Exploring Pain in Social Media: A Study on Perceptions and Discussions of Chronic Pain Conditions

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Table of Contents

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Abstract

Background: Chronic pain, an unpleasant sensory and emotional experience lasting over six months, affects a large proportion of the global population and significantly impacts health and quality of life. Certain diseases cause chronic pain, resulting in a social and medical misunderstanding that intensity the patient's emotional suffering. In recent years, the social media platform Twitter, now called "X," has become a valuable resource for research and discussion on chronic pain, providing an accessible environment for communication and information exchange.

Objective: To analyze content on Twitter related to fibromyalgia, headache, paraplegia, neuropathy, and multiple sclerosis, as well as characterize the profile of users involved in these conversations, identify prevalent topics, measure public perception, evaluate treatment efficacy, and detect discussions related to the most frequent non-medical issues.

Methods: 72,874 tweets in English and Spanish containing pre-specified keywords were collected between 2018 and 2022. A manual review was conducted on 2,500 tweets, and the larger subset was classified by machine learning methods. Subsequently, tweets related to chronic pain conditions were analyzed to examine their medical and non-medical content, types of X users, the origin of the disease, and the efficacy of treatments.

Results: Of the total tweets collected, 55,451 (76,1%) were classifiable. The most active users were healthcare professionals and institutions. The primary perceived etiology was pharmacological, and higher treatment efficacy was noted in neuropathy, paraplegia, and multiple sclerosis. Regarding non-medical content, there were more tweets related to the definition and understanding of the disease.

Conclusions: Social media platforms, such as X, are playing a crucial role in the dissemination of information on chronic pain. Discussions largely focus on the available treatments and the need to enhance public education, utilizing these platforms to correct misconceptions and provide better support to patients.

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"Exploring Pain in Social Media: A Study on Perceptions and Discussions of Chronic Pain Conditions"

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ABSTRACT:

Background: Chronic pain, an unpleasant sensory and emotional experience lasting over six months, affects a large proportion of the global population and significantly impacts health and quality of life. Certain diseases cause chronic pain, resulting in a social and medical misunderstanding that intensity the patient's emotional suffering. In recent years, the social media platform Twitter, now called "X," has become a valuable resource for research and discussion on chronic pain, providing an accessible environment for communication and information exchange.

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neuropathy, and multiple sclerosis, as well as characterize the profile of users involved in these conversations, identify prevalent topics, measure public perception, evaluate treatment efficacy, and detect discussions related to the most frequent non-medical issues.

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Conclusions: Social media platforms, such as X, are playing a crucial role in the dissemination of information on chronic pain. Discussions largely focus on the available treatments and the need to enhance public education, utilizing these platforms to correct misconceptions and provide better support to patients.

Keywords: Social Media, Fibromyalgia, Headache, Paraplegia, Multiple Sclerosis, Neuralgia, Chronic Pain, Infodemiology.

1. INTRODUCTION:

Chronic pain is defined as "an unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage" (IASP)[1]. This type of pain is considered chronic when it persists beyond the normal duration of time, typically for more than six months[2]. Chronic pain has a global prevalence of 30.3%, representing a significant impact on global health[3], with important implications both on a

personal and social level, leading to substantial loss of income, productivity, and quality-adjusted life years worldwide[4]. Additionally, individuals suffering from chronic pain often feel misunderstood by both their social environment and healthcare professionals[4]. This lack of understanding can exacerbate the emotional impact of pain, leading to feelings of isolation and frustration[5-7]. The absence of an adequate response from healthcare institutions and professionals may aggravate these feelings, causing patients to feel neglected and hopeless[5-8].

There are several diseases with neurological and musculoskeletal involvement that manifest with chronic pain, such as fibromyalgia, headache, paraplegia, neuropathy, and multiple sclerosis. These pathologies are a leading cause of disability and are associated with high morbidity rates, significantly impacting individuals' quality of life[9]. These pain conditions contribute to mental health issues, such as anxiety and depression, increasing the global disease burden and indirect mortality due to factors such as suicide and accidents resulting from temporary disability[9,10].

Social media has attracted the attention of millions of users worldwide due to the possibility of rapid communication, access to a vast amount of information, and its wide dissemination[11,12]. According to studies, more than 55% of the global population used social media in 2022[13]. Therefore, in recent years, medical research has focused on analyzing social media posts to understand diseases and their therapeutic processes better[14]. Additionally, social media allows individuals to create and share content in a more informal and spontaneous environment, unlike traditional media, where users are passive consumers[11,15-18]. Twitter, now called “X,” stands out as one of the most popular and widely used platforms, considered an effective communication channel[19] and the most employed in health research, with content analysis as the main focus[18,20,21].

Only a few studies have utilized social media to evaluate information related to patients with

chronic pain[18,22-29]. In our study, we analyze the natural language used in posts extracted from X regarding five chronic pain diseases with the following objectives: (1) conduct a quantitative analysis of posts on X from 2018 to 2022 concerning headaches, fibromyalgia, paraplegia, neuropathy, and multiple sclerosis, and determine which disease is most frequently discussed and which generates the greatest interest among users; (2) characterize the user profile that most actively participates in these discussions; (3) identify the etiopathogenesis of these diseases as attributed by X users; (4) analyze public perceptions regarding the treatment of these diseases; and (5) identify the most frequently discussed non-medical topics.

2. METHODS:

2.1 Data Collection:

This observational study, incorporating both quantitative and qualitative methods, analyzed tweets related to headache, fibromyalgia, paraplegia, neuropathy, and multiple sclerosis on the social media platform X. The aforementioned diseases were selected as they are common causes of chronic pain consultations. Subsequently, all tweets referencing these diseases were collected. The tweets had to meet the following criteria: (1) they had to be published from an open account, meaning public tweets; (2) they had to contain one of the following keywords (i.e., words mentioned in the tweet's content): “fibromyalgia”; “headache,” “migraine”; “multiple sclerosis”; “polyneuropathy,” “neuropathy,” “neuralgia”; “paraplegia,” “tetraplegia,” and their equivalents in Spanish; (3) they had to be published between January 2018 and December 2022, a broad period that allows for capturing extensive and ongoing discussions on social media about the topic; (4) they had to be written in English or Spanish. Additional data were also collected from the tweets: the number of retweets and likes generated by each tweet, which serves as an indicator of the interest generated by the corresponding content among users[28,30]. The tool used for tweet

collection was Tweet Binder, which has been widely utilized in previous research[28,31,32] and is capable of accessing 100% of public tweets.

