding the existing content on Google®, Facebook® and Instagram® on PD, it was possible to identify that most of them is of the generalist informative type and is in text format. As on Youtube®, most of the videos had informative nature and simple language, with an average length of 12 minutes. With the development of technologies and the growing search for quick health information on the Internet, it is necessary that health professionals/researchers are aware of the changes in the current scenario in relation to the health-information process, as well as the quality of the produced content, to actually serve as a tool for health education with proper scientific basis<sup>19</sup>.

The popularization of the use of digital media and its potential is increasingly explored, especially in the education process<sup>20</sup>. In this sense, the individual's degree of skill in search, understanding, learning and decision-making activities based on their health is understood as health literacy (HL)<sup>21</sup>. In the studies by LuBuono *et al.*,<sup>22</sup> and Krieger *et al.*,<sup>23</sup>, most of the research participants first used the Internet to acquire information about health, especially related to PD. Which is reinforced by the result shown in the study of Lim *et al.*,<sup>24</sup>, where participants showed desire for health information and development of autonomy and self-management. Thus, it is necessary that health professionals, creators and operators of digital platforms work together for the benefit of PD patients and their families, so that evidence-based information with superior quality reaches the public more effectively<sup>19</sup>.

The main content producers or names/profiles found, comprise: virtual libraries/manuals, private companies, health professionals, students, academic leagues and/or universities. Thus, social media promotes horizontal, non-hierarchical communication, which enables the establishment of collaborative, reciprocal and sporadic bonds with the public<sup>20</sup>. This type of relationship goes beyond the level of knowledge of the influencer, but permeates the way they behave and communicate. This determines potentialities as well as negative points, because as many profiles with technical mastery of the content can express/communicate and teach, as influencers without sufficient knowledge or theoretical-scientific mastery<sup>25,26</sup>.

There is a certain difficulty for Internet users to discriminate between good quality and misleading content<sup>19</sup>. On the other hand, Lim *et al.*,<sup>24</sup> explain the mismatch between individuals' information-seeking needs and the type of content offered on the Internet, with extremes between shallow/superficial explanations or inaccessible language to the general public. What is within the reach of qualified professionals, entities or research groups is to guide patients/family/caregivers to consume and critically select digital content, as well as to occupy the places of speech, gain credibility, trust and publish qualified content.

Although the initial search (phase 1) revealed a large amount of information about PD, there is a notable need for the development of specific content. Health education should be based on the unique needs of this population in order to address the challenges associated with living with a chronic disease and to promote self-management<sup>27,28</sup>. With this perspective, the materials developed in this study were created.

Regarding the obtained data in phases 2 to 6 of the study, characterized by the dissemination of LAM-SF/UFPR videos on Youtube® and shared in other media, the total number of views was 257 in a period of 45 days, as well as total viewing time of 4.7 hours and the average duration of views of 1 minute. The content also had a 100% approval rating by the audience. However, eight months after the first video was published, the data yielded 379 total views and a viewing time of 6.8 hours. When comparing the data obtained in a period immediately after the publication of the contents and eight months after the publication of the last video, it was possible to identify a non-expressive increase in the number of views. This result may highlight the need for constant updating/movement of the networks,

given the high demand for new information and the speed of communication. Thus, it is understood that in order to gain reach, growth and visibility, it is necessary to have constancy and maintenance of digital media in order to promote loyalty and bonds of trust with the content consumers<sup>29</sup>.

The videos included topics that are in accordance with the findings of the study by Qian *et al.*,<sup>29</sup> in which the main subjects searched for by users with PD were motor symptoms (pain and stiffness), choice of medication, and non-motor symptoms. Moreover, in relation to the total number of impressions (410 impressions) and total views (107 views) of each video produced, the content with the greatest reach on Youtube® were the videos "*Equilíbrio postural e quedas na Doença de Parkinson*" (postural balance and falls in Parkinson's Disease) and "*O que é a Doença de Parkinson*" (What is Parkinson's Disease?).

Such a result can be explained by the impact of postural balance and falls on the independence and functionality of individuals with PD<sup>30,31</sup>, which may lead to greater interest/curiosity of content consumers. In addition, the introductory video about PD may signal a lack of knowledge about the disease's basic characteristics. Regarding the type of device used to access the videos on the Youtube® platform, 83.7% used mobile devices, which corroborates the findings of Shu and Woo<sup>32</sup>, for which mobile devices were the main means for viewing educational content in older Chinese Americans.

Technological resources can be a strategy for monitoring, evaluation and health education for people with neurological diseases<sup>32</sup>. In this sense, the context of social isolation/distancing caused by Covid-19 has contributed to the acceleration of the processes of health evolution, communication and digital research. Thus, it is possible to relate technology with minimizing the disruption of the therapeutic process in the health professional/patient/information relationship. Health education through the Internet and social media can contribute to healthy aging, as well as overcoming cultural and linguistic barriers to access<sup>32,33</sup>.

Thus, it can be argued that the administration of health education through social media can be both beneficial and disruptive regarding accessibility to health information for people with PD. However, the difficulty in developing and understanding the dynamics of content dissemination and strategies for wider reach can be seen as a limitation of this study. Therefore, it is suggested that future studies help to understand the specific needs of people with PD regarding the use of social media and health education.

## CONCLUSION

The study was able to analyze and understand the content present in the digital platforms, being predominantly directed to the general public, with simple language and generalist informative character.

In addition, it was possible to develop video content on the LAM-SF/UFPR media platforms, which proved to be innovative and educational, with good public acceptability and understanding. The video construction process enabled the students and physiotherapists involved in the research to understand new forms of professional performance in health education through the Internet. In addition, the materials became free educational tools, which expands access to information and health in general, and leads to increased levels of public-social knowledge about the disease.

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