2.2 Content Analysis Process:

A total of 72,874 tweets were collected (*Figure 1).* A codebook was created to analyze the tweets, and we selected a total of 2,500 tweets, which were manually classified. A tweet was considered non-classifiable if its content was unrelated to the objectives of this study or if the content was insufficient to obtain relevant information. First, we analyzed the type of user. We distinguished between patients, patient's acquaintances, healthcare professionals, and institutions. To determine the user type, we examined the pronouns used (useful for distinguishing between patients and patient's acquaintances), the Twitter profile of the author (which helps identify healthcare professionals and institutions), or the content of the tweet (where the author identifies themselves as a patient, patient's acquaintance or professional, among others). Next, we differentiated between medical and non-medical content. A tweet was classified as "medical" content if it referred to the origin or cause of the disease and its treatment. Regarding the origin or cause, tweets were categorized based on whether they referred to an infectious antecedent, vaccination, stress, or drug administration. If the content was medical, we also identified whether the treatment was effective or not for chronic pain. On the other hand, for "non-medical content," we distinguished between three themes: (1) knowledge about the disease; (2) commercial issues or advertising; and (3) legal issues. The classification criteria and tweet examples are shown in *Table 1*.

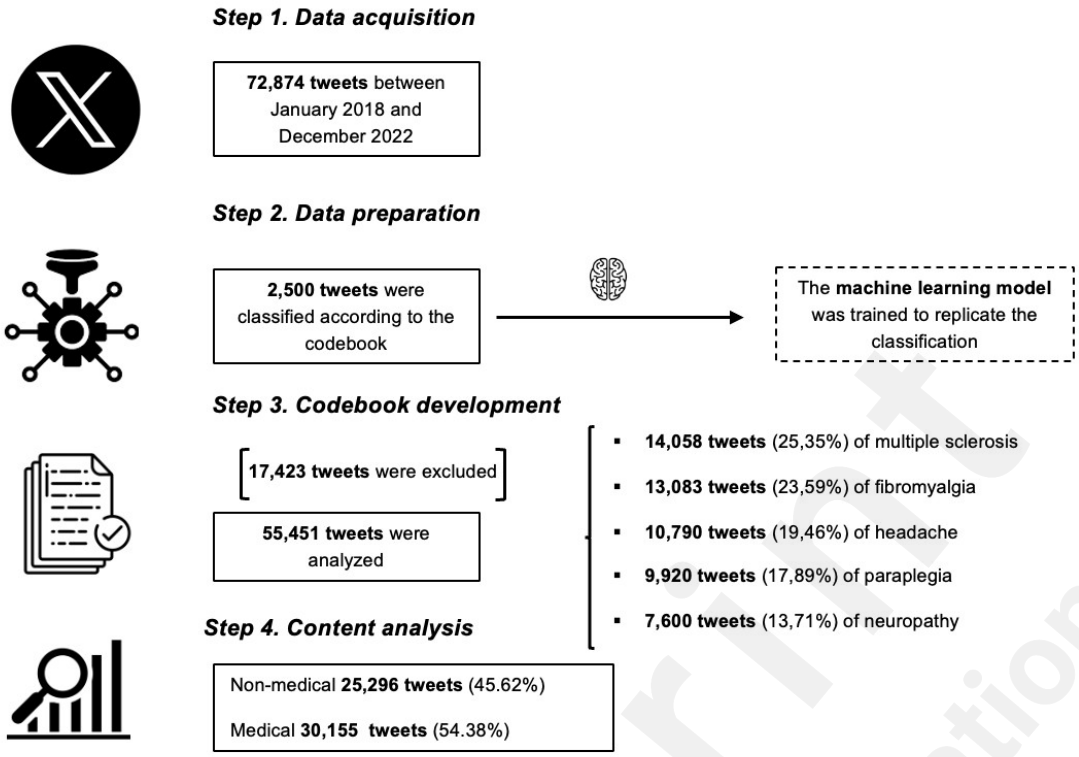

Figure 1. Flowchart of the Study Design.

Table 1. Category, Definitions, and Classification Examples.

Category	Examples
User Type *(refers to the person posting or sharing the tweet).* 1. Patients 2. Patient's acquaintances 3. Healthcare professionals and institutions	*1. "I'm feeling a bit down today. I've been battling a migraine since yesterday and ran out of my migraine medication."* *2. "Hello, we are raising money for my dear cousin who has a very aggressive and progressive form of multiple sclerosis."* *3. "@Med-: The 5% lidocaine patch is indicated for the relief of pain associated with neuropathy."*
Cause *(probable etiology of the disease).* 1. Vaccine or previous Infection 2. Stress 3. Medications	*1. "HHV6 infection showed a moderate correlation with nerve fiber damage in chronic fibromyalgia."* *2. "Worries and stress, many people are sick, and not from COVID, migraine."* *3. "Linezolid-associated neuropathy: a systematic review of cases."*
Treatment Efficacy *(whether the treatment is perceived as effective or not for chronic pain).* 1. Effective for chronic pain 2. Not effective for chronic pain	*1. "Medical News Today: spinal stimulation helps men with paraplegia walk again."* *2. "It's unlikely that focusing fibromyalgia treatment solely on inflammation in this group will produce optimal improvements in quality of life."*

Non-medical content: 1. Knowledge *(refers to general information about the diseases: definitions/theories/criteria, classification, etc)* 2. Commercial/Advertising *(advertising of the disease or related topics)* 3. Legal/Judicial *(refers to political/social/police complaints or claims)*	*1. "Fibromyalgia causes widespread body pain, extreme fatigue, and cognitive dysfunction. Symptoms can impact daily life and may lead to other complications, such as depression and anxiety."* *2. "We'll be talking with the charity soon! Remember that donations greatly help research on Multiple Sclerosis. Follow the charity here. Donate to the cause and win prizes."* *3. "Advocating for Cannabis Regulation is providing them with a powerful therapeutic weapon against multiple sclerosis."*
Usernames and personal names were removed.	

2.3 Machine Learning Classification:

Manually analyzing large datasets composed by thousands of tweets is often impractical; therefore, machine learning appears as a crucial tool in data analysis, encompassing three primary methodologies: supervised, unsupervised, and semi-supervised learning[33]. This study focuses on semi-supervised learning, which integrates elements from both supervised and unsupervised techniques by using a combination of labeled and unlabeled data to develop a machine learning model that replicates expert evaluations for the classification of millions of tweets. After preprocessing, where tweets are normalized by expanding negative contractions, removing special characters and repetitive text, and converting emojis into their textual equivalents, the tweets are translated into English to improve performance in certain machine learning applications[34]. The dataset, composed of 2,500 manually labeled tweets, is then randomly divided into two subsets: 75% (1,875 tweets) for training and 25% (625 tweets) for testing. The BERTweet model was selected due to its extensive application in the literature[35,36] and its training specifically on English tweets similar to those we are evaluating. To ensure that these models accurately replicate expert analyses, fine-tuning was conducted with the support of techniques such as Easy Data Augmentation (EDA)[37] to balance categories. The models were evaluated using the

F1-score, showing strong and consistent results with similar methodologies reported in the literature[38,39].

2.4 Statistical Analysis:

Descriptive statistics, including frequencies, proportions, and ratios, were used to summarize the number of tweets, likes, and retweets. The like-to-tweet ratio was calculated by dividing the number of likes by the number of tweets, while the retweet-to-tweet ratio was determined by dividing the number of retweets by the number of tweets. All statistical analyses were conducted using STATA version 16 (StataCorp LP).

2.5 Ethical Considerations:

This study received approval from the Research Ethics Committee of the University of Alcalá (Code CEI: CEID/2024/1/005) and adheres to the ethical research principles established in the Declaration of Helsinki. This research did not involve human subjects directly nor included any human intervention, as it utilized publicly available tweets. However, special care has been taken not to disclose users' names or any information that could reveal users' identities in this report.

3. RESULTS:

3.1 Total Tweet Count:

A total of 72,874 tweets were obtained. According to the codebook, 55,451 (76.1%) were classifiable, while 17,423 (23.9%) tweets were excluded. The classifiable tweets represented the diseases in the following order: multiple sclerosis with 14,058 tweets (25.35%), fibromyalgia with 13,083 tweets (23.59%), headache with 10,790 tweets (19.46%), paraplegia with 9,920 tweets (17.89%), and lastly, neuropathy with 7,600 tweets (13.71%). Based on their content, of the 55,451 tweets, 30,155 (54.38%) were classified as “medical” and 25,296 (45.62%) as “non-medical” (*Figure 1*). Regarding user engagement with the content, headache stood out with a like-to-tweet ratio of 468.80 and a retweet-to-

tweet ratio of 76.76, followed by multiple sclerosis with a like-to-tweet ratio of 163.12 and a retweet-to-tweet ratio of 47.97 (*Table 2*).

Table 2. Number of Tweets Published and Impact Ratios by Disease.

Category	Original tweets n (%)	Ratio like-tweet	Ratio retweet-tweet
Multiple sclerosis	14058 (25,35%)	163.12	47.97
Fibromyalgia	13083 (23,59%)	70.28	27.68
Headache	10790 (19,46%)	468.80	76.76
Paraplegia	9920 (17,89%)	10.37	4.65
Neuropathy	7600 (13,71%)	13.03	4.19

3.2 Healthcare Professionals and Institutions Are the Most Active Specific User Group:

The users who published the most tweets related to chronic pain-related diseases were "healthcare professionals and institutions" (43.43%), followed by "patients" (27.2%) and "patient acquaintances" (8.84%). When comparing by disease (*Figure 2*), "patients" were the most active specific user group in tweets related to headache (45.09%) and fibromyalgia (36.8%). In contrast, for paraplegia, neuropathy, and multiple sclerosis, the users who posted the most tweets were "healthcare professionals and institutions," with percentages of 43.4%, 67.51%, and 50.54%, respectively.

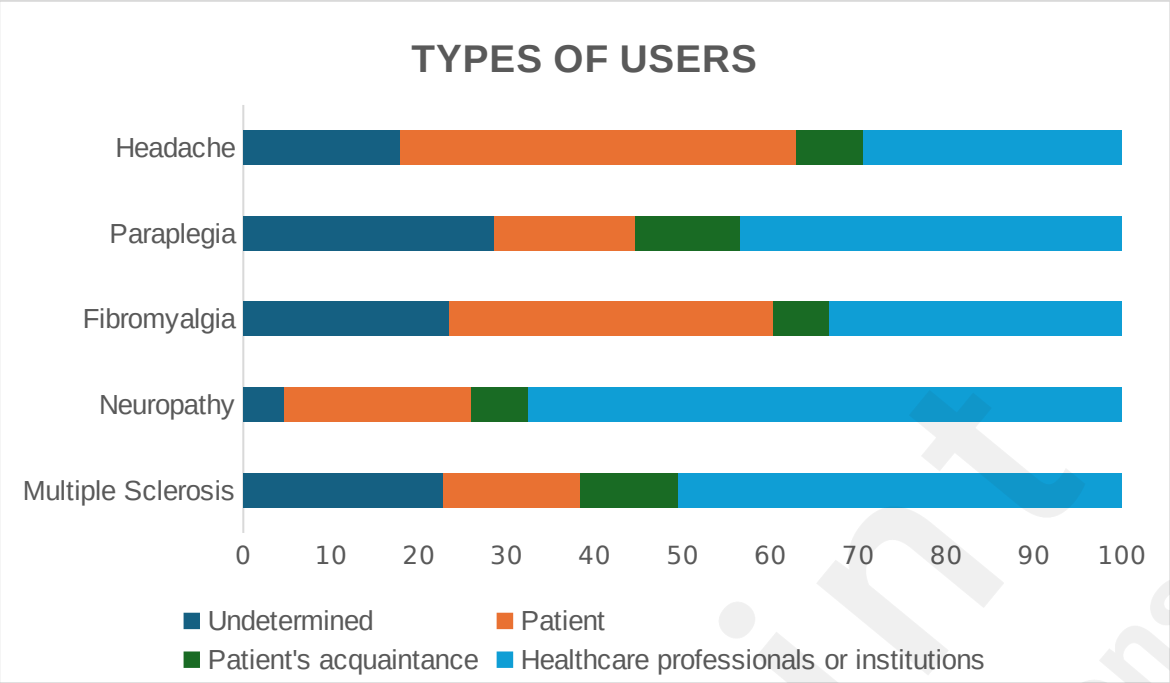

Figure 2. Percentage of Tweets Published for Each Disease by User Type.

However, although "healthcare professionals and institutions" were the most active users posting about these diseases, public engagement metrics were higher, in terms of likes, for "patients" and, in terms of retweets, for "patient's acquaintances" (*Table 3*).

Table 3. Count of Likes and Retweets per Tweet Classified by Different Categories: User Types, Cause, Medical Tweets and Non-Medical Tweets.

	Tweets		Ratio Likes-tweet	Ratio RT-tweet
	n	%		
Types of user				
Patient	15085	27,2	299,97	44,24
Patient's acquaintance	4900	8,84	258,23	71,75
Healthcare professionals or institutions	24080	43,43	50,72	20,15
Cause				
Vaccine / Infectious	3453	6,23	191,20	48,75
Stress	9690	17,47	405,75	64,41
Pharmacological	12515	22,57	81,78	23,04
Medical tweets				
Efficacy	20365	36,73	98,65	29,16
Non-efficacy	35086	63,27	184,22	38,46
Nonmedical tweets				
Knowledge	23661	42,67	59,87	21,53
Commercial	16034	28,92	140,20	37,43
Legal/Judicial	7428	13,4	164	41,74

3.3 X Users Perceive Pharmacological Etiology as the Primary Cause:

Out of the 55,451 tweets analyzed, the etiology of the disease was mentioned in almost half of them (46.27%). Regarding etiological subcategories, the majority of users identified pharmacological causes as the primary reason for the disease (22.57%). *Figure 3* shows the distribution of different causes according to the disease. Tweets related to headache and paraplegia more frequently discussed stress-related causes, whereas those related to fibromyalgia, neuropathy, and multiple sclerosis focused more on pharmacological causes.

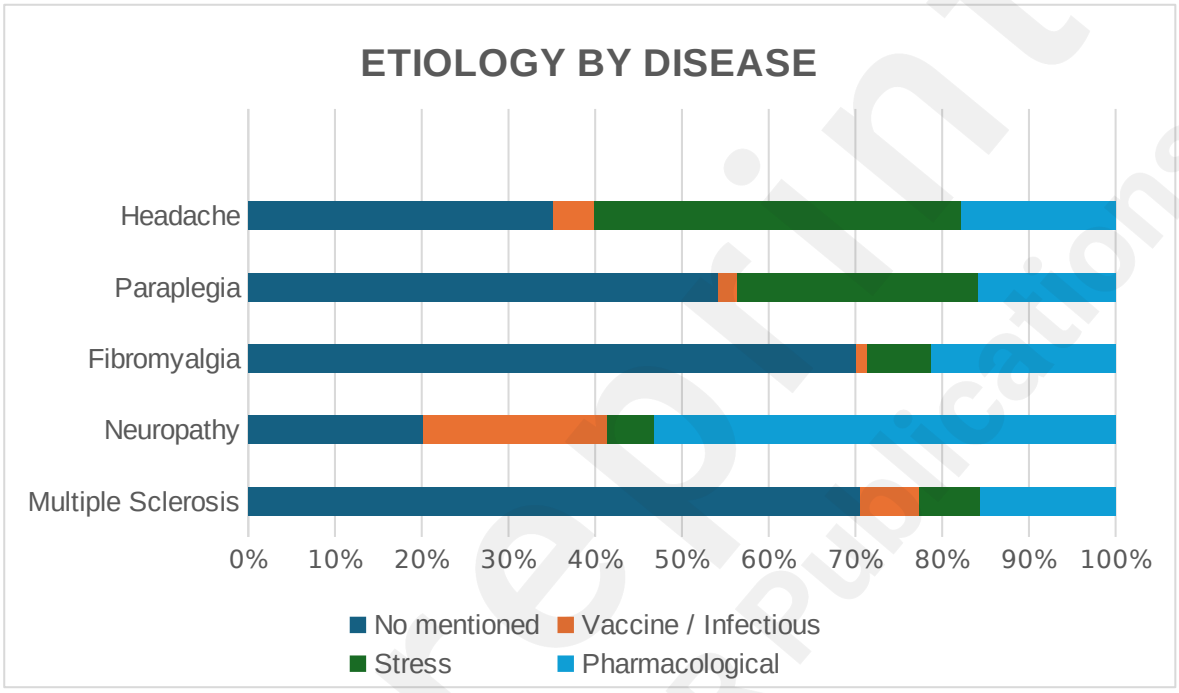

Figure 3. Percentage of Tweets Related to Each Etiology by Disease.

3.4 X Users Perceive Greater Efficacy of Treatments Used for Neuropathy, Paraplegia, and Multiple Sclerosis:

The analyzed tweets were classified according to their medical and non-medical content, with "medical" tweets (54.38%) being more prevalent than "non-medical" tweets (45.62%). Within the first group, X users discussed topics such as the efficacy of treatments used for different diseases. We found differences in users' perceptions regarding the efficacy of these treatments (*Figure 4*). On one hand, diseases associated with chronic pain, such as neuropathy, paraplegia, and multiple sclerosis, had a higher percentage of tweets expressing favorable opinions on the efficacy of their treatments, with 55.26%, 43.96%, and

34.8%, respectively. On the other hand, X users perceived lower efficacy, or did not mention it in the tweet, regarding treatments used for headaches and fibromyalgia, with only 32.81% and 25.77% of tweets reporting good efficacy, respectively.

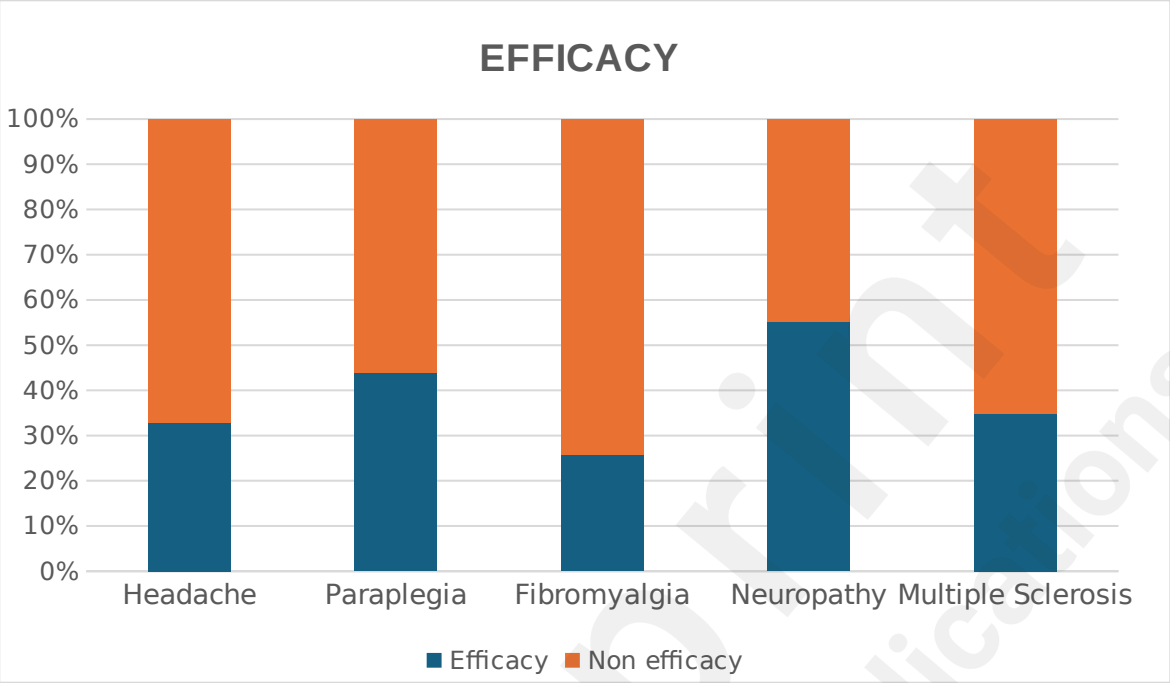

Figure 4. Percentage of Tweets Related to Treatment Efficacy by Disease.

3.5 Tweets Related to Disease Definition and Knowledge Predominated:

Regarding content, *Table 4* shows the distribution of tweets among the "non-medical" subcategories. The category with the highest proportion of tweets included references to issues related to disease knowledge, totaling 23,661 tweets, which is 42.67% of the analyzed tweets. This was the main area of interest across all the chronic pain-related diseases studied. References to commercial or advertising topics (28.92%) and legal issues (13.39%) were also detected.

Table 4. Classification of Tweets Based on Non-Medical Content (and Their Distribution Across Different Subcategories) Total and by Disease.

Category, n (%)	Total	Headache	Paraplegia	Fibromyalgia	Neuropathy	Sclerosis multiple
Non- classifiable	8328 (15,02)	3554 (32,94)	1124 (11,33)	1969 (15,05)	791 (10,41)	890 (6,33)
Knowledge	23661(42,67)	3164 (29,32)	4596 (46,33)	4701 (35,93)	4541 (59,75)	6659 (47,37)

Commercial	16034 (28,92)	2764 (25,62)	2727 (27,49)	4140 (31,64)	1296 (17,05)	5107 (36,33)
Legal / Judicial	7428 (13,39)	1308 (12,12)	1473 (14,85)	2273 (17,37)	972 (12,79)	1402 (9,97)

4. DISCUSSION:

4.1 Principal Findings:

Our analysis of tweets related to chronic pain conditions such as headache, paraplegia, fibromyalgia, neuropathy, and multiple sclerosis follows the model of recent research that uses X to evaluate public interest and communication patterns on health topics[24-29]. The fact that 76.1% of tweets were classifiable suggests that most of the content found was relevant to the study's objectives. Regarding disease distribution, the two dominant topics were multiple sclerosis and fibromyalgia, reflecting greater user participation in conversations related to these conditions. On the one hand, multiple sclerosis, being a chronic and disabling disease, may generate more discussion due to its increasing prevalence in recent years[33,34] and its greater demographic diversification, affecting a wider range of of racial and ethnic groups[34,35,40]. Additionally, new potential risk factors for disease development have been identified[36], as well as disparities in care and health outcomes among multiple sclerosis patients based on their socioeconomic status. This relationship is significantly influenced by the high cost of new immunological disease-modifying treatments, which are crucial for managing the disease[37,38]. Therefore, individuals with higher incomes and educational levels tend to experience less disability and less severe symptoms of the disease, even in a context of universal healthcare access. In contrast, those with lower incomes and educational levels present faster and more severe disease progression[39]. These aspects have contributed to increased public interest and awareness, not only among those affected by the disease but also among healthcare professionals, family members, and researchers. On the other hand, fibromyalgia also attracts considerable attention due to its controversial nature and diagnostic difficulties, which have led to an

increase in public awareness, especially on social media platforms[27]. The like-per-tweet and retweet-per-tweet ratios provide information about the public's interest in these conversations[30]. In this regard, the disease that has generated the most interest is headache. This is due to its high prevalence, being the most common disease among the five studied, affecting up to 9.5% of the global population[41-42], leading X users to actively seek support and empathy on social media platforms[43].

Our results also show that individuals with lived experience and their acquaintances appear to be less active in X discussions about chronic pain conditions, while healthcare healthcare professionals and institutions are the most active users, with their content focusing primarily on medical aspects. We expected that individuals with lived experience would be more willing to discuss these diseases, as observed in previous studies[24,25]. The significant presence of healthcare professionals on X is a positive finding. The use of social media by healthcare professionals facilitates the dissemination of health-related information and promotes two-way communication with users[28,29]. However, it is "patients" who speak about their own experiences related to headaches and fibromyalgia. A speculative explanation is that these diseases have a worse social perception compared to other conditions due to the invisibility and subjectivity of their symptoms. The emotional and psychological burden of living with these invisible conditions often leads patients to seek validation and social support. Therefore, these platforms may allow patients to express their frustrations and seek advice from others experiencing similar pain and symptoms[27,44]. These lived experiences could help reduce feelings of invalidation and better tailor therapeutic efforts[45].

Recent research findings highlight how digital platforms are valuable tools for assessing public perceptions of disease etiology[46,47]. First, the perception that stress is related to the onset and exacerbation of symptoms in conditions such as headaches and paraplegia is supported by the scientific literature. Several studies have found that stress is the main

trigger for migraine episodes in a large proportion of patients[48-50], while in the case of paraplegia, although the primary cause is usually physical damage to the spinal cord, stress plays an important role in exacerbating symptoms such as chronic pain and muscle tension. Studies have shown that individuals with spinal cord injuries may experience increased pain in situations of high stress[51-53]. Second, X users provide insights into how drugs may be implicated in the development or exacerbation of fibromyalgia, neuropathy, and multiple sclerosis. This claim aligns with a review of studies exploring how medications can influence these diseases. For example, in the case of fibromyalgia, the authors discuss how certain medications can cause similar symptoms, as well as induce or exacerbate disease symptoms[54,55]. Several articles also analyze how different drugs can induce neuropathies and review the mechanisms behind nerve damage caused by these medications[56,57]. Lastly, a review discusses drug-induced multiple sclerosis-like syndrome and explores the influence of pharmacological treatments on the induction, progression, and severity of the disease[58]. Therefore, all this justifies the increased appearance of these etiological subcategories in user discussions on platforms like X. Additionally, we are concerned about how poor treatment adherence for diseases such as fibromyalgia, neuropathy, and multiple sclerosis may be influenced by these beliefs about medication and concerns about their long-term adverse effects[59-61].

The analyzed data generally show that "medical" topics were more frequent than "non-medical" ones. Regarding "medical" content, X users discuss the effectiveness of treatments used for the studied diseases to seek support from others going through similar situations and exchange information and experiences about different therapies[62]. In this way, our research improves knowledge about public opinions, for example, on emerging therapies. Notable therapeutic innovations include the use of monoclonal antibodies targeting the calcitonin gene-related peptide (CGRP), which have shown efficacy in

preventing chronic migraines[63]; in patients with spinal cord injuries causing paraplegia, options such as spinal cord stimulation are being explored for pain treatment, with promising approaches enhancing neural plasticity[64-66]; in fibromyalgia, advances in understanding its underlying mechanisms have enabled research into repetitive transcranial magnetic stimulation (rTMS)[64,67] and cannabinoid therapy as potential treatments to relieve pain in these patients[68,69]; cannabinoids and magnetic stimulation[69], as well as nanomedicine-based therapies[64], are also being explored as future options in neuropathy; the frequent debilitating chronic pain in multiple sclerosis progression has also required the exploration of treatments with cannabinoids[70] and biologic therapies aimed at modulating the immune system and reducing inflammation[71].

Neuropathy and multiple sclerosis, despite being difficult-to-treat conditions, have therapeutic options that are appreciated by patients because they provide significant pain relief and improve quality of life. Advances in treatments for multiple sclerosis and paraplegia have also generated expectations and positive experiences, as reflected on social media[72,73]. Notably, despite the lack of a cure for multiple sclerosis and paraplegia, X users post about the effectiveness of their treatments because they value the improvement in quality of life, personalized therapeutic advancements, and the psychological and social support they receive[66,74-78]. Additionally, continuous innovation in research generates hope, reinforcing this positive perception due to the possibility of maintaining independence and functionality for a longer time[66,72]. However, current treatments for headache and fibromyalgia do not always achieve significant relief, increasing dependence on medications and their side effects[6,79-83]. The frustration, complexity, and multifactorial nature of these diseases imply that treatments are not as effective or appropriate, which may be reflected in social media data[27]. Therefore, these data help contextualize differences in treatment perception.

The codebook also revealed a noteworthy theme: the proportion of information and knowledge about diseases. It has been shown that inadequate knowledge of a specific disease can lead to the stigmatization and discrimination of patients[84]. An example is the historical rejection faced by patients with epilepsy. It was often believed that epilepsy had its origins in malevolent causes or was associated with sin or demonic possession, as well as the theory of epilepsy as contagion and madness[85-89]. These phenomena arise from misunderstandings or insufficient knowledge about why epileptic seizures occur[90]. Similarly, the stigmatization of depression is deeply rooted in the lack of information and understanding about the disease[91,92]. Therefore, chronic pain, which is difficult to quantify and measure, is often minimized or ignored by professionals and society, contributing to a perception of exaggeration or invalidation of the patient's experience. Among the diseases studied, headache and fibromyalgia are the least understood due to the invisibility of their symptoms and the absence of evident physical signs[93,94]. Patients perceive this invalidation from family members, close ones, the healthcare system, and society in general[95,96], which has a significant impact and exacerbates symptoms[45,96-98]. Studies have demonstrated that when a disease and its treatment options are better understood, patients are more likely to follow medical recommendations and have higher adherence rates[99-102]. In this way, social platforms are effective in educating the population about diseases and treatments, as well as fostering interaction between patients and professionals in a more open manner[41]. Consequently, the active presence of institutions and professionals helps counter misinformation and provide valuable resources by using social media for awareness and education campaigns about diseases. This is particularly important in an environment where misinformation can spread rapidly[103,104].

4.2 Limitations:

When interpreting the results of this research, several limitations must be considered.

Although our search tool has access to 100% of the tweets, it is possible that mentions of diseases using different keywords than those selected were missed. The inclusion of abbreviations, grammatical errors, as well as colloquial language by users may hinder the accurate search and analysis of the information. Furthermore, the demographics of Twitter users, who tend to be younger and belong to a specific socioeconomic status, do not represent the general population, which may limit the generalizability of the results in discussions about chronic pain. The design of the codebook and the analysis of tweets entail, as with most qualitative studies, a degree of subjectivity. Additionally, the content of tweets may vary over time, and the analysis being limited to tweets in English and Spanish may distort the perception of certain health issues. The influence of bots and fake accounts may somewhat affect our data. Finally, interactions on X, such as retweets and likes, do not always reflect a true understanding or perception of a topic, but rather its popularity or immediate appeal. However, we employed a methodology that has been consistently used in previous medical research on X[24-31].

4.3 Conclusions:

Our study addresses key aspects related to chronic pain and its implications for public health. It is observed that the main participants in discussions about these conditions are healthcare professionals and institutions, highlighting an opportunity to improve the dissemination of accurate information and optimize the understanding and treatment of this condition. Social media platforms, such as X, are playing a crucial role by becoming key resources where both healthcare professionals and patients discuss chronic pain. Furthermore, the predominance of discussions focused on treatment reflects the influence of available therapeutic options and their perceived effectiveness. Lastly, the study underscores the need to enhance education and public awareness, as a significant portion of the content on social networks centers around the definition and understanding of

chronic pain from a non-medical perspective. This highlights the potential of social media to correct misconceptions and provide better support to patients.

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CONFLICTS OF INTEREST:

None declared.

ABBREVIATIONS:

- CGRP: Calcitonin Gene-Related Peptide
- EDA: Easy Data Augmentation
- IASP: International Association for the Study of Pain
- rTMS: repetitive Transcranial Magnetic Stimulation

DATA AVAILABILITY:

The data sets generated during or analyzed during this study are available from the corresponding author upon reasonable request.

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Supplementary Files

Table 1. Category, Definitions, and Classification Examples.

Category	Examples
User Type *(refers to the person posting or sharing the tweet).* 1. Patients 2. Patient's acquaintances 3. Healthcare professionals and institutions	*1. "I'm feeling a bit down today. I've been battling a migraine since yesterday and ran out of my migraine medication."* *2. "Hello, we are raising money for my dear cousin who has a very aggressive and progressive form of multiple sclerosis."* *3. "@Med-: The 5% lidocaine patch is indicated for the relief of pain associated with neuropathy."*
Cause *(probable etiology of the disease).* 1. Vaccine or previous Infection 2. Stress 3. Medications	*1. "HHV6 infection showed a moderate correlation with nerve fiber damage in chronic fibromyalgia."* *2. "Worries and stress, many people are sick, and not from COVID, migraine."* *3. "Linezolid-associated neuropathy: a systematic review of cases."*
Treatment Efficacy *(whether the treatment is perceived as effective or not for chronic pain).* 1. Effective for chronic pain 2. Not effective for chronic pain	*1. "Medical News Today: spinal stimulation helps men with paraplegia walk again."* *2. "It's unlikely that focusing fibromyalgia treatment solely on inflammation in this group will produce optimal improvements in quality of life."*
Non-medical content: 1. Knowledge *(refers to general information about the diseases: definitions/theories/criteria, classification, etc)* 2. Commercial/Advertising *(advertising of the disease or related topics)* 3. Legal/Judicial *(refers to political/social/police complaints or claims)*	*1. "Fibromyalgia causes widespread body pain, extreme fatigue, and cognitive dysfunction. Symptoms can impact daily life and may lead to other complications, such as depression and anxiety."* *2. "We'll be talking with the charity soon! Remember that donations greatly help research on Multiple Sclerosis. Follow the charity here. Donate to the cause and win prizes."* *3. "Advocating for Cannabis Regulation is providing them with a powerful therapeutic weapon against multiple sclerosis."*
Usernames and personal names were removed.	

Table 2. Number of Tweets Published and Impact Ratios by Disease.

Category	Original tweets n (%)	Ratio like-tweet	Ratio retweet-tweet
Multiple sclerosis	14058 (25,35%)	163.12	47.97
Fibromyalgia	13083 (23,59%)	70.28	27.68
Headache	10790 (19,46%)	468.80	76.76
Paraplegia	9920 (17,89%)	10.37	4.65
Neuropathy	7600 (13,71%)	13.03	4.19

Table 3. Count of Likes and Retweets per Tweet Classified by Different Categories: User Types, Cause, Medical Tweets and Non-Medical Tweets.

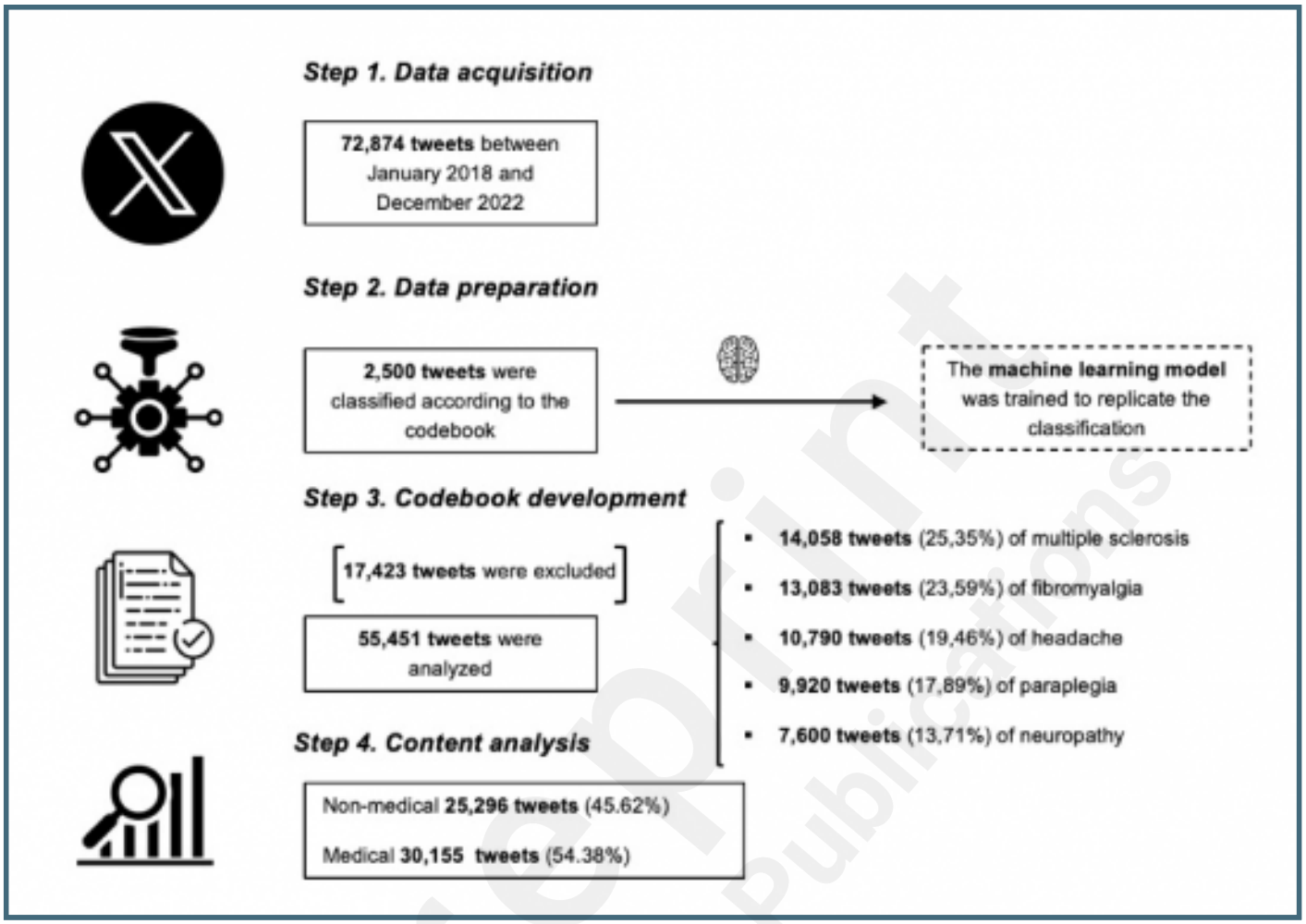
	Tweets		Ratio Likes-tweet	Ratio RT-tweet
	n	%		
Types of user				
Patient	15085	27,2	299,97	44,24
Patient's acquaintance	4900	8,84	258,23	71,75
Healthcare professionals or institutions	24080	43,43	50,72	20,15
Cause				
Vaccine / Infectious	3453	6,23	191,20	48,75
Stress	9690	17,47	405,75	64,41
Pharmacological	12515	22,57	81,78	23,04
Medical tweets				
Efficacy	20365	36,73	98,65	29,16
Non-efficacy	35086	63,27	184,22	38,46
Nonmedical tweets				
Knowledge	23661	42,67	59,87	21,53
Commercial	16034	28,92	140,20	37,43
Legal/Judicial	7428	13,4	164	41,74

Table 4. Classification of Tweets Based on Non-Medical Content (and Their Distribution Across Different Subcategories) Total and by Disease.

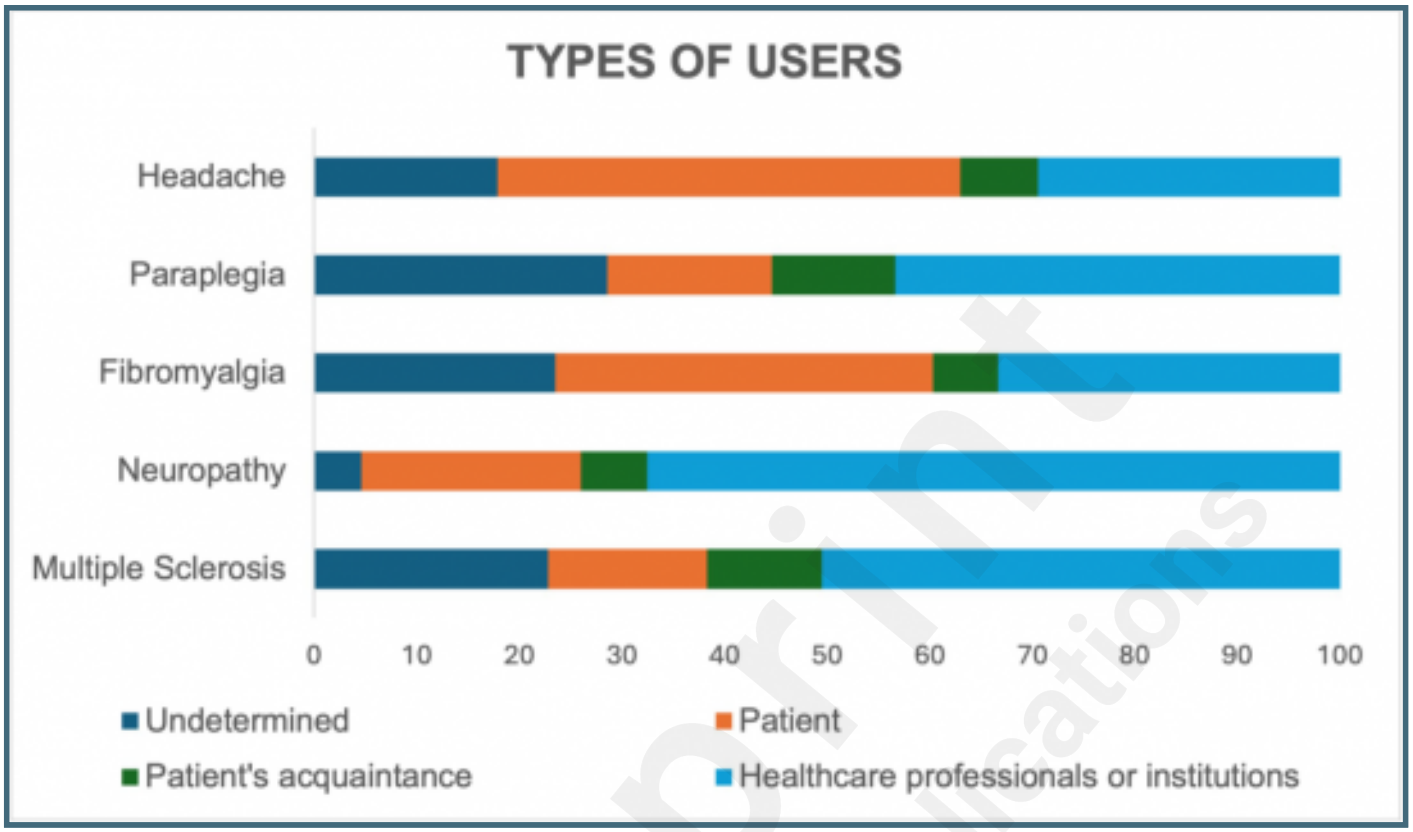
Category, n (%)	Total	Headache	Paraplegia	Fibromyalgia	Neuropathy	Sclerosis multiple
Non- classifiable	8328 (15,02)	3554 (32,94)	1124 (11,33)	1969 (15,05)	791 (10,41)	890 (6,33)
Knowledge	23661(42,67)	3164 (29,32)	4596 (46,33)	4701 (35,93)	4541 (59,75)	6659 (47,37)
Commercial	16034 (28,92)	2764 (25,62)	2727 (27,49)	4140 (31,64)	1296 (17,05)	5107 (36,33)
Legal / Judicial	7428 (13,39)	1308 (12,12)	1473 (14,85)	2273 (17,37)	972 (12,79)	1402 (9,97)

Figures

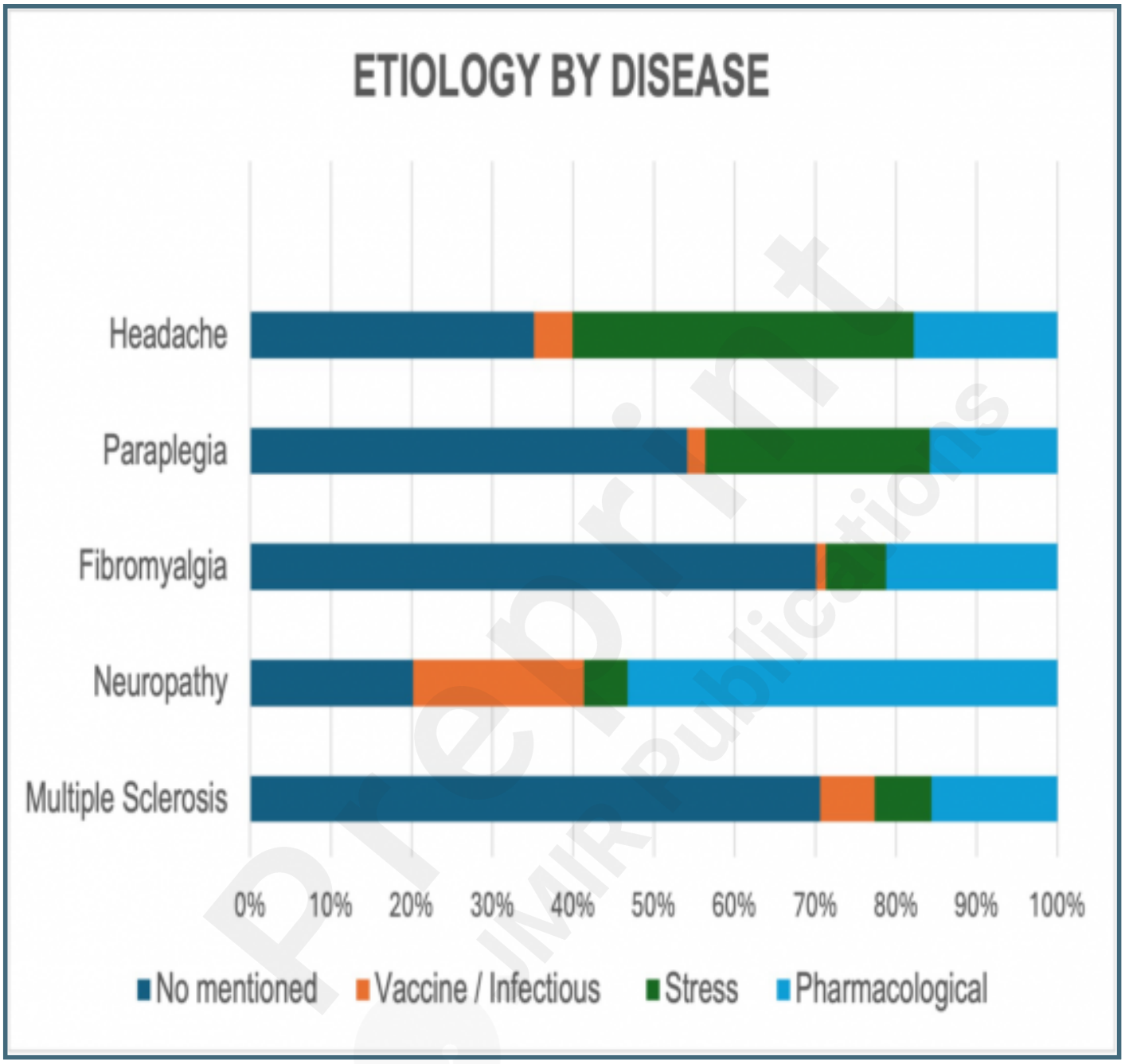
Flowchart of the Study Design.



Percentage of Tweets Published for Each Disease by User Type.



Percentage of Tweets Related to Each Etiology by Disease.



Percentage of Tweets Related to Treatment Efficacy by Disease.